Capabilities and Care: A qualitative exploration of the lives of carers of people living with dementia in Northumberland

Elizabeth Morrison (Libby)

Thesis submitted in partial fulfilment for the qualification of Doctor of Philosophy

School of Geography, Politics and Sociology
University of Newcastle upon Tyne

January 2023

Abstract

In the UK, the number of people living with dementia is predicted to double to two million by 2040. As a result, more families will be caring for a relative with dementia for longer and seeking to meet their increasingly complex support and care needs. Counties like Northumberland, with ageing populations characterised by outward migration of younger people and inward migration of older people, are challenged to provide the necessary care and support to a growing population of older people living with dementia. The challenges are especially pronounced when a high proportion of the population resides in rural communities marked by limited local amenities, inadequate public transport and often considerable distances from hospitals and other health services.

Using a standpoint theory approach, this qualitative study assesses the injustices and well-being of family carers of people living with dementia in Northumberland. Drawing on a relational ethics of care and a theoretical framework guided by the capability approach, the study explores carer capabilities by examining the health and social, spatial, and personal experiences of family carers and the impacts on their well-being. Based on in-depth interviews with 27 family carers, the study examines how key injustices intersect. The focus is on the complexities of care and caring relationships that are shaped by both personal and contextual factors. Within the context of limitations and deficits of the health and social care system and the local built environment, personal characteristics, including the type and stage of dementia, feelings of duty and obligation, expectations of care, and emotional drivers are shown to impact family carer well-being by diminishing their ability to convert capabilities into functionings or outcomes.

PhD Covid Impact Statement

Covid 19, for me, as for most of us, came as a profound shock. A set of exceptionally difficult circumstances beginning with my father's death and funeral, death of a much-loved aunt and moving house all occurred days before lockdown March 2020. These events would ordinarily have been difficult to cope with but dealing with a family bereavement during lockdown restrictions – including at that time being unable to visit my mum (living with dementia) in her care home, or to see my two daughters and grandson, was completely overwhelming. Sorting out my dad's personal affairs as his executor, a laborious process at any time, was compounded by slow, covid impacted bureaucratic systems. Another aunt living nearby, isolating, needed help and support. Mum got Covid.

Later in 2020, when care home visits were re-established, all visits to mum had to be pre-booked, were dependent on a negative covid test and were only 30 minutes (for an 80-mile round trip) usually outside or in a glass 'pod'. Visits were often distressing, as mum couldn't understand why she couldn't touch me or why we were wearing masks. Visits were constant reminders of participants in this research. I struggled whilst analysing transcripts, wondering how carers were coping and fearful that some might have lost their relative as the huge death toll of people in residential care became known. I often wanted to give up.

My caring responsibilities increased throughout the pandemic in 2020 and 2021. My daughter awaiting major heart surgery, faced three last minute cancelled operations, each time requiring me to drive 70 miles for multiple pre-op hospital visits because of covid testing and restrictions. Surgery finally went ahead in April 2021. She suffered life threatening post-surgery complications, intensive care for two weeks, and in hospital a further fortnight. Only one person, myself, was allowed to visit her due to restricted visiting and covid testing. Each day was spent providing care for my grandson and then visiting my daughter in hospital. A further month of post recovery support and care when my daughter finally got home, could only be provided by myself in order to minimise the risk of covid infection, thus denying my daughter and myself additional sources of family help.

Being unable to work in person at the university resulted in challenges to routine work due to lack of access to university facilities such as workspaces, library resources, IT hardware and in person supervision. The importance of remaining covid free due to restrictions for visiting care homes and hospitals as outlined above, meant that I could not attend in person on campus for almost two years.

My mum’s death in March 2022 concluded two years of intense caring responsibilities which have profoundly affected my health and well-being and impacted my ability to study effectively or sometimes at all. This would have been challenging without the pandemic, but covid related restrictions and constraints, created enormous additional burdens, with multiplying demands on my time, resources, and coping mechanisms.

Dedication

The writing of this thesis has been a labour. Not of love, just labour. But this dedication comes with love, for my mum and dad Laura and James Morrison.

Acknowledgements

Firstly, thanks must go to the people I interviewed for this research. Their generosity - giving of their often limited and precious time – was amazing. Also amazing was the care they gave or were giving to their relatives living with dementia.

I am grateful for the ERSC North East DTC studentship award which allowed me to undertake this research and further, enabled training opportunities. Thank you to my academic supervisory team – Dr Michael Richardson, Professor Tom Scharf and, in the earlier parts of the research process, Professor Peter Hopkins. I appreciate your support and guidance over the last five years - supervising during a global pandemic was a decidedly difficult task. Many thanks also to Professor Janice McLaughlin for providing a pastoral supervisory role over the last two years – walking, talking, and listening – her encouragement and support was invaluable especially during difficult personal circumstances. Thanks to my collaborative partner C4Age – Patsy Healey and Jane Pannell for help and support in the earlier parts of the research. I'd also like to thank Jenny Dawley, Post Graduate Research Administrator for patiently answering my numerous questions.

Since starting as a mature student undergraduate in 2012, many friends and colleagues have provided me with thought provoking conversations, support, and an ear to listen to my whingeing, over a decade now spent at Newcastle University. Special thanks to Kate (who will be very glad when this thesis is submitted!). Three cheers for Mary Hull, Dr David Walker, and Professor Derek Bell - for stimulating and helpful chats over coffee. I am grateful to son-in-law Sam, Diana, Paula, Sheila, Sam and Dot, Jen, Martine, Gillian, Karen, and the late Alice.

I have a fantastic family. Special mention goes to my sister Judy, who shared with me the majority of care for mum and dad and was a rock during this time; to my late aunt Marjorie, mum's sister, another mainstay during the hardest stages of this care; to my adored grandson Lincoln – taking him to visit my mum and dad in their care homes brought them such joy.

Lastly, and most importantly, thank you to my beloved daughters Carrie and Joanna who have supported me throughout – wonderful women of whom I am immensely proud.

Libby Morrison, January 2023

Table of Contents

Chapter 1. Background and Introduction

1.1 Context

Growing numbers of people will develop dementia over the coming decades and more families will be caring for a relative with dementia for longer and with increasingly complex support and care needs. Older people are more likely to be living with dementia and Northumberland has an ageing population many of whom reside in rural communities with limited local amenities, inadequate public transport and often considerable distances from hospitals and other health services. The demographic of Northumberland has seen changes with many young people moving out of Northumberland and older people moving in. Many carers have few children or other relatives to help them and formal support or care options including respite care may be limited. Carers of people living with dementia (PLWD) - usually one person, the partner/spouse or child (living geographically nearest) - who provide most of the care and support, experience detriment to their own health and well-being.

Reports of a ‘crisis in care’ have been rising significantly over the last twenty years. This crisis has its roots in the introduction of the National Health Service and Community Care Act in 1990 (Centre for Health and the Public Interest, 2016) which saw social care move from local authority provision to the private sector, so that ‘local authorities began to contract with private providers to provide care rather than deliver it themselves’. (Centre for Health and Public Interest, 2016, p. 7). Since then, care provided by local authorities has decreased substantially and private company provision has dominated over not for profit delivery. (Future Care Capital, 2019).

The crisis in care has been exacerbated with the introduction of austerity measures implemented in 2010 with spiralling costs for both individuals and local authorities. Cuts in local authority budgets have resulted in per person spending being reduced by 30% in real terms, in the Northeast of England (Institute of Health Equity, 2020, p. 95) including a reduction of 7% in adult social care budgets (p.96). As more people have asked for health and social care support less are receiving it (Bottery and Mallorie, 2023). Increased delays in transfer from hospital to social care settings (Johns, 2020) serve to highlight the lack of available social care provision in the Northeast.

Without a cure or more effective and preventative treatments for dementia, demand for health, social care services and third sector provision for PLWD and their family carers will continue to increase. With demand for *all* adult social care services likely to grow exponentially over the coming decade: latest projections suggest a 57% projected forecast increase in adults aged

65 and over requiring care by 2038 compared with 2018 and a 106% projected forecast increase in total costs of care for adults aged 65 and over by 2038 compared with 2018 (National Audit Office, 2021), the crisis in care will remain a challenging problem for both central and local government and continue to impact carers and PLWD.

1.2 Dementia

Dementia is a catch all term to describe a neurological condition which causes progressive deterioration in cognitive capacity, including memory loss, logic, and reasoning (Holmes and Amin, 2016, p. 687). The word dementia literally means out of one's mind, from the Latin root *de* – meaning out of and *men*s – meaning mind. It has been used to describe several different cognitive defects for many years (Andrews, 2017, Bayles and Tomoeda, 2007) with bio-medical approaches to dementia predominating in the latter half of the 20th century and into the 21st century (Cohen, 2006). Prior to this, senility was considered a natural part of ageing and decline in cognitive function was an expected correlate with old age. Even after the clinical condition of Alzheimer's was described by Alois Alzheimer in 1907, senility was regarded as both pathological and normal (Kaufman, 2006).

As the 20th century progressed, the recognition of dementia as a pathological condition began to predominate as understandings of senility and senile dementia became Alzheimer's disease. However, this 'gradual decoupling of normal ageing from distinct brain pathology' (Kaufman, 2006, p.26) is still debated within clinical medicine and gerontology (Downs et al, 2006) with some regarding Alzheimer's as an extreme of normal ageing (Herskovits, 1995, Lock, 2013). Dementia might best be considered in terms of a syndrome (Bayles and Tomoeda, 2007) rather than a particular disease as it is linked to other illnesses such as Parkinson's disease, nutritional deficiencies, vascular ischaemia, or alcohol abuse, or perhaps as a spectrum of ageing, along which pathological brain diseases acting as indicative markers (Bayles and Tomoeda, 2007).

During the 19th century, there was a growth in institutions as a way to manage social problems, including people with dementia whose families could no longer cope with them at home. People with dementia were routinely admitted to asylums and workhouses 'The belief that old people with dementia represent an intractable policy problem…predates the current 'dementia crisis' by over a century' (Andrews, 2017, p. 69).

1.2.1 Types of Dementia

There are many conditions under the dementia term umbrella including Alzheimer's disease, (AD) Vascular dementia, (VD) Dementia with Lewy bodies, (DLB) and Fronto-temporal dementia, (FTD). Some conditions have dementia as a secondary outcome from the primary diagnosis e.g. Parkinson's disease **-** linked to DLB (Donachy and McKeith, 2014, Vann Jones and O'Brien, 2014), Korsakov's/Wernicke's Encephalopathy**,** Huntington's disease**,** Creutzfeldt-Jacob disease**,** HIV, and Multiple sclerosis (Holmes and Amin, 2016). Conditions are not always discrete diagnoses but may be dual or overlapping diagnoses or pathologies called 'mixed dementia' (Alzheimer's Society, 2018a).

Accuracy in diagnosing, AD for example, can be problematic due to inconsistent practices in diagnostic techniques and failure to complete an autopsy (Lock, 2013). Some conditions may also be under reported, for example Korsakoff's syndrome, a chronic memory disorder caused by deficiency of vitamin B1, (thiamine) usually as a result of alcoholism or poor nutrition is a preventable disease which usually follows from an episode of Wernicke's encephalopathy (Kopelman et al, 2009, Alz.Org, 2018b). Dementia associated with thiamine deficiency is likely to be under reported (Galvin et al, 2010, Kopelman et al, 2009). Excessive alcohol use has recently been added to the list of preventable factors leading to dementia (Livingston et al, 2020) but professionals may be unaware of heavy drinking and the impact on health and other symptoms of Korsakoff dementia are similar to other types of dementia, which may lead to a mis or under diagnosis.

AD is the most common form of dementia, accounting for 60% of diagnoses. (Holmes and Amin, 2016). AD causes progressive memory loss, communication difficulties, problems with reasoning and logic and disorientation. It can also affect motor skills and balance. The majority of people who develop AD are over 65, with a small, but growing percentage developing the disease under 65 - described as young onset dementia (Alzheimer's Research UK, 2023). Although age is the biggest determining factor of an AD diagnosis, family history also increases the risk factor by three times. Recent research indicates that inflammation may be a contributory factor (Holmes and Amin, 2016).

Vascular Dementia is the second most common type of the disease, accounting for approximately 15% of cases (O'Brien and Thomas, 2015) or 20% of cases (Alzheimer's Research UK, 2016). It causes similar symptoms to those found in AD. There may also be a genetic predisposition or family history. The disease has a varied trajectory in symptom development and pace of progression.

Frontotemporal dementia (FTD) usually presents in younger people under 65 and is relatively rare - FTD accounts for around 2% of dementia cases (Holmes and Amin, 2016). Previously known as Pick's disease FTD is now a catch all term for a number of conditions including Behavioural variant FTD, Semantic dementia, Progressive non-fluent aphasia and FTD associated with motor neurone disease. It is characterised by difficulties associated with behavioural changes, aphasia, and semantic memory problems which are progressive. FTD has a stronger genetic component than other forms of dementia (Warren et al 2013).

Older people may also develop mild cognitive impairment (MCI) as they get older. MCI may appear worse than the forgetfulness associated with normal ageing processes but does not necessarily lead to dementia. However, people with MCI do have a higher risk of developing it (Alzheimer's Research UK, 2022a). A few causes of dementia are reversible, but most are not (Bayles and Tomoeda, 2007).

1.2.2 Treatments and Progression of Dementia

The progression of dementia by medical professionals is often evaluated using either a three-stage impairment evaluation – mild (early-stage), moderate (middle-stage), and severe (late-stage) (Alz.Org, 2018a) or by a seven-stage model using the Global Deterioration Scale (GDS) developed by Reisberg (Reisberg et al, 1982). The final stage seven showing very severe cognitive and physical decline and limited communication (Grossman, 2017). Earlier stages often go unnoticed by the person or family. Progression of the disease is not linear and will vary from person to person.

Years of research and large sums of money invested in the search for a cure or for efficacious treatments has been largely unsuccessful (Lock, 2013). Many large pharmaceutical companies have abandoned research into a cure for Alzheimer's and Parkinson's, (Whipple, 2018) and focussed instead on treatment as therapy. Some recent research developments point to 26 metabolite biomarkers in the blood and brain which could be identifiers for AD and might pave the way for more therapeutic treatments (National Institute on Aging, 2018) and the latest studies have provided the first evidence of a new treatment to slow down the progression of the disease (Gallagher, 2022). However, a single cure for dementia seems unlikely when dementia is an umbrella term for many different diseases (NHS, 2021).

Most drug treatments for dementia are only available for those with a diagnosis of Alzheimer's Disease, but efficacy of these treatments is limited, with the most recent NHS guidelines stating that treatments only 'temporarily reduce symptoms' (NHS, 2020). No new drugs have in fact been licenced for use with Alzheimer's disease in the UK since 2002

(Alzheimer's Society, 2022a). Although research is ongoing for good models of prediction identification of gene mutations which might cause AD, the research is challenging and time intensive (McDade and Bateman, 2017). Treatments whether drug or non-drug such as Cognitive Behavioural Therapy (CBT) do not reverse memory loss or other cognitive function, they can only help with some symptoms.

Mild to moderate AD and DLB are often treated with cholinesterase inhibitors. Cholinesterase inhibitors (CIs) do not stop progression of the disease but can improve function and alleviate some symptoms. VD has no available treatments and medication for FTD has had limited success, so most interventions are non-pharmacological (Warren et al, 2013). Long term outcomes for people with K/WE are sparse (Alz.org, 2018b) but recovery with a vitamin B1-enriched diet may be possible in approximately 20 percent of Korsakoff patients, however many will not recover (Coenan, 2016).

Emphasis on prevention not cure has received more attention (Lock, 2013, Reiss et al, 2020) with research published in the Lancet Commission focusing on 12 preventable factors – less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury (TBI), and air pollution, which might reduce and prevent numbers of people developing dementia (Livingston et al, 2020).

1.3 Prevalence and Cost of Dementia

The biggest risk factor for developing dementia is age, with 20% of people aged over 85 developing the disease (Holmes and Amin, 2016). Projections suggest one in three people are expected to develop the disease during their lifetimes (Alzheimer's Research UK, 2022b). Dementia prevalence is growing worldwide. The World Health Organisation (WHO) estimates there are 55m people living with dementia (PLWD) globally and predict this figure will increase to 139m by 2050. Dementia makes the largest contribution to the need for care, more so than any other type of impairment and chronic disease (WHO, 2015). It also comes at a huge economic cost. The total global cost of dementia predicted to be a trillion-dollar disease by 2018 (Prince et al, 2016, foreward) is now projected to cost 2.8 trillion US dollars by 2030 (WHO,2022). The numbers of people requiring complex dementia care in the global north has implications for the global south, with dementia care facilities for older persons from the North recently opening in Thailand (Johnston and Pratt, 2022).

The number of PLWD in the UK is also growing exponentially. Current projections suggest the present figure of approximately 700,000 people with dementia in the UK will increase to

1.3 million by 2025 (Imison et al, 2017) and double to over 2 million in the next 25 years (Wittenburg et al, 2020). The annual cost of dementia in England is approximately £24.2 billion, £10.1 billion of this total is from unpaid care. Social care costs are three times that of health, with PLWD and their carers paying for 60% of these costs whilst government only funds 40% (Wittenburg et al, 2020). Costs for both health and social care for PLWD can be very high. Northumberland NHS has a much higher than average emergency hospital admissions rate and Public Health England calculates that dementia costs more than the combined costs of stroke, heart disease and cancer (Public Health England, 2017). Table 1 in Appendix A shows projections for dementia numbers and care costs.

1.3.1 Local Context Northumberland

Northumberland is a geographically large county of which 96.7% is classed as rural (Northumberland County Council, 2018a) it incorporates pockets of urban sprawl with 51% of the population living in the 3% of urban land based mainly in the Southeast of the county. Its population is disproportionately rural and ageing in comparison to other counties in the Northeast - 49.1% of the population live in rural areas compared to the Northeast (18.8%) and England (18.9%).

The number of people aged 65+ is set to increase by 42.4% by 2031 (Northeast 37.2% and England 41% based on 2014 population projections, Northumberland County Council, 2018a). This figure has risen by 12% since the project proposal for this thesis was submitted in 2017, when 30% of Northumberland's population was forecast to be over 65 by 2035. (Northumberland County Council, Past Trends and Future Change, 2013). This proportion is likely to be increasing faster than would be anticipated due to general ageing, because larger numbers of young people are moving away from rural areas as older people have moved in (Northumberland County Council, 2007, Milbourne, 2012, Stockdale, 2011).

Accurate figures for the number of people living with dementia in Northumberland and the North-East are difficult to find, with conflicting figures from different sources. The latest information from Northumberland County Council states that 35,000 people living in the North-East have dementia, of which Northumberland has approximately 2,500 people who have been diagnosed with dementia, although this figure is likely to be much higher due to many people remaining undiagnosed (Northumberland County Council, 2022a).

Alzheimer's Research UK (2022c) gives the total number of people living with dementia in Northumberland as 5,324, compared to a national average of 3,570, with the percentage of population living with dementia in Northumberland 1.64% (National average - 1.28 %). As these figures are provided to Alzheimer’s Research UK by each Clinical Commissioning Group (CCG) in England, they seem likely to be the more accurate. Recent figures from the Office for Improvements and Disparities (2022) shows dementia prevalence in Northumberland remaining at similar levels to previous years. There is currently no Northumberland specific dementia strategy and the national dementia strategy due in 2022 has been delayed.

1.4 Carers and Caring - National Context and Background

> ‘A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support’. (Carers Trust, 2022a).

There are a number of terms in common usage to describe people, usually but not always family members, providing support to another with physical or mental health problems – ‘Carers’, ‘Caregivers’ or ‘familial carers’. It is important to note that some people reject these ascribed labels regarding terms such as carer inappropriate when they perceive the support given to a family member as solely a normal part of life (NHS, 2022). Additionally, there is often a sense of shame attached to neurological illnesses such as dementia (Kim et al, 2019) which may result in family carers concealing problems and delaying seeking help. Carer relationships are mostly dyadic – spousal or parent child. Caring responsibilities often begin prior to a diagnosis of dementia, as a person living with dementia (PLWD) begins to have difficulties with everyday activities. Both carer and PLWD may find the diagnosis and the subsequent information delivered by often unknown medical and social practitioners through bureaucratic systems of meetings, appointments, and form filling disorientating and confusing whilst trying to cope with the emotional impact of diagnosis (Alzheimer’s Society, 2022b).

1.4.1 Who Cares and What do they Do?

Carers UK (2019) estimate 6.5 million people in the UK are carers. This figure is likely to rise considerably over the coming years due to an ageing population, (Government Office for Science, 2016) with increasing numbers of people with dementia (Dementia Statistics Hub, 2022). Almost 700,000 people are currently providing care to someone with dementia in the UK with a high carer to PLWD ratio of 0.85 (Lewis et al, 2014). Carers providing care for someone with dementia are more likely to be older and female (Carers UK, 2019). Two thirds of carers are caring for a spouse and a quarter caring for a parent (Lewis et al, 2014). The 55-64 age group comprises the highest number of carers overall at over 25% (NHS Digital, 2022). Women provide over two thirds of care (NHS Digital, 2022) and female carers in the 50-64 age group experience higher levels of multiple generational caring responsibilities.

Age UK (2019) find that 68% of ‘sandwich’ carers (those caring for both older relatives and children) are women.

Care may be provided for only a few hours per week or upwards of 100 hours per week. Care can encompass myriad types of help and support, for example personal care – bathing, dressing, changing incontinence pads, giving medication, financial support, shopping, accompanying to health appointments, driving or social activities. The amount of care required increases greatly as dementia progresses (Mesterton et al, 2010, Lewis et al. 2014) with PLWD especially in the mid to late stages of the disease liable to need support during the day and night.

Carers Trust (2022b) report caring responsibilities have increased, compounded recently by the Covid 19 pandemic. Carers are caring for longer and the needs of the person they care for increasingly complex. Only 7% of carers said they received enough support, with their top three priorities being more money, better support for the person needing care and a break from caring (Carers Trust, 2022b).

More informal carers are now in paid employment (Carers UK, 2020a). One fifth of people of working age 50-64 are carers (Carers UK, 2019). Women find it harder to remain in employment and experienced financial difficulties more often than male caregivers. (Office for National Statistics, 2019). Nine in 10 employers asked about the effect of dementia caring on their employees said:

> ‘…these caring responsibilities were affecting their workforce – putting pressure on employees, causing physical and mental health problems, and leading to declined productivity, as well as the loss of valuable staff members’ (Carers UK, 2019, p. 15).

As a new generation of women works longer before receiving a pension, this ‘sandwich’ group may become ‘club sandwich’ carers, as their multi-generational caring extends to care for parents, children, *and* grandchildren (Zeitlow, 2014).

1.4.2 Where are carers providing care?

Late 20th century and early 21st century saw a ‘voluntary’ turn with government welfare provision moving to the voluntary sector (Milligan and Conradson, 2011). Social care has increasingly been met through community and grassroots organisations, informal volunteers, and predominantly by families. This ‘turn’ has altered the environments where care for people with complex needs takes place from principally institutional and local authority based to community neighbourhoods and the home. Two thirds of PLWD in the UK remain at home and a third live in residential care (Lewis et al, 2014). The majority of people living with dementia prefer to remain at home (Alzheimer's Research UK and Dementia Statistics Hub, 2022d) but as dementia progresses, family carers may have to cope with complex and challenging support needs and practical difficulties at home and PLWD may need residential provision. The number of people living in care homes in Northumberland is expected to rise from 2,535 in 2014 to 4,454 in 2030 – an increase of 75%. Most of these homes are privately run not local authority homes (Northumberland County Council, 2017).

1.4.3 Impact of Caring

Family caregivers suffer high levels of psycho-social stress (Rao et al 2021, Carers UK, 2021a), experience detrimental physical health and often suffer financial difficulties (Carers Trust, 2022b). Proposed social care funding reforms have been deferred, again, until 2025 (Department for Health and Social Care, 2022a, Booth and Duncan 2022). A recent Kings Fund post highlights a lack of progress on key goals in social care reform – with an insufficient workforce, high levels of unmet need and lack of choice (Bottery, 2022). The recent government White Paper on health and social care reform promises only £25 million to 'kickstart a change in the services provided to support unpaid carers' (Department for Health and Social Care, 2021, no page).

Family carers often score lower in quality-of-life indicators than non-caregivers (Rao et al, 2021). The societal cost of care rises in the later stages of dementia (Mesterton et al, 2010, Lewis et al, 2014). A recent State of Caring Survey (Carers UK, 2021b) showed increased mental and physical health problems for carers which had been heightened during the Covid 19 pandemic. Carers can experience loneliness and isolation as a PLWD's care needs increase. NICE guidance reports only 36% of carers who said they were able to have the social contact they would prefer as a consequence of caring (NICE, 2022). Women experienced more adverse mental health symptoms due to caring responsibilities (Alzheimer's Research UK, 2022e, Office for National Statistics, 2019).

Informal carers, particularly older carers can have their own health issues which they often ignore or neglect due to their caring role (ONS, 2019) and accessing primary health care services can prove challenging for caregivers (BMJ, 2021). Providing appropriate and sufficient support to family carers is critical to protect their own health and well-being and helping them to continue to care (ONS, 2021). Being able to take a break or secure respite services became more difficult during the pandemic, with 81% of carers providing more care hours but unable to take time off from their caring role (Carers UK, 2021b). Families reported some services closing whilst in addition contact with other family members or friends who might have offered support, was substantially reduced, or prevented during pandemic lockdowns.

1.4.4 Getting Help

Most PLWD will need some extra paid care or support in the mid to late stages of the disease. Local authorities will do a needs assessment to see if the person is eligible for support, provide a care and support plan and undertake a financial assessment to ascertain how much you need to pay to meet your care needs. Contributions to care costs are means tested (Alzheimer's Society, 2022). A recent CQC report highlights delays in assessments for people needing care, which has increased since the Covid 19 pandemic (CQC, 2022). Paid care can be provided by local authorities, third sector organisations and private care agencies. Local authorities usually have a list of care providers and also residential care homes in the area, detailing what services they provide. Choice of care provision may be dependent on the place you live – rural (and coastal) areas often having less options as health and care service delivery experience workforce difficulties with some providers leaving rural areas (Public Health England, 2019).

1.4.5 Carer Assessments and Taking a Break

> 'Caring for a family member, friend, or neighbour can be challenging and often comes at significant personal cost. Without sufficient support or meaningful breaks, it can take its toll on carers' emotional and physical health, their ability to work...' (Carers UK, 2021a, p. 1).

Key legislation pertaining to PLWD and their carers may be found in the Health and Care Act 2012, Equality Act 2010, Health and Social Care Act (National Data Guardian) Act 2018 and the Care Act 2014. The Care Act is an important landmark as it introduced a legal requirement for support for carers for the first time. It also equalised considerations of needs between the cared for and carer for the first time 'carers will be recognised in the law in the same way as those they care for' (Gov.UK, 2016, no page). Significant elements from the Act include: a right to a carer assessment and a support plan outlining how their needs will be met if they meet the local authority eligibility criteria. Support may be in the form of a break or respite from their caring role, or support to maintain hobbies or relationships. Although the Care Act is primarily directed toward local authorities and social care providers, increasing merging of health and social care (Caring Together Northumberland brings health care, social care and voluntary organisations under one umbrella) – may affect carer considerations, including health more broadly (Dalton et al, 2018).

Respite means being able to take a break from caring responsibilities (NHS, 2019). The word ‘respite’ is sometimes associated with negative terms such as ‘burden’. Alternative phrases such as ‘shared care’ or ‘short term care’ (Nolan and Grant, 1992, Stalker, 1996) or more recently ‘replacement care’ (Alzheimer’s Society, 2022c) is now more often used. Respite as a conception lacks clear definition (Rao et al ,2021) – who it is for and what it is intended to do. Respite may simultaneously be understood as both outcome for the caregiver and service provision for the care recipient, with Wolowski and Carr (2017) emphasising problems in assessing both the worth articulated by carers and care receivers and the limitations of its potential due to a lack of clarity regarding the form of delivery or provision. Respite may be delivered by access to a residential or nursing care home, through community centres or by a paid carer providing support at home (Carers UK, 2021c). When carer assessments identify respite care as the best means of addressing a carer’s needs, it is important to note that this can only happen if the cared for person consents to it (Gov.UK, 2016).

Taking regular breaks is vital to ensure carer well-being, yet 72% report being unable to do so (Carers UK, 2021a). Carers UK proposes the UK Government should provide an additional £1.5 billion to guarantee carers’ breaks (Carers UK, 2021a). A recent social services survey of adult carers in England 2021-2022, showed that there was a decrease in people accessing day-care or home care support services and in addition, carers taking a break for a period over 24 hours had decreased from 19.6% in 2018-19 to only 13.3% in 2021-22. Carers reported higher levels of stress and depression (NHS Digital, 2022).

1.5 Carers living in Northumberland

Northumberland County Council do not provide figures specifically for numbers of unpaid carers for PLWD, but the 2011 census shows the number of people in Northumberland delivering unpaid care grew from 33,609 to 35,697 since the previous census (Northumberland County Council, 2012). Carers Northumberland (2022a) do not have figures for carers of PLWD, but overall registrations of carers have increased year on year, with a 28% increase in 2021-2022. Using the figure 5324 of PLWD in Northumberland provided by Alzheimer’s Research UK (2022c) – and the ratio of carers to PLWD 0.85 provided by Lewis et al (2014) we can guestimate the number of carers of PLWD in Northumberland to be 4525 – although as detailed earlier, many people may not have been diagnosed with dementia, and people providing care may not have been identified.

Northumberland County Council, through its Ageing Well programme aims to bring partners together locally to help them respond to the needs of people with dementia. Northumberland

County Council considers the health and well-being of carers through its Health and Well-Being board and Joint Health and Well-Being Strategy (2018b). Carers are signposted to Carers Northumberland (2022b) which is the dedicated carer organisation for providing support, advocacy, and advice for unpaid carers in Northumberland. Carers in Northumberland needs may be assessed if requested (see Appendix K for assessment guidelines). Dementia specific advice is also available through a range of local third sector organisations including national organisations such as the Alzheimer's Society or Age UK.

The recent Northumberland County Council Joint Health and Well-being strategy document stated aims are to move away from a medical model focussed on diagnosis and treatment to one which instead promotes wellbeing and prevent ill health after '…an unprecedented increase in the demand on health and social care' (2018, p. 9). The report shows carer reported quality of life is decreasing. Measures to tackle this include:

> 'to consider the needs of both older persons and those of working age with care and/or support needs to promote choice, independence and maximise the opportunities offered by advances in assistive technology to support people in their own home…Support residents with caring responsibilities to sustain employment or return to the labour market.' (Northumberland County Council Joint Health and Well-being Strategy, 2018b).

The Integrated Partnership Board (IPB) which comprises 13 local authority areas including Northumberland, bringing together Local Government and the NHS, has published a recent draft document from the North East and North Cumbria Integrated Care Partnership: Draft Integrated Care Strategy which stated carer support aims include: better identification of carers, improved health and well-being outcomes through social prescribing, peer support, benefit advice and to 'improve access to respite care' (Integrated Care System North East and Cumbria, 2022, no page).

1.6 Rationale for the Research

My collaborative partner Co-ordinating For Age (C4A, Glendale Gateway Trust, 2015) contacted Newcastle University in 2015/16 actively seeking a doctoral researcher to explore ageing in Northumberland. C4A had brought different agencies and community groups together to explore how resources could be used more effectively in supporting older people in Glendale Northumberland. From this, they identified a lack of knowledge of local rural geographies and a confusion of sometimes overlapping services which merited further research.

My undergraduate Community Research project ‘Spatial Injustice of Carers in Northumberland’ in 2015 and my master’s dissertation ‘Care on the Frontline -The Changing Landscapes of Dementia Care at Home and in the Community’ (Northumberland) in 2017 combined with personal experience of caring for both my parents with dementia, for over 15 years in a semi-rural area of Northumberland seemed relevant to C4A’s research suggestion and resulted in the submitting of a thesis proposal with C4A as collaborative partners.

The key objective of the original thesis proposal was to assess rural disadvantage utilising an intergenerational approach through an exploration of changes to services for older people as well as the implications for familial care in rural Northumberland. Although the locus of the research is now primarily focussed on family carers of PLWD, the key aims and objectives of the original project, assessing rural disadvantage, health and social care services and implications for familial care remain fundamental aspects of the thesis.

A comprehensive literature review conducted before, during and after the data collection established two key literatures which have informed this thesis. The Capability Approach and Ethics of Care. The Capability Approach developed by Amartya Sen and Martha Nussbaum is a theoretical framework which foregrounds two key normative demands. That liberty to realise well-being is of fundamental consequence and that the freedom to realise this well-being should be understood in relation to the capabilities people have. Sen identifies people with disabilities as facing particular injustice in trying to realise capabilities and foregrounds a conversion factor which highlights ‘the difficulty in converting incomes and resources into good living precisely because of disability.’ (Sen, 2010, p.258). The relational ethics of care centres on our understanding of the ubiquitous nature of dependency and acknowledgement of this dependency is crucial to our understanding of care and care relations (Kittay, 2011, Held, 2006). Promoting a group identity of ‘carers’, assumes a similarity of group experiences which may eclipse the individual challenges experienced by carers. Bringing together both the importance of the individual freedom of carers (and people living with dementia) to realise well-being through a capability approach, whilst recognising the centrality of caring relations can help identify carer injustices in Northumberland and develop policies to alleviate them.

1.7 Structure and Aims of the Thesis

The thesis is made up of seven chapters: Introduction, literature review, methodology, three empirical chapters and conclusion. I had three main aims at the outset in order to explore the lives of carers of PLWD in Northumberland

- descriptive – asking carers about their everyday lives, the caring role, and the person that they cared for. The difficulties carers experienced and the impact of the role on their own health and well-being.
- explanatory – How and why did they do what they did. What were the causes of the difficulties they faced? What perpetuated them?
- Normative – What changes or recommendations might ameliorate any identified injustices and improve carers lives?

Research Question – Do family carers of people living with dementia in Northumberland experience personal and relational injustices which impact their well-being and what might alleviate them?

Objectives

a. Assess support for people with dementia at the point of diagnosis and the impact on the family carer by examining benefit, health, and social care systems. This includes: drawing attention to the ways that the individual rights of the PLWD are often at the expense of a more relational approach which considers the carer and the dyadic caring relationship equally; as well as identifying injustices experienced by PLWD which create concomitant injustices for carers.

b. Examine how carers of PLWD experience increasing spatial and temporal injustice as the person they care for needs increasing help and support. This includes: the ways in which the type of dementia, lack of family and community support options, and built environment inadequacies combine to limit the places they can go and the people they can see as well as difficulties accessing healthcare, limited paid care and respite options mean that carer capabilities – economic, social capital etc cannot be converted into functionings i.e., ‘beings’ and ‘doings’.

c. Explore the ways in which psychological or personal approaches to the loss of the person they care for through identity and recognition challenges, impact the carer well-being as final stages of dementia are reached and decisions between care at home and residential care need to be made. This includes: assumptions of care at home as best for PLWD, established both by health and social care institutions and inscribed as social norms, underscore self-imposed ethical frameworks of duty and responsibility which guilt, impede carers’ ability to focus on their own well-being, as well as the person they care for, places carers under substantial pressure to continue caring; as well as a lack of appropriate and flexible residential, respite and support options make final decision making acutely stressful.

d. Assess the applicability of a capability rather than resource-based approach to assess carer injustices, with potential recommendations for a capability framework to develop new policies.

Chapter 2. Literature Review

2.1 Context and Introduction

> '"What we owe to each other"' is an important subject for intelligent reflection' (Scanlon, 1998, in Sen, 2010, p. 32).

Care is a contested concept or one consisting of overlapping concepts of labour, practice, value, and virtue. Care may be considered in context of political theory (Engster and Hammington, 2015, Tronto, 1987, 1994), ethics and moral reasoning (Noddings, 1982, Slote, 2007, 2015, Held, 2006, Gilligan, 1993), as natural (Haidt, 2013, Engster, 2007, Mayr, 1961, Diaz, 2018), as a practice (Bubeck, 1995, Kittay, 1999) as work (Fisher and Tronto, 1990) and as (inter) dependency (Kittay, 1999). Dementia specific care is about the people who care and the people they care for, their communities - places and spaces they inhabit, and the social arrangements and institutions which impact their lives. Caring is relational, contextual, and situated.

This chapter will introduce the key theoretical and conceptual frameworks which have been utilised to inform the empirical data in subsequent chapters. The first section of the chapter examines different philosophical aspects of care literature, including key debates in relation to ethics of justice theorising, autonomy, relationality and spaces of care and justice. The second section appraises aspects of dementia specific care, with attention to personal and social factors including identity and recognition, social disability and medical models and carer well-being. The final part considers the Capability Approach as a conceptual framework within which justice, freedom and well-being of carers might be examined through an understanding of the personal, social, and environmental aspects of carers lives.

2.2 Ethics - Why do we care?

> 'We must defend a conception of our good which includes the good of other beings' (Collier, 1999, intro).

Care can be both work and an ideal, a 'practice and value' (Held, 2006, p. 39). Care is also a feminist issue. Both feminism and care have a multiplicity of meanings. But key to feminist thought, is to examine the world – structures, power, politics from new standpoints (Hartsock, 2004), to challenge the hegemony of androcentric epistemologies, and the subordination of women within patriarchal structures (Held, 2006, Noddings, 1982). Feminists have theorised care by examining the ways and the spaces in which care takes place, encompassing care theorising at both a private or familial level and at a societal and global level (McEwan, and Goodman, 2010). An ethic of care brings women's voices into moral considerations, rejects notions of universalist, autonomous, impartial, and rational individuals devising moral principles, and instead recognises real life ‘messy’ situations in which ethical decisions are made (Kittay, 1999, 2002).

Ethics can be considered the philosophical study of moral reasoning. There are three broad moral or ethical theories which have their roots in older ontological and epistemological theories. Deontological, consequentialist and virtue ethics.

Two philosophies dominated in the early part of the 20th century. The deontological ethics of Immanuel Kant and consequentialist or utilitarian ethics of Bentham and Mill (Held, 2006, Quinton, 1989). Kant’s categorical imperative is a deontological normative theory which emphasises the moral importance of motive over consequence (Wood, 2007, Warburton, 2013). Utilitarianism, first espoused by Bentham, (Collard, 2006, Hampsher-Monk, 1992, Nussbaum, 2004) and then developed by Mill (Britten, 1969, Habibi, 1998, McCloskey, 1971, Mill, 2008, Ryan, 1970, West, 2004) is a consequentialist, teleological normative theory which involves rational choices being made to bring about the greatest happiness to the greatest number.

In the latter half of the 20th century there was a renewed interest in virtue ethical theories such as Humean (Hume, 1978, Baier, 1987) or Aristotelian (Warburton, 2013, Moran, 2018, Shields, 2006, Nussbaum, 2004). Virtue ethicists argue that encouraging the development of virtuous people and societies, will help them to make better moral decisions. The focus is not on right or wrong actions as foregrounded by Kant or Mill, but on character development, flourishing or ‘eudaimonia’ (Moran, 2018). Slote’s (2001) virtue ethics promotes love and humanitarianism as desirable characteristics (over and above duty and obligation), and Nussbaum contends that a fair society would consider the needs of carers as well as dependents and also advocates a *care with love* as well as justice (2013). The import of our emotional responses as Hume argued in ‘Treatise on Human Nature’ (Hume, 1978) is now regarded as both scientifically and philosophically substantiated:

> ‘…our emotions and moral intuitions are in the driver’s seat. In the last few decades, a blizzard of scientific research has settled the argument between Hume and the ancients. Hume won’ (Rauch, 2021, p.22).

Caring also makes us feel good (Dias, 2018). Modern conceptions from positive psychology underscore a sense of purpose which may be combined with a natural desire to care (Seligman and Csikszentmihalyi, 2000).

All early ethical theories were androcentric. Women were considered ‘other’, feeble and incapable of rational thought (Held, 2006). As feminist theorising grew over the latter half of the 20th century, challenges arose to the hegemonic moral, abstract ‘universalist’ norms and rules which had dominated ethical thought. Non-ideal theories such as standpoint and ethics of care grounded in the real world and developed through experiences saw knowledge shift away from the ‘armchair’ theorising of philosophers to ordinary people.

2.2.1 The Development of the feminist ethic of care

All ethics are political. Rather than being a kind of ethics, feminist ethics may be thought of as how we *do* ethics (Lindeman, 2019) – it need not be explicitly feminist, but is written about from a feminist viewpoint. An ethics of care is a type of moral reasoning (Sevenhuijsen, 1998) and is often contrasted to ethical theories that rely on universalist impartial principles of deontological, utilitarianism and theories of justice. It challenges abstract legalistic and moral universalising (Walker, 1998) which prioritises autonomy and impartiality by centring a feminist view of interconnectedness, relationality with roots in the private sphere (Robinson, 1997). Androcentric theorising excessively idealised moral agency (Tessman, 2014) and ignored emotional ties and relationships (Held, 2006). Deontological ethics have been criticised for being inadequate in helping people make actual moral decisions, choose between potential conflicts of duty and for discounting emotion as relevant to morality (Warburton, 2013), Sen argues that ‘reason and emotion play complementary roles in human reflection’ (Sen, 2010a, p. 39). Mill’s utilitarianism has also been critiqued as if utility is the ‘ultimate appeal on all ethical questions’ *(*Mill, 2008a, p.15) this may lead to unethical consequences (Smart and Williams, 1973):

> ‘How does he avoid the charge that he subordinates liberal values, such as rights and freedom, to judgements of utility that are liable to undermine such values?’ (Kelly, 2009, p. 387).

Care ethics as a moral philosophical framework, has evolved through a more Humean sentimentalist approach to become a cross-disciplinary concept which has broadened to include political and global import in addition to philosophical reasoning (Keller, and Kittay, 2017), although our natural caring inclinations remain broadly parochial (Engster and Hmington, 2015). Early feminist philosophers in care theory, including Carol Gilligan (1993), Sarah Ruddick, (1980), Nel Noddings (1982) and Joan Tronto (1994) critiqued androcentric philosophies and foregrounded a relational approach to moral theorising. Gilligan (1993) argued that women deliberate on different aspects of ethical dilemmas in different ways to men, observing and deliberating on complex relationships and inter connectedness. An ethic of care is not an overarching theory but a normative approach to examine moral considerations. Feminist thinking addresses real relationships and the caring relations which connect them (Held, 2006) and the multiplicity of spaces and ways in which caring takes place.

2.2.2 Early Care Theorists

Early theorists recognised that caring is often devalued and considered menial, feminine, and centred in the home. Sarah Ruddick's seminal work 'Maternal Thinking' is the one of the earliest evocations of the caring role of mothers, and the practice of 'mothering' as distinct from the identity of mother (Ruddick, 1980). She observed that mothers find themselves simultaneously powerful, in the private realm of mothering, and powerless in the public domain 'Almost everywhere, the practices of mothering take place in societies in which women of all classes are less able than men of their class to determine the conditions in which their children grow' (Ruddick, 1980, p.343). Ruddick differentiated and problematised the roles expected of men and women arguing that rather than focussing on encouraging men to do more childcare, the emphasis should be to bring maternal thinking into the public realm. Ruddick viewed mothering as relational, generational and a specifically feminist philosophy (Ruddick, 2004).

Carol Gilligan in the early 1980's began to look explicitly at the differences in moral reasoning between men and women. In critiquing the work of Lawrence Kohlberg, who deduced from a series of experiments that women are deficient at applying impartiality, a prerequisite for 'mature justice reasoning' (Porter, 1999, p.8), Gilligan hears a 'different voice' from women. Women, says Gilligan spend more time evaluating the needs of themselves and of others (Gilligan, 1993) within the complex relationships with which they are connected, rather than the impartiality of reasoning Kohlberg attributes to male thinking:

> '…men often formulate moral problems as a conflict of abstract rights and rules, women seem to construe morality as a clash of responsibilities in situations where maintaining bonds with others conflicts with personal integrity' (Porter, 1999, p.9).

Nel Noddings was the first to posit care as an ethical theory after failing to recognise her experiences as a woman and mother within philosophical and moral theories favoured by consequentialists, contractarians, and Kantians. Care according to Nel Noddings is 'rooted in receptivity, relatedness, and responsiveness' (Noddings, 2003, p2). She prioritised the reciprocity of relationships at the heart of her ethic of care and accentuated the 'feminine' as a more naturalistic or innate way of caring. Noddings and Gilligan rejected criticisms that they were reifying an essentialist understanding of care as feminine, and thus potentially entrapping women in the private realm. Gilligan argues that the different voices of men and women, were articulations of a justice *and* a care perspective are both important. As men took on more caring roles, and women increased their independence, Gilligan believed both perspectives would be adopted by more men and women (Gilligan, 1993).

Joan Tronto describes care as having four elements – caring about, taking care of, care giving and care receiving. Tronto refuted claims of an essentialism in an ethics of care, by interpreting the work of Scottish enlightenment thinkers like Hume, 'men were viewed as capable of morally delicate feelings' (Tronto, 1994, p.25). Tronto argued that moral questions have been shaped by the boundaries which split the private from the public, morality from politics, rational thought from emotions or local customs and norms. 'By the time women were able to voice their demands for a place in moral and political life, the boundaries to contain their arguments within a lesser, private moral sphere were already in place' (Tronto, 1994, p. 25). Tronto explicitly considered care to be labour, labour which has historically been considered of less value than productive work (Arendt, 1958). Tronto (1987, 2013) argued that an ethic of care can provide an alternative framework through which we can view values, and the labour of care work which underpin public as well as private life.

Fisher and Tronto identified key ethical qualities needed to care effectively; to be attentive, responsive, responsible, and competent and highlighted deficits which might impact carers' ability to do so 'From the standpoint of the caregiver, any shortage of time, knowledge, skill or resources, impedes the caregiving process' (Fisher and Tronto, 1990, p. 44). Tronto (2013) later added a fifth ethical quality – plurality. This addition was an enjoinder for a society wide caring and solidarity. An ethics of care can thus encompass a broader understanding of care as a moral imperative for action of organisations and institutions in the public realm (Tronto, 2013).

Noddings may be considered to have delineated the first attempt at an over-arching care theory formulation (Groenhout, 2003), but Virginia Held's Ethics of Care (2006) is the first to provide a fully-fledged and comprehensive ethic of care. Whilst care can take many forms, including comfort, sustenance, and receptivity to emotional and physical needs (Porter, 1999), foregrounded as work (Tronto), a practice and disposition (Engster and Hammington, 2015) not necessarily requiring an emotional component (Bubeck, 1995) or as a virtue (Slote, 2007), both Held (2006) and Kittay (1999, 2011) argue that care must be explicitly considered as both value and practice. They contend that to focus on care as a virtue, risks minimising the labour component in caring and further that care is a social relation rather than a descriptor of a caring disposition. Sander-Staudt (2006) warns that if care ethics is subsumed into a virtue ethics it risks losing its broader emphasis on care '…the need to care about virtue and the need to care about care' (p. 37). Held foregrounds the relational aspect of care, and concurs with Tronto that care is labour, but care is much more than work, it is a moral imperative, making a key distinction between caring for and caring about and insisting that care must extend well beyond the familial and friendship ties with which it is usually associated. Care is a global need (Held, 2006).

2.2.3 Care Ethics and Justice

> '…the ethic of justice takes freedom as it's starting point, while the ethic of care takes obligation as it's starting point' (Clement, 1996, p.4).

As the ethics of care has evolved over the last 40 years, much of the debate has focussed on whether it is a sufficiently developed theory which is capable of challenging prevailing theories of justice. Justice is a concept with multiple meanings. Justice can be understood at the universal, aggregate, societal and individual level and within ethical, legal, and political theories and frameworks. Justice is about equal treatment. At its heart are conceptions relating to fairness: opportunities and outcomes, human rights, redistribution, equality, care, harm reduction and reciprocity. That people are autonomous individuals who through development of rights, justice, and liberty, are free to find ways to meet their needs and choices is the prevailing ethic in Western liberal societies.

Care theory as a normative ethical theory is often considered in opposition to an ethic of justice. Rather than an overarching theory of universal abstract principles, an ethic of care foregrounds dependency, trust, relationality and considers care as contextual and situated. Historically, theories of justice have favoured abstract rules and principles and impartiality as the guide to moral dilemmas. Justice considered as fair outcome and opportunity (Rawls, 1971) or Nozick's justice as a fair *process* (even if the outcomes are not):

> 'We are fated to live in a world of background injustice, each of us descended from both victims and victimizers. It is a virtue of Nozick's theory that it need not pretend that we might achieve perfect justice if only we could "even the score."' (Schmidtz, 2020, p12).

Abstract reasoning producing universal public principles subordinates the relational aspect of caring, both as value and practice to the private arena. This public/private binary is not only at the heart of the debates between care and justice (Kymlicka, 2002) which have dominated in feminist moral theorising, but at the heart of feminism itself 'the dichotomy between the public and the private is ultimately, what feminism is all about' (Pateman,1987, p.103). Kittay et al (2005) contend that as dependency is part of the whole lifecourse, the private/public separation of care may be due to a denial regarding eventual dependency. A focus on justice is usually about fairness, whilst a focus on care is about meeting needs (Held, 2006, Baier, 2018).

The theory against which the ethics of care have predominantly been debated, is John Rawls' liberal social contract Theory of Justice. (Rawls, 1971). Rawls favoured a liberal egalitarianism and presented an ideal theory which 'assumes strict compliance and works out the principles that characterize a well-ordered society under favorable circumstances' (Rawls, 1999, p. 216). The main precepts of this theory promote equality, justice, and equitable distribution (including of primary goods), defending individual rights and choice over a liberal utilitarianism. John Rawls principles of justice, and particularly the difference principle:

> 'social and economic inequalities are to be arranged so that they are both: (a) To the greatest benefit of the least advantaged' and the fair opportunity principle '(b) Attached to offices and positions open to all under conditions of fair equality of opportunity' (Rawls, 1971, p. 302).

Rawls' Social primary goods include basic liberties: of thought, conscience, freedom of movement, enough means or resources (income or wealth) to achieve a variety of ends. It does not consider people's diverse abilities or partialities or what they can do with resources. Its primary focus is the means not the ends (Rawls, 1971, Brighouse and Robeyns, 2010).

Rawls uses the abstract consideration of a veil of ignorance to expound on his justice theory. Rawls suggests that if one was behind this hypothetical veil of ignorance and had no knowledge of one's societal status i.e. – one would not know one's gender, wealth, class etc, then one would assume a rational actor must choose values, norms and dictums which would bring about the most just and democratic society. Theorists in this tradition argue that 'rational agents' formulate good principles of justice (Rawls, 1971).

Critics of Rawls have argued that he over-estimates the rationality of people behind a veil of ignorance (Fukuyama, 2022) or that an equality of resources might meet one's principles better than the difference principle (Dworkin, 2002). Gilligan's advocation of a 'different voice' (1993) in addressing moral problems led her to contend that this resulted in a conflict between rights and fairness – justice in the public realm, and responsibilities and relationships and care in the private sphere. Kymlicka (2002) delineated further this dichotomy between a care approach and a justice approach, by outlining three binaries distinguishing the two approaches: universal/particular, common humanity/individuality, and rights/responsibilities and he advances an ethic of care, which underscores the importance of relationships and responsibility is in opposition to the moral conception of justice – rights and fairness.

Care is not a replacement for justice theories, but it does bring a relational ontology to moral and ethical reasoning. Feminist philosophers have contended that deontological, consequentialist, and justice moral theories based on male experiences and theories often promulgate a cost/benefit analysis synonymous with economic resource evaluations. Within that perspective, the values of competition and domination are seen to undergird both the activities of the marketplace and rational moral theories which espouse fair process rather than outcome (Nozik, 1974, Heywood, 1999).

Recent care ethic theorists believe that liberal notions of justice fail to include notions of dependency and care (Held, 2006, Kittay, 1999 and Slote, 2015) and that social contraction justice, in particular Rawls, need radical reshaping to include aspects of health and disability which may be considered an especially important aspect of justice (Daniels, 2010, Venkatapuram, 2011, Terzi, 2010). Disability or ill health bring particular challenges to Rawls justice and resource formulations - a rich person with a disability may be worse off than a poor person without one. Kittay proposes, an additional principle to Rawls theory of justice in order to address the relationality of care:

> ‘To each according to his or her need, from each to his or her capacity for care, and such support from social institutions as to make available resources and opportunities to those providing care’ (Kittay, 1999 p. 113).

Bhandary (2019) disagrees with Kittay’s assessment of Rawls position and argues that a more procedural approach to caregiving can be incorporated into Rawls theory with only minor adjustments, and with a focus of autonomy remaining in place. Engster contends Bhandary cleaves too strongly to the liberal at the expense of the ethic of care and that ‘If care ethics is simply dropped into a thin procedural liberalism, the result will be a liberalism sprinkled with care but not a full-bodied caring liberalism.’ (Engster, 2021, p. 7) but he acknowledges that her suppositions from beyond the veil of ignorance do address a shortcoming in Rawls theory ergo that ‘Rawls does not include dependency care within his original position, and Bhandary rightly points out that this is a major oversight’ (Engster, 2021, p. 2).

Terzi (2010) argues that Rawls’ primary goods are considered in relation to average needs, and this is problematic when one thinks of a disabled person’s needs, which might be greater and more atypical. She posits two responses with which theorists usually address this dilemma: foregrounding a social disability argument or a medical impairment contention. Pogge contends that these disadvantages should be addressed by other duties than justice (Pogge, 2010).

Some theorists argue that ethical issues cannot be considered by both care and justice simultaneously. Gilligan (1993) uses the analogy of a vase with two faces and Ruddick, describes justice in tandem with care (1980). Held proposes that an overarching normative theory of care is required. Held does not reject the more intuitive, 'natural' or innate aspects to care posited by Ruddick and Noddings but does not believe this precludes an abstract moral reasoning. Men may be more likely to use a neutral, detached, and impartial abstract reasoning for moral dilemmas, but the messiness of everyday relationships and connectedness requires emotional responses and adept juggling of competing demands. This caring 'particularity' can be extended from the private to the public sphere in our civil and political lives – emotional responses to injustice can enhance our practical responses. Brian Barry believes that '...the alleged conflict between an ethic of care and an ethic of justice is a bogus one', (Barry, 1995, p.256) and that care can be incorporated into an ethic of justice whilst retaining impartiality. Similarly, Smith attempts to '…collapse a dualism which might otherwise force an unnecessary choice between care as conservative parochialism and justice as universalism indifferent to actual human relations' (Smith, 2000, p.102).

Kittay (2002) calls for a just care and caring justice and idea Held (2006) has also adopted breaking down dichotomies by melding care with justice - 'fairer caring' and 'caring justice'. Held contends that justice and care are both required in moral considerations, (although she is clear that care comes before justice), but she advocates attaching a 'weighting' on one or the other depending on the situation being evaluated. She espouses a unifying theory, potentially having a global reach, broadening our caring relationships or 'caring relations' from the local and particular, to the universal. Bringing the feminist ethics of care approach from the private to the public realm and centring relationality 'care ethics begins with a social ontology of connection' (Lawson, 2007, p. 3).

Held (2006) assumes that if we were behind Rawls' veil of ignorance, we would choose to design a society which put 'caring relations' at its heart. Held believes it is axiomatic that we would elect to care and to be cared for, as dependency is inherent in all human relationships and without care, one cannot survive. This seems a normatively attractive supposition, putting care at the centre of theorising, yet it is not clear that someone behind the veil of ignorance *would* choose caring relations. They might regard a liberal conception of rights, personal freedom, and choice as more likely to build a just society. Whilst some social scientists and geographers have foregrounded an ethics of care and a relational model (Lawson, 2007, McDowell, 2004) others like Nussbaum explicitly put individuality as prior to relationships (Nussbaum, 1999). Bhandary argues that when the true costs both to a PLWD and a family carer are calculated a caregiver may choose not to care if they were behind the veil of ignorance:

> ‘… [A daughter] her elderly parents who both suffer from dementia. Her life becomes fully consumed by the care required to keep her parents alive and, even with the care, her parents’ experiential quality of life is radically diminished. At that point, the cost of dependency care has to be recognized as a full human life with its own potential. As a society, if people want to receive care that imposes such a substantial cost on other people, then we will need to model predicted care needs and policies to enable us to meet them without undue infringements to autonomy. Once the true cost of care is included in the assessment of care needs, parties in the original position may opt against receiving unlimited care during the end stages of life if they know that they may be a provider rather than a recipient of this care’ (Bhandary, 2019, p.156).

A further difficulty in using an ethic of care framework, is the multiple sites and types of caring which women do. Care may be a value, but it is first and foremost work (Tronto,1987, Sevenhuijsen,1998) and women do most of it. Whether paid or unpaid women are disproportionately affected. Essentialising care ethics and foregrounding a ‘different voice’ may risk reifying women’s caring roles and moral outlook, (Card, 1990) if moral theories reaffirm subservient traits as virtues in a Nietzschean ‘slave morality’ thus diminishing issues of justice. If one was again behind the veil of ignorance, is there a way of ensuring that care responsibilities would be just? Kittay (2011) responds to accusations of ‘slave morality’ by pointing out that an ethic which arises from the work and standpoint of oppressed peoples is one capable of showing that they do have a voice, and it can highlight a value previously disregarded.

McDowell argues that ‘the notion of an ethic of care based on mutual obligations and relations of trust is as applicable to the public sphere of the labour market as it is to social relations in the familial or domestic arena’ (McDowell, 2004, p. 157). Foregrounding care as work (Tronto, 1987, 2013, Sevenhuijsen, 1998) as a ‘necessary labor…[which] cannot be abolished precisely because it is necessary labor’ (Bubeck, 2002, p. 176) means we should ensure that a fair and equitable society provides for carers through fair distribution of resources through social provision and just institutions. But in the UK, where both unpaid and paid care-work is mostly done by women (Barnett, 2005) applying ‘weighting’ and ‘fairer caring and caring justice’ to the complex interconnected lives of caregivers may be idealistic.

Rawls’ theory of justice is inadequate to address the complex needs of people with disabilities and their carers. It does not capture the messy, interconnected lives that people actually live. (Kittay, 2011). Although Rawls does recommend correctives for additional needs such as disability, these are not within his principles of justice and are assumed to be dealt with later by institutions (Sen, 2010a, 2010b).

However, although an ethic of care encapsulates the relationality of people's lives it may run the risk of reifying and lauding care and caring as a duty that we must and would naturally want to do - this may be especially prescient for women (Nussbaum, 1999) where the Capability Approach may bring a superior approach to subjective and resourcist conceptions of justice – this will be examined later in the chapter.

2.3 Care, Autonomy and Relationality

> 'The core promise of liberalism to protect individual choice remains intensely desired…' (Fukuyama, 2022, p. 45).

Mill's theory of liberty is an underpinning principle for many political philosophers who regard individual liberty of fundamental importance (Hayek, 1991, Hoag, 1986, Ryan, 1970, Gray, 1991, Riley, 1998). Freedom is a complex conception. Berlin posits that freedom should be considered as a dyadic concept comprising both positive liberty – *freedom to,* and negative liberty – *freedom from* (Berlin, 1969). Mill's Liberty or Harm principle is usually ascribed as being a negative concept of freedom, 'that the only purpose for which power can be rightfully exercised over any member of civilised society, against his will, is to prevent harm to others' (Mill, 2008b, p. 14). Mill argues that it is not freedom itself, which is of intrinsic value, but that liberty is a means to an end – the end being utility, or the greatest happiness.

Mill regards individual liberty, and the ultimate goal of the greatest happiness for the greatest number as compatible. He justifies liberty because he believes that true happiness can only be achieved through the development of human beings to reach their full potential, and this will add to the increased happiness of people overall (Hayek, 1991, Hoy, 1984, Ten, 1980).

Mill assumes autonomous rational individuals capable of self-realisation. Autonomy may be considered a component of liberty and is strongly linked to concepts of justice and freedom (Wood, 2007, Mill, 2008b, Taylor, 1991, Rawls 1971). Feminists have critiqued Kantian and Rawlsian conceptions of autonomy as problematic for several reasons. They fail to identify the self as relational; they foreground independence and autonomy at the expense of other values, and if autonomy is esteemed more favourably than care and interdependency then this might disadvantage women more than men and advantage able bodied people over disabled people (Mackenzie and Stoljar, 2000, Code, 1991, Jaggar, 1983). Yet acknowledging autonomy, particularly for women historically denied full rights and citizenship remains important.

Women's roles associated with the home may include assumptions of care work which lauds subjugating one's own desires to others. This 'self-abnegation' has been viewed by many feminist scholars as a gendered practice associated with women, with continuing debates as to how this affects one's autonomy (Mackenzie and Stoljar, 2000, Oshana, 2015, Westlund, 2003, Frankfurt, 1999, Nussbaum, 2001). If care is considered a moral ideal paradigm (Weicht, 2015), then as with deontological ethics foregrounding duty may also demand from an ethic of care an imperative that we should care – does a relational dependency, depend on self-abnegation and relinquishment of rights of freedom and choice?

Nussbaum contends that the ideal of the selfless caregiver has damaging consequences for those who provide care – usually women (Nussbaum, 2006), and as care is historically situated in the home/private sphere it thus situates carers (women) in opposition to productive roles and as participants in civic life (Weicht, 2011, 2015).

Feminist theorists have tried to address criticisms of autonomy by introducing the term 'Relational autonomy' (Mackenzie and Stoljar, 2000). Using the label 'relational' allows for an autonomy which is not predicated on rational individuals but instead recognises that autonomous people value social relationships of care and interdependence. Relational autonomy may also challenge certain notions of discrete personhood, accentuating that individuals are also rooted in social, spatial, and cultural conditions. Iris Marion Young prefers a conception of 'personal autonomy' which she contends is conceptually similar to negative liberty, but includes 'supportive independence':

> 'Certain forms of dependence and interdependence…should be understood as *normal* conditions of being autonomous.' (Young, 2002).

A relational ethics of care ontology may be closer in philosophy to communitarian moral theories (Shweder, et al, 1997, Smith 2000, Haidt, 2013) including African moral theories such as Ubuntu (Metz and Gaie, 2010, Metz, 2013, Chisale, 2018). Shweder and Haidt (1993) argue, an ethic of community which foregrounds the relational, families and communities is an important aspect of moral psychology and posit that we need to consider the evolutionary or biological underpinnings, the social or cultural historical settings within which we live, and finally our own personal experiences growing up within our families and communities. Haidt advocates Hume's 'messy, pluralist, sentimentalist approach…' (Haidt, 2013, p.141) over the rationalist, logic and reasoning of Kant, Mill and Bentham. This has corollaries with Adam

Smith's Theory of Moral Sentiments which also foregrounds that our morals derive from our social nature rather than abstract reasoning (Smith, 1976).

Metz specifically connects Ubuntu with an ethic of care. Although Ubuntu has some conceptions of individual rights and justice, it has greater similarities to an ethic of care in that it prioritises relationships. Metz argues that it broadens the notion of care to extend to others who are not just in a reciprocal relationship and like Held's universal theory of care, sees Ubuntu as an overarching ontology: 'According to Afro-communitarianism, the relevant relationship to prize is not merely one of caring for others' quality of life but, in addition, sharing a way of life' (Metz and Gaie, 2010, p. 284). This subtle difference in evaluating the two theories opens up windows of enquiry to situate an ethic of care in broader communitarian relational frameworks.

Communitarian conceptions may associate duty and caregiving with traditional women's roles within families (Shweder et al, 1997) sometimes to the detriment of women's autonomy (Haidt, 2013) but Chisale (2018) maintains that a proper understanding of relational ontologies foregrounds care as a normative collective position for both men and women.

In contrast to Chisale, Gouws and Zyl contend that Ubuntu in practice contains patriarchal norms and an ethic of care is better placed to deliver equality and justice to women (Gouws and Zyl, 2015). But Gouws and Zyl argue that '…individualist ontology has eclipsed relational ontologies such as a feminist ethics of care and ubuntu' (2015, p. 165). An individual rights framework continues to overshadow communitarian or relational ontologies, (Haidt, 2013).

Care ethics can incorporate autonomy, equality, and justice and perhaps it could be argued that it can be incorporated into existing theories, particularly in virtue ethics more broadly (Groenhout, 2003, 2014, Slote, 1998, McLaren, 2001). A conflict between ethics of care and justice might be argued to be a false dualism, with the relational aspects of care capable of producing a relational caring justice. Caring approaches should promote autonomy only within an ethic of care which elevates '…relational persons in better caring relations' (Held, 2006, p14).

Holstein posits that autonomy for many older people is a myth and centres a more relational model with an ethic of care better placed to address needs at end of life '…we need love and support as much or more than we need the chance to decide…' (Holstein, 2013, p. 638). Holstein argues that a moral lifestyle foregrounding care is not created by autonomous individuals but is as a result of relationships. Caring or being cared for is an important aspect, particularly when we are older, but autonomy and individual freedom remain crucially significant aspects of our lives which cannot be ignored, or set aside in self-abnegation without losing part of ourselves:

> 'To be the valuers that the ethical caring requires, we need to preserve in ourselves, as well as value in others, a certain spiritual integrity. Otherwise, we risk becoming simply tools or extensions of others' (Card, 1990, p107).

2.4 Spaces of Care and Justice

As care work and caregiving are place based and spatially impacted, the feminist ethics of care has developed since the 1980's across disciplines to include feminist geographies (McEwan, and Goodman, 2010), landscapes of care (Milligan, 2001, Milligan and Wiles, 2010) and therapeutic landscapes (Gessler, 1992).

Spatial justice is a comparatively recent label. It merges two constructs – social justice and space. During the 1970's, social justice became linked to other geographical theories (Harvey, 1973, Rosenburg, 2014, Lefebvre, 1991, Castells, 1978). More specifically with the combination of social justice and space, it created 'spatial justice' (Soja, 2009, Marcuse, 2009). Discourse on spatial justice has included Marxist (Marcuse, 2009) and post-modern (Soja, 2010, Foucault, 1977).

Both social justice and space constructions are open to a diversity of denotations. Space, Foucault argues ought not to be deemed as 'the dead, the fixed, the undialectical, the immobile' (Foucault, 1977, p. 70) and Lefebvre, a Marxist theorist in his seminal work The Production of Space argues that '(social) space is a (social) product' (Lefebrve, 1991, p. 26). Dominating notions of social justice are usually conceived utilising John Rawls' notion of redistribution, (Rawls, 1971) and a fair decision-making process as advocated by (Nozick, 1974) as key to spatial justice theorising. Spatial justice foregrounds a place-based conception of justice to people's lives –to the actual places people live – their homes, their communities, rural and urban spaces.

Harvey adjudged those ideas of space and social justice can only be analysed by examining human behaviour 'there can be no philosophical answer to a philosophical question – only an answer fashioned out of the study of human practice' (Harvey, 1973, p. 16). Soja, more recently has re-examined and developed Lefebvre's and Foucault's ideas on the character and construction of space, by foregrounding the conception of 'third space' – in which Lefebvre's spatial concept evolves to become *'spatial trialectics'* which incorporates both the real and the imaginary and that merging spatial with justice 'opens up a range of new possibilities for social and political action, as well as for social theorization and empirical analysis that would not be as clear if the two terms were not used together' (Soja, 2009, p. 4).

Marcuse asserts that there are two fundamental modes of spatial injustice – a) the imposed confinement of people in demarcated spaces which he labels the 'unfreedom' argument and the inequitable distribution of resources and amenities over a specified area, the 'unfair resources' argument. (Marcuse, 2009, p. 3). This correlates with the Rawlsian approach to resource allocation as discussed earlier in the chapter.

Most literature has focussed on the urban at the expense of the rural. French researchers such as Lefebvre and Castells dominated urban theorizing in the 1960's and 1970's, and when social justice and space combined in the early 1980's to form the term 'spatial justice' (Soja, 2009, p. 4) 'the term spatial justice became almost exclusively associated with the work of geographers and planners in Los Angeles' (Soja, 2009, p. 4).

Soja's third space and Marcuse unfreedom and unfair resource frameworks may provide useful ways to explore empirical data relating to care and carers, however, the predominance of urban theorising of spatial injustice may be at the detriment of rural considerations. Castell arguing that spatial justice in a rural setting may not fit within established theoretical frameworks. 'generally, researchers applied established theories without modifying them to the reality observed' (Castells, 1978, p. 11).

The literature suggests that carers and PLWD might be especially affected by 'unfreedom' due to infrastructure deficits particularly in rural areas with a lack of suitable accessible toilets, long distances to healthcare facilities and services. Difficulties result in carers being 'tethered to the site of caring……spatial behaviour is usually restricted to walking distance of the site of care or short car journeys…' (Kitchen, 1998, p. 349). These spatial injustices are compounded by a lack of appropriate public transport 'Society spacially disadvantages disabled people in the design and maintenance of public transport' (Kitchin, 1998, p. 348).

Rurality may also make carers more vulnerable to further injustices of unfair resources (Keating, 2008). Resources historically, have been predominantly targeted at inner city deprived areas. This injustice has been particularly acutely felt in rural health services, which has been chronically underfunded in recent years with 'the Cinderella services – elderly care, rehabilitation and support for carers – that have arguably been more silently squeezed' (Asthana, Halliday and Gibson, 2009, p.209).

Soja maintains that three factors class, race, and gender impact ‘locational and spatial discrimination’ (Soja, 2009, p.3), but age and disability should be equally influential in assessing spatial injustices. Spatial justice might intersect with the lives of carers and PLWD individually and relationally. A study in rural Scotland highlighted the importance of this:

> ‘… the importance of the heterogeneity within experiences of rural living, AND the need for service provision to recognise the individualised personal and spatial biographies of our participants’ (Blackstock et al, 2006, p. 173).

Although the influential book ‘Prisoners of Space’ was published over 40 years ago (Rowles, 1978) studies into the lives of older rural dwellers continues to be scarce (Hopkins and Pain, 2007, Bradley 1986, Milbourne and Doheny 2012, Stockdale, 2011) especially around familial care in rural areas (Tarrant, 2010, Milbourne, 2012, Milligan, 2000, Scharf and Bartlam, 2006 and 2008).

Health and social care services are affected by geographical factors such as rurality which strengthens the probability of loneliness, isolation, increased transport costs (Milbourne, 2012, Milligan, 2000, Bradley, 1986) and poverty (Milbourne and Doheny, 2012). Rural areas are places of older people - young people are leaving whilst older people (55+) are moving in. (Milbourne, 2012, Stockdale, 2011). These older people often have complex and long-term health needs (Stockdale, 2011), placing increased pressure on carers. Accessibility issues are important at an individual and policy decision making level:

> ‘There is merit in regarding accessibility as a spatial (or, more correctly, a space–time) dimension, which interfaces in a potentially constraining way with structural dimensions. This is as true at the level of the individual experiencing life opportunities and constraints as at the level of government policymaking. Accessibility is fundamentally about the life opportunities open to people. It is not a sufficient condition for social inclusion and social justice, but it is a necessary one. Of course, it cannot be universally or totally achieved (Farrington and Farrington, 2005, pp. 10-11).

Under theorising disability, ill-health, or age in justice conceptions, whether resource, subjective or spatial (especially rural spaces), leads to inequities and injustices being built into institutional and social practices.

2.4.1 Landscapes of Care

> ‘Landscape is the spatial form that social justice takes’ (Mitchell, 2008, p. 45).

Homes and communities are more than the physical spaces, but places to which people form emotional connections which are continually evolving in response to individual circumstances, legislation, governmental and financial decisions which have consequences for community life (Wiles et al, 2011). Homes represent spaces of protection and kinship, and these attachments can be valuable to the well-being of older people (Taylor, 2001).

Wiles et al (2011) emphasises the significance of the wider understanding of ‘home’ through the access to accustomed neighbourhoods and social networks. ‘Their attachment to place is not just an internal or emotional state it has a material impact: it is a tangible resource for ageing in place’ (Wiles et al, 2011, p. 365). Theories of ‘ageing’ and ‘places’ have spatial, social, and temporal aspects.

Landscapes of care have changed as more people with complex illnesses such as dementia are living longer, often at home. Ageing in place (Wiles et al, 2011, Davey et al, 2004, Means, 2007) has been advocated as best for older people with support needs allowing them to stay at home living independently in the community. It is financially advantageous, reducing care costs to both families and community service provision and protecting squeezed local authority resources. These exitutional arrangements, advancing a safe and connected environment (Taylor, 2001, Wiles et al, 2011) are usually compared favourably to institutional care, but there has been inadequate consideration on the effect on carers, as family homes begin to resemble care homes for one, potentially developing into spaces of imposition, loneliness, institutionalisation and eventually places which may be the antithesis of a therapeutic environment (Egdell, 2013, Gessler, 1992, Milligan, 2003):

> ‘The extent to which such exitutional care arrangements are an improvement over the old institutional ones is debatable’. (Milligan and Wiles, 2010, p.746).

The term ‘Landscapes of Care’ has been in vogue in geography and in other fields in recent years influencing wider genres of health geography, gerontology, and ethics of care (Bozalek and Hooyman, 2012). Landscapes of care, like an ethic of care, is a concept which can be used to appraise the ‘… relationships between people, places and care’ (Milligan and Wiles, 2010, p.736), unpacking caring practices in both public and private, and at local or national level. Furthermore, it can be used to assess discrimination, and reification of gendered caring stereotypes in the spaces in which caring practices are undertaken.

The last thirty years has seen a ‘voluntary’ turn as state provision of welfare has moved to the third sector (Milligan and Conradson, 2011). Local voluntary community groups, specialist organisations and informal carers and volunteers have progressively been expected to fill gaps in social care provision. This ‘turn’ has transformed the landscapes within which long term complex care takes place from primarily institutional and local council based to community and home. This complicated network of provision, combined with austerity policies and cuts in services has resulted in carers facing perpetually fluctuating and complex caring landscapes (Milligan and Wiles, 2010).

Valerie Egdell (2013) identifies carers, specifically of those with dementia, as facing particular challenges. As increasing numbers of PLWD remain at home for longer, the landscapes of care including informal and paid care, incorporate differing and changing expectancies. Egdell suggests that there are three factors to consider in the shifting landscapes of dementia care – navigating care giving roles, understanding boundaries and the varying landscapes of care. The landscapes include spatial expectations of carer proximity - i.e., the person living closest is responsible for care of another – often one sibling caring for a PLWD for example (Willyard et al, 2008) and further of gendered assumptions - a daughter is conventionally associated with caring. Sometimes the daughter undertakes caring responsibilities precisely because nobody else will do it (Egdell, 2013). The fluidity of caring boundaries can distort relationships, with differentiation between familial and caregiving roles becoming blurred. As private homes become places of prolonged and complex care, often resembling mini care homes with multiple technological or care aids, carers may often struggle to acknowledge their carer status, as a means to retain a sense of normalcy for their relationship role (Carduff et al, 2014). Residential or nursing homes are habitually viewed as places of last resort for both financial and therapeutic reasons (Owen and Meyer, 2012), and as a metaphorical black hole of irreversibility (Gilleard and Higgs, 2010):

> '…fear of loss of control and self-determination in combination with guilt at not caring enough by one's own or others' judgement fuels many nursing-home narratives, whose vision is often based on somewhat old-fashioned notions of such institutions, derived from Victorian poor houses, as quasi-prison facilities…' (Simonsen, 2017, p. 178).

Thus, local, and national policies foregrounded on a care in place policy, serve to help people stay at home and avoid the stigma and horror of institutional care. As this ageing in place strategy has led to 'care-in-place' through deinstitutionalisation of services (Milligan and Wiles, 2010), it has created 'part-institutions' in the home or community known as 'extitutional arrangements' (Domenech and Tirado, 1997). There is a risk that rather than ending care practices deemed institutional and unsatisfactory, may in fact reify them in a different landscape - re-institutionalisation of the home. It may also impact the well-being of other family members or carers:

> '…for each dementia sufferer living in the community there is at least one informal carer, whose physical and mental needs also need to be addressed' (Mukaetova-Ladinska, 2017, p. 342).

Focus on retaining independence and staying at home also risks affecting the relationship of the carer and the cared for person as the drive to maintain skills overrides compassion for the person struggling to retain them:

> ‘Another consequence is the sacrifice of warmth and friendliness in a relationship when one person’s overriding goal is to get another person to do things for her/himself.’ (Wendell, 1996, p149).

2.4.2 Therapeutic Landscapes of Care

> ‘Theorists are needed to generate and utilize fertile concepts like therapeutic landscapes to make sense of the ever-changing terrain of care and well-being’ (Cutchin, 2007, p193).

Landscapes of care frameworks can be expanded by the additional concept of therapeutic care. With burgeoning technological advances and equipment at home and in residential settings as above, there has been a failure to recognise the impact on both carers and cared for. Family homes often become spaces lacking in privacy, of loneliness, institutionalisation and not necessarily able to provide a therapeutic environment (Egdell, 2013, Gessler, 1992, Milligan, 2003).

Initially devised by Gesler (1992), therapeutic landscapes were originally considered places of convalescence. Williams (2002) and Conradson (2003) expanded the meaning to include places and spaces of healing including the people, animals and objects which inhabit it.

Therapeutic caring environments are not fixed (McLean, 2007) but vibrant, ever-changing places holding an array of social connections, persons, places, and objects and are produced by frequently altering social and institutional arrangements (Williams, 2007). Care and the spatiality of locations of care including therapeutic landscapes advocate a relational awareness. ‘relations and practices of care...are implicated in the social production of spaces’ (Conradson, 2003, p.451).

Therapeutic spaces may be found both in expected (Williams, 2007) and in unanticipated (Laws, 2009) places: at home, in the community, in residential care, in solitude and in everyday life. Residential provision for PLWD is often regarded negatively, yet care homes are sites where caring relations take place. Places of ‘intimacy and embodied intersubjectivity’ (McLean, 2007, p.323), where care-workers interact and engage directly with residents. When undertaken sympathetically, these living relations can provide healing for both giver and recipient of care, in the relational interaction and caring spaces (Kittay, 1999, Kontos, 2004, Kontos et al, 2017, Hammington, 2004).

Care in place at home utilising a ‘person centred approach’ (Kitwood, 1997) for PLWD may result in reduced attention on the impact on family caregivers. Williams (2007) suggests that home may not be ineludibly therapeutic for caregivers, ‘places can be simultaneously healthful and hurtful’ (Williams, 2007, p. 2), with carers well-being affected by an environment which may be concurrently beneficial or detrimental for health (Donovan and Williams, 2007).

Carol Jagger of Newcastle University talking on the Today Programme about research on future care home provision (Kingston et al, 2017) described a likely shortage of family and informal carers to support people living at home and suggested:

> ‘I’m not sure [home] is the most appropriate care for some older people…sometimes older people are being left alone for a long period of time and getting lonely. Care in a good [residential] home is probably better in some cases’ (BBC Radio 4, 2017).

Literature on care homes as spaces of care and healing are sparse suggesting that there has been ‘little in depth analysis of residential care settings as therapeutic landscapes’ (Cutchin, 2007, p.181) and continued negative media coverage of residential care for PLWD may preclude or hamper examination of examples of good care home provision.

2.5 Dementia and Care – Identity, Recognition and Relationality

> ‘A person is a being with a certain moral status, or a bearer of rights. But underlying the moral status, as its condition, are certain capacities. A person is a being who has a sense of self, has a notion of the future and the past, can hold values, make choices; in short can adopt life-plans. At least, a person must be the kind of being who is in principle capable of this, however damaged these capacities may be in practice’ (Taylor, 1985, p. 97).

The ethics of care foregrounds the importance of a relational approach as examined above. Care and caring practices are what we do and what we should do. Butler (2016) asserts that recognition is a mutual act of two or more people through the repetition of identification, thus identity and recognition is an important, reciprocal, relational process, without which well-being can be impacted. Mis or non-recognition can be considered harmful to well-being (Taylor, 1994). Identity is fashioned through our perceptions of who we are in relation to others and by this (mis) recognition of ourselves and our identity. It is produced by a dualism of opposites and ‘others’ (Said, 2003). Dementia establishes a space of ‘us and them’. People with dementia are existing but on the margins of the norms we ascribe to everyday lives. Changes wrought by dementia challenge our understanding of identity and selfhood bringing questions regarding recognisibility and meaning (Hughes et al, 2006, McMillan, 2006, Tanner, 2013).

Identity is a contested concept and may be considered in numerous ways – as a physical and psychological continuum (Parfit, 1984) selfhood as being embodied, (Hughes, 2014, Kontos, 2004) as personhood, (Kitwood, 1997) as a narrative process, (McAdams, 2001) or as socially created and reconstituted through performance (Butler, 1990) or interactions (Massey, 2004). Heidegger posits that one must be situated and aware, (Davis, 2004). Identity may also be understood as a plurality (Sen, 2007) or fluctuating as 'successive selves' (Parfit, 1984). Whilst Goffman (1963) posited three separate levels or types of identity: personal, social and ego identity.

Brock, (1988) and Parfit (1984) would concur that for personhood to remain, there needs to be psychological continuity. Matthews, (2006) and Hughes (2014) explicitly reject that memory is needed for psychological continuity. Kitwood, (1997) Kontos (2004) and Hughes (2014) argue that embodiment and embodied selfhood allows retention of personhood - 'we are embodied and we are situated' (Hughes, 2014, p71). Lindeman (2009) and Brison (2017) contend that a person in late-stage dementia with severe cognitive deterioration can nevertheless be 'held' in personhood. Hughes also foregrounds the relational as being crucial to the retention of a meaningful self. He suggests that even when dementia appears to change someone so much that they are hard to recognise, they remain in part because of their relationship to others – particularly family, but also to paid caregivers:

> '…at least in part, what I am as a person can be held by others. My relationships, in a sense sustain me. Even if I can't remember, they can.' (Hughes, 2014, p72).

Butler (1990) sees identity less of an innate essence or 'being' and more as a 'doing' (performativity). Following Foucauldian notions that bodily acts of practice reconstitute the body itself, Butler foregrounds these practices as a process of materialization '…that stabilizes over time to produce the effect of boundary, fixity and surface we call matter' (Butler, 1993, p. 9). Barad (2007) posits that the material reality of bodies is not just a social product and argues '…surely it is the case …that there are 'natural' not merely 'social' forces that matter' (p. 66). If our doing, or performativity is therefore our being, then there is *self* in whatever or however we are performing, and so caring for another is naturalised 'Precisely because a living being may die, it is necessary to care for that being so it may live' (Butler, 2016, p.14).

Despite differing sociological and philosophical conceptions of identity, it is often regarded with an immutability, which belies narratives of process and plurality '…we see very powerful expressions of fixity around identity' (Lawler, 2014, p. 5). Identity is created through the relational stories we recount and the ways in which we interpret them and thus challenge notions of separate, autonomous individuals – we require shared histories '…our narratives must, to some degree, accord with the narratives of others' (Lawler, 2014, p. 43). A recent radio broadcast with Richard Denton, the producer of programmes made with Johnathan Miller (who developed Alzheimer's), when asked what he had learned from him said 'personhood comes from the brain, and it comes from the memory...' (Miller, W. Lost Memories, 2021).

Having worth requires recognition. As PLWD experience loss of retention ability and other intellectual deterioration their 'identity' and thus recognition becomes problematic. Caregivers and other family members face being 'mis' or 'un' recognised by the person they care for, but they may also find it difficult to recognise the PLWD too. Identity and recognition correlating to caregivers of PLWD as well as the person themselves asks us questions about who has value and who does not:

> 'There are subjects who are not quite recognisable as subjects, and there are lives that are not quite recognised as lives' (Butler, 2016, p. 4).

Lack of value and recognition may impede sympathy for those whose admission of suffering faced through sickness or incapacity is considered unworthy, '…as if there was no such thing as suffering by inadvertence…' (Sontag, 2004, p. 36). Normative expectations of recognition reciprocity are used to distinguish between existing and living. Does caring for PLWD lead to a form of compassion fatigue (Sontag, 1979) where we both pity and deride them and the people who care for them? 'Thus, grievability is a presupposition for the life that matters' (Butler, 2016, p. 14).

Value through relational caring itself may be maintained when caregivers are able to acknowledge:

> 'The frailty and fragility of the fourth age can serve to remind us of our common humanity and the universal vulnerability of our bodies and our relationships...care is offered as a source of potential redemption. Embedded in a caring relationship, the orphaned body may seem less isolated…' (Gilliard and Higgs, 2011, p.141).

Ethics of care theorises our identities as created through relationships (Held, 2006). It values the ties we have with particular other persons. Caring for someone who does not recognise you, and perhaps who you also fail to recognise at some philosophical level may be predicated on an idealistic care ethic and deontological approach which acknowledges the embodied person and the continuation of valuability through the act of caring. If identity is mutually constituted through a reciprocal relationship and through an understanding of identity through narrative memory, then caring for someone with dementia who loses this narrative thread may be negatively impactful on carer well-being. ‘Memory is identity, and without memory, we have no identity...’ (Miller, Feedback, 2021). This philosophical and ethical understanding of dementia care is crucial to appreciating how carers’ personal responses to caring for someone with dementia may develop.

Clare and Shakespeare (2004) argue for a more relational approach when considering PLWD and their carers as memory decline in the early stages of dementia can have a profound effect on the identity of both individually. Negative conversational interactions may lead to Kitwood’s ‘malignant social psychology’ (1997) as cognitive changes wrought by dementia change the balance of power in a relationship and both partners in the relational dyad can struggle to retain a concept of identity (Clare and Shakespeare, 2004). Carers and families of PLWD may experience ‘dementia grief’ (Blandin and Pepin, 2017) or an ‘anticipatory grief’ (Alzheimer’s Society, 2021, Fulton, 1987) at the loss or future loss of the person’s identity.

Identities are constructed through the narratives of ourselves in conjunction with the narrative relationships with other people (Tolhurst et al, 2017, Baldwin, 2005, Taylor, 1989). We are constituted by the stories which we tell. As a PLWD’s memory and other cognitive skills begin to fail, the carer struggles to maintain this narrative connection with the PLWD. Not only does the narrative change (which it also would without a dementia diagnosis), but they must often adapt their own narratives to successfully adopt more successful caring techniques:

> ‘The fullest sort of individual identity is something we acquire gradually over the course of our development towards adulthood, which continues to change subtly even during our adult life, as we add fresh memories and fresh reflections on our past. It is this developed adult sense of self to which other adults respond, which they love or hate, when they think of an individual as most truly their unique self. Because it depends for its continued existence on recall, then there is a sense in which people with severe dementia have lost some of their identity as persons, so that they are ‘no longer the people they once were’’ (Matthews, 2006, p. 176).

Carers may experience a sense of bereavement at the social death of the PLWD prior to the physical death (Sweeting and Gilhooly 1997) and guilt if this leads to difficulties in making moral decisions (Tessman, 2014) about providing continuing care (Gallego-Alberto et al, 2022).

2.5.1 Care, Dementia, Disability and Justice

Wendell (1996) believes feminist ethics has two key challenges to address, which affect lives of people with disabilities (and carers). How to marry an ethic of care focussed on relations with theories of justice focussed on individual liberty, and rights. Emphasis on ‘independence’ can sometimes be at the cost of adequate care and in addition, prioritising ‘independence’ is lauded even when it may be wholly unrealistic:

> ‘…when we think of all people interdependent, we are less likely to imagine that those who give care do not also need it, more likely to ask what forms of care caregivers need...if everyone with a disability is to be integrated fully into my society, without being ‘the Other’ who symbolizes moral failure, then social ideals must change in the direction of acknowledging the realities of our interdependence and the value of depending on others and being depended upon.’ (Wendell, p150-1).

Considerations of justice, particularly social justice has been an essential component of social geographical research over many decades (Hopkins, 2021, Jones and Richardson, 2020) including care (Held, 2006, Lawson, 2007) health (Venkatapuram, 2011, Rosenberg, 2014) and gender (Jagger, 2017, Young, 1990) and as argued earlier in the chapter, a dichotomy in social political and moral theory with justice linked to the public realm and care allied to the home (Benhabib, 1987).

Dementia is often considered to progressively denude an individual of their identity, their personhood and therefore their citizenship. As cognitive function and the ability to effectively communicate decreases, concomitantly the person with dementia’s rights and expectations of active community involvement similarly decrease. Philosophical conceptions of identity and value are important aspects of dementia and disability discourse, with implications for citizenship, care, and justice. There is often a stigma associated with disability, ageing and with caregiving (Link and Phelan, 2001) which can be compounded by the additional burden of stigma created through the stereotyping and dismissing of older people (Degnan, 2012). Those who are deemed to have no ‘value’ or power (such as PLWD) suffer from a stigma and a diminishing (Link et al 2004, Link and Phelan, 2001, Green et al, 2005). Value is a contested concept, but our conventional perception of it usually lies within an economic and/or ethical framework. People deemed valuable persist in positions of dominance whilst those on the fringes are stigmatised as insignificant and without value (Skeggs and Loveday, 2012). There are thus moral challenges (Post, 1995) when considering PLWD’s personhood, agency, and value. Carers through their relation to a PLWD may experience stigma through association:

> ‘…an adequate philosophical theory of personal identity, however abstract it may sound, can have very practical consequences for the ways in which we think about, feel about, and deal with people with dementia’ (Matthews, 2006, p.177).

Diagnosis and the ongoing changing spatial and temporal world of carer and cared for, often including eventual entry into residential care, provides continual ‘biographical disruptions’

(Bury, 1982) There is a concomitant disruption in identity as PLWD and caregiver struggle to maintain the reciprocal process of recognition, 'valuing' and being 'valued':

> 'Valuable and grievable lives on the one hand, and devalued and ungrievable lives on the other hand' (Butler, 2016, p. 22).

Social justice for older people, people with disabilities (including those living with dementia) has been conceptualised through social models of disability (Shakespeare, 2014), citizenship (Bartlett, 2016, DEEP, 2016), exclusion (Walsh, Scharf and Keating, 2017) and through a human rights perspective (Cahill, 2018).

Disability which was once considered solely as a medical impairment (Hasler, 1993) has increasingly been studied as a social model of disability (SMD) (Barnes and Mercer, 2004, Oliver, 1983, 2004, Thomas, 2004). In the SMD *impairments,* medical conditions of the body or mind, may be considered alongside social and environmental *disability.* Injustices suffered by disabled people are due less to impairments than as a result of economic, environmental, and social barriers including the continuing stigma and discrimination maintained by able-bodied people (Shakespeare, 2014). Linking disability studies specifically with dementia has been a more recent development (Milligan and Thomas, 2016, Thomas and Milligan, 2018, Shakespeare et al, 2017), with Tom Kitwood's model of personhood (1993, 1997, Kitwood and Bredin, 1992) and Lyman's (1989) critique of the biomedical model of dementia being early influences in developing social templates of SMD and dementia specific considerations.

Kitwood is generally regarded as the first to move away from the medicalised understanding of dementia and towards a humanistic, psychosocial approach during the 1990's (Kitwood,1997). By insisting that personhood could remain throughout the progression of the disease, Kitwood foregrounded a person-centred care model 'dementia care mapping' by which he identified 5 needs - comfort, attachment, inclusion, occupation, and identity. By meeting these needs he argued, well-being would improve, and personhood could be maintained (Kitwood, 1997, Brooker, 2007). Prior to Kitwood's person centred framework, most of the literature focussed on the 'othering' of PLWD and carer burden (Sabat et al, 2011). Personhood is defined by Kitwood as:

> 'a standing or status that is bestowed upon one human being by others in the context of relationship and social being; it implies recognition, respect and trust' (1997, p. 7).

Kitwood's understanding of personhood encouraged others to accept that the person with dementia should remain '...valued as a person (a self) in the eyes of others, throughout the progression of the disease' (Bruens, 2014). Kitwood's concept of personhood can be challenging as he simultaneously held the view that 'the self could change over time but would also persist throughout the dementia process' (Bruens, 2014). This implies a consistent intact mental capacity (Behuniak, 2010) which by the very nature of the illness seem problematic.

Milligan and Thomas (2016) argue that it is the responsibility of society not PLWD to make appropriate adjustments, therefore increasing inclusion and citizenship. Bartlett and O'Connor (2010) concur foregrounding a social citizenship for PLWD (Bartlett, 2016). Kontos et al (2017) explicitly underline the relationality of citizenship through an understanding of embodied self-hood and through examination of stigma and its intersection with carers and PLWD. It is a philosophy which advocates the primacy of reciprocity and care of PLWD as full citizens in society (Kontos et al, 2017, Bartlett, 2016, Birt et al, 2017) Caring and being cared for – 'caring relations' can provide the reciprocal relationship where the act of caring and the receiving of that care in an interdependent relationship can invite a citizenship through the act of caring; a corporeal or embodied citizenship:

> 'How a society treats its most vulnerable members clearly reflects that society's character. A 'right' is something that requires no justification. People possess human rights as a matter of definition. People living with dementia have not, as a result of their diagnosis, lost their humanity or their human rights unless those of us deemed healthy decide to strip that humanity and those rights from them, in which case dementia alone is not to blame' (Sabat, 2018, p. xii).

Kittay (2002), however, highlights the dangers of envisaging a 'full-blown notion of personhood or citizenship' (p. 271) to address the lack of rights which people with disabilities have for so long been without. People should not need to be regarded as sufficiently 'persons' or possessed of citizenship for a just society to require that they should not suffer harm and should be cared for as valuable persons.

The social model of disability developed for people with physical disabilities has proved inadequate when addressing those with cognitive impairments (Shakespeare et al, 2017). Despite growing self-advocacy and activism from people with dementia (Bartlett, 2016) the very nature of the progressive medical impairment means that any activism will be challenging, only available to those in early stages of dementia and often short-lived. Social participation, citizenship, activism, and self-advocacy for PLWD must surely also rely on a carer to facilitate. Recent understandings of dementia as a human rights issue are problematic because considering one individual's rights may be in direct opposition to another person's rights – carers *share* the dementia experience (Shakespeare et al, 2017). The Convention on the Rights of Persons with Disabilities (CRPD), the Equalities Act (2010) and other legislation promote an individualist rather than a relational approach which fails to adequately address the social injustices of PLWD. A social or relational model of dementia (Shakespeare et al, 2017, Thomas and Milligan, 2018) which addresses the interdependency between PLWD, and carers would be better placed to tackle carer and cared for injustices.

2.6 Dementia Care and Carer Well-being

Citizenship and social inclusion for many PLWD is only possible if a carer helps to facilitate their social participation. An ethic of duty and relational care may indicate the rightness of such action, but there may be negative or unintended consequences for the carer in this situation (Davis, 2004). Supporting some people with complex and challenging behaviours may leave carers open to stigma and discrimination and encounter spatial and environmental disabling factors associated with the care practice or lacking in appropriate skills to manage. Kitwood (1997) implicates untrained carers (however caring and empathetic) in disabling PLWD through exclusions borne of ‘a defensive reaction, a response to anxieties held at an unconscious level’ (Kitwood, 1997, p. 14). Kitwood further argues that family carers are complicit in creating a ‘malignant social psychology’ – devaluing and diminishing someone - by failing to uphold the personhood of the PLWD through a person-centred approach. If, as discussed above, the carer feels that the person they are caring for no longer has the same ‘identity’ and that their caring is unreciprocated, or fails to maintain a sense of personhood, this admonition may lead to a ‘malignant social psychological’ situation for carers, who may feel devalued and diminished too:

> ‘If a carer feels that the person they had a relationship with exists no more, then they themselves are directly involved in the dissolution of personhood. Guilt compounds a bereavement that has not yet come to pass…his [Kitwood] trying to preserve personhood without memory, or rather, persons without awareness of their Being is more than a point of academic curiosity. The adverse consequences of his arguments concern family carers and how they may respond in their grief’ (Davis, 2004, p.376-7).

Davis challenges Kitwood’s personhood conceptions, arguing that carers’ guilt should be absolved by accepting that through the dementia disease process, personhood is not retained, and thus acceptance allows carers the means to begin the grieving process:

> ‘However, he must allow for a loss of personhood, for to deny this is to denounce the legitimacy of primary carers who no longer recognise a spark of their former relationship. He concedes that dementia means that inevitably, the pre-existing rapport can no longer be dynamic in the same way. But in postulating that personhood can ultimately be sustained, he prevents the initiation of a grieving process that should begin with the involution of the sufferer’ (Davis, 2004, p377).

Tolhurst et al (20017) concur that Kitwood's 'malignant social psychology' thesis might add to carer stress if they result in a sense that they have created negative caring environments. Literatures on carer guilt are scant (Gallego-Alberto et al, 2022, Prunty, & Foli, 2019) with more research needed – in particular the effect on women carers (Romero-Moreno et al, 2014).

Kitwood's approach to personhood avows that the PLWD comes first. This is problematic when taking a relational approach to care and dependency (Davis, 2004, Tolhurst et al, 2017). This approach may leave carers in a subordinate position as a both an individual and also within a carer dyadic relationship such as notions of 'couplehood' (Helstrom et al, 2007) or 'shared identity' (Molyneaux et al 2012, Davies, 2011a). Tolhurst et al (2017) and Clare and Shakespeare (2004) identify 'narrative collisions' within relationships where each individual may be in an unequal or competing position. This may be more apparent in spousal rather than parent child relationships.

Critics of Kitwood's individualist rather than relational approach to persons with dementia also highlight a lack of broader social and cultural experience and context (Tolhurst et al, 2017). Social situations can impact both the individual and the spousal narratives of care and caring (Bowlby et al, 2010). There may be social implications of intersecting 'corrosive disadvantages' to both PLWD and carer, jointly or separately (Wolf and De-Shalit, 2007):

> '…a strong value is placed upon the importance of personal independence and autonomy alongside the moral imperatives of rationalism and economic contribution (Post, 2000)' (Tolhurst et al, 2017, p. 43).

For good caring relations to be enabled, the carer must have the ability and or capability in addition to a desire to care for the person (Keady and Nolan, 2003). Societal expectations of carers are that they subsume their own needs to those of the person they are caring for (Shim et al 2012). This is particularly true for women who are often regarded as being innately nurturing and thus dutiful in caring for others - a reciprocal understanding of care giving within families, still more associated with women (Finch, 1993). The perennial focus on independence, individuality, and autonomy (Bowlby et al, 2010) at the expense of a relational view, reifies expectations within care and cared for, especially for women, increasing carer guilt. Weicht (2015) argues that a normative expectation of interdependency in an ethic of care may help to challenge these gendered assumptions.

Tolhurst et al (2017) highlight the risks of researchers downplaying certain aspects of dementia or the caregiving experiences (burden narrative) in an understandable attempt to counterbalance the overwhelmingly negative public perception of dementia. This could lead to the suppression of data which perpetuates these negative perceptions, minimising carer burden or stress, whilst promoting local and national initiatives to foreground a ‘living well’ or ‘ageing well’ agenda and perhaps ‘dementia friends’ initiatives at the expense of detailing the reality of carers of PLWD lives (La Fontaine and Oyebode 2014):

> ‘It is also important for researchers to consider reflexively whether a desire to represent the impact of dementia in a positive light result in a lesser focus on material which contradicts this desire…’ (La Fontaine and Oyebode, 2014, p1267).

Sabat et al (2011) remind us that most literature prior to Kitwood’s person centred work focussed on carer ‘burden’ and the ‘othering’ of people with dementia. But has a rebalanced focus on the PLWD been to the detriment of carers, if by placing emphasis on the individual at the expense of the relational both carers and the person they care for are marginalised:

> ‘A manufactured stance of positivity thus generated a zero-sum situation: the aim to bolster the position of the person with dementia requires the vantage point of the carer to be diminished. The well-intentioned attempt to elevate the status of people with dementia has thereby introduced new imbalances into academic thought. The goal to counter negative societal perceptions of dementia, however, should not lead to the difficulties of carers being invalidated. Moreover, insights into the interpersonal challenges encountered by people with dementia could also be underplayed.’ (Tolhurst et al, 2017 p. 48).

The starting point for a dementia care framework must be the consideration of both individuals and the relational dyad. Putting PLWD first (Kitwood, 1997) denies carers full agency and fails to recognise the powerful relational aspects of care. It also risks blaming carers for ‘malignant’ conditions and stifles carers concerns (Tolhurst et al, 2017 and Davis, 2004).

Kittay (2011) argues that power relations between carer and cared for are unequal and pretending otherwise is just a ‘sham’. These are the limits to a rights-based approach. Dependency and relational care should be seen as normative not other. The societal emphasis on independence leads to a negative perception of dependency, yet this is inevitable and a normal part of human existence. Foregrounding independence, autonomy, inclusion may come at the expense of the well-being of both carer and cared for, particularly in the later stages of the disease.

2.7 Care and The Capability Approach

As argued earlier in the chapter, justice and how to measure and evaluate it has been a site of competing philosophical and ethical theories and conceptual frameworks. Theories of justice are at the heart of questions about how we can lead better lives (Brighouse and Robeyns, 2010). The Capability Approach (CA) is a framework for examining personal, social, and environmental factors and injustices which affect freedom to achieve well-being. It is a normative theory which has Aristotelian roots but is primarily associated with Amartya Sen and Martha Nussbaum.

Sen and Nussbaum (Sen, 2010, Nussbaum, 2011) developed the capability approach to assess the freedom to choose, and the range of actual opportunities open to each person. Sen's capability theory was initially set out as a critique of utilitarian welfare economics and Rawls theory of justice. Utilitarianism's focus on happiness being too narrow and social justice frameworks needing to centre on what people could be and do rather than the technical possession of rights or resources (Bache and Scott, 2018).

This focus leads us forward from Mill's utilitarian based, Dworkian resource-based or Rawls social primary goods arguments to a wider conception of what liberty might mean. Sen (2010b) accepts elements of both Mill's utilitarian, and Rawls primary goods argument, (Rawls, 1972) but ultimately rejects both in favour of a comparative broader conception of what justice and freedom might mean. 'a direct concentration on the assessment of freedom, rather than counting the means to achieving it' (Sen, 2010a, p. 234). The CA, in contrast to Rawls' Theory of Justice is about the ends, not the means (Anderson, 2010). It is about *actual* freedoms. The CA underscores the things which people value – health, relationships, work, travel, and the freedom they have to choose from a range of options (Robeyns, 2017).

The capability approach is generally considered a framework for analysing well-being rather than a fully-fledged theory (Sen, 2010a, Qizilbash, 2012, Robeyns, 2005) although there are some who think it has a partial and narrow theoretical base (Nussbaum, 2011) others argue that the framework can incorporate other theories and or applications (Qizilbash, 2012, Robeyns, 2017, Engster and Hammond, 2015). It focuses on what people can actually 'do' and 'be' – capabilities, and what they can achieve - functionings. Capability may thus be viewed as an *opportunity* concept of freedom (Ruger, 2010). Sen (2010a) highlighting that although one may have the nominal freedom to do or to be it may not be possible to convert this freedom into real opportunities. Relocating the emphasis from the means or resources to the ends, the CA enables one to consider how two people who may have access to the same resources but who may have very different outcomes – a person with disabilities may be unable to achieve their desired 'beings' and 'doings' from the same resources as a non-disabled person. Sen thus foregrounds 'equal consideration for all may demand very unequal treatment in favour of the disadvantaged' (Sen 1992, p. 1).

Sen's conception of the CA does not offer a narrow definition of a 'good life' or the things that people have reason to value - a set list of capabilities, but rather the opportunities and range of options open to people to select from. Engster (2007) foregrounds caring as a 'minimal capability' based on two key points: All people are dependent upon others to develop their basic capabilities and in receiving care, individuals tacitly and logically become obliged to care for others. Nussbaum favours a more liberal individualist approach and has attempted a delineation of capabilities for a good life in a list of ten capabilities, which according to Nussbaum are not ranked but demand equal weighting (2000). Her capabilities are foregrounded on a notion of human dignity, and she develops Sen's ideas into a more comprehensive rights-based method (Lloyd, 2012).

Robeyns (2017) argues that Nussbaum (2006) and Wolff and De Shallit (2007) have developed the CA as a partial theory of justice and that that more conceptual work is needed to expand and develop the CA as a potential theory of justice. Venkatapuram (2011, 2012) views the CA as an alternative critique of prevalent social justice theories or as a partial social justice theory. Sen, however, rejects notions of a fully developed transcendental justice theory in favour of a comparative theory of justice - theorising *injustices* rather than justice (Sen, 2010a):

> 'At the heart of the particular problem of a unique impartial resolution of the perfectly just society is the possible sustainability of plural and competing reasons for justice, all of which have claims to impartiality and which differ from - and rival – each other (p. 12) …There may not indeed exist any identifiable perfectly just social arrangement on which impartial agreement would emerge.' (p. 15).

The CA might be thought of as theorising in a more *just way* (Drydyk, 2012, Watene and Drydyk, 2016). This may have corelations with Held's fairer caring (2006).

Arneson (2010) worries that a comparative theory lacks objectivity – it makes assumptions that people know what a good life is. Sen (2010a) parries this contention by arguing that *'objectivity'* can be differentiated from *'objective knowledge'* by utilising John Rawls *'reasonable persons'* argument:

> 'To say that a political conviction is objective is to say there are reasons, specified by a reasonable and mutually recognizable political conception (satisfying those essentials), sufficient to convince all reasonable persons that it is reasonable'. (Rawls, 1993, p. 119).

In order to highlight the importance of this shift in thinking, and to move from a Rawlsian notion of justice – means based, to an ability or end based, Sen (1992) employs a conversion factor. This enables the framework to examine how differing ability to convert means to opportunities (capabilities) or outcomes (functionings) actually occurs. Sen uses three conversion factors;

Personal conversion factor – these are factors internal to the person, ie their sex, age, disability (to this could be added psychological and emotional predisposition)

Social conversion factor – public policies, social norms, practices which unfairly discriminate, power relations related to race, sex, class etc

Environmental conversion factor – physical or built environment, geographical location, climate, pollution, building, roads, means of transport, toilets, communication etc

Applying this conversion factor to carers of PLWD for example, might allow us to examine the actual freedom to access the local community. A carer may be able to afford and have access to public transport to reach the local shops, but if the PLWD cannot cope with being on the bus, they are unable to convert the freedom to use it. Or a carer may be given a personal budget to purchase respite care, but if there are no care spaces available then they cannot utilise the freedom to access replacement care:

> 'Sen uses "capability" not to refer exclusively to a person's abilities or other internal powers but to refer to an opportunity made feasible, and constrained by, both internal (personal) and external (social and environmental) conversion factors' (Robeyns, and Byskov, 2020, no page).

Conversely, a carer of a PLWD may have freedoms which they voluntarily choose not to utilise even if this decreases their own well-being. A strong personal desire to care for someone else or a clear sense of duty and obligation may lead to relinquishment of freedom opportunities. Such agency has clear value in a CA approach:

> 'If someone lives poorly (with lots of functionings unfulfilled) but with many substantive freedoms not realized voluntarily, such an ascetic is accorded high well-being in capability space. The individual is free to choose from many different lifestyles and could also sacrifice own well-being for other reasons. In this respect, the capability aspect goes beyond a narrow well-being focus and stresses individual liberties to take autonomous action (Binder, 2014, p. 1204 and 1205).

2.7.1 Autonomy, Freedom and Capability

The importance of autonomy was discussed earlier in the chapter. That people are autonomous individuals who through development of rights, justice, and liberty, are free to find ways to meet their needs and choices remains the commonest ethic in Western liberal societies (Rawls, 1971, Dworkin, 1993, Russell, 2010). Despite challenges to dominating political liberalism brought by a revisiting of Aristotelian virtue ethics (Slote, 2001, 2007, 2011, 2015) and care or communitarian ethics which placing emphasis on relationality, with people embedded in society and tradition (MacIntyre, 1985, Sandel, 2009), notions of liberty and autonomy still dominate our institutions, our societal practices and our thinking.

As society has moved away from religion to a more secular society (Giddens, 1991, Taylor, 1989) it has become increasingly individualised and focussed on autonomy and freedom to choose. This in turn influences our conceptions of old age and ageing with 'more ambitious plans for old age as a result of the neo-liberal story of a biography of choice' (Dohmen, 2014, p. 34). Freedom and choice may be troublesome concepts, however, for people who have disabilities such as cognitive difficulties (Dworkin, 1993) and their carers, and traditional conceptions of liberty may, as with justice, be inadequate to include them. Agency may be linked to '*life choices'* but structure is linked to '*life chances'* whether experienced positively or negatively by an individual (Hendricks and Hatch, 2008). Well-being as a result of liberty may not always be achievable:

> '…the CA highlights that an individual's understanding of a 'good life' will shape the choices they make. However, individuals cannot always realise their capabilities, or may be constrained in their choices, because of structural inequalities, low expectations and/or circumstances leading to 'adaptive preferences'' (Egdell and Beck, 2020, p. 941).

Mill argues for justification of liberty on the basis of utility, but some critics have considered that Mill has failed in his justification 'the arguments and values he evokes in On Liberty are hopelessly at odds with the utilitarian ethics he espouses there' (Gray, 1983, p. 2). Mill's arguments appear to founder on two issues. Firstly, freedom might sometimes be sacrificed if utility is always the end point. If restrictions on individual liberty could be shown to bring about the greatest happiness of the greatest number, on what basis would freedom be justified, if utility is always the ultimate aim? The problem with placing utilitarianism as a 'single principle morality' (Gray, 1983, p. 2) is that Mill then goes on to assert another moral principle 'the harm principle' to justify liberty. Utilitarianism would seem to justify a paternalistic interference that adherents to the liberty principle would surely reject. If utility is the ultimate appeal on all ethical questions, then inevitably freedom must be sacrificed in some circumstances as a result 'It is quite one thing to see utility as important, which it must be, but it is quite another to insist that nothing else matters' (Sen, 2010a, p. 282).

The second problem for Mill is to rank individual liberty so highly 'Whilst I am inclined to agree with Mill's assessment of the importance of autonomy, it is certainly not a self-evident proposition – it is not even evident' (Berger, 1984, p. 295). Bok would concur, arguing that happiness can result from many different things, and that individual liberty might not be the most important of these (Bok, 2010). If one is free to drive a car, but one has no money to buy one, or one no longer has the capability to drive, then freedom instead may depend on good public transport. If we consider negative, or free from restrictions to argue for the justification of utility, what are we to think if restrictions on one's freedom could be shown to bring about greater utility? Perhaps an acceptance that freedom and utility are both important, but neither are the *most* important thing leaves opportunities for a different approach.

If the conception of liberty is extended from Berlin's (1969) negative freedom 'x' from restrictions and positive freedom 'y' to develop, by the addition of another factor 'z' – the *ability* or *opportunity* to be free *to* or free *from.* By adopting MacCallum's triadic framework to the concept of liberty, ' x is (is not) free from y to do (not do, become, not become) z, x ranges over agents, y ranges over such 'preventing conditions as constrains, restrictions, interferences and barriers, and z ranges over actions or conditions of character or circumstance' (MacCallum, 1991, p. 102), this methodological approach broadens the liberty concept to include notions of capability and ability. The Capability Approach manages to address the paradox of Mill's utilitarian arguments, by reframing his liberty principle, to a reconceptualised framework which includes a third dimension as espoused by MacCallum's triadic conception. The *'beings'* ie negative freedoms, to be free from harm and hunger and the *'doings'*, the positive freedom to participate, vote, travel etc, must be underpinned by a third freedom – the *'abilities'*, to be able or capable of being or doing.

2.7.2 Capability and Disability

As discussed earlier in the chapter, people with disabilities and their families may face additional injustices. The CA is well placed to examine structural and environmental deficits which create spatial unfreedoms through consideration of built environments and architectural design which may impede the freedom to function (Sen, 2010a). It can also examine health and social care structures, norms, and resources and the psychological or moral drivers which motivate and impact carers. This may be especially pertinent for PLWD and their carers.

Sen (2010a) argues '…a richer person with a disability may be subject to many restraints that the poorer person without the physical disadvantage may not have...' (p. 253). Sen asks us to consider the overall capabilities of people rather than their income or wealth as prime evaluating factors and to think of the actual opportunities people have, not equal opportunities. Rawls primary goods are the means to valued ends, whereas CA sets out that the means to a good life are not themselves the ends of a good life:

> ‘Equality of resources cannot sufficiently account for inequalities that are generated by people’s social endowments, whereas these can be accounted for in the capability approach.’ (Pierik and Robeyns, 2007).

In the CA, the ends themselves can also be means. For example, caring may be intrinsically worthwhile, an end in itself, but also it may be a means to achieving well-being. Conversely whilst caring might be a valuable end, it may also be a vehicle for decreased well-being. Choice and freedom are important in this respect:

> ‘Choice over functionings is viewed as being intrinsically valuable, and Sen recognizes the value of both well-being achievement, which is best represented by functionings, and well-being freedom, which is best represented by the scope and quality of achievable functionings in the capability set.’ (Foster and Handy, 2008, p. 5).

Focus on health capabilities is important as health is directly linked to well-being and ill health prevents and hinders people from making real choices (Lloyd, 2012). Discourses on health have included those of health as a human right in justice frameworks but may be problematic as health becomes a narrow focus based solely on resources (Lloyd, 2012). Ruger’s (2010) ‘health capabilities paradigm’ foregrounds redistribution of resources to those whose life expectancy is lower than average but contends that richer countries may be in a position to go beyond an average threshold. Pogge (2010) argues that the CA framework actually promotes an unrealistic and infinite resource demand in order that people with the greatest capability deficits can benefit. This may be problematic when considering ageing. Lloyd (2012) asserts that general principles must consider limitations on resources and further, that longer life may not be as important to older people than quality of life. Sen (2010) acknowledges limitations but by including non-utility information such as disability and illness in any framework and by rejecting a universalising theory of justice, instead focussing on injustice, expectations of infinite expenditure remain only aspirational:

> ‘…nothing can be more elementary and universal than the fact that choices of all kinds in every area are always made within particular limits…there are limits on what we can spend…what is true in elementary economics is also true in complex political and social decisions’ (Sen, 2007, pp.5-6).

Terzi maintains that a CA approach, therefore, is better than Rawls social primary goods at addressing these complex difficulties experienced by people with disabilities. Rawls consideration of ‘disability’ as something to be deferred after primary goods evaluation places disabled people as ‘other’ rather than part of human variability:

> ‘Disability in a capability view, does not entail duties of humanity, or solidarity, or even charity; rather, the approach strongly suggests that the duties toward all disabled people are indeed duties of justice’ (Terzi, 2010, p.167).

Kittay also believes that the CA promotes a positive conception of rights which is better able to protect disabled people. Negative rights may allow flourishing of individuals only if that individual is able to realise these opportunities and freedoms. She argues:

> ‘It is the obligation and responsibility of the larger society to enable and support relations of dependency work that take place in the more intimate settings…’ (Kittay, 2011, p. 56).

Yet focus on the individual can bring competing rights between both carer and cared for in an interdependent relationship, and if, as Nussbaum asserts:

> ‘The goal is to produce capabilities for each and every person: and not to use some people as a means to the capabilities of others or of the whole’ (2011, p. 35).

Then the relational aspect of care must account for the dyadic nature of that relationship and the impact of capability assessment of both individuals within it. The CA offers a means to examine the multiple ways that economic, social, political, and cultural factors can constrain people in their choices by (Robyens, 2005).

2.7.3 Relationality in the CA

Human beings may be considered both selfish individuals and social co-operative people. Critics of Rawls by communitarian thinkers such as Taylor (1989) and Sandel, (1998) object to Rawls priority of justice and defence of individual rights over the good. Drawing on communitarian ethical philosophies such as Ubuntu, might stretch the CA to encompass group capabilities, rather than individual capabilities, foregrounding solidarity as a means to care for the best lives of others (Metz, 2016, Hoffmann and Metz, 2017). Owens et al, (2022) examine the relational possibilities in a CA approach, taking a critical realist lens to examine capabilities as the relation between agency and material and social structures.

A broadened Capability Approach, which includes ‘…supplementation with an ethic of care’ (Kittay, 2011, p. 51) or an understanding of *‘relational autonomy’* (Mackenzie, and Stoljar, 2000) discussed earlier could bring a relational lens to the CA. Dubois and Rousseau introduce the concept of potentiality as a part of capability, which offers a useful way to consider carers in relation to the person they care for. Thus, a carer may have the ability to do something, but the potentiality of doing so is predicated on the relationship to the PLWD. The resources available, individual capacity – ability to do and potentiality to be -within their social context will determine the level of well-being (Dubois and Rousseau, 2008). Shakespeare et al (2017) also contemplate a relational model of dementia through a critical realist approach using a ‘laminated model’. This examines different layers ‘the biological, the psychological, the environmental, the social, the legal – which interact to produce the experience of disability' (Shakespeare et al, 2017, p. 1082). This approach has strong corollaries with the CA, where Sen identifies *'coupling'* of disadvantages' (2010a, p.254) – i.e., combining age and disability, or perhaps caring role as making it harder to convert resources into capability. Herron and Rosenberg, (2019) for example, underscore the coupling of care within rural contexts.

Criticism of the individualistic nature of CA, Ibrahim highlights the importance of 'collective capabilities' (2020) by linking to the moral theories of Ubuntu. This draws together the relational element identified in the ethics of care as well as notions of identity and recognition inherent in the Ubuntu philosophy of *'a person is a person through other persons'*. Liz Lloyd emphasises how vital social relationships are for health and well-being, throughout one's life, yet most policies are primarily focused on individuals. (2012). Lloyd evokes Kittay's 'nested dependencies' to describe an environment of care which facilitates caring relationships which are paid and unpaid (p. 87). Lloyd critiques the capability approach as being too individualistic, criticisms shared by Held (2006). Lloyd allows that the CA does sympathise with people with disabilities and acknowledges periods of dependency but argues the CA 'regards dependency as a deviation from the norm rather than a basic human characteristic' (Lloyd, 2012, p. 63). Nussbaum's clearly espoused liberal individualism (1999), despite her consideration of disability and justice (2006), might justify this criticism, but it seems at odds with Sen's stated support for people with disabilities and acknowledgement that '…1 in 10 of all human beings live with some form of significant disability.' (Sen, 2010a, p. 258). Criticism may more appositely be critique levied at Rawls' resourcist approach which does not consider disability in the original position. Whilst Sen argues people with disabilities are more likely to be living in poverty and need of more resources to 'lead the kind of life he or she has reason to value' (Sen 2001, p. 87), he highlights the importance of understanding the conversion handicap when analysing people with disabilities and their families' levels of poverty. Even with additional resources, they are not easily able to convert this into advantage. In a study examining percentage points of poverty disadvantage:

> '…only about a sixth can be attributed to income handicap and the rest to conversion handicap (the central issue that distinguishes the capability perspective from the perspective of incomes and resources' (Sen, 2010a, p. 259).

Lloyd argues that 'positive accounts of ageing have promoted an idealised version of the autonomy of a self-reliant individual who does not need care' (p.137). It might also be argued that negative accounts of losing independence and needing residential care have promoted idealised notions of carers as self-sacrificing individuals who would never let their loved one go into a care home. Lloyd Sherlock (2002) identifies positive aspects in the CA but believes that it does not fully account for the changes in capabilities wrought by ageing across the life course. These criticisms might be addressed by considering a more relational or collective approach when assessing disadvantage or well-being injustices.

Utilising a CA framework and an ethic of care approach enables a focus on both the well-being of both individual and relationships to identify injustices or ‘corrosive disadvantages’ through - personal (identity, psychological drivers), environmental (rural, spatial, built environment) and social (health and social care institutions, stigma and discrimination, societal norms, and expectations) injustices which hinder the conversion of resources to functionings and well-being.

2.7.4 The CA and Well-Being

Happiness and well-being are both contested concepts with a multiplicity of meanings. Although well-being is a crucial component of the CA framework, it may be conceptually under theorised. Identifying the importance of different understandings of well-being including hedonic and eudaimonic conceptions of happiness and acknowledgement of individual and relational aspects of well-being may be important when examining the complex lives of carers and PLWD:

> ‘well-being is greatest when people succeed at finding a balance between individual autonomy and independence on the one hand and connectedness with others on the other’ (Machielse and Hortulanus, 2014 p. 119).

Opponents of utilitarian thinking argue that utilitarian values may be coming to the fore again (De Vos, 2012) with the rise of politics of happiness and effective altruism theories (Layard, 2011, Mackaskill, 2016, Singer, 2015). They adjudge this to pose risks for individual autonomy and economic freedoms, with the IEA, arguing that ‘the government should focus on creating the meta framework of institutions that give us the freedom to flourish and improve our well-being’ *(*Booth, 2012 p. 32) rather than revert to a utilitarian utopia. The New Economic Foundation (NEF, 2012) and Bok (2010) concur that placing too much import on utility is a mistake, but although they agree that both economic and individual freedom are significant to happiness, it is only one of a number of factors ‘Disagreements only arise when libertarians claim that freedom is the only source of well-being’ (Bok, 2010, p. 47). An emphasis on equality of opportunity is difficult to maintain equitously as it fails to account for disability and illness. Sen rejects utilitarian arguments because moral, social, or political principles have no intrinsic value to utilitarians (2010a). In addition, a focus on utility may be problematic when one considers the hedonic treadmill or psychological adaptation (Diener, 2009) – we become accustomed to things which make us happier, including more resources, so eventually we have diminishing marginal happiness (De Graaf and Batker, 2011). People living in deprived situations may have low expectations and thus derive greater utility from very little, whereas a person with more resources, social capital and freedom may conversely have higher expectations and thus lower utility. If one has become fully ‘adapted’ then only new experiences, good or bad, will fundamentally affect one’s well-being and once your position restabilises, you revert to your baseline levels of happiness. Interestingly, Layard (2011) who espouses a utilitarian concept of happiness, recognises however, that there are some things to which we can never fully adapt, including ‘caring for a person with Alzheimer’s’ (p. 49).

2.8 Conclusion

Care and justice literatures offer opportunities to examine the social, spatial, and personal aspects of caring and dementia care. Several mid-level theories such as stigma (Goffman, 1976), spatial (Soja, 2010) or SDM (Oliver, 2004) are useful to examine specific features of dementia care and carer standpoints. However, an ethic of care, more broadly encompasses the relational, interdependent feminist framework which views care as both value and practice and offers an alternative standpoint from traditional theories of justice by which to understand and address carer needs. The CA proffers a comparative justice approach, focussed on individual freedom and well-being. Both approaches use a lens through which to consider justice and injustices which have useful applications for assessing the lives of carers and PLWD. Care is a moral imperative. The contexts within which we care and the outcomes of our care matter. In this sense an ethic of care might be said to have deontological, consequentialist and virtue ethical dimensions. But rather adhering to specific universalist principles, a set of prescribed virtues or a calculation of cost/benefit analysis, an ethics of care can examine complex problems by foregrounding a relational not rational approach, accepting the incommensurability of values that matter to us – care, duty, love, and loyalty. Feminist ethics considers care and relationships and how these are embedded in our everyday lives, both in public and private spheres. Moral agents recognise the multiplicity of caring interactions and ethical practice and the conflicts and /or interplay between competing conceptions of justice, rights, and responsibilities. An ethic of care foregrounds a relational and interdependent contextual view in contrast to the universal principles of justice – freedom, autonomy, impartiality.

Despite being normatively attractive, a unifying ethic of care cannot easily be incorporated into the hegemonic structural capitalist system of free market economics and dominating model of western individualism.   Caring and being cared for are part of the human condition, but individual freedom, justice, rights, and robust protections in legal frameworks nationally matter to people and may be vital to safeguard carers and the women who do the majority of caring. As Sen criticises attempts to create universal systems of justice 'I would like to wish good luck to the builders of a transcendentally just set of institutions for the whole world' (Sen, 2010a, p. 263), trying to apply a unifying relational, feminist, ethic of care may prove equally problematic, and may risk embedding carers in a role which can be prolonged, stressful and result in an inability to have their own needs met.

Justice might be viewed from a different standpoint to consequentialist or resource-based conceptions by advancing Held's notion of 'caring justice and fairer caring' (2006). This has correlations with Sen (2010a) and Nussbaum's (2011) Capability Approach offering a way to marry divergent opinions on principles of justice. A normative approach which emphasises the actual functionings of people – their 'beings and doings' moves us away from focussing on the 'primary goods' of Rawls, to the abilities or capabilities we have to convert resources into actual opportunities. Sen identification of a 'weighting' to overcome the conversion handicap of more vulnerable individuals, such as PLWD or their carers can stand alongside a relational ethics of care 'weighting' between decisions of care or justice (Held, 2006).

Individual freedoms *and* relational notions of dependency and interdependency are both important for assessing carer well-being and identifying injustices. A comparative justice approach espoused by Sen through the CA allows the evaluation of freedom and well-being as the prime importance. Reframing liberal emphasis on resources to one that promotes a broader conception of happiness and well-being, focussing on actual values, opportunities, and capabilities as a way to unify justice and care can better assess the lives of both caregivers and people with disabilities including PLWD:

> 'Given what can be achieved through intelligent and humane intervention, it is amazing how inactive and smug most societies are about the prevalence of the unshared burden of disability. In feeding this inaction, conceptual conservatism plays a significant role. In particular, the concentration on income distribution as the principal guide to distributional fairness prevents an understanding of the predicament of disability and its moral and political implications for social analysis.' (Sen, 2010a, p.260…'The remedy for bad reasoning lies in better reasoning…' p.49).

CA theorising can be used in research as conceptual, descriptive, explanatory, evaluative and normative approaches (Robeyns, 2017). It is perhaps used less often for non-normative and explanatory purposes but using a CA framework for assessing the lives of carers of PLWD seems a useful starting point in order to examine well-being and well-being actual freedoms, health and social institutions, the spaces and places where people care and the individual psychology and moral frameworks which determine how carers will respond to their caring situation. This theorising can lead later to the design and implementation of policies of change, by making a normative or ethical case for what needs to change.

A realist approach assessing injustice, freedom and well-being of carers may be better placed than idealist theories of justice to approach the complexities of care:

> ‘Philosophy must be realist. That means, roughly speaking, that it must start from and be concerned in the first instance not with how people ought ideally (or ought “rationally”) to act, what they ought to desire, or value, the kind of people they ought to be, etc., but, rather, with the way the social, economic, political, etc., institutions actually operate in some society at some given time, and what really does move human beings to act in given circumstances.” (Geuss, 2008, p.9).

The CA has most often been used to evaluate people’s lives at the macro level, highlighting limitations of GDP as a measurement of progress and gender inequality. This has had real import for the advancement of Human Development (Robeyns, 2017). Increasingly CA theorising has opened up new opportunities for conceptual reframing of social justice issues and cross disciplinary empirical research (Robeyns, 2017) including examination of spatial injustice by Israel and Frenkel, (2018) and Nordberg’s ‘capability of places’ (2020), employability (Egdell and Beck, 2020, Egdell and Robertson, 2021) health capabilities (Ruger, 2010, Venkatapuram, 2011), disability (Nussbaum, 2006, Terzi, 2020) and education (Nussbaum, 2002). But the CA may also be an opportunity to evaluate at both macro and micro levels by consideration of care and caring and broadening the approach to encompass more relational aspects of freedom. Contemporary political and social commentators continue to advance laudable caring practices (Kittay, 2002, 2011) and values like empathy, (Martinez, 2016) and kindness (Dorling, 2015), but a robust and practical framework, offered by a CA opens up new opportunities to examine carers lives – the spaces and places in which caregiving takes place, the motivations for caring and continuing to care, and the social and institutional arrangements which affect and influence carers and the wider society. In particular, it offers a conceivable mechanism by which to consider the intersecting or cumulative nature of multiple aspects of potential injustice - personal, social, and environmental, in order to evaluate the actual freedoms carers possess to convert capabilities into valued functionings. The CA highlights disability in terms of justice more effectively than other accounts (Terzi, 2020) and is therefore best placed to examine PLWD and their carers.

Chapter 3. Methodology

3.1 Introduction

> '…between what we can reconstruct and understand with our limited means – and the reality of which we are part, there exist countless filters: our ignorance, the limitations of our senses and of our intelligence' (Rovelli, 2014, p. 66).

Deciding on a methodology and choosing methods of data collection is predicated on myriad factors including ethical issues, time and budgetary constraints, type of research, positionality, experience, strengths, and weaknesses of the researcher.

Arriving at university as a mature student in my late 40's ten years ago, with no previous academic study experience has often left me feeling disadvantaged and ignorant. When I did a workshop on Imposter Syndrome, I knew exactly what that was and how it felt. Words like epistemology and ontology were unknown to me and horribly intimidating. Undertaking research in my undergraduate Politics BA and then in the Human Geography Masters required utilising and explaining research methodologies of which I was generally incognisant. At an early stage, someone told me 'Oh, just use a socially constructed grounded theory, that's what everyone does.' Dutifully, for my master's research, that is what I did. Sustaining this approach became increasingly difficult to maintain as this research progressed, both as an epistemological methodology and an ontological framework, related to my experiences and standpoint as a carer of PLWD and as a researcher. As Shakespeare describes his move towards a more critical realist approach, I too, changed my approach:

> '…a realist approach to the world, grounded in empirical research, appears to me more helpful, both politically and at an individual level.' (Shakespeare, 2014, p.71).

This PhD has been an opportunity to revise my thoughts, examine what I believe and why, how my experiences have shaped my understandings and developed my knowledge base. This is ongoing. Research is an iterative not linear process – thinking, reading, analysing, developing, rethinking. Thus, the paradigm – the set of conceptions and beliefs that encompass my ontological framework or entire worldview (Kuhn, 1996) – as I now understand it, lies more closely with a critical realist standpoint, than a social constructivist position. Like Shakespeare, perhaps I have never been sure where I sit – when I first heard the terms realist and idealist as a teenager, I thought 'Oh, I'm a bit of both of those!' and that feeling continues an idealistic realist, or a pragmatic optimist?:

> 'I am unashamedly eclectic and pragmatic in my theoretical allegiances, finding a plurality of approaches beneficial in the analysis of disability.' (Shakespeare, 2014, p.72).

This chapter will discuss the theoretical underpinnings to the thesis and the reasons why a participatory and grounded theory approach were rejected in favour of a feminist standpoint theory methodology. It will discuss the use of semi-structured interviews as the selected method for the data collection. I will summarise the access to research participants, the design, as well as arranging and conducting of interviews through a reflection of participant recruitment to the project. Ethical considerations will be examined and discussed. The effect of the Covid 19 pandemic on the research process is outlined, but a more comprehensive assessment is provided in the impact statement submitted with the thesis. The chapter will end with a review of the data analysis coding mechanism, a reflection of its efficacy and applicability and self-reflective considerations of the overall research process.

3.1.1 Decisions pertaining to method and methodology

> ‘Life is complicated. Experientially. Anecdotally. Analytically. But…we should still strive to understand using the best science and analytical tools we have’ (Dias, 2018, p. 707).

My Masters dissertation completed in August 2017, acted as a starting point when considering analytic and data collection methods for this thesis. Personal experiences working in care settings, as a paid support worker, and as a family carer had led me to believe that a qualitative auto-ethnographic participatory project would be appropriate, effective, and applicable. Due to time constraints inherent in a short dissertation project and logistical and ethical issues, I had reluctantly abandoned this method in favour of a social constructivist grounded theory methodology, using a feminist person-centred approach to guide a semi-structured interview process. I had however, included some auto-ethnographic reflections and observations based on my first-hand care experiences.

The opportunities afforded by a PhD thesis, for a longer, more in depth project, offered a chance for reconsideration of methodology and data collection. Relationships built up both professionally and personally over many years in the care sector, and the recent research at a care home for my master’s dissertation, undoubtedly offered opportunities for participatory co-produced research. Further, work as a research associate on another project about accessible toilets, had given me opportunities for collaboration with stakeholders, people with disabilities and their carers in a co-produced research project. Working directly with disabled people, foregrounding their voices through the making of a film, participation in workshops – where they had opportunities to speak directly to stakeholders including local councillors – highlighted the importance of giving voice to the powerless, the benefits of collaborative working and the sense of personal value. In addition, my collaborative partners at ‘Co-

Ordinating for Age' (C4A-Glendale, North Northumberland) had approached Newcastle University and actively sought a doctoral candidate to research the lives of older people in Northumberland. Early conversations with my collaborative partners were helpful, as they explained problems they had identified in co-ordinating support for older people (including PLWD), particularly in rural areas, with concerns that resources were being ineffectively used. Developing a research project with older people with dementia was a very attractive idea to me personally, with both parents living with dementia in Northumberland, timely given the prominence of ageing studies and research, and necessary - there has been considerable progress for people with physical or intellectual disabilities in being at the heart of developing services and support and for citizenship in the community but this is not the case for people with dementia where 'the struggle for citizenship has only just begun' (Bartlett, 2014, p.1291)

3.1.2 Deciding Not to Use a Participatory Approach

Participatory Action Research (PAR) involves participation, working and interacting with people to effect positive change. PAR is less a method than a framework or set of principles utilised in the design, analysis, and execution of research. (Pain et al, 2010). Immersing oneself in the research through a participatory action approach has corollaries with person centred planning (PCP) approaches which I have used for many years.

I had a number of concerns, however, which eventually led me to reject a participatory project. The complexities of assessing someone with dementia's ability to consent to take part in any research cannot be underestimated (Warner et al, 2008). Consent can be difficult to ascertain and can also be fluctuating (Social Care Institute for Excellence, 2020, Walker et al, 2000, Slaughter et al, 2007). I knew conducting research with PLWD might involve protracted ethics considerations due to issues of consent, and thus potentially delay the research. In addition, the caring role I had for both my parents with dementia at this early stage of the PhD was intense, and I was aware that my capacity to work effectively with other people with dementia might be emotionally draining. I decided against a PAR project with PLWD and began focussing instead on researching family caregivers.

I decided that utilising current skills rather than attempting new untested methods would be a pragmatic option. A qualitative research project using focus groups or semi-structured interviews of family or friends providing care for PLWD would allow me to use my experience of interviewing using Person Centred Planning toolkits and approaches (O'Brien and O'Brien, 1998, Falvey et al, 1997, Sanderson, 2000). I had contacts with carer organisations on both a professional and personal level which made me feel confident that finding participants would be relatively easy. At this stage of the project, I still favoured a grounded theory approach, but this too began to prove problematic.

3.1.3 Deciding not to Use Grounded Theory

Grounded Theory (GT) is a systematic and comparative approach of research to enable theory construction (Bryant and Charmaz, 2007). Since the publication of seminal works by Glaser and Strauss (1965, 1967), it has become one of the most popular methods across disciplines (Bryant and Charmaz, 2007, Strauss and Corbin, 1997). GT is pre-eminently a method of analysis (Clarke, 2012, Gibson, 2007, Glaser, 1992). Using a social constructivist approach challenged the prevailing orthodoxy of positivism by propounding that qualitative analysis could generate theory by joining 'epistemological critique with practical guidelines for action' (Charmaz, 2014, p.7).

Theories are useful mechanisms by which we try to make sense of questions, and theorizing is the way in which we develop them (Charmaz, 2014). By conducting data collection and analysis as the process progresses there are opportunities to use constant comparison *grounded* in the actual data (Charmaz, 2014). Categories and concepts are examined in relation to extant literature in a bottom-up process which centres the data (Charmaz, 2014, Conlon et al, 2015). Researchers utilising GT should avoid conducting the literature review until after the analysis has been done.

This was problematic for me given my prior knowledge and familiarisation with some of the literature. Lo (2014) critiques Glaser and Strauss's enjoinder (1967) that researchers using grounded theory distance themselves from extant literature so that they might avoid situating the data into predetermined theoretical structures – a position echoed by Charmaz's social constructivist GT (2014) - by foregrounding instead a *critical realist* grounded theory approach. Prior knowledge of extant theories and literature can thus be utilised to examine data anew, to critically study patterns, incongruities, relationships and to develop or expand upon concepts and theories. Thornberg (2012) concurs adding that as personal preconceptions cannot be entirely eradicated, using a more realist or *informed* approach, by acknowledging the process, sensitivity of the researcher and a degree of self-reflexivity to one's positionality can enable a situating of emerging grounded theory data *within* pre-conceived knowledge.

Critical realist grounded theory approaches (Oliver, 2012) are scant in the literature, but this perhaps along with informed grounded theory (Thornberg, 2012) seemed to offer a lens correlated more closely to my ontological framework. A researcher can hold that some data is socially constructed but that some is not. Knowledge is not *merely* a social construction (Lukes, 2005) and therefore does not preclude approaches which are compatible with both social constructivism and realist epistemological conventions. Grounding the data does not preclude a critical realist lens nor the value of a multi-theoretical approach (Shakespeare, 2014).

3.2 Theoretical Framework - From Social Constructivism to Critical realism

> ‘It marries the positivist’s search for evidence of a reality external to human consciousness with the insistence that all meaning to be made of that reality is socially constructed. It accepts that the social constructions themselves can constitute what we know as the reality of our social worlds’ (Oliver, 2012, p.372).

Positivist and realist approaches which favour general laws are usually associated with scientific or natural sciences, and quantitative data collection whilst social constructivism, (note, social constructionism and social constructivism are often used interchangeably, but strictly speaking social constructionism encompasses a more collectivist approach in comparison to constructivist as an individual experience of reality (Charmaz, 2014), or interpretive methods are associated with social science and qualitative methods (Mallon, 2019, Gorski, 2013). However, not all researchers who gather qualitative data are necessarily social constructivists and conversely not all quantitative researchers are empiricists or realists. There are, however, often correspondences between epistemological positions and data collection methods.

3.2.1 Social Constructivism

Social constructivism is an epistemological theory which aims to describe our experiences and what we can understand about them. Social constructivists regard knowledge as a product of social influences, how we gain knowledge is dependent on and can vary according to different times, places, and contexts (Gorski, 2013). There is no system of acquiring knowledge which can be objectively correct as the method itself is a creation from social factors. It challenges orthodox assumptions that knowledge comes from impartial objective study of the world, i.e., it is counter to positivist or empiricist scientific enquiry (Burr, 2004, Latour and Woolgar, 1986).

Using social constructivism is often deemed at odds with an empiricist perception of thought, whose basis of knowledge is derived through our senses. Social constructivists, however, would contend that what we see through our senses is, itself, a result of social influences.

What we see is influenced by the way we view the world. We can only analyse our observations by utilising concepts and ideas of which we have prior knowledge. Different people may interpret the same phenomena in different ways (Crotty, 1998). What we observe, what we see and hear is meaningless without prior knowledge. And this prior knowledge is a product of social factors. Analysing discourse is considered an important aspect of constructivist theorising, and a method by which meanings can be ascribed (Burr, 2004). Constructionist theorising offers opportunities to examine how trends or 'facts' are socially constructed, to appear naturalised – i.e. women are more caring.

Using a social constructivist framing allows us to examine the *meanings* that people give to their specific situations and what relationships *represent* to people. A researcher may find shared understandings between groups of individuals. The role of the social constructionist scholars is to identify and describe these shared identifications – while always being aware that her own prior understanding of the world – her own positionality – will shape or determine how she interprets other people's accounts of their experiences.

Social constructivism encompasses a type of relativist knowledge (Gorski, 2013). Social constructivists might be considered on a spectrum of 'strong' to 'weak', with some critics arguing that 'strong' constructivists have taken relativism too far. Mallon arguing that naturalists can benefit from constructionist researchers but also decrying the '…more radical anti-scientific and anti-realist theses widely associated with social constructionism' (Mallon, 2019, no page). Fischer broadly concurs but also highlights distinctions between post-modernism and social constructivism in order to 'defend a constructivist epistemology' (Fischer, 2019, p. 134).

3.2.2 Critical Realism

> 'What we need is to correct our intuitive notion of reality from excessive rigidity, not to give it up entirely. Reality is out there, and we describe it. Renouncing this is renouncing our desire to understand…' (Rovelli, 2022, no page).

Critical realism is a wing of philosophy which aims to differentiate between what we have the ability to discern or observe and that which we cannot – i.e., the world which exists outside of our human conceptions. The term 'realist' may be considered a normative or prescriptive view of how things are. (Pratt, 2013). We make distinctions between real and observable:

> 'CR is a much more internally consistent and philosophically developed framework for those who have decided to follow the 'realist turn' away from positivism and constructivism' (Gorski, 2013, p. 659).

Critical Realism saw a shift from post-modernist or post-structuralist emphasis on epistemology to a more ontological underpinning which is compatible with feminist SPT (Satsangi, 2013, Gillman, 2016, New, 1998). CR is comprised of ontological realism, epistemological contingency, and critical reasoning. Gillman cites Satsangi's (2013) enjoinder to ally Bhaskar's CR with feminist SPT 'given the latter's intrinsic embedding of values with facts' (Gillman, 2016, p. 465).

Bhaskar (2017) describes CR as being comprised of three key elements – Ontological Realism, i.e. realism about the world, Epistemological Relativity – all our knowledge is relative, and Judgemental Relativity – we can judge some concepts or ideas to be better than others. Smirthwaite and Swahnberg (2016) prefer the term judgmental rationality to judgemental relativity as people make rational choices between opposing concepts or ideas. Judgmental rationality is not the same as some more critical relativism of the more uncompromising forms of postmodernist and constructivist thought which foregrounds that all standpoints have equal merit (Smirthwaite and Swahnberg, 2016, Marshall 2012).

A critical realist accepts that all knowledge is fallible (Yeung, 1997) incomplete and revisable (Sayer, 1992) but not necessarily equally unsound. Bhaskar makes a distinction '…between a natural world as it really is and our changing concepts of it' (Gorski, 2013, p. 664). This differentiates a 'naïve' realism (Rovelli, 2022) from critical realism (Gorski, 2013). Researchers must acknowledge that their understandings are burdened by preconceptions. CR researchers accept a material reality but consider interpretations of that reality depend on one's position or standpoint. Bhaskar explains a CR rationale which argues social praxes need concepts, but concepts always have a material underpinning (Bhaskar, 2011). Bhaskar theorises that CR provides standpoints or perspectives rather than specific applicable investigations (Bhaskar, 2011).

Bhaskar rejects both interpretivist and constructivist positions in favour of a 'critical naturalism' which denies that there is any clear division between social and natural sciences. Critical naturalism thus allows for a linkage between ethics and science (ethical naturalism), where both biological and social sciences may have contributions to make as to how individual and community well-being might be improved. Gorski argues that social sciences are not, nor should they be value neutral:

> 'They presuppose an axiological commitment to human well-being. Social science cannot generate specific directives about how we should order our lives or societies. But is does produce prudential principles' (Gorski, 2013, p. 669).

Gorski suggests Nussbaum and Sen's Capability Approach may be a productive approach to consider an ethical naturalism. Given Sen's assertion that we can be 'ethically objective' using 'reasoned scrutiny' (2010a) this appears both a normative and functional approach. Critical Realism has an *emergent* ontology, meaning we need to study events and experiences in light of the sum of their parts. The experiences of carers of PLWD, examined in this thesis, have multiple influences. A CR approach offers an opportunity to examine and identify some of these and how they relate to each other. CR researchers provide explanations not just descriptions of what they observe and analogously with grounded theorists they move critically between the data and the literature:

> 'Critical realism has much to say on the philosophy of the social sciences, but it leaves the theoretical and methodological work to each substantive social science. The real need, as a result, is to achieve a dialectical mediation between philosophy (concerning ontology and epistemology) and the social sciences (concerning theory and methodology) (Yeung, 1997, p. 53).

3.2.3 Standpoint Theory and Feminist Approaches

> 'Feminist epistemology – is or should be – about finding ways to draw knowledge out from experience' (McLaughlin, 2003, p.54).

Developments in grounded theory concepts as outlined by Lo (2014) and Thornberg (2012) above, seemed intuitively more attractive to me as my prior knowledge of the subject matter could not be dismissed or unaccounted for. Existing feminist literatures on approaches to grounded theory led me to consider feminist standpoint theory as a more apposite way to position myself, and the prior knowledge and experience of dementia care in relation to the data, literature, and subsequent analysis. Feminist thinking is an effective mechanism by which to challenge taken for granted knowledge.

A feminist approach may be twofold - feminism understood as fundamentally being about improving women's lives and thus an analytical device, or as the way in which the research is approached and undertaken. Feminist qualitative research using standpoint theory offers opportunities for a diversity of methods and thinking. Knowing that women have historically (and continue to) provide the majority of unpaid care (Age UK, 2019) made utilising a feminist analysis of care work prescient and relevant, but the foregrounding of the *relational* offered by a feminist *approach* rather than using a feminist analytical lens was the starting point for this research. A feminist *approach* was appropriate to examine pre-conceived ideas about the gendering of care work – exploring assumptions and stereotypes of all family carers of PLWD. Feminist geographers have primarily focussed on women and women's lives, but it also offered opportunities to examine growing research into men and masculinities (England

and Dyck, 2014, Gorman-Murray and Hopkins, 2014) and masculinity and place (Richardson, 2015). The numbers of male carers are growing (England and Dyck, 2014) making up 42% of carers in the UK, with men often finding it harder to ask for support or to acknowledge their carer role (Carers Trust, 2014).

Feminism has multiple schools of thought or philosophies which researchers might utilise to analyse and interpret data, for example radical (Dworkin, 1981, Firestone, 1979) liberal (Friedan, 1982, Nussbaum, 2000) marxist (Rowbotham, 1992) intersectional (Crenshaw, 1991) and post-modernist or gender theory (Butler, 2004), but feminist standpoint theory (Harding, 2004) with its loci focussed on the lives of the marginalised (Ackerly, and True, 2020) including carers and the care work that they do offered an apposite approach. Utilising standpoint theory (Harding, 2004, Harroway, 1988, Hartsock, 2004 and McLaughlin, 2003, Kenney and Kinsella, 1997) rather than grounded theory, given I had prior knowledge of caring and carers of PLWD led me to believe that an objective and standpoint position was better placed as a methodology.

Methodologically, family caregivers of people with dementia characterise a particular standpoint. Standpoint Theory (SPT) examines the material position and experience with its foundations derived from both second wave feminism and Marxism (McLaughlin, 2003, Hartsock, 2004, Harding, 2004). Feminists in SPT recognised tensions between structure in Marxism and agency (McLaughlin, 2003) and further, that Marxism regarded concerns related to the private sphere – such as care work – of lesser import (Hartsock, 2004 and 1997).

Feminists foreground the importance of our collective knowledge and experiences to advance theories and to affect change (Hartsock, 1997). Feminist approaches to ethnographic examinations highlighted to me the importance of interview participants standpoints and ethics of care literature added an ethical and moral component which allowed for a deeper reflection and examination of the data. Feminist ethics of care epistemologies have been sparsely considered in empirical research methodologies (Sahraoui, 2019) yet '…feminist standpoint theory and care ethics literatures speak to each other' (Sahraoui, 2019, p.16).

Accentuating the voices of family carers of people living with dementia, allows us to hear the 'different voice' highlighted in Gilligan's work (1993) and a feminist standpoint challenges dominant ways of thinking by foregrounding the care *work*, mostly associated with women, as a superior standpoint (Hartsock, 1983, Ruddick, 2004) including the material and bodily world of care and care practices – bathing, feeding, supporting and toileting. 'Caretakers are immersed in the materials of the physical world…' (Ruddick, 2004, p. 163).

3.2.4 SPT, Reflexivity and Positionality

SPT offers opportunity for ethical considerations through foregrounding feminist qualitative reflexive practices (Oleson, 2007, Dankowski, 2000). Feminist critiques of early theoretical iterations relying on objective viewpoints (Oleson, 2007) lead to a failure to recognise the positionality of the researcher and a tendency to universalise from intuitions gleaned from data, thus risking the loss of multiple and differing perspectives. Oleson (2007) argues that early conceptions of grounded theory which foregrounded researchers commencing with a blank slate is at best idealistic at worst dangerous yet true reflexivity by the researcher may also be an unrealistic expectation of a researcher to offer a full account of the research process and the data analysis (England, 1994, Rose,1997). 'Degrees of reflexivity' may be more accurate (Mauthner, and Doucet, 1998). There might be a risk of placing too much emphasis on the researcher rather than the participant. But the research process can still foreground the researcher/participant relationship, whilst acknowledging that it does not present 'value-free objectivity' (Oleson, 2007, p.425).

Utilising a reflexive method involves the examining of one's own positionality and *how* that positionality will impact the work you do. Reflexivity requires one to assess both the possible positive aspects as well as the negative outcomes of one's own position in relation to the participants in your research. Reflexive thinking is a continual process throughout the research (Kohl and McCutcheon, 2015). My ever-changing personal situation, particularly relating to the care and then death of my parents has affected me, my position, and the way I view the prior data collection. Acknowledging this is important. Some of these reflections have undoubtedly brought depth to my data analysis, but I am aware that it may also have coloured certain aspects of my thinking in ways that even persistent and conscientious self-reflection may not uncover. No research, no data collection method or analysis can be fully objective, but recognising the relationship between researched and researcher, their relative positions, the social and cultural contexts within which they exist, does not preclude a search for the truth and a *degree* of objectivity. Nor conversely, does examining the material lives of carers debar examination of positionality of the researcher. One can acknowledge and accommodate both positions:

> 'Morally, a philosopher who uses his [her] professional competence for anything except a disinterested search for truth is guilty of treachery…the true philosopher is prepared to examine **all** preconceptions' (Russell, 2010, p.743).

My life has been shaped and continues to be shaped by the places, the situations, and experiences of caring, but that does not debar me from attempts to examine the standpoint of other carers; though pre-conceived ideas and theories are known both to the researcher and the researched, these can still be acknowledged, whilst centring the data collected as the focal point, remaining rooted in the participants experiences:

> ‘Our very understanding of the external world is so moored in our experiences and thinking that the possibility of going entirely beyond them may be rather limited. All this does not, however, indicate that positionality cannot be partly or wholly overcome in ways that take us to a less confined view’ (Sen, 2010a, p. 170).

Situating oneself as a researcher utilising SPT opens up opportunities for dynamic interactions with participants, development of new theories and analysis by using the data directly in building ideas and frameworks in an iterative process. But it *is* complicated and will perhaps always leave the researcher feeling insufficient (Mruck and Mey 2007).

Adam Smith in his Theory of Moral Sentiments (1976) uses the expedient of an ‘impartial spectator’ to ask us to examine our own behaviour as we would wish an impartial person to examine it. A post-empiricist turn in the philosophy of science rejects the notion of an impartial spectator. But an enjoinder to remind the researcher to be self-reflective and further to reflect on the data collected by participants using an ‘open impartiality’ to examine and interpret their standpoints or positions, may be a useful one:

> ‘The need to transcend the limitations of our positional perspectives is important in moral and political philosophy, and in jurisprudence…trying to go beyond positional confinement is also central to epistemology’ (Sen, 2010a, p. 155).

Thus, acknowledgement of our partialities and experiences does not preclude a search for objectivity.

3.2.5 Observation and Auto Ethnographic Experiences

Auto ethnographic accounts are not impartial accounts but can still be partially objective. Autoethnography is a relational concept (Turner, 2013) well suited to feminist geographer enquiry and ethnographic inquiry supports standpoint theory (Sahraoui, 2019). This thesis is not an ethnography, nor an autoethnography, but it has some autoethnographic aspects (Besio, 2009). I included the few autoethnographic observations in this thesis only where it felt pertinent and added depth to a discussion.

Utilising a SPT position allows for auto-ethnographic data collection through the everyday personal experiences of caring for a PLWD. Insights into the complexities of care, whether the day-to-day minutiae of life, or the emotional and psychological challenges which affect paid and unpaid carers as they negotiate issues of identity and loss, gleaned from prolonged contact, interaction and through observation were fundamental in shaping some of the chosen themes discussed in the interviews (Charmaz, 2015). The SPT method helped me to interpret some of these insights gained through personal experience, as well as allowing me to become aware of different carer experiences '…living and working within a particular community in order to understand how they work from the inside….' (Cook, 2005) and have added depth to the research, in conjunction with the interview process. Although not mixed method by design, these auto-ethnographic and observational aspects associated with my life have added an additional layer methodologically and this can be a valid way for researcher, and researched, to produce thick data (Valentine, 2005).

Using auto-ethnographic observations does not reduce the validity of more rigorous scientific research, instead it adds depth to it (Adams, et al, 2014). It helped me to make sense of the data I collected, and further it (hopefully!) engages the reader. A number of participants in the interviews told me *'You get it'* because my own experiences had given me a greater understanding of the carer and cared for relationship.

3.2.6 Integrating Critical Realist and Standpoint Theory

> 'Not all feminist approaches are antirealist, but nearly all are normative, offering prescriptions for revising both scientific practice and concepts such as objectivity and knowledge that have direct implications for realism' (Chakravartty, 2017, no page number).

STP can be considered as both an explanatory model and a method (Harding, 2004). Researchers, through interaction with participants gain '*situated knowledges'* (Haraway, 1988). Although CR and feminist SPT have only recently been connected (Flatschart, 2017, Gunnarsson et al, 2016), critical realist ontologies can successfully incorporate a standpoint position, as examination of the lives of women or other oppressed groups, carers and PLWD, involves examination of the actual world researcher and researched live in:

> 'Feminist standpoint theorists are therefore committed to making strong claims about the real world, claims that capture that world to varying degrees of accuracy. Standpoint theorists take this realist position even though they enter into these philosophical critiques through questions of epistemology, not ontology' (Albert et al, 2020, p. 362).

Standpoint theorists examine the lives of women and other oppressed groups whose experiences may have been overlooked by deliberately creating research questions and suppositions from the standpoint of these groups (Ackerly and True, 2020, Harding, 2004):

> 'Feminism makes claims about the nature of social relations and adduces various sorts of evidence for these. It points out the falsity of dominant accounts of the social world and argues on the basis of rival accounts that deep and wide changes should take

> place. A realist approach (and an ethically naturalist one) is therefore essential to the feminist project' (New, 1998, p. 366).

Critics of SPT say it risks being unobjective if all knowledge is relational to the observer and thus risks reducing knowledge to the individual experience. Edwards, (2014) argues that SPT does not reject realism and does provide objectivity by asking us to be reflexive *and* objective and Bhaskar propounds a relational discernment as fundamental to a CR position:

> 'Realists argue for an understanding of the relationship between social structures and human agency…they advance an understanding of the social as essentially consisting of or depending upon relations. This view is in opposition to both atomistic individualism and undifferentiated collectivism' (Bhaskar, 2011, p.3).

Some aspects of the social world are constructed but there are some material and real-world aspects which underpin this. There is therefore objectivity in standpoint. Aspects of both critical realist and standpoint theories can link to ethics of care and capability literatures examined in chapter two. By acknowledging the primacy of both the individual and the relational, that knowledge can be both socially constructed and have a material underpinning. The empirical data and auto-ethnographic reflections in this thesis bring personal experiences of researcher and researched together, allowing both individual and collective knowledge to be shared and created. From its Marxist roots, SPT acknowledges a type of empiricism through observation and experience creating knowledge and differentiating between the superiority of some knowledge over others (Hundleby, 1997). Discrete groups of people experience diverse understandings about society and the world they live in. People's lives are not neatly packaged, but messy, complicated, and truly diverse. Detachment, disinterest, and scholarly observations can provide useful insights into people's lives, but a more relational standpoint perspective can also bring degrees of impartiality and objectivity which elicits richness, depth and nuance giving rise to good data.

Using Crotty's framework (1998), the following table summarises the theoretical perspectives and methodology which have shaped this thesis:

Paradigm	**Critical Realism**
Ontology	There is a mind independent world - realist
	Experience is interpreted - critical
Epistemology	Knowledge can be both socially constructed and have a material underpinning. Knowledge is described and explained.
Theoretical Perspective	Feminist

Methodology	Standpoint Theory
Method	Person centred semi-structured Interviews

3.3 Choosing a Method

> ‘The beauty of qualitative research is the ordinariness captured from everyday life’. (Silverman, 2022).

Consideration of different methods of data collection is predicated on the research question itself, potential ethical issues, practicalities, skill set of the researcher and constraints or barriers which are temporal or financial. I have experience over many years in facilitating focus groups with a variety of participants professional and lay, carers paid and unpaid, young, and older, learning disabled, as well as facilitating Person Centred Plans. Generally, focus groups are less onerous to organise, have the advantage of gathering a group together at one time which is often less costly financially and timewise. A large amount of rich data can be generated expeditiously. Further advantages of talking to family caregivers as a group is the potential for the expression of a range of views and reciprocal sharing of ideas as well as the potential for generation of new ideas ‘…participants share their views, hear the views of others, and perhaps refine their own views in light of what they have heard’ (Hennink, 2014, p.3).

I had two main reservations about conducting focus groups with family caregivers. The first was a practical consideration – carers can find it very difficult to take time away from their caring role, therefore finding a time which would be suitable for a group to come together would be challenging and might mean a loss of diversity in any focus group I set up. Time constraints or issues can be a factor which is less recognised in focus group planning and execution (Hopkins, 2007a). The second reservation was based on personal experiences of support groups for carers. Knowing which carers are going to be comfortable in a focus group style setting can therefore be difficult to predict. In addition, ‘opening up’ and sharing sensitive details may be extremely challenging for some people in a group setting, and further the group dynamics and interactions may be difficult to facilitate, with some people dominating at the expense of others. (Smithson, 2000). I opted not to hold focus groups but decided to keep them as an option for follow up research if time allowed later in the research process. I elected, therefore, to ask participants at interview if they might be willing to take part in a focus group at a future date.

Choosing semi-structured interviews was for me, then, an easy and obvious alternative; having conducted many interviews, often with carers, over the last few years. Social sciences have long relied on interviews as a method of knowledge production. The term 'inter-view is an interchange of views (Kvale, 2010). Semi-structured or unstructured interviews can be described as 'soft' (Longhurst, 2010), relaxed, informal, or ethnological interviews (Punch, 2005). Interviews are a method of gleaning individual experiences which may find common understandings with other people (Atkinson, 1998). Semi-structured interviews are usually made up of discussional exchanges which allows one person to collect information from another person (Longhurst, 2010). Utilising PCP tools allow participants to tell their histories and stories of their lives, which can be an important aspect of human interaction (Atkinson, 1998).

3.3.1 Person Centred Planning Approaches as Interview Technique

I had utilised semi-structured interviewing techniques in combination with person centred planning toolkits before, with positive feedback. These techniques can be a valuable way to conduct interviews (O'Brien and O'Brien, 1998, Kesby et al, 2005, Falvey et al, 1997, Sanderson, 2000). Person centred planning (PCP) places the person at the centre of the process. PCP toolkits were originally developed to use with people with learning disabilities, but the 'person centred' approach is eminently suitable to be used with any person or persons.

Person centred planning is a framework of techniques and tools encompassing shared values that allows facilitators to plan *with* a person not *for* them (O'Brien and O'Brien. 1998). Feminist research methodologies are well suited to incorporating PCP approaches. Communicating appropriately using a range of methods, a flexible approach to the places and times where planning takes place, foregrounding open questions, listening, and responding, creating, and maintaining a rapport with the person are all central to good practice in PCP facilitation. Supplementary to good Person-Centred facilitation is the review process built into the planning sessions – summarising to check you have the correct information, and to allow any feedback from the participants creates an iterative process.

Utilising PCP techniques can help to identify relevant questions and topics for discussion, but these are kept necessarily broad and are not prescriptive. Pre-populated diagrammatic posters, (see Appendix B) can provide a focal point for interviewees and allows the researcher to move sequentially (or not) from theme to theme allowing discussions to range freely, whilst observing the posters, facilitates adherence to the parameters of the topics at one level, but does not preclude the creation of new themes or subjects. As the researcher populates the posters by writing in coloured pens as the interview progresses, the interviewee often notices patterns or links within or between themes, and often uses the opportunity to write things on the posters themselves. I also audio record all my interviews, but the poster provides a supplementary source of data, which can be useful as a reminder of key points recorded during the interview, whilst the researcher is transcribing at a later date '…feminist researchers are likely to continue to refine and elaborate the method of interviewing as more and more experience with it is built up' (Punch, 2005 p. 173). Participants often express surprise and a positive reaction to the posters at the end of an interview 'I didn't know my life was so interesting!'

3.3.2 Feminist Approaches to interviewing

Oakley (1981) argued that early interview processes were often androcentric and hierarchical foregrounding interviews which were 'scholarly and detached' (Stanley and Wise,1993 p.154). This 'masculine' style of interviewing maybe oppositional to more 'emotional' styles typically associated with women. Values of 'objectivity, detachment, hierarchy and science' were usually linked positively to men whilst adjectives for women were negatively ascribed as less important '…sensitive, intuitive, incapable of objectivity and emotional detachment' (Oakley, 1981, p.38) Feminists have challenged these masculine views by foregrounding feminist methodologies which value subjective experiences and embrace less hierarchical and more reciprocal relationships between researcher and researched (Oakley, 1981).

Generalisability from subjective accounts maybe problematic and thus 'the proposition that our interviews are meaningless beyond the context in which they occur is a daunting one' (Miller and Glassner, 2004 p.125). The subjective nature of interviews, the difficulties and constraints which prevent us from fully describing anything or having the necessary language to do so are inevitable qualifications to research of this kind. In addition, we must accept that our own positionality as researcher and particularly within the social, political, and environmental contexts within which any interview takes place are all factors which shape and influence. Nonetheless, this does not preclude rigorous and rich research (Miller, Glassner, 2004).

My own position as a carer of parents with dementia, leaves me vulnerable to criticisms of partiality in my research and a lack of objectivity and emotional detachment. These accusations cannot be entirely refuted or parried, nor should they be. Yet sensitivity, intuition, emotional involvement, and empathy are valuable attributes and approaches when interviewing and need not be considered ‘unobjective’. Person centred and feminist approaches are well suited as harmonious interview techniques and methods.

3.4 Recruitment of Participants

Recruitment of participants took place over a period of three months. Within the timescale of a qualitative research PhD, allowing for in depth interviews, I had concluded that twenty-five to thirty semi-structured interviews would be sufficient to provide enough data for analysis. Any less risked the research lacking necessary depth or inadequate demographic range and enough data from which to generate meaningful categories and themes. More than thirty interviews might have created time and logistical pressures on the recruitment process, thus delaying analysis and writing up of the research; transcription, and management of a large amount of data generated from qualitative interviews can be challenging and time consuming for the researcher. A researcher may have the financial means to pay for transcription services (which I did not) or the technological facilities to transcribe oral interviews to written formats. I have tried using voice transcription – my Scottish accent appears to cause problems for the software! Immersing myself in the data, through transcription, allowed me to hear sound of people’s voices, the nuances, inflections, the sighs, the laughter, and the critique of one’s own questioning style, with its deficits, omissions and partiality enabled a self-reflection which promotes good practice, and was a crucial part of the analysis and coding. Therefore, aiming for a maximum of thirty interviews seemed appropriate. I planned to conduct the semi-structured interviews with family carers – perhaps one or two stakeholders if it seemed applicable, with an option for a limited number of second interviews or focus groups if time allowed.

3.4.1 Access and Gatekeepers

Use of gatekeepers can be a useful way to gain access to potential participants in a qualitative research project (Barbour, 2008). However, using gatekeepers is not risk free, but can produce additional and unexpected challenges (Chaudhuri, 2017):

> ‘Critical reflexivity should focus not exclusively on the relationship between the researcher and the researched but also on the network of actants, of which gatekeepers are a part’ (Campbell et al, 2006, p.118).

I encountered several gatekeepers throughout the research period including my collaborative partners who acted as introductory gatekeepers to a care facility provider. Managers at the care facility then acted as further gatekeepers to the family caregivers of PLWD who used their services. Managers of other organisations also had a minor gatekeeping role in allowing me opportunities to advertise for participants through their networks.

The positionalities of gatekeepers and our own positionalities as researchers can be problematic in a number of ways – power dynamics and organisational hierarchies can lead to ethical conflicts of interest, bias, and a lack of neutrality (Chaudhuri, 2017). Researchers can even become ‘quasi gatekeepers’ themselves by choosing participants who may reflect pre-conceived ideas held by themselves (Campbell et al, 2006). Continual self-reflective practices can help the researcher to identify the biases which influence them, acknowledge the power differentials between themselves and the researched.

People in positions of power can use that power to direct the researcher, prevent access to participants or narrow the range of participants the researcher can contact (Campbell et al, 2006). Gatekeepers may be under pressure to restrict or conceal information which might place themselves or their organisation in a bad light, or conversely may try to present a positive image by the same means. Being aware of the potential for agendas which gatekeepers might overtly or covertly have in opposition to the research must therefore be part of the evaluative self-reflective process (Reeves, 2010). Further, the relationship between the gatekeeper and the participants may also involve power differentials which may affect the impartiality of data collection (Chaudhuri, 2017). For example, if an organisation is the only access that a family caregiver has to help and support, they may be very reluctant to express any negative views about the provider for fear of losing the support they have.

Gatekeepers can also be crucial to the research process by being generous with their knowledge and expertise, genuinely wish to support the research and the research process and offer open and fair access to the researcher. The researcher’s position can also be beneficial or positively biased when they have prior knowledge of or a good working relationship with the gatekeeper. I had contacts in Northumberland from being a participant in previous research projects, from my own personal experience as a carer for PLWD and from employment in the care sector for many years. My collaborative partners provided additional contacts, and word of mouth added another two participants. Ensuring I was cognisant with good practice and responsive to issues as they arose enabled me to retain a focus on the gatekeepers I came into contact with as the project progressed (Campbell et al 2006).

3.4.2 The Recruitment Process

In order to recruit potential participants for the project, an information sheet was sent out to

a) My collaborative partners Co-ordinating 4 Age to disseminate information about my research to their contacts

b) To a variety of organisations made through my own contacts, professionally and personally, with a request to share details of the research through their networks

c) Participants who had been suggested by those I had already interviewed

d) Local organisation after an online search

Adoption of this approach provided a successful initial communication with several potential sources of recruitment. Carers Northumberland agreed to put information about my research and my request for participants in their monthly newsletter. My collaborative partners provided introductions to a care facility and provider in mid to North Northumberland, who then agreed to identify caregivers I might contact (See Appendix G for an example of email letter). Discussions with the managers led to my information sheet being posted on notice boards, included in an online newsletter, and disseminated in person by the day-care manager. My collaborative partners also suggested local care homes to contact and provided a further contact at a dementia charity. The contact put me in touch with a grassroots organisation in the north of the county. I made direct contact via email with these people. Two participants were recruited through word of mouth after being contacted by someone who had already been interviewed, and they contacted me. I contacted directly one third sector manager asking for an interview.

Responses in the first phase of interviewing were immediate. The day the newsletter came out from Carers Northumberland, I was contacted within minutes by telephone by three carers of PLWD. Contacts from this source soon totalled nine participants who had agreed to be interviewed and a further one participant who had found out by word of mouth from a carer registered at Carers Northumberland. Contact with the manager of two local care homes also quickly led to an additional family carer. Five further persons were identified by a care provider/facility. In order to get a good demographic mix of participants, I designed a simple grid detailing the age, sex, ethnicity, address, relationship to cared for person, educational attainment etc. of the interviewees. Initial responses reflected local authority statistics for Northumberland – with more women than men responding, almost all participants being white/British, with high number of degree level education, (but often first in family from a working-class background), and some working-class carers (see Appendix I). By luck, rather than design, most participants were geographically distributed throughout Northumberland except for one area in North Northumberland. Hoping to ensure a sample of participants which was as geographically representative as possible, I contacted my collaborative partners to ask if they had knowledge of how to contact carers in this particular area. An introduction by them via a dementia charity led to me contacting a dementia support group, which had originally been set up by the dementia charity but was now run as a self-organising entity. A further eight participants were recruited after I attended one of their group meetings and outlined my research to them. Two further interviewees came via word of mouth from a colleague who knew my research area, and from direct contact with myself. Only one interview was with a professional– contacted directly by myself. A final total of 27 carers of PLWD and one manager were recruited over a period of three months. The ease and speed with which participants were recruited indicated to me that carers of PLWD were very keen to talk about their experiences.

3.4.3 Practical Issues - Preparing and Managing the Interviews

Initial contact was by email or telephone call prior to setting up an interview. The practicalities of holding interviews are often dependent on numerous factors and considerations which can impede, constrain, or limit the available options. Family carers are often time-poor, balancing complex workloads with caring duties. The driving ethos underpinning the interview, was to minimise disruption to the interviewee both in terms of work and/or caring responsibilities and to ensure that participants did not incur any additional expenses by taking part. Further, I wanted to ensure that accessibility was prioritised. As such, I offered potential participants a range of time options and venues for interview – this included daytime, evenings, and weekends and a variety of venues including their own home, at a local community venue, at a café etc. This helped to establish at the outset a mutual understanding of caring challenges. Participants were asked whether they had any accessibility or additional needs regarding how or where the interview was conducted

Most participants chose their home as the place they felt most comfortable, but interviews also took place at a meeting room of a local third sector organisation, at a meeting room at the university, at an accessible disability charity office, and at a neighbour’s house. One interview took place at the person’s workplace during their lunch hour, most took place during the day, but several were in the evening. Participants who were interviewed outside their home were offered travel expenses, but no-one claimed them. The accessible room was paid for through the project, this enabled a participant with additional physical needs to be interviewed at a venue which was accessible to them. I provided tea and coffee and biscuits at venues away from the participants’ homes. A thank you letter was sent to each participant after the interviews.

3.5 Ethical and Personal Considerations

All research involves ethical considerations (Babb, 2012, Bell, 1993, Punch, 2006). Ethical issues may be encountered throughout a research project and thus requires continual self-reflexivity and awareness as the research progresses as well as acknowledgement of positionality throughout the process (Hopkins, 2007, Rose, 1997, Pain and Francis, 2003, Mauthner and Doucet, 2003). Many intersecting factors have the potential to create power imbalances and influence our thinking and that of the researched. These include, but are not limited to – age, (Macnicol, 2006) gender (Oakley, 1981, Valentine, 2005, Stanley and Wise, 1993), class (Sayer, 2005) and ethnicity (Crenshaw, 1991). These intersecting aspects, shape our values and the ontological frameworks in which we situate them. Ensuring that no physical or emotional harm be caused to participants, is the starting point for any ethical research project. Different aspects must be addressed in order to maintain the highest ethical standards, but key must be an understanding of the relationship of the researcher to the researched, the sensitivity of the topic and the potential vulnerability of the participants. Re-evaluation continues throughout the research project (Babb, 2012, Punch, 2006).

3.5.1 Ethical Approval and Risk Assessment

Full ethical approval was applied for and agreed by the university ethics committee prior to research in the field taking place in October 2018 (See Appendix C). This involved informing them of the planned fieldwork and how the interviews would be conducted, how I would recruit participants and how I would store the data. An information sheet was designed for all potential participants, (both for one-to-one interviews and focus groups) consent forms for both audio and written material, and a debriefing sheet post interview. Two sets of these documents were created – one for family carer participants and one for stakeholder participants (See Appendices D and E for example information sheet and consents). A robust risk assessment was also submitted as part of the ethical approval application detailing potential hazards whilst conducting the research and what measures I had put in place to reduce or remove risks to myself and to participants. The completion of the ethics form and risk assessment did not preclude on-going consideration of my ethical standpoint throughout the project, and as such I have consulted my supervisory team on several occasions to discuss potential ethical dilemmas and my responses as an ethical researcher.

3.5.2 Personal and Professional Relationships – Building Trust and Setting Boundaries

My own experiences as a carer for my parents with dementia, as a regular family visitor to residential care homes arguably made it easier for me to feel comfortable meeting with other carers of PLWD, including talking about sensitive issues, and as outlined above allowed me access to gatekeepers and participants which might not have been possible otherwise. Using person centred interviewing techniques with which to conduct the research foregrounded a reflexive open style of interviewing. There are risks to sharing information with participants, and these cannot be dismissed or discounted. Insider status of both myself and the participant may lead to certain topics being taken for granted and thus underexplored, or priming them, even if this is unintentional, to talk about specific issues or ideas which you have shared.

However, sharing information about my own caring roles both paid and unpaid was crucial in helping to establish an early rapport with participants. Knowing that I ‘understood’ and empathised with their caring responsibilities and role helped to reduce power differentials and accusations of voyeurism or appropriation (Valentine, 2005, Punch, 2006):

> ‘The principle of reciprocity, sharing your experiences and exchanging ideas and information with participants, is now widely accepted as good research practice’ (Valentine, 2005 p.121).

In addition, living and working and caring in Northumberland myself, also contributed to the building of a rapport with the participants.

3.5.3 Emotional Welfare of Participants and Researcher

Interviews with family carers of people with dementia had the potential to be emotionally charged sessions, including disclosure of sensitive information, and eliciting distress responses from the participant or myself. It could also potentially provide a space where the interviewee experienced a therapeutic environment where sharing some of the difficulties of their caring experiences might be seen as shedding a burden. Person centred interviews of this type which I have conducted in the past, have indeed provoked strong emotional responses - laughter, tears, anger, guilt, and frustration.   As the safety and well-being of research participants, both emotionally and physically is paramount, when planning, conducting, writing up and completing a research project, I ensured that everyone I interviewed was aware of support organisations including carer groups, where they could access help and advice if required. I raised awareness of issues pertaining to confidentiality and disclosure as interviewing family carers of vulnerable adults, raises the possibility of disclosure of reportable safe-guarding issues. I completed a two-day Mental Health (MH) first aid course in 2018 (Appendix F). This gave me a greater depth of understanding of MH issues, increased knowledge of safe-guarding and responsibility – knowing where and who to signpost those who might require help. Acknowledging potential risks as a researcher and making provisions for support, if necessary, is good practice.

Research of this kind can also impact upon the researcher – both positively and negatively. Caring for my parents with dementia whilst being involved with this research project has undoubtedly at times been difficult. I was not just conducting my research but also living it, day to day along with the participants. Corbin and Morse (2003) posit that ‘researchers and participants co-construct ethical realities during the course of the interviews’ (p.348). Hearing the stories of participants can bring back painful memories, but there are considerable benefits too, as my personal experiences bring greater understanding of the lives of family carers and thus makes it ‘…easier to build a rapport with your research participants and conduct interviews if your project is linked to your own interests’ *(*Valentine, 2005 p.113). This emotional dichotomy, deep engagement and empathy with my interviewees juxtaposed with an intellectual detachment has been a delicate balancing act. Mostly this balance, due to considerable experience of interviewing over many years has been relatively easy to maintain. There have been however, several occasions where the participants and I have shared a tear, or, and thankfully mostly, shared laughter. Very often this laughter articulated a black humour which we were both aware of and provided moments of profound understanding. Shared understanding between I as a researcher and the people I interviewed occurred during some interviews when I or the participant automatically finished one another’s sentences because we knew what the other person was going to say. This shared understanding also occurred when a response from the participant elicited a further relevant question from myself which illustrated to the participant that I understood what they were telling me. These exchanges with the participants were unscripted, reflex responses borne of a shared understanding and knowledge. As such, these observations illuminated and added depth to the data through mutual understanding.

Feminist interviewing techniques foreground the interactive and emotionally shared experience, which underpins all my research. Knowing when to step away and switch off from research, is vital. Transcription and data analysis are solitary activities, where the researcher is alone with their data and their thoughts. These times were again emotionally dichotomous with moments of insight and moments of deep sadness. On several occasions it has been important to step away, shut the laptop and walk on the beach. I have also benefited from longstanding help offered at a local carers group, good pastoral supervision and family support.

3.5.4 Data Storage and Confidentiality

Ethical practice must include considerations of data storage and security (Nichols-Casebolt, 2012). Prior to commencing the interviews, and as part of the consent to participate, I discussed with participants confidentiality, particularly how their data would be used, their identity anonymised and information securely stored. Names were changed, identifying information and transcriptions were anonymised A data storage plan was completed as part of the ethical approval process. Data was stored securely on the university's online password protected server and, on a password protected laptop. Paper documentation was stored in a locked cabinet. The data storage plan was reviewed along with ethical considerations throughout the project.

3.5.5 Revisiting Ethical Considerations – Bereavement and Covid 19

The death of my father two years ago, just before the first Covid 19 lockdown in March 2020, in the middle of my PhD research was a profoundly disorientating event. Although long expected his death after such a protracted illness, and within the context of my research and a global pandemic was a bereavement like no other. It opened a new window onto my research. I had now experienced caring for someone with dementia from diagnosis to death. Participants I had interviewed who had already experienced the loss of the person they had cared for came more clearly into focus. Lockdown, knowing that current carers were probably cut off from family and friend support, or because the PLWD was in residential care caused me anxiety and pain. Seeing the death notice in the local newspaper of the husband of a carer I had interviewed left me feeling hollow and sad. My mum's death earlier this year, bookended the PhD research process and ended 15 years of caring for my parents. Experiences such as these are intensely and acutely felt. Writing a thesis which involves consideration and analysis at the deepest level, of a topic which has dominated my life for so long, has often been beyond challenging, objectionable and something which I often wished I had never undertaken.

Listening to transcriptions and trying to analyse data effectively was often a painful process, and at times felt detrimental to well-being, but it has also been a vital part of locating my experiences in the research. Facing head on these challenges, when it might have felt safer to walk away, close the book and abandon the research, has been an important aspect for this research and for me personally. Being responsive to evolving ethical considerations is necessary for good research and to foreground safety and well-being (Rapley, 2001), but essentialising of 'safe-guarding' practices for participants who might prefer to 'regard themselves as capable and agentic beings, rather than vulnerable subjects in need of 'safeguarding' by me' (Gatrell, 2009, p. 120) is a prescient admonition for researchers to involve participants in deciding what is safe for them and in addition an apposite reminder for researchers themselves.

3.6 Choosing Thematic Analysis

Starting with a conventional research question and design format proved difficult for me during my undergraduate degree and again in my master's degree. Using grounded theory seemed applicable for a more flexible type of analysis:

> 'Your research questions and study design evolve as you proceed, rather than emanating from deducing a hypothesis from an extant theory or following a tightly preconceived plan' (Charmaz, 2015, p. 59).

Silverman concurs, arguing that qualitative researchers should avoid early hypotheses and simply focus on what is happening here. (Silverman, 2013). As described above, grounded theory was difficult to utilise as a methodology, but it became clear that this also applied to GT as an analytic tool. I instead adopted a 'grounded' thematic analysis (TA) which corresponded well with the PCP posters used in interview.

Thematic analysis is a way of coding qualitative data which involves construal of the data by the researcher in order to explain both implicit, and observed ideas contained within the data (Guest et al, 2012, Clarke and Braun, 2017, Boyatzis, 1998). Researchers need to interpret and analyse not just describe raw data. TA does not usually inform how the data is going to be collected but is rather 'solely an approach for analysis' (Clark et al, 2021, p. 537).

Guest et al (2012) argue that thematic analysis is closely linked to grounded theory. Researchers using grounded or thematic techniques will both begin with the data by reading and transcribing transcripts, distinguishing themes and then evaluate and interpret similarities or differences in those themes. Grounded theorists will then begin to develop theories from the data (Guest et al, 2012, Bernard and Ryan, 1998). At this point there may be a departure from grounded approaches, as thematic analysis may not provide development of theoretical templates - although it does not exclude it.

Themes may also be considered categories (Corbin and Strauss, 2008). Themes can be both a 'category of interest' (Clark et al, 2021, p.537) which may relate to the research aims or questions, or a group of codes or even synonymous with a code (Clark et al, 2021). A code can be considered a concept (Corbin and Strauss, 2008), a catalogue of themes, or a set of themes with related markers and stipulations (Boyatzis, 1998). Charmaz, (2014) highlights the differences between thematic coding and grounded theory coding – this indicated to me that I had a somewhat hybrid style of coding which was still substantively 'grounded' (p121 and 123).

Themes can develop inductively from the data, deduced from the literature or other theories, or generated prior to the data collection through personal experience. Prior research or experience can lead to putative codes being developed in advance of the data collection. My experience caring for PLWD and previous research lead to broad themes of interest with which I populated PCP posters prior to interview. I had six broad themes on the posters at interview: Northumberland, Dementia, Diagnosis, Residential Care, Caring Past and Caring Present. Each of these themes had some tentative sub-themes or codes recorded on the poster. These codes were chosen because of preceding research and study and through personal experience. For example, the theme Northumberland had sub-themes relating to the area: health and social care services, rurality, community. The theme Residential Care had stigma, negativity, and cost as provisional codes.

Coding is a means to summarise or paraphrase the transcription data by creating small ‘packets’ of information (Boyatzis, 1998) which are a summation of larger chunks of text. These packets can be examined to identify themes or place them within the pre-research themes. Coding involves searching for patterns, reiterations, the language used, including metaphor or analogy and also omissions, hesitations, emphasis and timbre and pitch of speech. Comparing and contrasting convergent and divergent codes which in turn create themes. The initial ‘open coding’ (Charmaz, 2015) helps to develop categories in which to situate the data. Constant comparison between early coding of transcripts was possible because I transcribed earlier interviews whilst still conducting subsequent interviews. As the coding of earlier transcriptions progressed, several categories reached saturation point – i.e., each interview added the same point to develop certainty in a category. After six interviews, two categories had reached saturation point and led to me amending further interviews to assume the categories and use to ask questions about how the category linked to other potential ones – driving cessation and abandonment by services after diagnosis.

3.6.1 Coding the Transcriptions – early stages, open coding

All the interviews were audio recorded and subsequently transcribed verbatim. A prolonged and arduous process – each interview lasted at least an hour – and each hour could take 6 to 7 hours of transcription. The transcribed interviews were all saved as documents online, but also printed out. I find annotating scripts online very difficult and prefer to use highlighter pens and pencil notes on hardcopies. Each printed interview was laid out alongside the poster I had completed on the day of the interview. Whilst I listened again to the recording, I read through the transcripts, pausing the recording as I went to make notes, highlight key quotes, and to make comparisons to the written posters. The key points I had noted on the poster were indeed often important and the transcription and the poster complemented each other. But occasionally, the transcription highlighted something I had missed on the day, or which could only be appreciated by the close attention to the subsequent recordings. Listening to an interview again allows the researcher to hear emphasis, and tone, inflections, hesitations, and contradictions. It also allowed me to notice omissions in my questions or subtle guiding or leading of questions which I had not intended or been aware of. David Silverman (2022) highlights the importance of re-reading transcripts and re-listening to recordings repeatedly as each time you will hear something new, sighs, hesitations and other subtle clues which may have previously gone unnoticed. Silverman also underscored the importance of the sequence of the interview data as well as the data itself. The history/biography of the participant on the handwritten maps, was useful for some aspects of sequence, particularly during the interview itself, but the maps were less able to convey the sequence of the narrative, and thus re-listening to the recordings and using the typed transcriptions was beneficial in understanding the order with which participants organised their narratives. I did not begin my research with a ‘blank slate’ - my slate was written all over in dense script, which highlighted my prior knowledge of care and caring practices. But I did hold back from analysing my own experiences in light of the coding and data analysis of this research, tempting though it often was, until much later. I could not have undertaken this research project if I had not wanted to make sense of the experiences, caring for my Mum and Dad, but I did not fully place these experiences under the microscope until the findings, discussion and literature chapters had been written. The coding and thus the development of the thesis relied on interpretation of subjective accounts, but a degree of objectivity was possible through the collective knowledge gleaned from participants and myself.

The first coding stage involved a close analysis line by line, examining and asking myself by asking what is actually happening here, what are the participants saying, what assumptions am I making, or might I be making, and what am I missing or taking for granted? ‘Coding is the name given for connecting conceptual description to data’ (Urquhart, 2013, p.35). This offered opportunities to be open to new ideas, by foregrounding the narratives and the repetitious process of re-reading transcripts– sometimes months apart, garnered new details and new avenues to explore.

The coding process did not always follow established coding methods. Boyatis (1998) outlines three broad stages of thematic analysis which involve sampling, coding – including comparison and reliability, finally checking the validity, and interpreting the results. Braun and Clarke (2006, 2013) foreground a more reflexive six-pronged approach; habituation to the data, early coding, theme identification, theme re-examination, theme definition and lastly evidence for the themes used. The coding and thematic analysis I undertook was broadly in line with Braun and Clarke's six step process, but I did not follow it slavishly but rather adopted a method which was iterative, and non-linear (Clark et al, 2021).

Thematic analysis offers a flexibility to the researcher which allows for 'generalised' ways of working which are not prescriptive. Thus, in an initial attempt at coding I thought that I might develop a hashtag # system for line-by-line coding – I wondered if using colour coded hashtags, with each coloured hashtag denoting a key one-word or one category. Using hashtags in eportfolio and Mendeley had suggested to me that this might be a quick way of coding densely worded transcriptions. I realised quickly, that this was confusing, and I ran out of different coloured pens! I continued in a more traditional way by making notes in the margins of typed transcriptions, with a summary of key points at the end which had identified tentative categories to compare with subsequent analysis of other transcriptions.

It can be argued that the posters I used with very broad categories whilst interviewing pre-empted some thematic coding - themes can be understood as big groupings which may come from either the literature, the collected data or both (Urquhart, 2013), or were indicative of top-down thematic analysis (Braun and Clarke, 2006) rather than bottom-up grounded theory. However, the key themes or categories used on the posters were utilised in a PCP facilitated manner – i.e., they were employed as a means to help participants focus on their narratives, identify links and relationships themselves and prompt discussions – this is the 'structured' part of semi-structured interviewing. A starting point from which the interviews can take place. Interview participants could and did deviate from the themes in the pre-populated posters, and the 'personal history' of the person very often had a larger influence on the proceeding conversation. Core categories for a theory, suggested by GT, can therefore be seen as themes – they are, after all, large categories. However, core categories grow inductively from the data contained in the narratives and are thus still grounded in coding. In an informed approach, pre-conceived themes suggested by extant literature and prior personal experiences seemed appropriate and useful and not in opposition to an overall bottom-up approach.

3.6.2 Selective Coding – second stages

From open coding, I moved to selective coding. This involved writing short summaries and bullet points to explore the categories and themes and thus build up an analysis of the data. (See Appendix I for summary participant information). At this stage I had large flipchart sheets laid out on the floor at home and on campus (I well remember people walking around me as I sat in a sea of paper!). Each transcriptions summarised codes and key quotes were added to the flip chart and separately onto a word document. Under each theme on the flip chart, I placed bullet points (packets) for each participant. Separately I collated key quotes, printed them, cut them out so I could move them around as the themes developed and evolved. Each tentative theme was elaborated and expounded upon, these were in turn printed and laid out on the floor with bundles of key quotes from participants. As the analysis continued, and the literature was read and re-read, these themes were further populated with additional coding, some themes were amended, occasionally discarded.

Moving from the first steps in analysis to the next was challenging. I worried about the validity of what I was doing. The Covid pandemic began, my dad died, and I felt stuck, tired, and despondent at these early stages. Imposter syndrome bringing thoughts of shortcoming and illegitimacy (Addison et al, 2022) needed constant challenging. It was hard to adhere to Morse's admonition that 'Researchers must learn to trust themselves and their judgements and be prepared to defend their interpretation and analyses' (Morse, 1997, p. 447). An interruption of studies at this point was helpful. Coming back to the data after six months away brought some new energy and perspective. Re-listening to tapes and re-reading all the transcriptions lead to checks on the reliability and the validity of the themes I had identified so far (Guest et al, 2012, Corbin and Strauss, 2008, Boyatzis, 1998).

This chart shows some of the first codes and broad themes from the analysis:

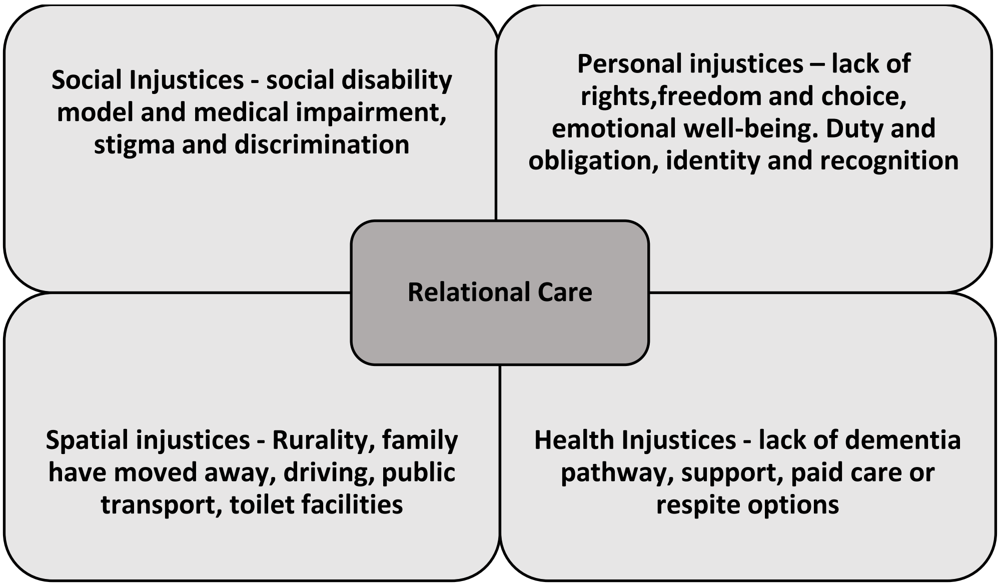
Themes	**Codes**
Dementia	Dementia services
	Information and diagnosis
	Pathway
	Symptoms/loss of identity
	Incontinence and personal care
	Treatment and Futility
	Safety and Danger
Rurality/Northumberland	Driving
	Primary, secondary, and tertiary healthcare services
	Infrastructure and access
	toilets
	Social services
	Third sector and paid care
	Families and communities
Caring	Wellbeing
	Emotions - guilt
	Moments of joy
	Moments of fear
	Never thought it would happen to me

	Social Isolation/Loneliness
	Valuing care
	Women's roles/Male Carers
	Families and communities
Care Homes	Stigma
	Language used to describe
	Lack of
Unfairness/Injustices	Spatial, Temporal, Austerity/Cuts
	Finances
	Duties and responsibilities
	Lack of choice
	Rights – whose rights

3.6.3 Recoding and Refining – building categories, and themes

Key categories began to emerge through the coding process and both new and extant thematic areas continued to be populated and developed. An emphasis on injustices – personal, social, and rural/spatial became clearer along with relational impacts of dementia care. Each category involved some interpretive comparison as well as direct comparison (Guest et al, 2012). For example, questions I asked participants regarding driving cessation could be compared directly – who informed the DVLA of a dementia diagnosis, the PLWD, the family carer or the GP/health professional? The impact of driving cessation on the PLWD and themselves had a greater interpretive element – for example, a carer who could not drive themselves and would be impacted more by driving cessation of PLWD might ascribe differing descriptions of the person's ability to drive. During this stage, the literature I was already cognisant of was extended to include more depth – specifically ethics of care, justice, and injustice, including spatial, and CA literature. New themes led to new literature being critically assessed – including social and medical models of disability, identity, personhood, recognition, and dementia specific care literature. Moving toward the writing up stage, the iterative process shifting between literature and analysis shaped the resulting themes.

Broadly, these themes remained throughout the writing up stage, but emphasis on different aspects and reading and re-reading literatures continued to the very end of the thesis. The following chart outlines the final key themes.



3.7 Writing Up the Findings

Moving from the thematic analysis to the writing up was a protracted, complex, and frustrating experience. Creating a structure from the huge amount of data generated took time. Ultimately, a researcher needs to decide what to include and what to leave out (Corbin and Strauss, 2008, Oliver, 2013, Silverman, 2013). Initially I had considered using a carer specific format – each chapter being a Who, What and Where – i.e. who the carer is, what they do, where they care, linking to the three areas in the Capability Approach – i.e., environmental, personal, and social as meta themes. I then planned to use the three stages of dementia care, early mid and late stage and have each stage examining one of the meta themes. But with considerable links and intersections between each stage, and conversion factors applicable in all three stages, this led me to make adaptations early in the writing up process. Developing a linking theme to use as a marker between each stage allowed each chapter to bring together key categories and themes. Therefore, I decided to retain the dementia stage progression, but not to try and shape the chapters to cover explicitly all the conversion factor areas, rather each chapter was divided into key themes within the meta theme of dementia care stage (Guest et al, 2012). Chapter four, for example, focusses on the early stages of dementia care. Social barriers and injustices dominate in this chapter, but there are also some environmental and personal factors which are evident but developed more fully in later chapters. Key ‘higher themes’ within this chapter were the *diagnosis process* -hindsight stage, carer response to it, sense of abandonment, *embedding of the carer role* – assessments, finances and development of the carer style, *post diagnosis* – early difficulties, lack of help from health and social services and *driving cessation* – this acted as a bridge between the next chapter, but also highlighted the intersection of the meta themes, highlighting the connections between social, environmental and personal factors.

I had numerous relevant and excellent quotes from participants. Initially I used them all for each theme when writing first drafts of findings chapters – I could not at this stage decide which to keep and which I would have to reject due to space constraints. First drafts therefore were enormous – 36,000 words for one chapter alone! Eventually, I settled on a quote which best encapsulated the point being made and reluctantly cut the other quotes.

3.8 Conclusion

> '…what do we want social science for? First consider the paradox that the very things which make knowledge possible—our ability to monitor our own monitorings, to learn and hence to change our interpretations, actions, and responses—are also things which make social science difficult' (Sayer, 1992, p. 251 and 252).

Concepts and ideas and how we frame them help us to understand or make sense of the world we live in. We need ways and methods of analysing, describing, and interpreting our research and the concepts we use. Theories allow us to build arguments, test hypotheses, and situate one's research relative to extant studies. Theory can also be a prism through which one can view one's research. A thesis offers opportunities to refine ideas through an iterative process where ideas and concepts are constantly analysed and challenged through reading, writing, reflecting, and adapting. The epistemological theory which has shaped this thesis is both critical realist and standpoint theory. Some aspects of the social world are constructed but there are some material and real-world aspects which underpin this – objectivity in standpoint.

Knowledge is relative, imperfect, and reliant on the given circumstances and perspectives within which we live our lives, but there exists nevertheless a reality outside of these contexts. No amount of reasoning or objectivity can guarantee truth (Sen, 2010b) but choosing 'the best reasoned procedure' and 'being as objective as we reasonably can' (Sen, 2010a, p.40) is surely the best way to proceed with any research.

Feminist ethics and principles underpinned my research. Employing semi-structured interviews to understand the subjective experiences of family caregivers may well elicit criticisms of bias or lack of objectivity. But our standpoints as researchers and the ontological frameworks within which our understandings are shaped, must promote at least a semi-subjective viewpoint. My data collection and analysis were an opportunity to use a feminist SPT approach. Taking a realist Standpoint Theory framework for this qualitative research project allowed a degree of flexibility and offered opportunities for self-reflection and auto-ethnographic observations to supplement the data collected through person-centred interviews. Speaking to participants and locating my own experiences alongside theirs opened up a dialogue between the data and the existent academic sources. Gilligan’s ‘different voice’ argues that women reason in a different *way*. Rather than distinctive feminist methodologies, we may regard feminist outlooks as entering existing methodologies (Crotty, 1998), to examine the world and critique and develop values, through an understanding of injustice/s created by oppression in a patriarchal world. Feminist enquiry into care and care practices and relationships are well placed to observe and explain these injustices.

There are constraints, drawbacks, and numerous ethical considerations to any method of data collection including interviewing. Acknowledging limitations of any research is fundamental to the research process and to the final thesis. A self-reflexive approach throughout in addition to a degree of objectivity can produce good quality rigorous research which remains grounded in the data. Intersecting relations with others, whilst having the potential to create hierarchical power imbalances, also has the potential for reciprocal and equitable knowledge exchange. Analysing data from qualitative interviews requires an acknowledgement of the subjective positions of both researcher and researched. Research has the potential to be psychologically draining. Immersing yourself in the data can at times be exhausting, maintaining some level of detachment from the process difficult. These feelings are heightened in this case due to the sensitive and deeply personal nature of the research and the analysis and write up stages taking place during a global pandemic.

Striving for an ethical and realistic methodology allows us to find gaps in research, shore up or critique current theories and share evidence which may lead to new avenues for epistemological and ontological concepts and theories which ‘... can strengthen a theoretical conviction or alert us to a misreading’ (Holloway and Jefferson, 2007, p.67). There is no ‘right’ theory, just conceptions and perspectives that are a better fit than others. The personal experiences which create our ontological frameworks and viewpoints, which shape our understandings and interpretations of knowledge, and guide our ethical positionings are complex, with conscious and unconscious emotional, psychological, cultural forces shaping and influencing the researcher and the researched in an iterative creative process.

Chapter 4. Diagnosis and Early Stage Caring

4.1 Introduction

This section marks the first of three findings and discussion chapters drawn from the empirical research into carers of PLWD. These chapters broadly equate to the three staged approach - early, mid, and late - commonly used in dementia care literature (Alz.Org, 2018a).

The first stage, which can last for months or sometimes years, can be sub divided into a four-pronged process. Firstly, the hindsight or acknowledgement phase, when the carer or the person with dementia, usually after considerable delay, finally takes the first steps toward a diagnosis by approaching their primary health practitioner. Secondly, the diagnosis itself, usually a combination of primary and secondary healthcare assessments, examinations, and scans. Thirdly, the steps which embed the 'carer status' - recognition as a caregiver with primary health care providers, employers, legal and financial powers, carer assessment and referral to social services or third sector providers, the establishment of the 'carer style' often through resolution of the carer to acknowledge their familial duty and responsibility to the PWLD rather than recognise themselves as carers. Finally, the post-diagnosis early stages of care, where carers and PLWD continue their lives with minimal health and social care support.

This stage comes to an end as the disease progresses, and carers begin to struggle to care for the person with dementia. There is often a tipping point where a carer begins to realise that outside help or additional family assistance may be required as they struggle to provide support to the PLWD and to cope with behaviours that challenge, leading to the mid-stages of care. Driving cessation and the complex decision-making which carers face when supporting the PWLD is used to illustrate this shift from the first stage to the mid-stage of caring, when the individual impact of the illness has a profound relational impact on carer and cared for, and conflicting individual rights emerge.

This first stage begins the exploration into three dominating and interconnected injustices which affect the well-being of those caring for someone with dementia – social, environmental/spatial and personal factors. As discussed in the literature review the theoretical and conceptual frameworks – ethics of care (Held, 2006, Tronto,1994, Noddings, 2003, Kittay, 2011, Engster, 2007) and the Capability Approach (Sen, 2010a, Nussbaum, 2011, Robeyns, 2017) are constructive in examining both relational and individual carer injustices and the difficulty converting capabilities to functionings, or well-being. In these first stages, a relational ethics of care conceptual framework is drawn on more widely and the CA more extensively in chapters 5 and 6.

(Quotes from interviewees use pseudonyms, initials LM denote myself. Please see Appendix I for demographic and key care information for each participant)

4.2 The Hindsight and Acknowledgement Phase – Realising That Something is Wrong

‘…never in my wildest dreams did I think this would happen.’ (Flora).

Increasing longevity and greater numbers of people living with dementia is a relatively new phenomenon, preceding generations having been more likely to die of heart disease or cancer (BBC, 2016a). Surprise at a diagnosis with dementia is therefore a common reaction (Aminzadeh, et al, 2007). A quarter of carers interviewed expressed considerable shock and amazement at the PLWD’s diagnosis. Most participants had no previous experience of dementia thus carers often did not recognise early dementia signs and knowledge was usually confined to memory loss rather than other cognitive difficulties or presentations of the illness.

In hindsight, carers were frequently able to identify several cumulative signs that the PWLD had exhibited, sometimes years prior to the diagnosis, but which they may have dismissed as the PWLD being ‘lazy’ or to not paying attention:

> ‘I mean, I think he’s had it for years, this dementia thing, because yeah, I used to put it down to being lazy’ (Winnie).

For a fifth of participants, these aggregate signs went unnoticed because gradual changes were overlooked by a person living in proximity to the PLWD and were instead detected by work colleagues or other family members:

> ‘It’s funny because when you live with somebody …changes are very, very gradual and my concerns were first really raised with me er... by work colleagues at her works do…and one or two of her friends took me to one side and said, “we’re a little bit concerned about Maureen, that she’s become really forgetful about things”. So, it was obviously evident in her work’ (Quinn).

Although memory loss is associated with early signs of incipient dementia, a quarter of participants described other symptoms of dementia with which they were unfamiliar. These symptoms included problems with disorientation - loss of map reading or navigation skills, and processing or reasoning difficulties. Some of these participants described a similar hindsight mechanism which had been unavailable to them synchronously, but which had become apparent after their knowledge of dementia had been enhanced and when a substantial period had elapsed enabling reflection and analysis:

> ‘He used to be an excellent reader of maps and navigator and I found him one day just pouring over this map not being able to understand which way it went or where he was and that was really worrying…. it was quite a few years from that to his dementia diagnosis’ (Tanya).

Delays in diagnosis are common (Boise et al, 1999, BBC, 2016b). A synthesis of studies over thirty years examining barriers to dementia diagnosis, identified themes including a fear of diagnosis resulting in denial, lack of knowledge and normalisation of symptoms or unawareness of perceived need (Parker et al, 2020). These factors were acutely apparent in carers narratives. Recognising cognitive decline can be painful for both carer and cared for and can lead carers and PLWD to avoid a diagnosis. Although dependency and interdependency are part of all our lives (Kittay, 1999, 2011, Weicht, 2011, 2015), hyper-agential notions of choice, independence, and autonomy lead to ‘fears of dependency, frailty and the gradual loss of our sense of agency, identity and our status as persons’ (Higgs and Gilleard, 2016, p.11).

Early symptoms can also be mistakenly attributed to psychological or emotional explanations. Although two in three people diagnosed with dementia are women (Alzheimer’s Research UK, 2022e), it can often be mis-diagnosed, in women (Kiely, 2018). Women often outperform men in standard memory tests, disguising early dementia signs (Kiely, 2018) and early onset dementia symptoms may be misinterpreted as depression or linked to menopause (Link, 2019, Davey, 2013). Two male carers highlighted gendered delays in diagnosis.

Quinn describes supporting his wife Maureen in her early fifties, as the GP diagnosed depression:

> ‘She was made redundant 2012 and then had an appt with the GP, who referred her to the psychiatric services erm and they came …he said it could be due to depression which we were both convinced that it wasn’t that, cos she was a very happy go lucky…. she was a very outgoing sort of person ……so she was prescribed anti-depressants and she agreed to go onto them’.

For others, ‘odd’ behaviour was the immediate red flag which led them to think that something was wrong, even if this was not anticipated as being dementia linked. As we saw with Flora’s shock at diagnosis above, being unaware that her husband might have dementia did not preclude her recognising that something was amiss:

> ‘And I remember going this one day, and we went to one of the hotels for lunch, and it had quite an extensive menu and that sticks out in my mind and Ernie suddenly can't go through the menu. He couldn't choose something to eat, and we’d all decided what we wanted, and I kept saying to him ‘come on Ernie do you not fancy anything?’ And

> he said, 'oh I don't know', and it just went on and on and on…. and I knew then there was something just not right' (Flora).

Six interviewees had anticipated a dementia diagnosis because they had previously cared for someone with dementia and early signs resonated, or because the person they cared for presented with dementia symptoms which are common in a dual diagnosis such as MS or Parkinson's Disease leading to dementia:

> 'I think I realised she had dementia right from the start …well, actually her mother had dementia and she followed a similar pattern.' (Neville).

Whether responding to cumulative observations of difficulties over several months or years, or because they recognised symptoms, most participants, rather than the PLWD, eventually approached their GP to express concerns.

4.3 The Diagnosis – D Day

Most interviewees described their relative being referred by a GP after an initial consultation to a specialist older persons dementia consultant or mental health team. Further assessments and scans would then be undertaken, and a diagnosis given. If medication was advised, it was prescribed by the specialist and thereafter the PLWD was discharged back to the care of their GP. For almost all the family carers I interviewed, this process had been completed, and the person with dementia had been discharged from any dementia specialist care. Only if the PLWD was continuing a medication regime which required review, or if they had or subsequently had developed behaviours which challenge was there any ongoing or re-referral to specialist support (usually a Community Psychiatric Nurse - CPN from the mental health team).

It was not always clear, however, who had diagnosed the PLWD, where that diagnosis had taken place, nor who was providing ongoing additional support over and above primary health care teams. This underscores a common lack of clarity about 'who's who' which leaves carers and PLWD confused about professional's roles, departments and jurisdictions and leaves them unable to articulate specificity about a disjointed diagnostic process (Robinson et al, 2011, p. 1037):

> '…there's so many blinking agencies you don't know who you're dealing with…. it's like it's all bitty' (Krissie).

A lack of 'joined up' specific dementia support was a continuing theme throughout the narratives of most carers and confusion about 'who's who', as explained above, persisted post-diagnosis. Often if I asked participants where they had found information or who had given them advice, they were unable to remember:

> '…so many people have come over the last two or three years from social services and different people from different departments and you often wonder who's who' (Olivia).

Struggling to recognise who to turn to in fragmented and confusing service provision is clearly acute, as Alzheimer's Society (2022b) in recognition of the bewildering number of people across services that carers and PLWD may encounter have created a downloadable booklet in which appointments can be recorded.

Information at the point of diagnosis by medical professionals was inconsistent. Most participants reported a lack of in-depth advice on the type of dementia diagnosed, the projected pathway of the disease or specific coping strategies in managing the condition. For those diagnosed with vascular dementia, mixed or an unclear diagnosis, follow up was usually deemed unnecessary as often no treatment, bar those medications for co-morbidities such as diabetes or high blood pressure, were available. As Una sadly reported:

> '…no treatment, just coping' (Una).

A few patients with Alzheimer's Disease had been prescribed medication - mostly Cholinesterase inhibitors (CIs). These do not halt the progression of the disease but may improve some functions and reduce or ameliorate symptoms. Regrettably, these medications often lose their efficacy as early as six months into treatment and they can also have considerable side effects (Casey et al 2010, Lazris, 2015). Lack of functional, effective long-term treatment options or other medical intervention therefore renders further specialist support unnecessary. Some carers were painfully aware of this when the PLWD was subsequently discharged from further specialist care. Wendy, who had cared for her mum until her death, speculated that the person with dementia is effectively disregarded after diagnosis:

> 'there was also very much a feeling at the time, and I don't know whether that's changed, that with the diagnosis of dementia that person is written off………I think maybe some health professionals, obviously not all of them…think that, ….you wouldn't do it with somebody with cancer but they kind of think that…this is the end, this is the diagnosis so whether this person drags on for the next 10 years …they're not really an interest to us anymore'.

Several carers felt angry with their GP or dementia specialist. Neville, like Wendy felt his wife was no longer of any interest after diagnosis. He was clearly indignant and frustrated at the lack of communication from the consultant and the subsequent disregarding and lack of follow up:

> ‘she was diagnosed by a consultant …he came along …I found it really irritating actually, he’d ring and leave a message and you’d try and ring back and they’d just never answer the phone or the phone would be blank or whatever so you could never get to him if you wanted to and then we were more or less wiped off the books anyway from what I can make out, you never hear from them, they never come along’.

Kenneth also expressed anger, believing his mother had not received an appropriate or timely diagnosis, in contrast to the expeditious diagnosis of his father. His father had been diagnosed quickly and had also had regular meetings with a dementia specialist. In contrast, his mother’s diagnosis had been protracted and there was no further specialist referral. Kenneth felt that his mother’s incipient dementia was misdiagnosed as a side effect of tablets for angina, despite his mother performing badly in a dementia assessment test:

> ‘The dementia test was farcical. You sit there at the doctors, he’d ask her these questions and he said right that’s excellent you’ve passed …what d’you mean she passed, she got it all wrong I’ve been sitting listening to this …it was absolutely ludicrous’ (Kenneth).

Over a quarter of the respondents articulated a sense of hopelessness and uncertainty at the point of diagnosis. Unlike many other illnesses, the prognosis for someone with dementia does not have a clear trajectory. Although dementia is now the leading cause of death in the UK, and thus the long-term prognosis is clear, the pathway is decidedly *unclear*, both in duration and complexity (Alzheimer’s Society, 2021). Nadia, caring for husband Quentin and Winnie caring for husband Norman both recognised that uncertainty regarding duration and complexity, underpinned their anxiety:

> ‘I don’t know how bad it’s going to get or what the timescale is going to be.’ (Winnie)
>
> ‘We know it’s a progressive illness, we know it is…. but you don’t know how it will develop or how fast’ (Nadia).

Carers and the person they care for with dementia are faced with the challenge of an illness which has uncertainty yet inevitability at its heart. Izzy, caring for her dad Joe, just recently diagnosed, compared this uncertainty to a diagnosis of cancer:

> ‘[if it was cancer]…..like you know what to expect, the doctors are always there informing ….you might be at this stage, you might be at that stage ….your results are showing this….I don’t feel, other than that memory test we did at the end of Sept at what state we are, what do we do, what’s next…what do I expect ……. and it’s the unknown, isn’t it?’

4.3.1 Reactions to the Diagnosis

Responses to the diagnosis began a grieving process (discussed in more depth in chapter 6) which may be described as specifically a ‘dementia grief’ (Blandin and Pepin, 2017) an ‘anticipatory grief’ (Alzheimer’s Society, 2021) or follow a pattern described in Kubler Ross’s five stages of grief (Kubler-Ross, 1997, Kubler-Ross and Kessler, 2014). *Denial* sometimes by both the person with dementia and the carer (Parker et al, 2020) linked to the hindsight phase introduced above, *anger* and frustration as the reality of the diagnosis sinks in, *bargaining* if I do my duty and care well, then they won’t have to go into a care home, *depression* or profound sadness as the grieving process begins, and finally *acceptance* as carers acknowledge and accept confirmation of what was suspected. There was often a mismatch or lack of synchronicity between different grieving stages experienced by carers and by the PLWD, this could be particularly acute when experienced by couples (Robinson et al, 2005).

Reactions could differ markedly between carer and the PLWD. With a stoical acceptance of the diagnosis by the person with dementia in contrast to immense sadness of the carer, as Flora explains:

> ‘[The diagnosis] was traumatic for me. Ernie took it in his stride. I always remember when we went and I was thinking it's not going to be anything, I was really upset but Ernie seemed to take it fine, ……. I said, ‘how do you feel?’ and he said ‘what will be will be’.

For other participants, contrasting responses could be conversely expressed by carer and cared for. Neville iterated this not just in the initial reaction, but as a later positive coping and enabling mechanism:

> LM ‘…. you faced up to it very early on?
>
> Neville ‘...yes, I…can remember Brigitte being very upset and of course I was [but]…you sort of get to the point where that’s the way it is. You’ve just got to get on with it …try and remove the emotional side of it as much as you can …it doesn’t really help very much.’

Unforeseen responses could also illuminate the changes wrought in the person due to the disease. For the carer, in hindsight, observing an apathetic response, or an unexpected reaction of acceptance of the diagnosis, reinforced it. Tessa articulates this in describing her husband Ian’s response to the diagnosis given by his doctor:

> ‘I didn’t process it at all. [the diagnosis]….He’s never reacted…. when the doctor told him the diagnosis, I mean he has just told you something quite amazing, life changing. He didn’t seem to have reacted it was amazing’.

Several carers acknowledged oppositional responses either from themselves or from the PLWD – foregrounding concealment or silence on the subject, or in contrast talking openly about the diagnosis. Reticence on the topic could be determined by the PLWD due to an inability to comprehend the diagnosis, or to retain a memory of it. Placing the carer in a quandary as to whether to talk openly about the diagnosis, thus potentially upsetting and re-upsetting the PLWD each time it was discussed. Refusal to discuss the diagnosis might also be driven by the PLWD because they *were* aware and understood the implications of the diagnosis. Winnie described her husband's awareness of the diagnosis but his reluctance to be 'labelled' by it:

> 'Norman didn't really want to know' [re diagnosis] LM – So does he know? Winnie 'oh yes, yes, [but] he didn't want to be labelled.'

Conversely, concealment could also be carer driven. Two carers concealed the diagnosis – one by way of distraction techniques to avoid discussions and another using the euphemism 'memory slippage'. Both carers argued that concealment protected the person with dementia from distress. Wendy acknowledged that this concealment caused difficulties later but remained confident that the decision was the right one for her Mum:

> 'We agreed generally that in front of mum we would just call it memory slippage, or a bad memory and she was happy with that. It was just not worth putting her through the extra stress…It would have been like her sitting on a time bomb which she would have been waiting for her brain to dissolve …and it would have been….…. too cruel. It did make for problems for me …later on …but I wouldn't change what I did' (Wendy).

Denial, in addition to being a part of a grieving process, can also be in collusion with other family members, health and social care practitioners, often for practical and emotional reasons and often with a reluctance to broach defences created by the denier or within a relational understanding of denial as Salecl recognises in Kubler-Ross' observations:

> 'In the late 1960s, in her seminal work on dying, Elisabeth Kübler-Ross noted that there was a symbiotic relationship between the doctor's and the patient's need for denial. She observed that doctors who embraced denial also encouraged it in their patients, while those who could talk more easily with their patients about the terminal nature of their illness enabled their patients to speak more openly as well.' (Salecl, 2020, p.91).

For those who had waited a considerable time for a diagnosis, it brought a sense of closure, and relief (Carpenter et al, 2008). Carol, who has been caring for Colin for almost 20 years described a palpable sense of relief:

> 'In a funny way it was reassuring….it had a name, and I wasn't just imagining something'.

4.3.2 Looking for Answers – 'Good Luck, You're on your own now!

Almost all participants considered the information given at the point of diagnosis inadequate. This was evident even when comparing narratives of diagnosis, a decade apart. Nettie whose husband Henry was diagnosed in 2010 said:

> 'I can't remember getting anything. No, I can't' (Nettie).

Krissie, whose husband Neil was diagnosed in 2018 described a similar experience:

> 'Well, I don't think we were given a lot. I mean we had the letter and it said what it was, said it was Alzheimer's and Vascular dementia, and basically, you know, things were going to alter, but that was about it' (Krissie).

After diagnosis, participants described a general pattern which involved the consultant or GP signposting them to Carers Northumberland (2022b) , Citizens Advice, (2022) and to other third sector organisations such as Carers Trust (2022a), Carers UK (2021b) Alzheimer's Society (2017) or Age UK (2022a). This aids establishment of a dementia diagnosis as a social care and not a medical issue from inception.

The shock of diagnosis may have prevented some interviewees from taking in information on the day, and health professionals may also be reluctant to overload the person with dementia and their family carer at this time:

> 'I probably got thrown a booklet ..laughter…have a read of that there's my phone number on the back if you need anything …but we'll never answer it ….laughter…and the problem with it is someone will leave their phone number it's not just these its occupational therapy as well …by the time you ring up these people have left …..so there's no continuity'(Kenneth).

Participants were generally positive about help and support received from third sector organisations, but a few participants had been disappointed or profoundly disagreed with some of the information with which they had been provided. Dementia type specific advice was especially hard to find, and carers usually used the internet to research specific aspects associated with the type of dementia that the person they cared for had been diagnosed with – Alzheimer's, Vascular Dementia, Lewy Bodies:

> 'I cannot think of any other serious disease, that will eventually be terminal, where the sufferer is cast out on relations without even a speck of training…. cos I said, 'Can you give me [information] on what's going to happen to her?" and they said "Oh, we can't tell you that, cos every case is different" (Wendy).

Most carers actively sought out information shortly after diagnosis - voluntarily going on training courses, researching the internet, reading books and or asking advice from friends. One or two carers said they deliberately avoided seeking advice, or that the information that they garnered through research was so depressing that they stopped looking. It is hard to comprehend the sense of despair after a diagnosis – even when it is expected, and even when it gives a name to the difficulties that the person and the carer have been experiencing. The knowledge which people have about dementia predating the diagnosis is a knowledge which often fills them with fear (Page et al, 2019). They may not have in depth understanding of the dementia journey, but they do know how it will end. For some, particularly in the early stages after diagnosis, when grief is raw, they do not want to know what lies ahead. Izzy, caring for her dad, newly diagnosed:

> '…I'm not going to lie to you, there are times where I think…. I can't be bothered, I can't cope. That sounds awful, but I can't cope or deal with today, finding out something new, that I'm then going to have to deal with…' (Izzy).

Neville initially sought out information on dementia, but then stopped for a similar reason. Books and information on dementia, whilst trying to be helpful and in some cases uplifting, can in some cases be demoralising, depressing, and frightening:

> Neville - 'I suppose I read all the books, I started reading …a depressing one was one by John Suchet'….and he had a golden rule of never self-pity….and er …that helped him through it and generally I think that's probably the best.'
>
> LM - 'You've found that helpful?'
>
> Neville - 'You know it doesn't help particularly ….so just get on with it! To be honest I find it terribly depressing you know, …. I do read a bit, but I try to read about something else'.

Postcode variations existed in third sector and private sector delivery, with participants highlighting some good local provision regarding advice in some areas, and inadequate support in others.

A lack of 'relational information' from direct interaction with professionals (Allen et al, 2020) rather than information gleaned from non-relational resources such as the internet or booklets, was evident in most carers' narratives. It was not always clear whether this was due to accessibility issues or because professionals lacked the appropriate knowledge.

4.4 Embedding the Carer Status and Role – Practicalities and Bureaucracy

Most carers described a similar pattern of engagement with health and social care providers in the early days of the diagnostic process. Participants often described a period of flurried activity around the point of diagnosis – scans, assessments, referrals to consultant psychiatrists, dementia specialists or to other mental health services. This could be followed by visits from social services, financial/benefit advice or assessment, referral to third sector organisations. Registering as a carer with local health, social care and third sector organisations should acknowledge and assess need associated with the care and support being given, and entitlement to statutory rights regarding employment as well as financial assistance through state benefits. Acknowledging ones' carer status also serves to embed the carer – usually the spouse or child - in the carer role. They become the designated contact person. Paradoxically, once embedded in the role of carer, carers found that their carer status conferred little dementia specific help, additional burden of bureaucratic 'care work', an expectation that they would continue to care, with no system of review of needs or capability to continue the carer role.

4.4.1 Carer Assessments - Assessing Capability to Care

The Care Act 2014 defines the carer role, and statutory responsibilities. It introduced the Carer's Assessment - the legal right for carers to request and receive a Carer's Assessment (Carers UK, 2014). Anyone supporting a PLWD is therefore entitled to a carers assessment. The assessment is designed to evaluate the effect that caring is having on you and to suggest and advise appropriate help or training which might help you in your caring capacity. Assessments are usually undertaken by someone at your local authority, for example a social worker. The guidance assessment document being utilised in Northumberland is attached (see Appendix K).

Not all the interviews conducted discussed carer assessment – this was often the case where the PLWD had already died or was in residential care but in the interviews where carer assessments were discussed (16 from 27).

- 10 participants had not had a carer's assessment (1 person had actually asked for an assessment, but had not had one)
- 2 had had an assessment
- 4 people didn't know if they had had one or not

Dementia UK state that 'you may have to be quite forthright in requesting the assessment takes place' (Dementia UK, 2019). This appears to be an accurate appraisal of assessment uptake in Northumberland. The lack of assessments and/or their ineffectiveness in Northumberland was further confirmed by Emily a manager with a third sector organisation. She concurred that Carer's Assessments in Northumberland were often not being done, were not being done properly or were an afterthought and even when they were undertaken, the reality was that they had nothing to offer the carer:

> 'Local authorities are doing carer assessment [as an afterthought] – social workers and care managers do a needs assessment for the person with dementia and then the Care Manager just thinks, 'oh I'll do the carer assessment whilst I'm here'. [the carer] you don't get a chance to prepare or arrange to have it done whilst the cared for person is not around.' We can refer people for a CA, but if social services don't have the person on the books, they don't have much to offer, and social services mostly just refer people to Carers Northumberland. You can't put in a support package for a carer if the cared for person hasn't been assessed. And then there will be a financial implication likely if they do'.

The difficulties in obtaining an assessment and as outlined above were clearly reflected in the interviews I conducted - only two participants had had a carer's assessment. One participant had asked for an assessment, but had been 'fobbed off':

> '…. I had been in touch quite a bit with *** and they'd said, "you're entitled to a carer's assessment, and it's important for you to have one". [Asks social worker] "Can I have a carer's assessment?", [social worker] "well yeah, but we'll get your mum sorted out first" …which in hindsight I think is the wrong way round, cos they can't get mum sorted out if they don't know how much I can take. I think we might have seen that social worker twice actually cos I definitely asked her twice…. about the carer's assessment and I was fobbed off.' (Wendy).

Another participant had had an assessment but admitted that '…nothing really came out of it' (Olivia).

Kenneth, through his role as a trustee for a local charitable organisation, was aware of his entitlement to an assessment. His words echo those of Dementia UK that carers might need to be forthright in asking for a carer's assessment:

> '…even though I was a trustee for ****, I wasn't offered an assessment…(laughter) …I mean to be quite honest I didn't need it but the fact was I wasn't asked, and if I put myself into the position of some people who would need it and people I see at support groups who aren't as assertive as me and don't push themselves ...that's quite worrying' (Kenneth).

Some carers had not realised they had had an assessment – a chat over the phone had been recorded as an assessment. Emily believed that assessments were mostly a paperwork exercise with a view to providing as little as possible to protect budgets, lacked proper review and as so few care packages were now available, did not result in any real benefit to carers.

4.4.2 Working and Caring

Key areas examined in the assessment include a carers ability to look after themselves and their home, difficulties maintaining leisure activities or relationships with family and friends, getting out and about to shops and accessing training and education. (These areas and the impact on carers well-being will be examined in chapters 5 and 6). In the early stages of dementia care, a further assessment area, combining caring and employment responsibilities, is more pertinent.

The Care Act (Legislation.Gov.UK, 2014) sets out statutory rights for carers, including time off in the event of an emergency, a request for flexible working (note *request*, not entitled to) and to be protected from discrimination (Carers UK, 2019). Some employers may provide more generous carer provision within individual contracts with employees. (Carers Trust, 2022c).

Twelve of the carers I interviewed, were retired at the point of diagnosis, but seven, now retired, had been working at the point of diagnosis. Most of these two groups were spousal carers. Of those carers still working, all except one was a woman and all were children of a PLWD. One male spousal carer who was retired, continued to work part-time on a self-employed basis.

Women are more likely to be carers (Carers UK, 2022b, Age UK, 2019), working women, both full and part-time provide more unpaid care than men (ONS, 2013) are more likely to reduce working hours or give up work to care (Carers UK, 2022b). Women often find themselves in the caregiver role by default, (Egdell, 2013) through stereotypical assumptions of women's societal roles or because no-one else will do it:

> 'I wasn't even asked; it was just assumed…. you know, nobody said "do you work", which I did….it was just assumed that I could incorporate this into my life….' (Wendy).

Middle-aged women are more likely to find themselves with multi-generational caring roles 'sandwich carers' or even 'club sandwich carers', struggling to maintain employment and are more likely to face financial difficulties than male carers (ONS, 2019, Zeitlow, 2014). This was reflected in the narratives of those women who are (or who were at the time their caring role began) under pension age. Difficulties juggling the complex demands of care, family and work had resulted in over a third of female carers giving up paid employment, reducing hours or retiring early. Katherine, caring for her mum Elizabeth as well as her teenage son described a slow move from full, to part-time paid work eventually becoming a full-time carer to her Mum in 2017:

> ‘then I went back [full time] in 2008 but I finished in 2011 altogether and then I had a part time job three days a week….and then obviously I finished that last year when my mum was in hospital...it’s getting the best scenario for my mum but also for my...husband and son ...it’s trying to get that fine balance all the time’ (Katherine).

Getting support to working carers can be problematic and carers may be reluctant to discuss their situation with their employers (Carers Trust, 2022c). Carer support groups often meet during working hours, third sector organisations advice lines may have similar Mon-Fri opening hours, resulting in barriers to working carers accessing services. Online resources such as carer forums can be accessed at different times and proved more useful for working carers. Working participants were aware of support organisations for carers locally but admitted that they were unable to access these support groups or training they offered due to work commitments:

> ‘well, I’m on all the newsletters and things, but I just can’t go to all these things where they’re helping carers. I say ‘don’t forget the working carers’! (Eloise).

Even when a caring role had come to an end because the PLWD was now in residential care or had died, the impact of their caring responsibilities (women statistically were found to be more likely to experience anxiety and depression because of caring, Age UK, 2019) still affected two participants. Tina, who has cared for her Mum for 17 years (currently in residential care) for many years juggled family life and care for her mother who initially after diagnosis lived three hundred miles away. Caring for such a considerable length of time has at various times affected her mental health and ability to work. Tina’s husband refused a few years ago to have any further involvement with her care – the behaviours which challenge exhibited by Tina’s mum had proved too detrimental to their relationship for him to continue with it. The toll wrought by this complex caring situation prevented Tina from working and eventually left her de-skilled and unable to get work commensurate with her degree qualification:

> ‘Well, this is one of the reasons [care responsibilities] why I didn’t end up going back to work immediately, and now I’ve left it too long, which is why I have to do silly jobs’ (Tina).

Acknowledging her carer status to her employer did help Wendy when her mum’s dementia care needs began to make work untenable. Wendy put in a request for flexible working and her workplace agreed. Wendy described this as a huge relief. However, the effect on her self-employed work was profound with implications for her future financial security apparent three years after her mother's death:

> 'My self-employed role I couldn't …I couldn't look for new clients I had to fairly contain the amount of work that I did because from a relatively early stage…I was probably spending anything from 2 to 4 hours a day with her [Beryl] and ringing her several times a day as well …so it did limit my ability to take on work. That's had a knock-on effect on my finances, it will have a knock-on effect on how I …you know, pensions and my old age and all of that,' (Wendy).

Growing numbers of people in self-employment (ONS, 2018) offers more flexible working but this may have both favourable and negative consequences. Neville was still working part-time, post retirement, from home. This he considered manageable, but a serious incident involving his wife with dementia had exposed safety implications of him trying to combine working and caring:

> Neville - 'We had an awful incident back in January…I …er…she's got a horse and rides…and she was alright going local, …she never got lost…she was going out for a ride one morning… I was having a bit of a problem with [work] at the time….so I was a little bit distracted. An hour's gone by, better go and see where she is. So, I got in the car… and at that point the phone rang, and it was a friend of hers … "just seen Brigitte on her horse, on the A69"'
>
> LM - 'Oh my god!'
>
> Neville - '… I kid you not I did 120 on the way to where she was …She'd gone on the A69 and was stopped in a layby ...this is obviously a dual carriageway, so I got there...and I realised, how on earth are we going to get her off the verge and to the next exit [which] was about 300 yards up the road. But she couldn't get there on the grass verge you had to get there on the road, so I realised I'd have to ring the police. So, the police turned up and I explained the situation …if you can escort us, [laughter] I'll lead her in the car up the road … so that's what we do'.

Working, and caring may become increasingly challenging as the symptoms of dementia progress. As a carer myself for almost 15 years, I have never been offered a carers assessment. Employers, including the university have allowed and supported flexible working, but self-employment has been severely disrupted and often impossible. Working and caring is foregrounded in government initiatives such as Work Preparation Support for Carers (Gov.UK, no date a) and local programmes such as the Return-to-Work Carers Project (Carers Northumberland, 2022b). Carers are encouraged to view working as conferring financial and well-being benefits. Yet it is difficult to see how carer well-being will be increased unless carer assessments are robust and under continuous review, including who takes on the carer responsibilities when the person is at work. Care and caring are also work (Held, 2006, Tronto,1994, Bubeck, 1995) and not just a virtue (Slote, 2007) Separating 'work' from 'care' in initiatives to get carers back into employment, establishes care as solely as a value rather than a value and a practice, diminishes and devalues the work that unpaid carers do. The label ‘carer’ appears to bring increased responsibilities and duties, yet it is not proper ‘work’. Kittay, (1999) explicitly regards caregiving as work, arguing theories of justice are inadequate without foregrounding principles and *practices* of care. She rejects essentialising women with care *roles,* instead she foregrounds unpaid carers dependency *workers* and dependency *relations.* Work is also a crucial aspect of who we are and how we see ourselves. Katherine’s sense of identity was profoundly changed when she gave up paid work to care for her mother:

> ‘I mean for me; it’s been such a change from when I was working. After twenty years, finishing that – I had my identity with that. And then that stopped….and then I’ve changed again into this…’ (Katherine).

The importance of identity, to both carers and cared for will be explored in more depth in chapter six.

4.4.3 Finances and Benefits - Embedding the Carer Role

One important aspect of caring for PLWD – finances, had plainly been communicated to carers early in the diagnostic stages. Almost all had a financial Lasting Power of Attorney (LPA) in place, allowing carers to act on behalf of the PLWD when it became necessary (Dementia UK, 2020). Only two current carers, both working, did not have a financial LPA in place – citing difficulty in finding time to set it up. One carer had a deputyship (often applied for instead of an LPA when the PLWD has already lost capacity to consent). The majority had been advised to get an LPA either by a third sector organisations, a GP, or another health professional. In comparison only 7 carers had a health and welfare LPA in place. It was unclear why financial LPAs predominated over health and welfare LPAs nor whether it was professionals and/or families who were prioritising financial matters over health and welfare. Emily speculated that there may be a number of possible reasons - LPAs can be costly, and families may rank the financial LPA as more important if you have to pay for both LPA’s (families may be entitled to an exemption for doing the health and welfare LPA, but many may not know about it), completing one LPA may seem onerous enough or they believe a health and welfare LPA will not confer any real choice or say in future treatment.

Financial as well as legal and health responsibilities for the person with dementia, are practical and necessary steps to safeguard the PLWD (Alzheimer’s Society, 2022d) but they also serve to embed the family carer in their caring role. They become the contact person for health and social services, third sector organisations as well as benefit agencies.

About a third of participants had experienced financial challenges in the earlier stages after dementia diagnosis of their family member. These difficulties fell into three categories - negotiating the benefit or pension system, the burden of bureaucracy associated with financial decision making and handling the changing role of carer and cared for.

Most of the PLWD were in receipt of the Attendance Allowance, several collected Personal Independence Payments (PIP) and a few carers had received the carers allowance. Most participants had received some little or no advice on benefit entitlement. Benefit forms, in particular the Attendance Allowance form (Age UK, 2022b) were hard to fill in, too long and appeared designed for people with physical disabilities not cognitive difficulties. Several participants expressed sympathy for people who were applying for a state benefit for the first time, acknowledging that prior experience which made them cognisant of the benefit system was a considerable advantage. Teresa had had help from *** with benefits forms and LPA, but she had also had previous familiarity with them:

> ‘So, I wasn’t too bad with them. But anybody that’s not used to them, I think you would look at them and think oh…….’ (Teresa).

A few older women carers, who might be described as having a more ‘traditional’ role in their marriage, experienced an additional disadvantage on top of the onerous form filling, due to having very little knowledge of the financial matters which their husband had previously presided over. Finding themselves with full responsibility for all financial decisions provoked a fearful response and concomitant anxiety as they took on this new role. Benefit agencies, banks and other authorities could prove intimidating and often unsympathetic:

> ‘...the most difficult thing has been getting my head round dealing with finances, insurances, the banks. I mean I still fiddle around. Because of my personality that's something Quentin always did, and I was happy to leave him to it and I hate handling other people's money, I've always been scared, it can panic me when I had to phone the bank even now when it’s a lot more sorted. And I was determined I was not going to be beaten by it, but it has, and …. these authorities are not very understanding or sympathetic at all most of them.’ (Nadia).

These challenges could be further compounded if their husbands objected to them taking over what had previously been their realm of activity. Tanya had noticed a growing chaos as her husband Sam tried to do a tax return. Normally something which had taken him a few weeks, now stretched into months. The division of labour within their marriage had always been predicated on the assumption that Tanya dealt with domestic affairs and Sam with financial ones. Finally, a letter from HMRC which included a fine for a late tax return alerted Tanya to the problems which Sam was now experiencing, prompting her to intervene:

> '….and that's when it really dawned on me that I ought to take over this and he was very reluctant to get me to do this…' (Tanya).

Dealing with financial aspects of care could be time consuming and frustrating. Dealing with multiple agencies – local authorities, banks, DWP, as well as the bureaucracy associated with health and social care and third sector organisations, all of whom have different forms that need to be filled in and who have different systems of working can be extremely burdensome on family caregivers. Carers clearly became more firmly embedded as the contact point, making it harder to devolve responsibility to someone else who might have been able to give practical assistance. A few participants had managed to divide the financial and care aspects between siblings in order to alleviate the burden on one person, but for almost all the carers I spoke to, they took responsibility for all financial and administrative tasks:

> 'I mean this bank man; I'm so fed up with. Because although we've got the EPA (Enduring Power of Attorney) and an LPA you've still even though they're registered they still have to have pieces of paper… and we've to see them with the passport and the driving license and the utilities bill…… and there's those signatures that all these people need even though its registered even though they've got the bits of paper they still want you to sign their bits of paper. It takes hours. [friends] say things like well let me know if I can help but you think well what could they do or what would they do?' (Nadia).

Neither of the two youngest carers had a financial LPA in place – both were working and cited time constraints as the reason. The only other person who did not have a financial LPA, did have a deputyship. Quinn, caring for his wife Maureen who has Early Onset Dementia, experienced difficulties securing his wife's private pension, benefit claim confusion and a lack of advice:

> '…. she was being treated for depression he [Private pension assessor] took the view that it was something she could recover from so they wouldn't pay out her pension and he tried to get her to do tests……and she couldn't do it and again she just broke up in the end and he cut the interview short but he was very very cold… there was no empathy on his part. You just felt, he must have seen so many people perhaps trying it on in the past that he immediately labelled you as somebody who was just trying to get a pension….I think if at that time of diagnosis...somebody who is experienced could…talk through all the issues and….and just point you in the direction of all the support you could get, …I mean even things like benefits …no one ever mentioned benefits to me at all…….I had applied for carers allowance as well and what I hadn't realised was erm carers allowance is taxable so it was 8 or 9 months…. down the line I read somewhere that it was taxable so I immediately had to inform the tax people and I got this big bill for income tax…the form that you fill in for the PIP is all aimed at physical disabilities but what you have to do …think about it carefully …so they say 'is she capable of getting onto a bus' ..and you think lets go back a few steps back from there …she's not capable of finding the bus stop…if she went through the back door she wouldn't be able to find the bus stop! …There must be people who fill these

> forms in and they'll try and literally answer ...cos I could say, she's physically fit of course she can get on the bus… I think there must be a lot of people who fall down on these forms and don't get the benefit they're entitled to…purely because they answer questions in a very literal sort of way' (Quinn).

Making mistakes by filling in forms incorrectly or claiming the wrong benefits can be costly. I remember filling in the Attendance Allowance form for my dad and experiencing the same sort of difficulties as Quinn trying to answer unanswerable questions. Age UK (2022b) describes the form as 'daunting' and Citizens Advice (2022) 'difficult'. LPAs can be completed without a solicitor, but often these forms can seem daunting too. The application for deputyship (which I had to do for my dad) entails an even more onerous process – application to the court of protection is costly, done through a solicitor and can take a considerable time to complete. Once the deputyship is established, the deputy's duties include a yearly online declaration of expenditure, a duty I found extremely arduous – sometimes reducing me to tears (Gov.UK, no date b). On one occasion, I was asked to bring all the financial and legal paperwork relating to my dad to the care home where he lived, to be scrutinised by an assessor from the Office of the Public Guardian. Six years' worth of files full of paperwork – I had to use a shopping trolley to carry them, being told that the meeting must be held at the place of residence of the PLWD and could not take place at my own home. Currently, these additional duties are not required for LPAs, but the assessor told me she believed that in future they would.

4.4.4 Carer Style - Duty, and Responsibility – It's my job

Although most carers described a lack of information and a sense of abandonment by professionals after the diagnosis, there was often, paradoxically, an assumption that the care role was, however, their job. This assumption was usually expressed in terms of duty and responsibility.

A deontological assumption of duty was the driving force for most of the carers interviewed. Duty and responsibility to care for the PWLD were articulated in five distinct approaches sustaining carers' ratiocination and ontological frameworks. Drawing on Kant's deontological rights and duties, (O'Neill, 2018, Wood, 2007) Hume's 'messy sentimentalist' (Haidt, 2013) approaches, ethics of care foregrounds a relational ontology which captures the complexity of carer and cared for. Care as a virtue, a practice and as work in addition to a moral framework within which carers situate themselves, the PLWD and their relationship in the wider community (Kittay, 1999, Sevenhuijsen, 1998, Engster, 2007, Haidt, 2013).

For spousal carers, the sanctity of marriage vows was a common motive for foregrounding duty ‘I did promise to look after my husband in sickness and in health for richer for poorer…’(Olivia). This was strongly linked to the second reason carers gave for explicating their strong sense of duty – reciprocity. The understanding that their partnership contained a reciprocal element to which they had agreed – this too was often linked to marriage vows ‘I just see it as looking after the wife and I’m sure if it was me, she’d do the same.’(Neville). A third approach, usually associated with a parent/child relationship was understood as a repayment of debt or the switching of roles from ‘carer’, to ‘cared for’, ‘Mum’s looked after me all my life and I think it’s my turn’ (Beverley). Other carers expressed a sense of duty as a natural order, a part of life and something which was inevitable ‘I thought, he can’t help it and I can’t help it we’ve just got to get on with it. It’s the Northumbrian way of going on.’(Winnie). The final approach to duty was linked to a sense of societal or familial expectation. ‘I think it’s just because it’s families doing it…you look after the family, and you’re just expected to do that you know…’(Una).

Drawing on ethics of care literature, care is a relational practice (Gilligan, 1993, Engster and Hamington, 2015, McDowell, 2004, Kittay,1999) and value in which duty and responsibility are invoked in response to need. Duty or obligation in the abstract can be considered oppositional to notions of autonomy or individual rights and linked to virtue ethics or virtue as a subset of care ethics (Groenhout, 2014, Slote, 2001, 2007). Caring practices are usually partial or familial – we care about those closest to us, our families and those in our local communities (Noddings, 1982, 2003, Engster, 2015, Haidt, 2013). Marriage vows, reciprocity, familial care interdependency and justice may not necessarily be seen as oppositional but can be seen in the context of societal expectation and norms – some contexts may call for partiality and some for impartial reasoning (Tronto, 1987,1994). Care in rural places can in addition have a parochial element which links people to places and embeds societal and familial expectations more strongly in local communities. This can lead to accusations of parochialism and a narrow understanding of care as only towards our families (Smith, 2000, Sen and Williams,1982) but the embedding of carers through legal, financial, and health and social care systems in Northumberland would preclude any other type of caring value or practice:

> ‘The relationships between care and justice, individualism and community, partial concern and impartial judgement, the private sphere and the public sphere are, in fact, ones of multiple and cross-cutting connections. The importance of the feminist literature on an ethics of care is that it points towards the embeddedness of moral dispositions in social practices and inter-subjective relations.’ (Barnett, 2005, p. 592).

Carers, when asked why they cared expressed a sense of duty explicitly in opposition concepts such as choice or rights. This was articulated as a combination of both societal expectation and the natural order:

> ‘I don’t think I’ve got much choice…. I think you’re just there, and you do it’ (Flora).

Eric gave a similar explanation for why he did what he did but more explicitly linked his stoical sense of duty to one of lack of rights and choice. This lack of choice, like Flora, is sensed as inevitable, natural, expected:

> ‘I just see it as my duty to care for Shirley and my responsibility to do it. I don't think about my rights as such. Or perceive myself as having them really, I guess...Would I do it again? I would have to do it again. It doesn't matter, I have no choice in it’ (Eric).

In these early stages after diagnosis the carer clearly communicates the connectedness to the person they care for, the primacy of relationality – at its core, the identity and recognition of each other in their familial relationship – as a husband and wife, father and daughter, mother, and son (Kittay, 1999, Noddings, 1982, Driver, 2005). Some carers articulated a deontological framework which encompassed intersecting approaches to duty and responsibility resulting in conflicting feelings about their caring role. Quinn, despite being critical of services for not being pro-active simultaneously acknowledged his own sense of responsibility, linked to his marriage vows and his ability to manage:

> ‘I just thought we’re married, it’s my responsibility…I feel that around all services erm, no-one is that proactive and it would have to come from me…as a user…and so far, I’m coping, I think, but I can see it will get worse…’(Quinn).

Quinn then admits that the situation could deteriorate. The sentence tails off, perhaps indicating the questioning of his ability to act dutifully in the future:

> ‘…many of our responsibilities [are] not freely entered into but presented to us by the accident of our embeddedness in familial and social and historical contexts.’ (Held, 2006 p.14).

A quarter of participants felt that they lacked any choice in taking on their caring role. Carers Northumberland run a training course on ‘How to say No’, but the reality is that most people feel that they cannot say no. As carers become registered as such, with the concomitant legal and financial elements put in place the ability to say no, even if they wanted to, recedes:

> ‘…How to say ‘no’…but you can’t, you’ve got to just get on.’ (Nadia).

The strength of carers' sense of duty and responsibility and the coterminous feeling of guilt if they did not care, reinforced by family and societal expectations, reifies the carer role. Two carers openly expressed an anger when people told them that they were doing a great job caring for their loved one. Tanya's heartfelt rejection of this, perhaps sums up the complexity yet simplicity of competing and coexisting aspects of informal caregiving:

> 'I don't accept people telling me I've done a wonderful job, no, no, that's not what happened, what I did…. it's life' (Tanya).

4.4.5 Carer identity – Changing Relationships

Participants acknowledged a change from spouse or child relationship to formal carer, but it is unclear from their narratives when this occurred. Krissie's account of her repositioning from wife to carer implies a gradual awakening to her changed role which had now been completed:

> 'I'm getting used to the idea because you know you go from being a wife to a carer, and you think "hang on, I was his wife and now I'm his carer!"' (Krissie).

Nadia's narrative similarly implied a gradual process, but she indicated that this task was still continuing 'I said to a friend the other day... "I'm learning to be a nurse"' (Nadia).

Flora expressed an anger at a) the assumption that she was considered a nurse and b) that at her age it should even be an expectation. This was directly correlated to whether her husband was reaching tipping points to needing residential care. Flora's husband in addition to his dementia had co-morbidities which created a multiplicity of barriers to them both:

> 'I keep saying I'm not a nurse, I'm 77 years old almost and I'm not a nurse, shouldn't be treated as a nurse' (Flora).

In spousal relationships the change from wife or husband to carer could sometimes be less disorientating for the carer if their relationship had already included a uni-directional caring element, often associated with traditional women's roles within marriage. Nettie conceded that caring was part of her identity to such an extent that she could not envisage what she would do if her caring role ended:

> 'I like to care for people...so I don't know what I would do if he [husband] was in care…' (Nettie).

For others, the change in their role and therefore their relationship was more profound. Laura, like Nettie also saw her identity very much as being that of a carer, but unlike the other participant children of a PLWD, Laura had been a young carer from a very early age, so the role/reversal of parent/child had in fact taken place a considerable time ago. Izzy was more representative of the child whose relationship with a parent had undergone a reverse dynamic:

> '…What I'm starting to realise now is it's roles reversed. It is "I am now the parent" … nope…I am now the carer…you know its roles reversed parent carer/child carer' (Izzy).

For Tessa, this dislocation of self-identity was because of the changing role she had within her marriage. Having previously never managed financial affairs, a role her husband had always occupied, Tessa found having to take over this role extremely difficult. Within many relationships, individuals often have proscribed roles – 'the carer', 'the manager', 'the gardener', 'the driver' or the organiser'. Adapting to these new roles, particularly later in life can be challenging and perhaps disorientating.

Drawing on ethics of care theorising allows a focus on the relationality of care, and the moral frameworks of duty and expectation which drive carers. Considerations of duties and responsibilities are crucial when evaluating any theories of justice (Robeyns, 2017, O'Neill, 1996). The strong sense of duty, its relationship to carer guilt and implications for carer well-being and the importance of identity will be explored in more depth in chapters five and six.

4.5 Early Days Post Diagnosis – Barriers to Help: Still on our Own

Once a diagnosis of dementia had been confirmed and carer status reified through financial, legal, health and social care means, carers and the PLWD were usually left to carry on with their lives with no obvious extra help or support. The strong sense of personal duty and responsibility to care was frequently and paradoxically juxtaposed with a sense of abandonment by professionals and implied injustice at perceived diminishment of rights and choices. Many carers articulating that the inadequacy and unfairness of dementia support was because it was considered a social care issue, rather than a medical problem.

As challenges grew, incrementally, as dementia progressed, carers turned to primary health care services and occasionally social services for help and support. Ongoing support from primary health care providers in Northumberland for the carer and the PWLD were mixed, and postcode dependent. Of those who talked specifically about their primary health care service, (only four did not), eleven described their GP service as poor, three reported difficulties with their GP, but this was mitigated by a good relationship with nursing support provided by the practice. Four participants described their GP practice as good, supportive, and easy to get appointments, and four described their GP as outstanding. Accessing GP services was often problematic for several reasons – rurality and transport issues, appointment systems, lack of continuity and communication challenges, discussed further in chapter 5.

4.5.1 Access and Appointments

In theory, being identified as carers (recorded in their notes) by GP's or Social services should confer advantages such as appointment priority or easier access to the team. Carers should also be referred to a carer support organisation, such as Carers Northumberland, or dementia specific support, such as Alzheimer's Society so that they can access a range of support and advice for carers.

Some surgeries had acknowledged or recorded carer status, but this did not always lead to any preferential treatment when it came to accessing an appointment or as with carer assessments, check-ups did not appear to offer any tangible benefits. Quinn's frustration at re-referral to the same organisation as the only option, is palpable:

> '…. support from the GP, because Maureen has Alzheimer's and I'm a carer we both have an annual check-up at the GP …not only is it a physical MOT ...but it's supposed to discuss Maureen's condition and how I'm coping as well. But again, I've felt that …it's almost ticking a box. It's a very cursory thing...they'll say, "how are you getting on" …they'll say, "how's Maureen, getting any worse?" …It's really difficult to talk about Maureen in front of Maureen cos she's not daft…. and it's demeaning…. so that's very difficult ...I struggle to be honest at that point…And then they'll ask me when I go how I'm getting on and point me towards the same [support organisation] - *again*!'.

Despite being identified as a carer, Xena, caring for her husband Charlie who has dementia and COPD describes the difficulty she had one day trying to see their GP:

> 'I rang one day Libby, for an appointment. All morning I rang for an appointment for Charlie because his breathing was bad. I'd started him on his rescue pack, and I rang and rang and rang. Couldn't get through. So, he was fit enough then to drive. Got to the health centre. And I stood in the queue. I said, 'can I see a doctor he's not well'.' 'you've got to ring', I says 'I've rung all morning since 8 o'clock to get through and can't get through'. She says, 'have you got a mobile phone'? I say 'yes'. She says, 'well ring from your mobile phone'. So, I went outside and rang and rang and rang, and back into the health centre where I was before. She said, 'they're in a meeting'.' LM 'does the GP know that you're a carer? Xena – yes…well it should be on his records cos they have been told...'.

At this point in the narrative, Xena's husband Charlie was still driving, enabling them to get to the surgery, but he was clearly very ill that day. Being acknowledged as a carer did not appear to affect the attitude of the practice staff member or bring Xena and Charlie any extra help or support.

Carers living in rural or semi-rural locations or those who had physical or cognitive disabilities had additional difficulties accessing their surgery or hospital. Patient transport to hospital appointments was helpful but could sometimes be difficult to arrange. Journeys to local hospitals could be a 120-mile round trip and sometimes this was for a very short outpatient appointment. Using patient transport for such an appointment can mean leaving the house early morning and not returning until late afternoon. Participants living in Berwick were furthest from most hospital services – two carers reported very large taxi fares in emergency situations to take them home from Cramlington hospital to Berwick and Hexham. Accessing GP services could be costly and time consuming. Xena again:

> LM - 'You now no longer have a car, how has that impacted [on you and Charlie]?
>
> Xena - '…it means I have to do all the shopping in the village, which is more expensive which then impacts on your income.'
>
> LM - 'and things like doctor's appointments and stuff like that are they …what's your public transport like?'
>
> Xena - 'you have to get a taxi…. it's not bad, its seven pounds to get there and back [to go to the GP] ….one week for tests, then the next week for results. And I says, "can you not phone the results, cos we come in a taxi?", "no, because there might be something different they might need more blood tests"
>
> LM - 'And there's no other transport that you're aware of that would take you in?'
>
> Xena - 'No. I mean neighbours' yes ...but then again, I don't like bothering them…. I mean you drive all your life…well he's driven and then when you REALLY need your car, you're not fit enough to drive it'.

Difficulties obtaining an appointment were a considerable barrier to half of participants, as evidenced in Xena's narrative above. Changes to appointment systems – introduction of Doctor First or telephone first models (McKinstry et al, 2017) was a common complaint and had caused particular problems. The Doctor First model uses a triage system from the patient's initial phone call or email. GP's phone back the person and decide whether they need to attend the surgery or can be dealt with over the phone. One cannot book an in-person appointment in advance – an appointment will only be arranged after the phone consultation. New online booking services are increasingly being utilised, yet older people and disabled people are less likely to use the internet (Age UK, 2016). Participants in North Northumberland raised problems with the Doctor First system in accessing their GP. A local support provider believed that the recent merging of several practices in Northumberland had caused problems, with some GP surgeries now being very large.

When I asked participants how easy it was to access their GP, several respondents laughed sarcastically:

> LM - ‘How easy is it to get a GP appointment?
>
> Flora - ‘Hard (laughs) WHAT appointment?’

My own experience of trying to get a GP appointment is very similar to Flora and others, and since the Covid 19 pandemic access has become even worse.

4.5.2 Continuity of Care

Initial difficulties in accessing their GP above, resulted in further problems trying to maintain continuity of care with the same doctor. Being unable to make appointments in advance made this almost impossible for some carers and PLWD. Being able to discuss, often complex or distressing aspects of dementia are fundamental to better care and support options, but this is precluded if trust has not built up in the relationship not just with the GP and patient, but also with the family carer:

> ‘…you just see anybody basically’ (Olivia).
>
> ‘…now you see a different doctor all the time. How do they get to know who you are?’ (Flora).
>
> ‘The emotional support is zilch’ (Neville).

Continuity of care from the same GP was rare, but when the person with dementia and their carer *were* able to see the same GP regularly, this could make a significant difference to them. When GP care was good, and in some cases, carers described the care as exceptional, continuity was of prime importance alongside a recognition of their carer status, empathy, and a relational approach (Noddings, 1982, 2003, Tronto, 1987,1994, Slote, 2007, Held, 2006) – an awareness that both cared for, and carer were linked in ways which needed a different approach to the usual patient/doctor relationship. Eric chronicles here a completely different experience to others described above, even referring to their GP on first name terms:

> ‘I have to say the health professionals have been excellent up here, absolutely excellent. She's [Shirley] been well looked after. I think our GP is extremely supportive. We always see our doctor ***. We always see her and she knows everything there is to know about Shirley and I and she treats us as a couple almost rather than treating us as individuals…..if Shirley has an appointment with her I always go and Dr *** is perfectly ok about that she knows that's going to happen because apart from anything else Shirley won't remember what the doctor said to her…… so often you hear horror stories about some of the surgeries…. I mean one of our members here [local support group] told us some weeks ago that he went to the doctor about a specific thing and wanted to also ask the doctor about something else and he wouldn't talk about the something else. He just come about problem A as it were, not talking to you about problem B, you will have to make another appointment. Couldn't believe it when I was told that, so much so that the contrast when we went yesterday to the appointment with Dr *** was actually my appointment. I wanted to

> see her about something and as it turned out something arose during the day which Shirley wasn't happy about and ... so I said Well come with me and we'll see if Dr *** will talk to you about your problem and she did' (Eric).

Eric and Shirley's doctor recognised the prerequisite to understanding their needs in a *relational* way. The ethics of care relational framework acknowledges both the individuals and the relationship and the well-being of both the carer and the cared for (Kittay, 1999, Sevenhuijsen, 1998, Held, 2006, Gilligan, 1993). Although this good support did not materially change their situation, feeling cared for and listened to and understood was an important supporting factor. Eloise similarly valued the trust which had built up through continuity with her mother's GP:

> 'So, Dr *** is the best doctor there's ever been, and I only see him…and there's trust there that's incredible even though [Mum] can't remember most things she can remember him. And he's great, he's got a really great attitude, no nonsense doesn't over-prescribe and very, very sensible, not a panic merchant.' (Eloise).

Trust is an important aspect of the care relationship (Baier, 1987, Kittay and Meyers, 1987, Kittay, 2011) and of social capital (Putnam, 1993). Although Eloise's mother's dementia had reached a stage of profound memory loss, her relationship with her GP had remained intact thanks to long term continuous interactions.

4.5.3 Communicating

Carers often described the challenges they faced as the PWLD dementia symptoms affected their ability to cope with doctor appointments. The medical model of disability highlights the impairments which can affect a person's abilities and the social model of disability describes the social arrangements which create the disabling of people with impairments – both impairment (biological) and disability (social cultural) were important elements in these challenges (Shakespeare, 2014, Stalker, 2012):

> 'the distinction between biological/individual impairment and social/structural disability is conceptually and empirically difficult to sustain…. impairment and disability cannot be easily extricated…the social and the biological are always entwined' (Shakespeare, 2014, pp. 21 and 22).

Thus, the attitude, availability, continuity, and ease of access to a doctor could often be socially disabling and the ability of the carer to negotiate these barriers and challenges to support the PLWD were compounded by the individual impairments of each PLWD. Some PLWD became stressed and confused at appointments, being unable to comprehend what was being said or done, perhaps forgetting why they were there or what was being said to them.

Quinn explained how upset his wife could get at appointments and assessments, and this would intensify what was already an extremely difficult situation:

> ‘The problem was whenever she had to face up to any of these appointments, she would get very emotional….so that perhaps had an impact …….and one test, I think he cut short in the end because she was getting upset by it’.

Depending on the type, stage and presentation of symptoms, the person with dementia could show varying degrees of awareness of their condition and/or cognitive difficulties. Some carers described the PWLD remaining in denial of or having forgotten the diagnosis:

> ‘I think even now I don't think he realises that there's a problem…. I don't think things sink in. Or if they do sink in, they just go out of his mind, and he forgets about it’ (Theresa).

This presented the carer with a range of challenges when supporting the person through diagnosis and at later appointments. It could also create a mismatch of emotional responses between carer and cared for - when the person with dementia showed little response or awareness of the enormity of the diagnosis, whilst the carer was experiencing profound sadness.

Further obstacles carers faced when accompanying the PLWD to the appointment were talking about impairments or problems in front of the person:

> ‘I find it a bit difficult to say things when Connell's there. Because obviously I have to go in with him and Dr *** will ask Connell something and Connell's reply is sort of everything's absolutely fine. So, then I'll say …. oh well you know it's not really, you're forgetting this, you're doing this, you're doing that, but I think you're kind of limited as to what you can say when he's there. [but] Dr *** did say to me the last time we were there you know if you have any problems, or you want to talk about anything just get in touch which I said I might do. But I sort of feel well really what, apart from keeping an eye on him, what else can they do?’ (Theresa).

Conversely, some carers expressed guilt about talking about the PLWD when they were not there. These oppositional challenges were especially prescient when carers, PLWD and doctors addressed the issue of driving cessation, discussed later in this chapter.

Several carers largely avoided health care services sometimes because they thought no help would be available, or because they didn’t want to ‘bother’ the doctor. Xena’s daughter urging her mum to be more pro-active in asking for a GP visit, and Carol expressing dismay at having to call paramedics when other people would then be denied the ambulance.

The impairments and social disabling factors intersected and combined in the relational carer/cared for dyad to create barriers and difficulties accessing salient support and help in health and social care settings. At this early stage just after diagnosis, the social/structural aspect was the most exclusionary factor. Impairments provided a greater challenge in the mid-stages of dementia care, detailed in chapter 5.

Carers often described the problems they faced during health care appointments as the overlapping nature of the components described above – caring for someone for whom they did not want to talk about in front of the person, tick box or cursory check-ups, lack of continuity of care and coping with the emotional toll on the person they cared for. This was compounded with anger at the additional burden arranging and attending such appointments caused them. Neville expressed a deep sense of frustration at what appeared to be a pointless attempt to address the needs of PLWD and their carers:

> ‘The GP…well I'm a little bit scathing.….classic example…we got a letter from the health centre saying, as part of our ongoing checks for people with dementia can you come in and make an appt for 20 minutes and you'll see doctor whoever, i.e. not your normal GP, so I did, made an appointment, turned up went into see this GP, sat down, went through the normal pleasantries. Right, she said, ‘why are you here?’ (Neville).

Three quarters of the participants currently had no Care Manager or social worker, 12 had had some initial contact with social services but had been signed off, and no longer had one, and 2 did not know whether they had a named contact at social services or not. Of the six participants whose cared for person did have a named social worker or care manager, two said that they had had good support and help from them.

Carers raised several concerns regarding the support (or lack of support) they had received from social services. A key criticism was the deficiency of actual services available to PLWD and their families. Carers expressed frustration that if they were ‘self-funding’ (their income or assets placed them over the threshold for help) social services would expect them to organise care themselves:

> ‘The second time I got in touch with social services was when I felt I wasn't getting out, Maureen had stopped…used to do lots of walking and she was quite active, but she had lost interest in that I couldn't get out with her …so I got in touch with social services to talk about some sort of care …somebody came out to see me but as soon as they found out I'd be self-funded they said “oh you'd probably be best just getting a private agency” (Quinn).

Carers' impression was of help only being available when their situation deteriorated to the point of crisis:

> ‘it's not been as easy getting a care manager they come to see you…and we've asked them a lot of things …we did feel a little bit that, until there's a crisis point ….’(Una).

Several carers described being discharged or signed off very quickly post-diagnosis:

> ‘It was basically a quick one off do you need anything, right we’re going and …and then when you did ring them well they’ve been discharged and you’d have to start again…I found that quite irritating I mean obviously they’ve got targets, we’ve all got targets and there’s austerity, but keep them on the books!’ (Kenneth).

Emily agreed a lack of continuity and poor communication were key issues carers faced.

4.6 Driving Cessation – ‘driving’ towards the Middle Stages

Recognition that the person they cared for was having problems driving was a common predictor for carers to re-connect, often after some considerable gap, with health and or social services to get help. Acknowledging that help was needed, was often recognised as a tipping point for carers – moving them and the person they cared for from the early stage - coping at home and in the community independently and co-dependently with each other, to stage two where difficulties multiplied and there was usually an acceptance or admission that some outside intervention was needed. Reaching out for assistance leads to profound changes as the dyadic carer/cared relationship broadens to a triadic of carer, cared for plus professional/s or tetradic, as family or friends’ involvement increases. This tipping point could be accompanied by feelings of guilt, sadness and anger as the carer and person with dementia were confronted with the first demonstrable interference in what was or had been a very long parental or marital relationship as cognitive changes in the PLWD render notions of them as an autonomous individual, capable of rational decision making untenable.

Acknowledgement of needing assistance, also exposed carers to the first realisation of how little help would be available to them at this middle stage of the dementia journey. The carer became aware of how firmly embedded they were as carer, their lives increasingly impacted by the progression of dementia in the cared for person, yet the individual liberty of the person with dementia in conjunction with their interaction with health and care professionals or government institutions, disproportionately weighed against their rights as a carer, and in some cases the general public, to be free from potential harm.

Despite actively seeking help and support, most carers identified both a triadic relationship between the PLWD, the DVLA and the clinician, from which they were excluded yet paradoxically, there was implicit expectation that they ‘manage’ the growing crisis. Whilst recent guidelines on driving with dementia indeed foreground a triadic relationship of decision-making between individual, clinician and DVLA, this research found family carers, by default, becoming de facto assessors of capability, responsible for informing the DVLA, supplying the information on which clinicians or DVLA based potential assessments of driving proficiency. The carer found themselves overtly or sometimes covertly obliged to manage the disclosure of diminishing driving competence as well as the day-to-day effect on the person with dementia if they are told they can no longer drive.

For most carers, where driving was something the PWLD had previously done or was still doing, instigating the process which would eventually result in driving cessation was a traumatic, complex, and often protracted one. During one of the first interviews I conducted, the issue with driving cessation arose almost immediately, without prompting, of the participant's own volition – she *wanted* to talk about it. Subsequent interviews followed a similar pattern, and I very quickly adapted my interview preplanning to include a question about driving cessation. I had expected that discussions around driving might include the essential nature of car ownership in rural Northumberland, and it did, but the process of driving cessation and the multiple aspects to it became a greater issue, and one which served to illuminate key aspects of other parts of participants narratives.

Eighteen participants had or were currently having difficulties associated with the driving or driving cessation of the person they were caring for. Two people described the person they cared for with dementia as voluntarily giving up driving with no issues. Of the remaining participants, the PLWD had never driven or no longer drove. There were four key aspects which affected the carer and the person with dementia (some were stand-alone issues, and others were interconnected, or complexity layered)

- an expectation from professionals that they assess the driving capability of the PLWD, and the dilemmas thus faced by the carer in talking confidentially *about* the person, or *in front* of the person and further, an expectation that they would facilitate the informing of the DVLA, and the concomitant challenges that this brought when supporting the PWLD to accept a driving cessation decision.
- The day to day managing of the driving of the PWLD – including safety worries, fear, and anxiety. After driving had ceased, mostly a relief for carers, but challenges coping with the PWLD's anger or frustration.
- The implications of living in rural Northumberland without a car – and the spatial diminishment of their world, and increasing social exclusion.
- Psychological effect of driving cessation – loss of identity for mostly male drivers regarded as 'the driver of the family', loss of independence and carer guilt.

4.6.1 Assessing Capability and Informing the DVLA – Whose job is it anyway?

Drivers aged over 70 must fill in a self-assessment form every three years to renew their licence. There are now 5.6 million drivers over the age of 70 in the UK (Gov.UK, 2022). Driving ability decreases with age and with specific morbidities including dementia (Carr and O'Neill, 2015). Older drivers are generally safer than younger drivers, however, crash involvement rates increase from age 80 (Dept for Transport, 2016). Of the 35.3 million licence holders in England and Wales, an estimated 3.4 million have not disclosed notifiable medical conditions to the DVLA (Direct Line, 2016).

The Secretary of state for transport acting through DVLA must ensure all licence holders are fit to drive. People with a 'relevant disability' must not drive – people with a 'prospective disability' (such as dementia) may be granted a driving licence prior to the development into relevant disability. Currently, 1 in 3 people with dementia still drive (Alzheimer's Society, 2022e). It is the responsibility of the person diagnosed with dementia to inform the DVLA and their insurance company. The DVLA may ask the person to take a driver assessment and may ask the doctor or specialist for medical reports about the person. If the person with dementia refuses to inform the DVLA, and the doctor believes the person poses a serious risk to others, they should disclose the relevant medical information to the licensing agency. A doctor may tell someone that they must stop driving immediately if they feel the dementia or other medical condition warrants this, or as a precaution pending further tests (Gov.UK, Dementia and Driving, no date, c).

There are a number of 'red flags' in the recent clinician guidelines (Royal Society of Psychiatrists, 2019) which might indicate a person should stop driving – it was unclear whether carers were aware of these red flags, or the legal requirements set out above. It is recognised that assessing deterioration in driving ability is challenging for clinicians (Hird et al, 2016). Assessments are usually based on clinician's desk-based evaluations rather than regular assessments of driving ability, and although regular assessment is recommended (Rapoport et al, 2018). GPs are almost wholly reliant on the PLWD and their families updating them. Difficulties in getting a GP appointment, lack of continuity of care, and signing off from social services and health specialist services very early after diagnosis, as enumerated above, begs the question whether clinicians in Northumberland are in a position to, or can be expected to follow the guidelines comprehensively or scrupulously:

> Neville - 'The driving…that was a major episode…it became obvious 2 years ago ...she was not really…you just didn't feel safe….and it was probably more than that, 3 or 4 years ago. It's a question of how you deal with that, if I mentioned it, we'd have

> World War 3 ...so …we had multiple discussions on it. "I think in my view you should perhaps consider not driving anymore", "aaargh, have you any idea, so I can't use the car, you don't want me to scratch the car?" [Brigitte] "well no I don't but I obviously don't want you to kill anybody either"
>
> LM - 'Did you tell the DVLA about the diagnosis?'
>
> Neville - 'erm…yes, yes, yeah well I think you have to by law, so she had to ….reapply for her licence every year ….so it had gone on for a while and I guess the first 3 or 4 years without a major episode … but then fortunately I discovered that they have these assessments and there's one not that far away from here, so I said well I think you should go along and have that. So, I sorted it out nearly 2 years ago…and of course she failed, but then at least that wasn't my decision'.
>
> LM - 'Did you ever wonder if the GP or somebody else might have asked for an assessment or as you say taken that decision out of your hands?'
>
> Neville - 'Yeah…The GP's attitude was "well we rely on the family to tell us"'.

There are clearly some tensions between upholding the rights and freedoms of the PWLD yet acknowledging that eventually the person may be increasingly unable to drive safely or ability to assess their capability. The carer in the early stages can find themselves paradoxically both decision maker and decision recipient – often to their own detriment.

Izzy is a young woman in her early 30's who lives at home with her father who has been diagnosed with fronto-temporal dementia. Izzy is beginning to struggle to maintain her job as her dad becomes increasingly confused. He is terrified of losing his licence and having to stop driving. Her insistence that he was currently fit to drive was juxtaposed with an oppositional fear that he might pose a risk to others and feeling she might be held responsible if he did:

> Izzy - 'The psychologist decided to do another memory test...he had severely gone down… I have noticed that deterioration now… but as soon as he gets into the car, and he's like switched on, does it, drives away.'
>
> LM - 'So he's still driving?'
>
> Izzy - 'He is still driving.'
>
> LM - 'Is that a source of anxiety for you?'
>
> Izzy - 'Not really, because I know he only drives down the village and back. He did actually a couple of weeks ago…came to pick me up from a friend's house in ***, so it's only about a 10-mile drive but that was super stressful for me because …. he brought my car. "You be careful with my car!".
>
> LM - 'Has he informed the DVLA?'
>
> Izzy - 'Yep, I've done that… I'll go with him every now and then, it's probably every 2 weeks I'll say "oh come on let's go down to the shop or come on let's go to Hexham" and I kind of gauge it and night times is a big no-no and I think that's just his sight…but I will intervene when that's needed …My friend, whose dad had it….he

> was carrying on driving regardless, so in the end they had to hide the car…until he totally forgot about it. Now my dad is nowhere near that stage yet, but you know…
>
> LM - '….it does…feel as if other people put the onus and responsibility on to you? If somebody else said "actually you've had this diagnosis we're now going to have to …make you resit your test or…"
>
> Izzy - 'Yes exactly. I get the, not the aggression, that's the wrong word,…but I [might] get the blame because the psychologist says to me "and how's his driving? Have you noticed anything Izzy?" and I'm like "no it's fine" but you'll ask my dad and say …. right hand turns …'
>
> LM - 'You're being asked to say something in front of him then?'
>
> Izzy - 'Yeah… and I'm like well "is this on my say?" and when I read the letters back it says, "his daughter Izzy has said that there's no difficulties with driving blah blah blah", but I'm thinking "oh my god…if…god forbid, if anything happened would that come back on me?" I think maybe when it does come to that it might be that I have to have a discussion with his psychologist or have a discussion with the GP so that it doesn't sound like it's coming from me because that will not make my home life very good at all it would have to be a decision from somebody in authority and not me feeding the psychologist "oh yeah, he's fine"'.

Izzy narrates complex and zero-sum decision-making options. Admitting to health professionals her concerns, risks jeopardising her relationship with her dad, and will lead to a devastating loss for her dad when must stop driving. Failure to disclose a deterioration in driving creates fear that someone might get hurt and that she may be culpable. Izzy's narrative highlights the problem of relying on and expecting relatives to assess driving competency. Izzy narrates a disconcerting story of contradictions – expressing anxiety about him driving her car and acknowledging her dad's night-time driving limitations, hints at problems with right hand turns. Yet she states that his driving did not cause her anxiety. Her fear of his devastation at being unable to drive is clearly a strong motivational reason for her to continue to facilitate his driving.

Participants were often unclear who was responsible for informing the DVLA after the person they cared for was diagnosed with dementia, with some believing, erroneously, that it was or would be their responsibility. The legal responsibility to inform the DVLA that they have been diagnosed with dementia is that of the driver:

> LM - 'can I ask if he was driving, was driving causing any problems?'
>
> Nadia - 'yes he only stopped driving when I…he had to renew his licence and I wrote to DVLA and said he wasn't safe to drive….and you know you have to fill in this quite complicated form…'
>
> LM - 'and how did he feel, did he know that you were going to say that you didn't think he was safe?'

> Nadia - ‘He couldn’t believe that they wouldn’t renew his licence… because he’d argue, he kept phoning them, so he was well enough to do it then. He couldn’t pick up the phone and dial a number now.’
>
> LM - ‘so he was phoning the DVLA?’
>
> Nadia - ‘Yes he was phoning and saying, “why haven’t you renewed my licence” yes…’
>
> LM - ‘so did he not know you’d written in?’
>
> Nadia - ‘He didn’t know I’d written in…I was really concerned he wasn’t safe to drive; he’d bashed the car putting it in the garage. On one occasion, he turned the wrong way, so I was the one who said he’s not safe, it’s not fair to other people. And I felt bad about it, it was the first time I’ve done anything deceitful that he didn’t know about. But I couldn’t for safety’s sake for everybody I felt I had to do it. I was deceiving him because I didn’t tell him.
>
> LM - ‘if a doctor had made that decision instead of you would that have been helpful?
>
> Nadia - ‘Much easier, much easier yes… well I mean I did say to the doctor that I was going to do this, and he said, “oh no he shouldn't be driving”, but it was me initially’.

4.6.2 Stopping Driving - Why Can’t I Drive? Where is the Car? Where are the Keys?

> ‘…you don’t mention the word car **at all** you know…’ (Winnie).

Carers expressed a range of conflicting emotions when discussing driving - fear at potential anger and aggression from person with dementia, danger to carer if they hid keys or car, sadness at loss of independence. There was considerable anxiety about safety of others, and their duty and responsibility to protect them from harm. Conflicting emotions led to guilt at feeling forced to act in ways they considered deceitful – talking about the person to professionals ‘behind the person’s back’, or uncomfortable having to talk about driving deterioration in front of their loved one. Remarkable lengths were taken by carers to deal with difficult situations.

Kenneth describes the dilemma he faced when not only trying to encourage his dad to stop driving, but simultaneously feeling obliged to protect his Mum, who had multiple health issues. Kenneth articulates the range of emotional responses that this complicated scenario induced – frustration, anger, guilt, and fear for both parents:

> ‘…we had to take the car off him. He would not give up the car and it was scary it was. He used to take my mother out and my mother didn’t want to go, she was in tears it was literally too scary…I got…a chap, I don’t know where he come from, could have been social services or someone like that …who had a chat with him and he was adamant he wasn’t going to give it up and eventually I just took the keys …it was actually the motability car for my mother he was driving and eventually I just got the keys and I drove it back up to *** and handed it in …it was one of the most difficult things I’ve ever done …trying to get his driving licence revoked… I didn’t actually

> get it revoked I just ripped it up. I just tore it into pieces…it's wrong, but I couldn't have him driving …he was all over the road …I mean there was once I could hear the car in the drive sitting in the drive and he couldn't get out the car he'd clicked the central locking and didn't realise what he had done, banging on the windows trying to get out of the car' (Kenneth).

The very real danger which can occur when someone is unfit to drive is made frighteningly clear in Theresa's account of a trip home from Edinburgh. The potential risk to herself and to other road users cannot be understated:

> 'Connell always used to drive because I didn't like driving places to you know, big places. And he was fine but then there was one time and I do think it was when he was first starting to show signs. We were coming back, he was driving back from Edinburgh, and we veered off the road, hit the side of the road into the middle of the road, very fortunately there wasn't anything coming.' (Theresa).

Taking the keys from the person with dementia is a strategy which is often suggested (Adler and Rottunda, 2017). The Alzheimer's Society factsheet on driving (2022e), acknowledges the challenges carers face and says that carers may, where possible, 'hide the car keys, sell or give the car away, disable the car or lock the steering wheel, or park the car out of sight'. These were all strategies implemented by some carers in this research, usually in response to an accident, 'near miss' or as a preventative measure when driving ability had clearly deteriorated. Tina's use of the word 'stole' in this account indicates a level of guilt and sense of wrongdoing even though her Mum had been involved in a serious accident:

> '…she had a bad accident on one of, do you know as you go into London that really big 5 ways roundabout? somebody went into the back of her after she stopped dead…(Tina)
>
> LM – and was this before her diagnosis of dementia?
>
> Tina - 'oh this was well into it …'
>
> LM – had she informed the DVLA of her diagnosis?'
>
> Tina - 'I don't know. I think probably…Actually how we dealt with it the car stayed and rotted in her space until I sold the flat, but I stole the keys…'.

Preventing injury to her husband and other people motivated Krissie to take Neil's keys but she also acknowledges his frustration, sadness, and anger at being denied access to the car. His ability to retain information has led to a protracted conversational loop which continually sustains discussion of the contentious issue:

> Krissie - 'well when we saw Dr *** from who we got the diagnosis I'd already stopped him then. I did most of the driving anyway.
>
> LM - 'How did you stop him?'

> Krissie - ‘I took his key… and I just said he wasn't driving’
>
> LM - ‘Was he unhappy when that happened?’
>
> Krissie -’Well he wasn't best chuffed. I took him to [a daytime class] one day, and he wouldn't get out the car and he said, “everybody knows you drive me here’” I said “Neil, everybody knows I do most of the driving anyway”. He said, “you don't want me to drive’” and I said, “no I don't…because you'd be devastated if you hurt anybody, and I’d be devastated if you got hurt”.

Krissie has not surrendered Neil’s licence to the DVLA however, as she discovered that her insurance would increase if she removed him from her cover. Olivia has to reiterate daily to her husband that he can no longer drive:

> ‘But he still to this day doesn't think he can't drive. He still thinks he can drive and although I've said to him on numerous occasions, we have a letter Harry, from the DVLA they've taken your licence away you cannot drive. ‘Well, why not?’ You know? And each day, every day without fail we may be going to the supermarket we walk out of the supermarket, and he'll say, ‘where's the car?’ (Olivia).

The presentation of the dementia, the symptoms that challenge and the effect on the relationship could positively ease or negatively challenge the driving cessation decision making process and outcome. Tricia’s mum Penny was very amenable to the kind of decisions which can prove so distressing to others. Tricia said simply ‘she stopped driving’. When I asked if it was voluntarily, Tricia said ‘yeah. I think my sister borrowed Mum’s car, and that was kind of the end of her driving really’. In contrast, Flora, placed in a situation of fear, angrily tackled the driving problem head on, and demanded cessation:

> ‘…I remember the last he ever drove the car…all we were doing is going to Tesco and he couldn't even get round the kerb. He was on the kerb, and I said ‘Ernie, Ernie!’. And then we got to the traffic lights at **** and I was “**stop stop stop**”. Anyhow we managed to get to Tesco and as soon as we pulled up in the disabled bay, I just put my hands out and I said “Ernie, keys please”. I said, “that is the last time you will ever drive this car, any car”. And he just did. Never said a dicky bird’ (Flora).

It is hard to read a narrative such as Flora’s without thinking that many people, including clinicians and social work professionals would be critical of the manner of the prevention to drive, invoking notions of autonomy, rights and choice yet might they be covertly extremely relieved at Flora’s intervention? Whilst one could also argue that this approach is detrimental to the well-being or dignity an infringes individual rights etc, one might also suspect that in the long term, this direct approach, may have caused *less* harm to both Flora, Ernie and potentially others. It does, however, serve to highlight how frightening it is being in a car with someone who is losing the ability to drive safely, and that Flora’s instinctive angry reaction was born of a sense of self-preservation.

Perhaps one further and acutely problematic facet of this intensely complex driving decision making, is the fluctuating capacity of the person with dementia, and the ensuing complications it entails for the carer. In the following scenario Winnie reacts angrily when her husband Norman, whose driving had for some time been giving her cause for concern, decides to drive to his god-daughter's birthday party in Southampton. Norman's subsequent actions prompt police involvement and concern, yet later, he passes a driving test resit and can continue driving:

> 'I said, "That's far too far, you're not going to do that, and I'm not going.' In the dark all that way for a party in Southampton and coming back. He said, "I'm going, I'm going". I said, "well if you're going, I'll make a stand and I'm not going" …she said she would put him up [goddaughter] so I said, "I'll print out the google directions" …and the end result was he never got there…His friends phoned up and said, "Norman's not arrived". Next day there was no word, …by 5 o'clock the following day, we reported him missing… He had slept the night in the car and the police had said they thought he might have a 'condition'. And he had to sit the driving test again. Well, he was utterly horrified and mortified and all, but he **passed it!** … But that was the real start of it…you don't mention the word car at all you know (laughs) but we finally, about a month ago, managed to sell it. It sat on the forecourt for a year cos it was the idea that it was still here, and he could drive it. He has also in the meantime developed sleep apnoea, …he was supposed to report sleep apnoea and dementia [to the DVLA] but he has reported neither. But the car is sold so you know…that was really the beginning of it all when it got really bad.' (Winnie).

Difficulties accessing primary health care and lack of continuity of care preclude the establishment of trust between PLWD, carer and clinician, and hampers the ability of clinicians to effectively assess changes in the PLWD relating to driving ability.

4.6.3 Living without a car in rural Northumberland

Journeys by car increase in rural areas (Travel in Urban and Rural Areas, 2010). As a predominantly rural county, Northumberland faces complex challenges to its transport networks, with limited public transport options in some areas (O'Connell, 2019) and cuts to services over the last decade due to austerity measures. Further cuts to transport routes since the Covid 19 pandemic, including potential loss of bus and rail services, (Holland, 2022, Smith, 2022a) may lead to further reliance on personal car use.

When asked how easy it would be to manage their caring role without a car, those who drove overwhelmingly agreed that it would be extremely challenging for them. Words such as 'disastrous' (Laura) 'nightmare' (Katherine) 'we would be stuffed' (Krissie) were common responses to the question. Of particular concern was being able to attend hospital or doctor appointments, (including the additional time added to the day if forced to rely on patient transport) socialising, shopping out with their immediate vicinity, financial penalty if forced to use taxis – if taxis were indeed available and having to rely on other people. Much literature on dementia and transportation focuses on urban rather than rural areas (Rapoport et al, 2020). Spatial injustices and solutions linked to health and transportation challenges in urban areas may not necessarily be the same in remote and rural areas (Blackstock et al, 2006, Innes et al, 2005, 2011) and how they may adversely impact PLWD and their carers. Rapoport et al (2020) highlight the significant gaps in the literature, the crucial importance of transport access in rural areas – citing Alston's (2018) assertion that although driving may not be a right, access to transportation is.

For carers who did not drive themselves, considerations of the potential restricting spatial and temporal aspects of caring (Bowlby, 2012) are central in order to explain dilemmas they faced and the decisions they made. There were appreciable limitations on where the carer and the person with dementia could go without a car, due to a deficiency of reliable transport options - one carer advised that there were no taxis available in winter where she lived - and worries about additional costs incurred if taxis were needed to get to hospital or GP appointments. Dementia behaviours which challenge could also make public transport use extremely demanding. These carers although aware of declining competence in driving ability of the PLWD, often delayed reporting or minimised safety concerns.

In the following account, the doctor raises concerns about Olivia's husband's driving ability, but Olivia failed to see the problems with his driving. Needing assistance regarding orientation whilst driving is a 'red flag' (Royal College of Psychiatrists, 2019):

> Olivia - '... if he could get inside a car today, he would drive it. He wouldn't have forgotten how to drive; he wouldn't know where he was going because he didn't know where he was going whilst he was still driving. We would get to the end of the road, and I would say "go left here", and he'd go left. But he did everything else…Well it was obviously difficult because at that time…I'd had 3 cancer operations - one in 2014, one in 2015 and one in 2016, and I was having difficulty getting around… Ok, if I had felt unsafe with him then I would have said something, but I didn't, I felt quite safe with him. The question was telling him which way to go because he lost his sense of direction…the psychiatrist …was very concerned "If a child ran out in front of Harry, would he be able to stop"? I think he would have, but the psychiatrist wouldn't have it… they felt he wasn't safe because of the Alzheimer's.'
>
> LM - 'So has that had an impact on what you can do now that you don't have the car?'
>
> Olivia - 'Well yes it does. There's a bus stop at the end of the road along there and we can get the bus down into *** and we can get the bus across to Marks and Spencer's and Homebase and we can get the bus up to Morrison's. I used to take him out to *** Garden Centre…we used to go on the bus, but latterly …coming back he's very

> agitated on the bus …every time the bus stops to let somebody off, he's wanting off…so I had to stop that'.
>
> LM - 'So you're a little bit more limited in where you can go?'
>
> Olivia - 'Yes I mean [daughter] does take us out at weekends, but we are more restricted these days'.

Jett et al (2005) cite a willing co-pilot as one of the reasons for continued driving after a dementia diagnosis. Byszewski et al, (2010) found that caregivers mostly agreed with the decision for the PLWD to cease driving, although the research does not indicate whether participants were rural or urban dwelling.

Xena, despite the difficulties they would subsequently encounter without a car, realised her husband was unsafe to drive and went to extraordinary lengths to set up a counterfeit assessment:

> LM - 'Did Charlie used to drive?
>
> Xena - 'mmhm'
>
> LM - 'When did he stop driving?'
>
> Xena - 'erm…couple of months ago. Well bit longer than that but his licence …I made sure he got rid of his licence …I did a sneaky thing actually…I said he had to have a driver's assessment because he was 80 …and I knew he wouldn't pass. "I don't have to" [he said], I said "you do". So, I pushed, and this chappie came, and he took him out. Failed, miserably…'
>
> LM - 'So somebody from the DVLA came out?'
>
> Xena - 'No. I got somebody to do it [whispers].
>
> LM - 'So you asked somebody?
>
> Xena - 'Yes, just a local.'
>
> LM - 'So you pretended this person was from the DVLA?'
>
> Xena - 'Well…the DVLA was over in ***! And we had to drive there…well …How could he drive there?'
>
> LM - 'So they had offered for him to be tested there?'
>
> Xena - 'No, they didn't, I rang them up…no… they had nothing to do with it.'
>
> LM - 'So basically you got a neighbour to pretend they were from the DVLA?'
>
> Xena - 'Yep yeah.'
>
> LM - 'and did he [Charlie] accept that then, that he was…
>
> Xena - 'no.'
>
> LM - 'He took it badly?

> Xena - ‘yep…well he just kept going on “I can drive, I can drive”, so I had to hide the keys…erm…but now the car’s gone, my son has got it, out the way.’
>
> LM - ‘When he got the diagnosis did anybody say they were going to inform the DVLA?’
>
> Xena - ‘No. I was told I had to …I did it. Trying to get through was a nightmare but I did eventually to report that he was …had Alzheimer’s…’.

When Xena says, ‘how could he drive there?’ she admits his driving capability is already severely compromised. Fear for herself and others pushes Xena to create a fictional assessment as a way of managing this complex situation, even though as non-drivers, they will face considerable limitations on where they can go. As Xena said above ‘I mean you drive all your life…and then when you REALLY need your car, you’re not fit enough to drive it’

A recent Transport for the North report (2022) found that over 30% of people living in Northumberland live in areas where transport related social exclusion is high. The report highlighted rural towns, fringe areas and coastal communities as particularly vulnerable. The report identified older people as a group which suffered more from a lack of, or limitations to alternative transport options for non-drivers and underlined how crucial car ownership was to residents in Northumberland leading to similar risk taking, as evidenced in my data, by participants in the Transport research in order to carry on driving:

> ‘The issue of car dependence also appears among older respondents. Across the examples provided, respondents describe that having few or no feasible alternatives to using a car to access key destinations means that they feel compelled to drive. As well as the potential for financial difficulties linked to car ownership, including the issue of forced car ownership described previously, respondents connect this to feeling compelled to ignore medical advice and driving licence conditions when their eyesight or other aspects of their health impacts their ability to drive.’ (Transport for the North, 2022, p. 71).

Social exclusion through poor transport and communication links contribute to loneliness, isolation, lack of access to basic facilities and services and impacts the well-being of those excluded.

4.6.4 Driving as Identity - After the driving stops

> ‘He was very unhappy about his car licence being taken away “All his independence gone” he said’ (Tessa).

The profound sense of anger, sadness, frustration at the loss of a licence and being told to stop driving cannot be underestimated. Not only is driving a practical solution to rural transportation, but it is linked to a person’s sense of autonomy, independence and even identity. Byzszewski et al (2010) in their study of reactions to driving cessation of both caregivers and PLWD underscore the depth of feeling that some PLWD express when driving ceases. Although carers often expressed profound relief when the PLWD stopped driving, often after a period of protracted conflict with themselves, this relief was tempered by sadness and guilt as the PLWD reacted to their inability to drive.

In earlier parts of Xena's interview, she underscores their traditional marriage roles, with Charlie the 'man of the family' and 'the driver', with Xena's role as the housewife. The strength of these roles and their relation to each other contribute to the fear that Xena has that Charlie's sense of identity will be eroded and he might blame her for being forced to stop driving. Driving, especially in rural areas is bound up with a person's identity – a manifestation of their capability, 'masculinity', and role as independent person.

For Izzy's dad, driving is a crucial part of his identity. As being honest with health professionals about her dad's waning driving ability is fraught with personal and relational considerations about how her dad will feel if he knows she has instigated steps toward driving cessation, and safety fears that someone might be hurt or that she will be implicated if she does not make these disclosures:

> '…and that is one of the biggest anxieties [for] my dad "no-one will take my licence away from me…". So, the day that happens, is going to be terrible.' (Izzy).

Care theorists have emphasised the importance of viewing dependency and relational care as normative, accepting as natural duties and obligations (Kittay, 1999, 2011, Holstein, 2010). Driving cessation draws on ethics of care theorising to explicate the changing dyadic relationship between carer and cared for, the complex triadic relations between doctor, patient and carer and issues of dependency and autonomy. It also highlights the spatial injustices which people living in rural areas experience without having access to a car as physical and cognitive impairments intertwine with socially disabling factors. The personal carer style, environmental and social aspects are crucial factors in assessing injustices and impact on carer well-being as a result:

> 'The health and social consequences of driving cessation need to be recognized and addressed by health professionals, transportation planners, and policymakers. Failure to fully recognize the magnitude and importance of this transition among elderly adult drivers will compromise goals of improving the quality of life in old age, both now and in the foreseeable future'. (Foley et al, 2002, pp. 1288-9).

Feminist philosophers have foregrounded relationality in opposition to traditional western notions of the rational, autonomous individual (Robinson, 2011, Clement, 1996, Brison, 2017, Held, 2006, Massey, 2004, Holstein, 2013). Driving cessation guidelines place a higher value on preserving autonomy and liberty of the PLWD, rather than examining the relational impact on carers, or indeed *their* autonomy. Subjugating one's own desires or 'self-abnegation' has been viewed by many feminist scholars as a gendered practice associated with women. How this affects one's autonomy has been the site of some disagreement (Mackenzie and Stoljar, 2000, Oshana, 2015, Westlund, 2003, Frankfurt, 1999, Nussbaum, 2001). This research evidenced some subjugation of both men and women carers inherent in their complex decision-making regarding driving cessation which was detrimental to their well-being. Autonomy is a troublesome concept for people who have cognitive difficulties, (Dworkin, 1993) and foregrounding the autonomy and decision-making capacities of PLWD is clearly very important. But valuing autonomy over the relationship may prioritise PLWD over carers.

Locating answers to the difficulties associated with driving cessation of PLWD need to be multi-agency, begin at earlier stages – preferably prior to dementia diagnoses, and focus on rural specific impacts. Assessments and discussions about driving cessation must be on a regular basis. Solutions will not necessarily mitigate the pain, sadness, and anger of PLWD, but the progressive nature of the disease, and the growing numbers of people who will be affected, means that difficult conversations must be had. This empirical research supports other research highlighting a lack of support prior to and after driving cessation (Farmer et al, 2020).

The societal emphasis on independence leads to a negative perception of dependency, yet this is inevitable and a normal part of human existence. Holstein (2013) posits that autonomy for many older people is a myth, she foregrounds a more relational model and an ethic of care as better placed to address the needs of older people than prioritising autonomy and individual rights.

Driving cessation is specifically a *relational* problem – focusing on the individual rights of the PLWD denies the rights of the carer. Discussions need to be earlier, reviewed, and relational effects assessed. Dickerson writing in the most recent report from Alzheimer's Disease International (2022) advocates 'Best practice is to plan for the transition from driver to passenger with the initial diagnosis, especially if it is early and the individual with dementia can assist with planning and potentially learning to use alternative services, if available' (p. 211).

4.7 Chapter summary

In this first stage, carers often expressed a profound grief and sadness at the diagnosis. Carers usually experienced emotional responses similar to those observed in grieving processes. A dementia diagnosis was the end point in itself, with no pathway, no treatment, no cure, and no hope.

Carers expressed a sense of abandonment, with little or time limited follow up or support post diagnosis. Information about dementia at the point of diagnosis was usually generic and deemed inadequate. Most carers had not had a carers' assessment or did not know if they had had one. The quality of ongoing health care was postcode dependent, with very little treatment options or continuation of specialist health provision. Lack of continuity of care, problems accessing their GP because of difficulties procuring an appointment and sometimes an absence of care or empathy shown by the GP or health practitioners were common issues. Social care services were mostly insufficient and time limited. Most carers wished that they could be 'kept on the books', even if in the early stages they did not need any help, proactively 'checking in' with them periodically. Third sector and dementia specific support organisations often offered good sources information – particularly financial and benefit advice, access to support groups and referral for carer assessments, but did not provide much dementia-type specific support. Carers used online resources to find information on different kinds of dementia.

A strong sense of injustice and unfairness was articulated regarding dementia care as second class with comparisons often made to support received by people with cancer. Cancer care being medical - is therefore NHS and free, whereas dementia care is almost entirely non-medical, i.e., social care and means tested (Kings Fund, 2019). Although funding has increased, participants sense of injustice at the lack of healthcare provision, investment and research is borne out in recent research (Luengo-Fernandez et al, 2015, Alzheimer's Society, 2017).

The carer is embedded in their carer role at an early stage, as practical, financial, and legal decisions are made. Health and social care, DWP, and legal systems liaising with one individual. If a PLWD does not have capacity, then these organisations require an individual to act on the persons behalf – by default, this is usually the partner or child living nearest to the PWLD. This expectation of becoming the 'single point of contact' for all care matters becomes embedded through LPA's, deputyships, appointed persons for DWP, registering as a carer at GP's, carer organisations and social services. This happens relatively quickly after diagnosis. Financial LPAs, almost always in place, were evidently prioritised over health and welfare LPAs.

Carers had a very strong sense of duty and responsibility and desire to ensure their loved one was supported and enabled. Becoming a carer was not a role which was welcomed, nor were the onerous decision-making tasks which accompanied it, but they accepted it was their duty to do it. Most of the participants laughed or struggled to connect with the idea that *they* had rights or choices – such choices that they had, related to making best interest decisions for the PWLD, rather than themselves. The carer is 'lined up' for their role, whilst the person with dementia has capacity – legal responsibilities combined with person centred approaches from health and social care providers ensure the autonomy of the PWLD, and yet almost all major decision-making at home falls on the carer – particularly as the dementia in the cared for person progresses.

Carers begin to face impediments to effective caring as this first stage comes to an end. Driving cessation exemplifies the multiple aspects of relational care which impacted them, the PLWD and their relationship. The carer's rights and well-being are often subordinated to those of the PLWD and further the relational aspect is also undervalued or unacknowledged. Complex intersecting deliberations lead to agonising carers decisions.

Carers became de facto driving assessors, obligated to observe and report decline in executive function and concomitant loss of ability. Most carers did not want to have to tell the person with dementia to stop driving but they felt responsible for the decisions made, and the outcomes. Whilst recognising that '…continued driving by people with significant cognitive impairment can cause worry and stress for their loved ones' and 'can be a source of conflict between them…' (Royal College of Psychiatrists, 2019, p. 4), the guidelines offer little practical advice for families struggling with driving cessation challenges.

Carers expressed anger and frustration at the lack of help in resolving problems and guilt if the person refused to disclose diagnoses to the DVLA, and they were obliged to do so themselves. Living without a car in Northumberland could severely limit where some carers and the person with dementia could go, if the carer could not drive themselves spatial limitations on their lives were juxtaposed with considerations for safety - fears for the person, themselves, and other road users. Sadness at the loss of independence and identity associated with driving cessation, could also be tempered with relief that the PLWD was no longer driving. Difficulties confronting someone about problem driving could place immense strain on the relationship as the PLWD disputed and rejected criticisms of their ability to drive and threats to their sense of identity and independence. Driving cessation cemented changing in roles within marriages or parent/child relations, leading to further sadness for carers as the relationship dynamics with the PLWD shifted from interdependence to dependence. Spouses expressed particular grief - reciprocal care *within* a partnership became care *as* the relationship.

Relational ethics of care literature has been drawn on to examine the complexities of a caring relationship with a PLWD. It provides a moral and political framework to foreground dependency and interdependency. Care ethics can be used to examine care as an intuitive and reciprocal practice and value, or to scrutinise the deontological position of duty and responsibility as a virtue. Caring is a constantly negotiated position. Participants focus on care as a virtue was in continual dichotomous opposition to their articulation of disadvantages, injustices, and diminution of individual rights through their relational caring practices. Utilising a broad conception of an ethic of care (Fisher and Tronto, 1990) would place an onus on health and social care institutions and organisations to be responsive, responsible, attentive, and competent. When considering driving cessation, this would involve not just attending to the individual rights of the PLWD, but a proactive and reactive, focussed approach to listening to carer concerns about the impact on their well-being of coping as driver skills deteriorate and the effect of actual driving cessation.

Chapter 5. Middle Stages of Care

5.1 Introduction

The previous chapter saw driving cessation as a marker, delineating the move from early-stage dementia care to mid-stage caring practices. This chapter has five sections examining these middle stages of care. Carers reported increasing and multiple factors leading to social and spatial exclusion, isolation and marginalisation which frequently impacted their health and well-being.

Section one will examine the medical symptoms and presentation of dementia which highlight the effect of dementia impairment on both PLWD and the carer including the embarrassment and social stigma carers experience. The second section will explore a range of personal factors including limited family support in Northumberland, the emotional toll of caring, and concomitant impact on well-being. The third section will explore social support institutions and services, including third sector and formal care provision, emphasising a lack of specialised, person centred services and facilities for people with mid to late-stage dementia. Part four examines the spatial limitations experienced by carers as holidays or breaks become increasingly challenging and they experience difficulties sourcing appropriate respite provision. The final section examines how these medical, social, personal, and environmental factors transect, through a discussion of the challenges of incontinence and personal care as potential tipping points between mid to late-stage care of the PLWD.

5.2 Medical Impairments and Everyday Caring

Only two participants said they had experienced minimal or mild challenges in supporting their relative with dementia. Most interviewees described a range of distressing symptoms and resultant caring challenges. Medical impairments were of varying complexity, duration, and fluctuation but typically the PLWD experienced accumulative progressive impediments. Carers described four broad areas of impairment which caused most support difficulties, worry and embarrassment which often led to social exclusion – communication (including cognitive, reasoning and memory loss), challenging behaviours, safety concerns, and anxiety.

5.2.1 Communication

Forgetting names, everyday words, and the ability to do simple tasks, often asking the same question repeatedly are common features of dementia (Alzheimer's Society, 2016, 2017). These dementia symptoms featured in every carer interview; they were less indicative of behaviours which provoked the greatest challenges, but rather understood as an attritional source of irritation to carers:

> '…and a lot of the time he constantly repeats on and on…and it really wears me down…' (Una).

For those whose memory loss was profound, memory aids such as labels and pictures to aid negotiation in their homes, using old photographs to retain memories of family members or past events are often recommended. Several carers expressed scepticism about memory aid advice they had received. Tessa adjudged talking about the past to manage dementia symptoms of no benefit. Izzy, questioned whether reminiscing benefited the carer rather than the PLWD:

> '…because that's how I want him to stay? [how he used to be] or is it easier because that's how *he* remembers?' (Izzy).

Eloise articulated frustration at 'memory questions'. Her strategy was to accept that no memories are stored or can be retrieved. She used the analogy of the TV programme the Generation Game:

> 'I say to people – imagine a conveyor belt, but you would never see that item again or remember that item again. It's literally passing through' (Eloise).

Memory loss often required carers to act in ways which could be uncomfortable and antithetical to them - obfuscating or concealing information which they knew the person they cared for would be unable to retain – benevolent lies. For example, omitting to tell the PLWD that someone had died or telling someone at the last minute about a change of plans, to avoid causing distress; sometimes called Therapeutic Lying (James, & Caiazza, 2018).

As cognitive function declined carers articulated impediments to decision making and logical processing (Alzheimer's Research UK, 2016). As memory loss is often the defining characteristic of dementia, this can be frustrating for carers and cared for alike, as other people failed to understand actual challenges because they thought forgetfulness that was the most pressing issue they faced:

> 'He didn't have the classic symptoms of dementia. You think of people forgetting. Forgetting where they've left their car, forgetting people's names and what they did yesterday…that wasn't the major problem…he lost his idea of logic. He became totally illogical' (Tanya).

Problems with cognitive reasoning affected almost every aspect of daily life. For carers, this could be especially challenging. Izzy confessed that she often didn't know what she would be going home to, or the questions he would ask. Quinn described a sense of disorientation as his wife's interjections into a conversation became increasingly bizarre:

> '…her chain of thought would be just completely illogical…she would come in with something really on a tangent…and that wasn't what we were talking about, it was nothing to do with it!' (Quinn).

Apathy (which can be a manifestation of depression) and communication problems, or sometimes both were prevalent factors affecting the PLWD. Five participants related social and spatial limitations because the PLWD wanted to do nothing or go anywhere. A further six participants described communication difficulties as a major factor in social withdrawal by the PLWD and therefore by extension themselves. Activities and interests previously held by the person often ceased. This could include enjoying time with children and grandchildren. Xena sadly recounted that 'He just sits there all day…'. Theresa's husband similarly had withdrawn from most social activities and interests:

> 'But he doesn't have much interest in anything now. I mean he used to love football and he's not in the slightest bit interested in the television or football or anything really' (Theresa).

Carers of PWLD with apathetic symptoms were particularly lonely and isolated, deprived of meaningful conversation and interactions with other people. They were often unable to continue activities or maintain social relations with friends and families. Verbal communication difficulties often increased markedly as the dementia progressed. This could contribute to apathetic behaviours, as the person voluntarily withdrew from social interactions. Communication problems also led to other people withdrawing as they found conversations with the PLWD exhausting or bewildering. Kenneth explains:

> 'I do think the neighbour visits dropped off a little…
>
> LM – 'Why d'you think that was?'
>
> Kenneth – '…it's difficult to find something to say apart from talking about dementia …it is hard, I work for *** as a befriender and it's hard to even plan half an hours chat with someone when you're trying to draw it out of someone…I think it's because relationships change and people don't know what to say …some people don't know how to talk to someone with a disability in a wheelchair …and they don't know how to talk to someone with dementia'.

Wendy noticed her mum's withdrawal from social interactions as communication became more difficult and Una recounted seeing her dad in the pub one day and noticing his loneliness and isolation:

> ‘...he’s in a crowd of people who are really friends of his and things but …he just sits there, and he doesn’t…know [how to] respond to conversations…’ (Una).

Communication deterioration contributed to further isolation for the carer as social events became too demanding. Tanya recognised that her husband’s communication difficulties and apathy had created difficulties for him and for herself in social settings and at home:

> ‘But the problem with dementia is communication with my husband. He can’t converse properly, the words get lost, so it’s very difficult in social situations. I mean if you take him to social things… I feel it’s imposing on other people because he can’t communicate, it makes it awkward… [At home] It’s very bland for us. There are no ups and downs he never seems very smiley…. I find conversation [difficult]…I talk at him all the time and occasionally I get a sensible answer and sometimes I get rubbish’ (Tanya).

The feeling that she was ‘imposing’ on other people by bringing her husband with dementia to a social event was one which was echoed by other participants. This appears to be borne of a combination of embarrassment on the part of the carer, stigma (Goffman, 1976, Link and Phelan, 2001) or lack of understanding on behalf of other people, friends, family and wider community and discomfort of the PLWD themselves (Kim et al, 2019).

As memory loss became more profound, communication was increasingly challenging. Participants missed conversations and admitted to being ‘bored’. Neville relates one of the saddest aspects of daily life:

> ‘I suppose one of the things I really quite miss, or perhaps miss as much as anything, is actually being able to have a normal conversation’.

Communication difficulties led to the withdrawal of carers and cared for from social interactions. Spatial limitations and social exclusions were both partially imposed through continued misunderstanding and lack of knowledge by other people and self-imposed by the carer and PLWD leading to isolation for both. Social exclusion can lead to isolation and loneliness (Walsh, Scharf and Keating, 2017) profoundly impacting well-being (Mukaetova-Ladinska, 2017, Donovan and Williams, 2007). Recent research identifies loneliness and social isolation as a contributing factor to developing dementia (Wang et al, 2022) potentially placing carers of PLWD at additional risk themselves.

5.2.2 Medical Impairments - Challenging Behaviours

Specific behaviours which challenge such as aggression, sexual disinhibition, or very inappropriate language were reported by a third of participants. These behaviours resulted in limitations on social opportunities, and often left the carer anxious, fearful, and struggling to cope with day-to-day challenges for which they were often ill equipped, with little training or specialist advice.

Nadia’s husband sometimes had difficulty swallowing. Although she thought people’s attitudes to dementia had improved, she felt obliged to tell people Quentin had dementia, by way of explanation for any odd behaviours. However, even this could not always prevent embarrassment and discomfort experienced by herself and her husband:

> ‘I mean it's better than it was, that is definitely so, but now you say to people “oh I'm sorry Quentin has dementia” I mean invariably, we were out, the last time we went out for a meal and I can't do it again, we were in a nice French restaurant in **** which is one of my favourite places and he was sick at the table and the tables are fairly close together and I apologised to the people round about and they were all very pleasant at least to my face but one chap said “oh yes my dad had it.” But it’s embarrassing and I felt mortified. The staff were lovely, but I don't think we'll ever be able to go back’ (Nadia).

Despite other diners and restaurant staff being kind and accepting, this situation caused Nadia real distress, and had led to her restricting future social situations. Carers recounted embarrassing comments made by the PLWD which were out of character. Carol’s husband had remarked about a care worker ‘…look at the fat arse on that’. Izzy’s father had called her a ‘big fat beefer’. Nettie’s husband Henry with frontal temporal dementia could be sexual disinhibited and aggressive. Nettie described Henry as being ‘touchy feely’ with women. This has caused significant issues including for his daughter-in-law, who now refuses to be left on her own with him. He has made inappropriate comments to women in community settings – ‘My god you've got some pair of tits on you’! This has on one occasion led to a serious incident:

> ‘…a lady actually slapped him very hard across the face...I didn't really make a fuss about it…I was very upset… but I suppose some people just can't cope with things that like you know’.

Nettie’s doctor had given her a letter explaining why Henry might act inappropriately, which she always carried with her. I asked her how his actions impacted on her day-to-day life:

> ‘I don't let it to be honest. I think it’s my age. I think you know if I was much younger it would bother me but I’m thinking what the hell you know and I'm sorry but just get a life. And I mean I always say to them “look he will try and kiss you, proffer your cheek”. I say that is probably the best way rather than rebuke him altogether. Because he could get probably cross. I know he kicked a nurse in the hospital last time he was in…’.

She described several occasions where Henry was also extremely aggressive to her. Both Nettie's GP and social worker want Nettie to get more help but despite Henry's aggression and violence Nettie is reluctant - 'I'm very independent' she says:

> 'he was being horrible to me he's being absolutely horrible and awkward and nasty, and I said "oh Henry, why are you being so horrible to me? You know I do my best for you". He says "because you're a fucking horrible bitch!"…he was like being taken over by somebody else he was just not himself at all his eyes were strange he was screaming and he was shouting…I've got 3 exits out of this house and I had them all open Libby because I was ready to run because I was frightened…if I'm here on my own with him I'll have to just escape I'll just have to run'.

This interview with Nettie raised numerous aspects of the challenges which dementia presentations can bring. Despite Nettie's stoical iteration of her situation, the potential for serious harm to herself, to health and social care practitioners, to family members and to members of the public are stark. Henry's dementia symptoms have the potential to put himself, Nettie, and other people at risk. Implicit within her narrative are the concerns of her doctor, mental health team and social services. There is a delicate balance which professionals must negotiate to protect the freedoms of both carer and cared for, versus the safeguarding of both.

Krissie had also experienced physical violence from her husband:

> 'I mean you know like everybody he can have a temper, but I mean he has hurt me you know and bruised me arms and hands and I can't come to grips with it. The talking nonsense, the repeating things...I've come to terms with all of that. It's the aggression. [last week] and that was the worst one, that was the only time I felt frightened…'.

Confrontation and aggression could be a response to supporting the PLWD with everyday simple activities. Even with additional help from paid carers, some complex support challenges could not be satisfactorily addressed. Quinn faced when trying to shower his wife posed the same difficulties for paid carers:

> 'it's always a fight to get her in the shower… On most occasions she will say "no" …she'll refuse to go in and you can tell by her attitude that it's not going to happen, whereas other occasions, she might protest, and she'll swear at you, but you know it's not quite as violent a protest, if you keep plugging away, she'll give up and go in ...'.

Embarrassment, anxiety, and fear dominated these particular narratives. Drawing on SMD and medical model literature highlights the challenging nature of dementia and the difficulty in social adaptations which would help carers or PLWD in these situations (Tolhurst et al, 2017, Shakespeare et al, 2017). The relational aspect of care underscores the impact of challenging behaviours on the carer *and* other people. Foregrounding a social citizenship for

PLWD (Bartlett, 2016, Bartlett and O'Connor, 2010) and arguing that society not the PLWD needs to adapt in order to promote inclusion and citizenship (Milligan and Thomas, 2016) is problematic when addressing some specific behaviours that challenge. As more PLWD continue to age in place (Wiles et al, 2011, Davey et al, 2004, Means, 2007) more carers of people with complex support needs are likely to socially self-exclude in order to minimise these challenges. Women experiencing aggressive or violent behaviour from a spouse may be particularly at risk suffering relational vulnerabilities (Harding, 2017), detriment to their well-being (Agarwal and Panda, 2007) and raises clear safeguarding issues (Alzheimer's Society, 2022d).

5.2.3 Medical Impairments – Safety and Wandering

> '…But then there came a time when I knew I couldn't leave him because he was too far gone.' (Tanya).

Wandering is a well-known phenomenon of dementia (Cipriani et al, 2014). Over a third of carers narrated incidents of the person going missing, occasionally resulting in police or family assistance. Several carers left the PLWD on their own at home. There was acknowledgement from carers that this could not last, was risky or caused the PWLD distress. After an incident had occurred, some carers did not leave the PLWD alone again, but despite the risks, other carers with few support options had to go out and 'hope for the best'. Knowing that the person was at risk was sometimes weighed up against restrictions of the PLWD's freedom or the restrictions placed on their own freedom. Several carers had not realised the risk of leaving the PLWD alone, or had downplayed the risk because there was still an assumption that the person, they cared for was 'not that bad' or 'hadn't reached that stage yet'.

Tina who has been caring for her mother for 17 years admitted that it was easy to miscalculate the ability of the person with dementia to understand instructions:

> 'I think everyone's made the mistake of saying "well just stand here while I get the car", and then coming back and they've disappeared. Or you have to ask a passer-by, who has no say if they wander off or do something' (Tina).

Nadia had restricted where she and her husband went because of a previous incident with wandering:

> '…you stay on this seat, sit here and he would not remember that he was supposed to. Then he'd be wandering round looking for me. Panic, coaches were about to leave, where's Quentin? We lost him in Winchester once and that's 4 years ago as long as that…' (Nadia).

Olivia had similarly limited holiday options as husband Harry's wandering increased. Even with help from her children, they had been unable to prevent him going missing from a hotel:

> 'We thought well there's three of us to keep an eye on him, but we stayed in a hotel and of course he escaped. He was wandering around in his pyjamas in the hotel so we've got to now go to a cottage somewhere we can lock the doors' (Olivia).

Restricting access or egress to the PLWD could include locking interior doors. Winnie whose daughter was returning home for Christmas had asked her mum to put a lock on the bedroom door upstairs, because her dad had wandered into the wrong rooms whilst at her house. Norman struggled to find his way back to bed in the night. Winnie had suggested her daughter sleep downstairs to avoid problems:

> '…he has problems going to the loo sometimes in the night and then he gets lost where he is…'.

Norman was 'lost' all the time:

> 'He doesn't know his way round this house…I mean can you imagine; he takes his plate from there [points to the table], and the sinks there [points to the sink] and he walks over there with it! [points to the other side of the kitchen]…' (Winnie).

Tessa's husband Ian went missing in London, so she now uses a tracking device if they are in an unfamiliar place. Strange places are often very difficult for people with dementia as their spatial and memory cues become confused. Home can provide a safe environment at this stage (Taylor, 2001, Wiles et al, 2011) but this may lead carers to assume that the person they care for is still safe in familiar environments, yet eventually this too will pose problems for the PLWD, and it is impossible to predict when this might happen. When I asked carers what might act as a tipping point between coping themselves and needing additional paid help either at home or in a residential setting, safety was one of the key reasons given. This would often be articulated in terms of wandering/going missing, yet this had already often happened. Although Tessa's husband does still wander off at home, she isn't worried about this 'so far':

> 'I leave him quite a lot at home on his own. And he often just saunters off to ****[but] If I can't leave him at home on his own yes. If I can't trust that he can stay there safely, then I'm in trouble …[laughter]' (Tessa).

Tessa's 'so far' implicitly concedes that this situation may change, and that her own freedom will then become constrained. Theresa's husband has also gone missing when staying at his daughter's house. Theresa and her husband Connell, live all year round on a residential caravan park, close to a busy dual carriageway. Theresa feels this living arrangement brings safety and security despite her husband wandering:

> ‘I suppose in a way we're lucky that way [living on the park] because if I had to restrict him, if I had to keep him in all the time or go everywhere with him, I think he would be really quite agitated. Very difficult’ (Theresa).

Drawing on autonomy and freedom literature (Mill, 2008, Berlin, 1969), illustrates the conflicting relational aspects of supporting a person with dementia to be free and safe whilst protecting one’s own freedom. Choices made by PLWD and their carers also involved other people – police, neighbours or in Theresa’s case other residents living on the park. There is an expectation that other people on the park will help if Connell wanders too far. Theresa’s narrative underscores again the relational nature of care (Held, 2006, Kittay, 1999) and its impact on both her and her husband’s ability to retain freedom. Carers with no paid or family support often had limited options – restricting the PLWD could cause frustration and potentially aggressive responses from them and leaving them by themselves posed clear risks but might be the only way a carer could leave the house, often to attend to mundane activities such as shopping or attending appointments.

Olivia’s husband had not only gone missing on holiday but had also wandered away from their home and from other places too. He has climbed fences, squeezed through hedges, escaped from a care home, wandered off from a garden centre and onto the bypass nearby. He was known to police, who have looked for him on several occasions. Olivia was advised by social services to get a tracker device, costing £350 but it does not work where they live in North Northumberland. A local dementia support group have struggled to support him:

> ‘they're now getting an alarm put on this door. They can't lock it you see because it's a fire door so they're getting an alarm put on it. He can't go back until they've got this alarm fitted. But also, they say if he decided he was going they couldn't stop him, because it's infringing on his human rights unless I have a letter from the doctor saying that he hasn't got mental capacity’.

Olivia has had to get a letter from her GP to confirm that her husband does not have capacity, and therefore the support group can put an alarm on the door. This narrative emphasized conflicts between safety aspects and the freedoms and rights of the PLWD – and these rights took precedence over the concerns of the carer. It also underscores the continual and multiple challenges that carers face – the actual medical impairment of wandering and social disabling through mistaken assumptions that technology would work in a rural area and the resulting financial cost, burden of bureaucracy associated with risk assessment.

5.2.4 Medical Impairments - Anxiety

Anxiety, and its manifestations, is a common problem for PLWD. For five participants, this anxiety acutely affected the person they cared for and impacted on themselves. A particularly difficult aspect of this was being followed. This led to carers who may already have been restricted spatially in their communities, also being restricted in their own homes:

> 'but he just doesn't like me going out or …he just likes me THERE…When I go in the bath, I never lock the door …if I was to fall or if he needs me …he'll shout "are you alright up there?" or if I go to the loo "are you alright"…if I get up to do a job "why're you doing that. Just leave it alone, just sit down"… I find it quite difficult sometimes' (Xena).

Whilst I was interviewing Xena, her husband, across the road was looking anxiously out of the window and shouting for her. The interview had to be somewhat shortened as a result. Having very little personal space can be especially challenging for carers. Being able to take a break, even for a few minutes, can be almost impossible:

> '…what actually irritates me, and I can't help it, I do get very irritated, is that he follows me about…It's the following. I just can't. I go in the kitchen sometimes take a breath and think five minutes, and he's there behind me, and I think "oh go away". You feel awful but…' (Olivia).

Eric's wife Shirley suffers from extreme anxiety. If he is away, even for a short time, her anxiety was intense. Day to day issues which to most of us would be easily understood and coped with left Shirley with egregious anxiety. Here, Eric enumerates the multiple and conflicting challenges which his wife Shirley's dementia presents:

> 'Silly little things…are big issues for her and very stressful for the carer…obvious things, they're not obvious, not simple for the person with dementia…She gets terribly, terribly anxious...her anxiety levels are so bad that she's not able to travel, she's not able to sleep outside of her own bed, we can't go and visit our sons or if we do it's a nightmare for her. We did go and visit a couple of months back because they just had a new child, a new grandson for us and we did go and stay the night with them, but it was awful for Shirley. She was dreadfully confused. Similarly, it's prevented me from getting carers to help because she won't have anyone stay in the house with her, she won't go and stay with anybody.'.

Eric had tried organising a befriender help from a local third sector organisation, but Shirley could not cope with it:

> 'She just wants to have me there basically and that's nice for her but no good for me'**.**

Although routine could bring order and continuity to PLWD and their carers, it could, in of itself be another tying aspect and the source of immense distress when routine could not be adhered to, as Eric has already explained above when discussing Shirley's anxiety. Eric describes it thus:

> 'It's weird, but she's desperately tied and terribly bound into her basic routine. Routine – it's terribly important to her'.

A social model of disability (SMD) (Oliver, 1983, 2004) may address Lyman's (1989) critique of the biomedical model of dementia by challenging predominant assessments of disability as mostly a problem of medical impairments. A SMD can show how people are limited by social arrangements and built environments. But although connecting disability to dementia has seen progress (Thomas and Milligan, 2018, Shakespeare et al, 2017), dementia impairments prove problematic for SMD theorising. The impact of 'impairment effects', (Thomas, 2004) on carers must be distinguished from the disabling effects of environment. Both impairment effects and disability intersect in multifaceted ways, creating 'corrosive disadvantages' (Wolf and De-Shalit, 2007) for carers, but it is important to make a critical distinction between the two (Thomas, 2004) or we run the risk of diminishing the impact of impairments and obfuscating the realities of carers' lives (La Fontaine and Oyebode, 2014, Tolhurst et al, 2017).

Half of participants felt that there was a broad lack of understanding about the nature of dementia. This was sometimes because other people had a fixed (either through their own experiences of dementia care or through stereotypical representations of dementia as being primarily memory-based difficulties) notion of what having dementia entailed, or because they had no experience and therefore lacked knowledge and understanding. Krissie used the Dementia Choir programme on BBC (2022) to point out what she felt were sanitised depictions of dementia:

> 'It all seems hunky dory on there [dementia choir programme]. Alright, they say silly things and get mixed up, but it's *not* like that'.

Misperceptions of dementia could lead to a lack of understanding of the challenges faced by carers and PLWD or conversely an assumption that the person was fine when they were not:

> '…I take my mum out for a coffee …"well, isn't she good"…(laughter)…you know she's wet herself this morning and I've had to wash her and ...they haven't got a clue…One of my cousins who I don't particularly care for, came in the summer, rocks up ten past six at night couldn't be a worse time when I'm doing the tea making my mother's bed cos I've changed her …"she looks well"…I could have smacked her in the face, you know that! …(laughter)' (Katherine).

Katherine articulated strongly here her anger and frustration. I related acutely to this conversation. On several occasions, friends, family or health and social care professionals implied that my sister and I had exaggerated my parents cognitive decline or challenging behaviours. This was deeply upsetting as well as frustrating.

5.2.5 Medical Impairments - Coping with Stigma and Embarrassment

Challenging behaviours by the PLWD were often a source of embarrassment or discomfort to both the carer, the person they cared for and other people, although several carers identified other people's reactions as the cause of awkwardness rather than the PLWD. Individual carers used different strategies to manage awkward social situations. Several carers coped by developing an 'it's their problem not mine' attitude.

Almost half of carer participants had encountered negative attitudes and reactions of other people, including family, regularly identifying a stigma associated with the word dementia or Alzheimer's. Nettie's friend could only whisper 'he's got dementia'. Laura concluded that 'in people's heads they think that dementia is just the worst thing possible'. Eric believed the stigma was so strong that some families abjured any link to dementia:

> 'I don't think people understand, just how difficult it is…and you know the stigma that surrounds it…loads of people and families in denial. I think it's terrible. I've heard of one or two cases where families are just in denial, and they just won't get any help at all for the person that's got the diagnosis'.

Several carers felt reluctant to disclose a diagnosis to prevent people making assumptions about the cognitive ability of the PLWD:

> 'I think I just worry about…the way he is perceived really, because for all that he has Alzheimer's, …he can be as smart as a dart' (Izzy).

Izzy's observation implied value in being 'smart' and conversely devalue in cognitive decline. Later in the interview, Izzy acknowledged the stigma associated with cognitive rather than physical debility:

> 'It's because it's a hidden disease, isn't it? It's hidden within your body and it's not a physical wound that you can see. It's something which is within your mind…the outer thoughts of people, the stigma that might go with it'.

Here, Izzy expressed an understanding of separateness of mind and body, and the importance of to her of mind *over* body (Parfit, 1984, Miller, 2021).

Carers also recognised discomfort in others whilst often expressing embarrassment themselves when the person they cared for acted in unusual or challenging ways. This awkwardness might stem from a lack of knowledge of the disease and so how to respond to a person with dementia. Shame associated with frailty of the body (Kristeva, 1982), the disabled body (Wendell, 1996.) and specifically with the demented mind (Behuniak, 2011) leads to a devaluing of PLWD (Butler, 2016) and perhaps carers sensed a devaluing of themselves, as stigma through association (Van der Sanden, 2015) or ‘courtesy stigma’ (Goffman, 1963). Understanding the impact of stigma means recognising and measuring it (Link et al, 2004).

Una recounted a situation where she felt embarrassed herself, and unsure how to deal with an awkward situation. It also highlighted her sadness and discomfort at a disease which had affected the ‘philosophical being’ (Davis, 2004) of her father rather than the physical manifestation of the disease, which his actions demonstrated:

> ‘…dad sits in the pub and he often taps his hands on the bar and then as soon as there’s music on - he used to love jiving years ago when him and mum were young - and he thinks every time he comes in the pub, especially the weekend he thinks he’s looking for the music to jive …and I find that a bit embarrassing but I know where it’s come from because it was something he liked to do… most of the time everyone thinks it’s good, it’s just more so me that finds it embarrassing’.

Una describes her embarrassment as the primary problem, but she may also be describing a fear that people are laughing at or humouring her dad rather than genuinely enjoying his jiving. This correlates with her acknowledgement of the dad who ‘was’ and the dad who is ‘now’.

A few carers complained of family and other people’s inability to understand or respond appropriately to a PLWD as a factor in increasing isolation for themselves and the person they cared for. Katherine is more explicitly angry that she and her mum are effectively ostracised in their local community:

> ‘[regarding dementia] …It’s a very lonely thing and you find out who is there for you and who visits. I can take my mum to the café [locally] and some folks don’t know how to react. I hate that. Just come and say hello, she knows who you are! Some folks just don’t, and that really annoys us. It’s still my mum, it’s still Elizabeth’.

It matters to Katherine that people recognise her Mum, the person, her identity, as still there and lack of acknowledgement angers her. The importance of identity and recognition (Taylor, 1994, Butler, 2016) will be discussed in more depth in chapter six. Wendy recounts increasing isolation and loneliness because of perceptions of her Mum, but also because of the actual behaviours which challenged. Lack of knowledge of the disease, as identified earlier in this section, led to mistaken presumptions from other people that they could manage caring for a PLWD:

> '…Another problem for me, was other people's perception of Mum…she was very repetitive, it could get boring and irritating – I lost friends in droves. Or people would say "oh yes of course, my mum has dementia, I know how to deal with it, we'll take your Mum out". And then they would be horrid to her, and horrid so that Mum would notice…really quite blatantly horrid'.

Several participants felt that stigma and discrimination surrounding dementia was easing somewhat and that being able to use the 'D' word had become more accepted, but only a few carers said they had challenged other people's negative attitudes or perceptions of PLWD. Eloise whose narrative contained the most positive view of dementia felt no embarrassment. Her understanding and rejection of embarrassment through personal shame linked to the actions of her Mum, were in contrast to most other participants:

> 'I just don't get embarrassed, and I just think "well, unless I've done something shameful, why would I be embarrassed?" And why would anything that my Mam does make me embarrassed?'.

Eloise admitted to being embarrassed by her mother when she was a child and argued that this had led to her as an adult being fearless in the face of any discomfiture. Eloise's acceptance of her Mum in the 'now' rather than in comparison to the past may have enable her to be more sanguine about behavioural challenges. Nettie and Tina described a more pugnacious approach which was borne of anger and frustration at other people's attitudes:

> 'I think people are very nervous… [around people with dementia] I don't want to make people uncomfortable, but on the other hand I think there's a level which…yes, why can't YOU be uncomfortable for a bit!' (Tina).

Nettie additionally placing the burden of responsibility regarding social interactions firmly on other people, and not the person with dementia, is also able to recognise that ignorance of the disease may explain some of the reactions of other people:

> 'I think you know, if I was much younger, it would bother me, but I'm thinking "what the hell…and I'm sorry, but just get a life" …there's so many people…they're miserable people and they don't understand'.

The narratives already discussed in this section illustrate the discomfort and embarrassment which can be experienced by both carer, cared for, family and friends and the wider community. The SMD (Barnes and Mercer, 2004, Oliver, 1983, 2004, Thomas, 2004) and relational ethics of care (Held, 2006, Noddings, 1982) are useful frameworks to identify and challenge stigma and discrimination so clearly experienced by PLWD *and* their carers. Tina tells a story which highlights both the discrimination she and her Mum faced AND the difference which can be made when someone challenges it:

> '…some people are lovely. Mum and I used to go every week to ***…and [we did] the old-fashioned things like sitting in the window and pass[ing] comments on the world. But one day she was having a strop about something and people on the table behind were complaining to the manageress and saying we shouldn't be allowed, we've come for a nice day out…And the manageress said "well, here's your money back, would you like to go somewhere else…".

Raising awareness of the 'othering' they face by able bodied people (Shakespeare, 2014) and greater awareness of dementia symptoms and behaviours which challenge could make a real difference to carers and the person they cared for.

5.3 Carers lives in Northumberland

Most participants lived rurally or semi-rurally. Most did not have family members nearby. Three quarters of carers I interviewed had children – 19 with grown up children, 2 with a child under 18. Between them they had 40 children, nine of whom lived overseas and 15 lived outside of the Northeast. Five children did live in the Northeast, but over 60 miles from their parents. Only nine children lived locally – of these, two were underage, one worked away on the oilrigs, one lived at home but was not involved in a caring capacity. Two gave little or no help, two sons gave occasional support and one daughter helped weekly. Children often gave considerable telephone support and visited but had little input in day to day caring of a parent or grandparent:

> 'I'm on my own here, my daughter is in France……and Norman's brother lives in Reading, so we have no-one here' (Winnie).

For those carers who looked after a spouse, there were several key aspects expressed about the involvement in care of a parent by their children. The worries they expressed – not wanting to be a burden on their children, concerns that children would struggle to juggle work and young children with an additional caring role were to some extent borne out by the reflections of participant children who were caring for a parent or parent. They had often made difficult decisions to give up work, move house to be nearer their parent or in one or two cases the parent had moved in with their child. One carer had two daughters, but she didn't want them involved in a caring capacity. Occasionally, carer participants had help from other members of the family – siblings, uncles, and aunts, but this was rare. Such additional help when it was available was often intermittent and dependent on their work commitments.

A quarter of spousal carer participants and a smaller number of parental carer participants who also had grown up or dependent children 'sandwich' carers, expressed a mix of sadness that their children lived too far a way to help juxtaposed with a desire that that they be free to live their own lives, perhaps in ways which had not been available to themselves. Una caring for her father has two grown up children:

> '…I've got 2 children but they're away from home now …one lives in another country so there wouldn't be a support there. They're very good and worry about my dad and that but em, there's more opportunities for children to go away like, when I was younger you didn't really go'.

Family carers were very aware of the difficulties of employment locally and why their children had moved away. They were also acutely cognisant of the demands and pressures which their children already faced often juggling careers and childcare:

> 'I can't ask my girls to look after him, they're working, busy. I've got a daughter who's doing a PhD and working (laughter)…and she's got five stepchildren!' (Tessa).

There was often an explicit iteration of the 'not wanting to be a burden on their children' but the narratives also contained an implicit wish that their children had not had to leave. Xena's narrative confirms she does not want her family to get involved in caring for her husband, but she also hints at a sadness that they are so far away:

> 'I think it's very difficult, because my children have moved away, but they're one of millions I suppose who move away for their jobs. And there's no-one close to help…the children aren't going to come back here to live, to care for him cos they've got their jobs in London.'.

Beverley articulated the paradoxical wish that her children did not face the difficulties she had, whilst caring for her mother, but this was coupled with an admission that she would not wish to be abandoned by them if she needed care herself in later years:

> '…I gave up my life to look after my mum, I don't want my kids to do that, but then I don't want to be on my own…[I] want them to live their lives…do something different'.

This highlights the additional layer of emotional guilt and our understandings of duty and responsibility – the undermining of these key familial roles through changes in rural communities, economic pressures which see young people move away, but simultaneously older wealthier people move to 'holiday' destinations, lead to a complexity of intergenerational notions of who, what, where and how care takes place.

A few spousal carers found it extremely painful for their children to see the parent with dementia, particularly if the presentation of the illness had led to extreme personality change, or because there were physical symptoms, such as incontinence or severe cognitive decline. Tanya in addition, revealed a strong desire to protect her children, not just from the cognitive decline of their father but also the toll it had been taking on herself:

> 'I didn't want them to get involved with care. I felt protective of them, maybe I should have got them more involved I don't know, but I just didn't want to… I just felt uncomfortable that they were seeing their father decline… in that way and I didn't want them to see that I was upset about it'.

Perhaps this discomfort can be linked to the profound sense of loss of identity, not just for the person with dementia, but more broadly for the whole family. As relationships and family dynamics change, the identity as a family, as a kin group becomes fragile. As the PLWD forgets who family members are, each individual and collective aspect of family life – it's identity and recognition, becomes a site for a deep sense of loss and bewilderment.

Participants demonstrated a further dilemma. Wishing that their children or other relatives were able to help more, whilst conversely feeling anger and frustration at any 'interference'. This undoubtedly common situation was both an intergenerational interaction – parents and children or grandchildren, and a cross generational one between siblings or aunts and uncles. The protectiveness and irritation are exacerbated when the carer is caring for another person with dementia:

> '…mum you need to do this, mum you need to do that' (Nadia).

Xena's narrative conveys both the gratitude that her daughter and granddaughter have arranged her visit to a family party and that they want her to go, and the guilt at leaving her husband. In addition, there is the implicit sense of her having been corralled into going whether she wants to or not:

> 'My granddaughter's 21st that's how it started ...cos [she] was desperate for me to go and so was my daughter. And I said, 'I can't', and she said, 'you can, this is what I'm going to do', and she arranged it all which was great…. and I did go down for one night to London. And had carers in all day and all night'
>
> LM – 'ok, and how did that go?'
>
> 'Not very well I don't think but, they [paid carers] ...they didn't tell me …they wanted me to have a good time …but when I came back, they said he'd been a bit anxious at first but then he'd settled down'.

Xena gives a further example of this inter-family negotiation of competing interests – the daughter worrying about her mum, Xena feeling guilty at leaving her husband, and perhaps a sense of ambivalence at her daughter's intervention:

> '…and I said just the other week, when Charlie fell out with this fella [paid carer, who lets Xena get a short break] "well, just cancel it all". And she was cross. (Not cross with me) "you're not cancelling", she says "you're not mum, you need that time out on your own, whether it's just to go to the village or whether it's to do whatever you

> want to do for two hours". I leave him for an hour, two hours, so he's only on his own 2 hours'.

Children's interventions were often couched in terms of anxiety about what would happen if their carer parent was to become unwell themselves, and a sense of the inevitability that they would eventually be unable to care for the PLWD. This led to an encouragement for securing paid care, or attendance at local dementia or day-care facilities to give their other parent a break from caring. Parents were often aware of this dilemma for their children but felt an extreme pressure, often from their spouse who did not want to leave them, from the guilt they felt when they did, and for the lack of appropriate facilities or care available. This combined with the knowledge that their children would struggle to take over the care if they could not, led to a determination to carry on themselves:

> 'I mean if I went, if anything happened to me, he would have to go into care. I mean I know we've got [their children] but they've both got their homes and their jobs and families you know?' (Theresa).

When it was the child rather than the spouse caring for the parent, a differing set of complexities arose, often with other siblings or relatives. Similar expressions of frustration at both lack of help, understanding of the levels of care and of interference was evident in narratives from Laura, Kenneth, and Katherine. But there was a far stronger sense of 'abandonment' in their role as carer and a resentment that the burden of care was almost wholly carried by themselves.

When asked what would happen if something happened to her, Laura replied:

> 'Oh god, things would fall apart. I mean my uncle is great and his wife …but…they would just never be as involved as I am as much as they'd want to be they just couldn't cos of work they've got jobs'.

This acknowledgement of the reasons why her uncle and aunt cannot help more mirrors comments made above by parents about their children. Kenneth, who after taking early retirement, moved from his home in London back to Northumberland to care for both parents with dementia, expressed resentment of his brother, who had little practical or emotional involvement. Once one person (usually the spouse, or if it is a child, the nearest geographically) begins to offer support and care to their family member living with dementia, they can find themselves inextricably tied to the carer role. There was still a strong expectation that women should be the key carer and this could leave male carers adrift. There were support groups dominated by female carers where men did not feel that they fitted in.

Some family members did want to visit, but the challenges of the behaviours of the PWLD could sometimes prevent this as we saw in section one. The intergenerational caring of the past, with extended families of working class (especially mining in Northumberland) communities in one house or street has gone. Young people priced out of the jobs and housing markets have left and moved away (Milbourne, 2012, Stockdale, 2011). This has combined with an outlook of individualism expressed in the 'they have to live their lives' afforded to children of participants, but a strong sense of duty and responsibility expected from themselves.

Rowles pioneering 'Prisoners of Space' (1978) brought new insights into the lives of rural older people, but further research into older lives and their communities remain scarce (Hopkins and Pain, 2007, Bradley 1986, Milbourne and Doheny 2012, Stockdale 2011, Scharf and Bartlam, 2006, Tarrant, 2010). The impact of changing familial relationships in rural areas (Tarrant, 2010, Milbourne, 2012, Milligan, 2000, Scharf and Bartlam, 2006 and 2008) was clear in the participants narratives with many participants children or siblings having moved away (Milbourne, 2012, Stockdale, 2011), leaving them to care for PLWD on their own. Loneliness and isolation can be exacerbated by rurality (Milbourne, 2012, Milligan, 2000, Bradley, 1986) and understanding participants narratives can only be appreciated by recognising their spatial biographies (Blackstock et al, 2006).

For those carers who had some help from their children or other family members, many expressed considerable gratitude for the help they provided. The familiarity of a loved one sharing in the caring roles could bring inexpressible comfort.

5.4 Guilt and the Emotional Toll of Caring

Guilt as experienced by the interviewees generally fell into three categories – guilt that they were still able to enjoy their lives whilst the person they cared for could not, guilt when they had become angry and frustrated with the PLWD, and particularly strong guilty feelings when they felt unable to cope and had to ask for help.

In the earlier part of this chapter, we heard how difficult it was for Eric to leave his wife for an hour or two to take part in a hobby he enjoys. His wife would be angry with him when he got back, and it was becoming increasingly hard for him to leave her at all. He described knowing that she was desperately unhappy if he left her leaving him feeling extremely guilty.

Tessa, whose husband's apathy has increased as his Alzheimer's progresses recounted feelings of guilt similar to those of Eric. Her husband, Iain is often angry with her if she has been out with friends:

> ‘All my friends keep telling me “You must keep up with your social life”, but I feel so guilty…I go out and have a nice life, and he sits at home doing nothing. And every now and then, he’s in a black mood and he tells me he’s sitting at home with nothing, while I go out…’.

Tessa is faced with a zero-sum option - stay at home with Iain and not go out, which is what he wants her to do, or try to maintain her connections with friends, which angers Iain. Guilt at maintaining friendships or enjoying everyday hobbies and activities, was often expressed as ‘selfishness’ on the part of the carer, and even as shame. Kenneth’s guilt at deciding not to take his mother to a specific dementia group because he played football at the same time, was palpable:

> ‘I think there was something [dementia group] on a Tuesday…but I’m ashamed to say that I play football on a Tuesday…and there’s got to be something for me’.

Izzy’s critical assessment of her ‘selfishness’ leads her to the realization that her anxiety is produced by the guilt she feels leaving her father:

> ‘Like Saturday night I stopped over at a friend’s house, just purely out of selfishness…because I know what he’s like beforehand…” I don’t want you to go out to your friend’s house”. So, there’s a bit of guilt and I think the guilt causes the anxiety’.

Accepting that they themselves might have needs over and above the needs of the person they cared for was often difficult for carers to acknowledge or accept. Taking some time away from their caring role induced guilt, sometimes explicitly:

> ‘I [was] feeling so guilty about leaving Dad last night. And ***[her son] said “Mum, don’t feel guilty…you deserve some me time”’ (Nettie).

Or implicitly:

> ‘I don’t feel that he’s bad enough to have to go into day care. It would only be for my benefit not his benefit…’ (Theresa).

Theresa here, is unable to feel that she might be allowed to benefit. It also highlights the real lack of options available as carers negotiate complex decisions regarding the safety and wellbeing of the person they care for. Leaving them alone can place them at risk but being unable to maintain social activities can be detrimental to the PLWD and the carer.

Asking for help can be an admission that the carer is not coping or in their own eyes, that they should be able to manage. And although carers often express anxiety about what might happen to the PLWD if they were unable to care, nonetheless asking for help from others proved to be guilt inducing:

> '…I feel guilty if I can't help my mum doing stuff, and her medical appointments, God! if I ever have to cancel one because we just can't do it, I feel horrific about it' (Laura).

Not only did Laura feel guilty about the impact on healthcare services, but her guilt also extended to her aunt and uncle, who provide occasional care to Laura's mum:

> '…we've had quite a lot of hospital appointments and I feel a bit guilty asking *** and *** all the time cos we have so many hospital things going on'.

Carol, similarly, worried about 'bothering' professionals:

> 'I got the paramedics again. I always feel guilty getting them because they could have been seeing to other people'.

Several carers articulated feelings of guilt (and relief) as they left the person to be cared for by someone else. Katherine describes taking her mum to a day care centre for the first time:

> 'I took her up…I was very, very anxious, it was like taking your child to school for the first day. I cried all the way home…" You sit here beside me" …"No, I have to go Mum"…but it's the best thing I've done'.

These small steps, which begin to separate carer and cared for, were precursors to the much bigger step which might eventually lead to the PLWD moving into residential care. Experiencing feelings of guilt (Gallego-Alberto et al, 2022, 2019) was a very strong feature of most interviews. Feeling they had not done enough (Simonsen, 2017) or that deterioration in the PLWD was their responsibility (Davis, 2004, Prunty, & Foli, 2019) led to decreased well-being especially of women carers (Romero-Moreno et al, 2014). These feelings of guilt were often continuous at this stage and will be considered again in the next chapter:

> '…but sometimes when he [repeats himself] … you think "oh God, don't say that again" …and you know he can't help it, but you do feel guilty' (Una).

5.4.1 Struggling to Cope Emotionally

A few carers described losing their tempers whilst trying to manage a challenging caring situation. This could involve shouting, irritation, and threats. Laura, again expressed guilt, struggling to combine work and her caring role she became tearful during the interview as she described the day-to-day stress she was under:

> '…I do shout, I can't help it. I try and try, most of the time you know, 70% of the time we're fine…I threaten to take things away…like I say, "if you don't drink your water, you're not going to have your cigarettes", or I say, "I'm going to put you to bed". And it's wrong, and I feel awful for doing it…but sometimes…she's so stubborn…I get upset, I've been at work all day…'.

Social services at the point of this interview were actively seeking respite for Laura and encouraging her to take a break but Laura's previous negative experience of her Mum being taken to a residential care home when she was on holiday, had left her with a very strong antipathy to residential care. The ability of Laura to manage competing care and work demands, coupled with the emotional and psychological impact of caring since childhood, was compromised by these complexities.

Several carers were clearly under intense and sustained pressure which had a detrimental effect on their mental health. Five had sought medical help. After Katherine's Dad had died, followed by her Mum's dementia diagnosis, the caring role became overwhelming, and the grieving process which might have naturally taken place after her dad died was hindered by the demands of caring:

> 'So, I went to the doctors and started crying…and he says "you're grieving for your Mum and Dad" … I had six sessions with this woman at the surgery…I cried for the first couple of sessions…and it was just nice to offload to somebody…'(Katherine).

Wendy sought help from her GP after suffering a panic attack and Eric had self-referred himself to a talking therapy initiative for people struggling with their mental health. All three described the interventions through therapy as helpful. Several carers concealed from other people how challenging the situation had become and the concomitant impact on their well-being. Maggie sadly confided that caring for her mother-in-law had put a strain on her marriage. Theresa articulated the pressure to meet societal expectations of appropriate responses:

> 'I think you tend to try to put on a brave face or a happy face to people that you meet outside. I mean you don't walk around and say, "this is dreadful…"'.

And a societal expectation that one *should* cope:

> 'I know it probably sounds silly, but I think I feel that I should be able to cope'.

The stress of caring for some participants was evidently injurious to their own well-being (Bhandary, 2019, Mukaetova-Ladinska, 2017, Davis, 2004).

5.4.2 'You need to look after yourself!'

> '…spinning so many plates and not knowing which one will drop first' (Enid).

Winnie describing the complexity of her caring role expressed clearly how precarious her position might become should she become unwell herself:

> 'And I always believed that I would have enough resources and resilience to cope with anything. But if you had a sudden health problem you maybe couldn't do what you

> wanted to do. So that was quite eye opening for me. …Because we are talking about things none of us have got experience in – unknown territory.’.

Over half the participants I interviewed were acutely aware of the multiple tasks they juggled daily, thinking for ‘two not one’, the pressure to maintain their own health in order that the PLWD they cared for would be kept safe and well, or like a house of cards the whole caring structure would crumble, ‘If something happened to me, oh god things would fall apart’ (Laura). Looking after oneself or ‘self-care’ seem an impossible task when one had a challenging caring role. Despite being encouraged to ‘look after themselves’, this was often an empty phrase which frustrated and angered carers. Those who were lucky, as evidenced above, had managed to access some support and therapy to protect their own mental health, others recognised that their own health and well-being was the last to be acknowledged, and that time and space constraints caused by the caring role minimised the chances of being able carve out some time for themselves.

When I asked carers whether someone had ever told them “They needed to look after themselves”, many emphatically agreed, a number laughed ironically at recognition of a shared ‘in’ joke:

> LM ‘Over the years, people have told me “You need to look after yourself”
>
> Katherine ‘Oh, I get that all the time [laughter] I get that every day’
>
> LM ‘Well in which case, here’s a list of things I’d like you to do’
>
> Katherine ‘[laughing] I know, “pack my case. Do my shopping”’
>
> LM ‘So, that’s obviously frustrating for you as well?’
>
> Katherine ‘Yeah, and it gets to the point, it’s easier to do it for yourself…’.

This exchange illustrates the reciprocal knowledge that I and carers often shared. Interviews were peppered with instances where carers finished my sentences or where they laughed as we appreciated a dyadic understanding of a particular issue. Katherine and I both appreciated here that when people suggest we look after ourselves, this does not mean that they will offer any assistance or make suggestions which will enable us to do this. In addition, it highlighted (to us) that they did not understand the nature of the caring role we inhabited.

Xena, in a similar exchange with me makes this connection even more explicit:

> LM ‘People say “you need to look after yourself”
>
> Xena ‘Yes, yes’
>
> LM ‘D’you get that?’

> Xena ‘ALL the time, yes, yes. Look after yourself? How can you? You can’t alter the situation you’re in…you just do the best, that you can’.

Tina, interrupted me before I finished my question, so quick was she to recognise what I was saying and to express her frustration:

> LM ‘Often carers are told “you need to look after yourself, self-care” and that sort of thing….’
>
> Tina ‘Nobody tells you HOW though!’.

Carers were often only too aware of the personal toll and the need for a break, respite, help and support. But it was often extremely difficult to see how it could be achieved. As some of the narratives in this chapter elucidate, the combination of structural and medical impairment factors in addition to the carer’s personality/mental and physical health, can combine to create such demanding caring scenarios, that being able to accept, access or utilise time and space in which to care for oneself can prove impossible.

And yet, staying well enough to carry on caring was essential. A dilemma which worried many carers, as we saw earlier with Laura. Katherine articulately explains:

> LM ‘…what would happen if you were ill?
>
> Katherine ‘oh! [Laughter]…don’t even talk about that…[laughter]
>
> LM ‘sorry’! … [more laughter]
>
> LM ‘has anyone ever had a conversation with you about what would happen if you got ill?’
>
> Katherine ‘...naaa, god help us! …I have to keep healthy…I can’t be ill…’.

Winnie had been pro-active in shoring up her mental health to care successfully for her husband, but her narrative implicitly highlights a level of guilt, or self-care? When she describes the steps, she has taken to do so:

> ‘I thought “I’m going to do it [care for her husband] as well as I can” … And I thought “I’m selfish enough to protect myself. So, I do certain things myself. I go to my aquafit, I go to a medicine dance…and I write my poems and perform my poems”’.

Winnie’s actions might be described as ‘self-care’. Self-care was something that carers admitted they were often exhorted to do. It is undoubtedly one of the ubiquitous sayings which most irritated me (and still often does!) when my caring role was at its most challenging stage.

By mid to late stages of the illness almost every aspect of the PWLD lives required help and support, which could be both physically and mentally demanding. Carers could be woken up at night, sometimes multiple times. They needed to support the person to all appointments and social activities. Carers were responsible for all household tasks and financial decisions. Many carers spoke of the impact on their mental health including depression, but several carers had significant physical health issues including cancer, surgeries, and stroke. Several carers expressed apprehension about what would happen if they needed to prioritise their own health. Neville, requiring knee surgery outlined potential concerns:

> '…I'm probably going to have surgery on my ankle, which may mean I can't drive for three months. Well, what do you do? I'm convinced I should go ahead with it. You have issues straight away…I'll have to get [supermarkets] to deliver, get taxis, get friends to take us here there or everywhere!'.

Carers during these mid stages of dementia care experience high levels of stress and decreased well-being (Rao et al 2021, Carers UK, 2021a, Mesterton et al, 2010, Lewis et al, 2014), often neglecting their own health (ONS, 2019). Over emphasis of self-help or self-care (Sacks, 2020) at the expense of actual relationships and connections (Puttnam, 2000). The majority of participants spoke of increasing social isolation (Nice, 2022), with friends and families living too far away to provide additional support.

5.5 Social Institutions and Services -Third Sector and Formal Care

More than half of carers had stopped, were unable, or chose not to attend dementia specific services in their communities due to a lack of appropriate services for the PLWD, to avoid other people with dementia and/or have some time for themselves or because of the challenging behaviour of the PLWD (including the person being unwilling to go). Some carers enjoyed attending support groups with the PLWD, but others were unable to attend carer specific support groups because the person they cared for could not be left as the dementia was so advanced, or they chose not to go, preferring alternative use of their limited free time.

5.5.1 Carer and Dementia Specific Services

Dementia services in the community were of varied quality, specificity, and availability - some areas had good support whilst others had very little. Several national and local third sector organisations in Northumberland were considered helpful and effective, but some criticisms were voiced at the lack of funding to support continuation of dementia initiatives. A weekly support session, for example offered to one carer and PWLD caused distress when the service was withdrawn after six weeks. Overall carers appeared to be accessing few third sector services.

Accessing any carer specific support was challenging due to their caring role. Inability to leave the PLWD on their own and being unable to secure appropriate support and care for them, to attend support groups or training was often impossible. Tanya succinctly explaining the difficulty:

> '… I couldn't go to the meetings because I needed somebody to care for Sam. It's one of these things that is a problem intrinsically – you can't actually help the carers because they can't get out to [attend]'.

Emily acknowledged the difficulty trying to support carers like Tanya:

> 'It is support for the carer and cared for in one place [that's needed] so the carer can potentially leave the cared for person for a couple of hours. [There is a] struggle to get help to carers of people with dementia because they can't leave the cared for person'.

Some dementia support groups provided a service which was for the carer and the PLWD. One group which catered for both carer and cared for together *and* separately, was highlighted by Tanya as a service she had found valuable:

> 'Those forums were useful, the ones that he came with me to because they had people who had dementia and they also had carers. And they used to have an overall session for everybody and then we'd break into two groups. The groups with the people with the condition and the people who were the carers. And some of those were interesting and useful – when he was still able to go'.

Tanya here, with the final sentence 'when he was still able to go', a prescient reminder that even when groups are good, set up well, easy to access and enjoyable, they will inevitably become inaccessible as the dementia progresses. There were no services which offered specific support to people with EOD and their carers. There were three carer participants who were caring for someone diagnosed with EOD, and one carer whose mum's primary diagnosis of MS had now had an additional diagnosis of dementia and was under sixty. Both carer and cared for were frequently much younger than someone characteristically associated with dementia. This was problematic for as the PWLD often had very challenging behaviours and were physically fitter than an older PLWD. Consequently, care needs and challenges were concomitantly higher. Although Quinn lived near both a market town and an urban town in Northumberland, there were no appropriate services available for his wife, in her fifties:

> '…when Maureen was very first given the diagnosis of Alzheimer's erm the doctor from *** hospital in *** who came to the house to tell us, to talk us through it ..erm she started thinking about what could be offered to her at that point in terms of social ..social groups and she just said well … we don't really have anything suitable for Maureen, of that age, you know…'.

Neville, living in a small village in the west of the county and caring for his wife, also diagnosed in her fifties, had likewise found no services suitable for his wife:

> ‘No. there’s nothing there at all. There is a thing called a memory café… I just wouldn’t dare take Brigitte along there she would hate it. There are a lot of very elderly people ...and she would…well …she would hate it.’.

Laura, whose mum had MS and dementia, had day care at a local third sector organisation several times a week. Laura praised the staff and facilities but acknowledged that her mum did not really fit in, was too young and like Neville’s wife felt uncomfortable with the predominance of older people:

> ‘I always make mum go to [day care centre] ..she never wants to go, when she gets there she doesn’t mind it at all but you know she’s said many, many times, everybody’s old there...she spends most of her time chatting to the workers there …and I would never ever slate what they do they’re brilliant, but it’s not really catered for somebody like my mum you know, it’s the best we’ve got and luckily they’ve got nice staff there that she likes to chat to and she finds a level with them’.

One area in North Northumberland was a good example of a place which had poor infrastructure – limited local transport, public toilet provision and problematic GP services, but conversely it had a vibrant semi-grassroots initiative in a well-attended dementia support group. This group was holistic in its approach and firmly embedded in the local community. Carers praised its inclusivity, with both carer and PWLD welcomed making it easier to access because they didn’t need to find someone to look after their PWLD. The group was also viewed as a reliable source of information derived from the experiential rather than the professional.

Theresa described her initial reluctance to attend but had found it a supportive and valuable resource for her and her husband:

> ‘But I must admit that when *** was first suggested I wasn't keen [but] we thoroughly enjoyed it and we love going now, and I think it makes a big difference because there's not just the two of you together all the time. You know you get company; you get to talk to different people about different things...’.

Behavioural challenges of the PLWD, however, still impacted the ability of the group to provide support and meaningful activities. One group member explained that despite having access to sufficient means, thanks to donations from generous fund raising in the local community, trips out and other activities had proved too problematic to organise. Multiple attendees with behaviours which challenge can place too many demands on event organisers and carer attendees. It was also acknowledged, as Tanya explained above, that as the dementia progressed, ultimately the carer and PWLD would be unable to come to the group.

Several participants who accessed carer support groups derived support and help from them but a few did not. Quinn felt he did not really fit in with a carer group which was predominantly female and older than himself, but he also expressed the need to have some time to himself, rather than time spent with other carers:

> ‘The vast majority of people there [carer support group] were elderly older women …older than me anyway… I just wouldn’t really fit in…… I …personally I try to stay fit and active and I’m happier just going off spending a bit of time by myself going swimming going walking’.

Laura and Katherine both talked of a temporal dilemma, having other jobs that they needed to get done took precedence over attending a support group. These spatial and temporal dilemmas often affect working carers trying to balance duties and responsibilities with care considerations (McKie et al, 2002), especially women (Carers UK, 2022). Katherine, like Quinn, also spoke of a need for relaxation whilst her mum was away. Tanya attended a few carer support meetings but had decided that they were not for her. Rather than a source of support, Tanya found it a depressing place to be:

> ‘I found it wasn’t for me. All I was hearing was other people’s problems. I didn’t want to hear about other people’s problems, I’d got enough of my own thank you very much!’.

Community activity options for the PLWD, often suggested by well-meaning professionals, family, or friends, often explicitly failed to consider the carer. If you are going to singing sessions, dementia Cafés, art classes, or gardening etc, then the carer will have to come too. This can simultaneously feel like yet another job for the carer and even being forced to do something that you may not like. Nadia articulated a sense of frustration at the imposition on her own life:

> ‘…all the professionals I mean...they tell me what I should do and I said, “you're just finding me another job”. (laughs). Well, there's an art room up on the top of *** which is geared for [people with dementia]and I think the artist she's sort of doing it in a semi-voluntary capacity because I think they pay a fiver. And she's got some students who go in. But again, I would have to take him I would have to go with him and stay with him… - that's *their* solution’.

Setting aside precious free time to attend a group must be balanced with the very real need for a break. Nadia articulates real restrictions to her freedom, both a positive freedom to be able to do something she chose (Berlin, 1969) and negative freedom, freedom from restrictions on what she could do (Mill, 2008). CA literature identifies the addition of capability to conceptions of freedom to bring a wider assessment (Maccallum,1991, Sen, 2010a). Ethics of care literature highlights the relational aspects of caring practices often in opposition to autonomy (Clement, 1996) or foreground a ‘relational autonomy’ (Mackenzie and Stoljar, 2000). A broadened Capability Approach, which includes ‘…supplementation with an ethic of care.’ (Kittay, 2011, p. 51) might allow examination of relational restrictions on people’s ‘beings’ and ‘doings’, inability to convert resources to functionings and assess the effect on their well-being.

5.5.2 Challenges for Services providing support and care

Dementia being a catch all term for numerous different diagnoses, challenging behaviours, and stages of disease progression, makes support difficult, as Eric acknowledges:

> ‘Of course, one of the things about dementia, it affects each sufferer differently, sometimes even if it’s the same form of dementia, like Alzheimer’s, sufferers will not always manifest in the same sort of way…’.

Carers individual experiences, whilst having shared commonalities with other carers led to profoundly diverse caring challenges. Helpful information for one person with dementia could be entirely wrong for another. A few carers expressed a sense of unease at advice received at support groups, often volunteer led, which they felt might be inappropriate or wrong. They speculated as to the efficacy of training volunteers may have had. Kenneth, although he had enjoyed the support groups he attended, did have concerns about them:

> ‘…although I say I like support groups, they’re not always ideal because at a support group I’ve noticed recently, you can be given the wrong information, cos it’s not experts that are telling you things, it’s Chinese whispers and …if someone’s walking away with the wrong information. Well, … its volunteers that facilitate these meetings …maybe more training for facilitators? But if you get a group where you have sort of very over-powering people in that group who will always give their point of view.’

Krissie and Nadia questioned the preponderance of voluntary sector support and the expansion of services from organisations whose original aims and had no specific link to dementia, querying their ability to provide specialist dementia care support. Almost a third of participants had found some advice from professionals to be inadequate, contradictory, or unhelpful.

Carers also expressed frustration when health workers gave health advice which failed to consider the practical difficulties, they would experience trying to implement it. Carers were told to do something, but not *how* to do it. Wendy’s frustration and anger at the lack of awareness she experienced from an audiologist was palpable:

> ‘Mum should have been wearing a hearing aid, but she didn’t because she found them very uncomfortable…so I took her to see an audiologist and said, “could you just run through with mum, …could you check them…how she puts them in…”. She was

> horrible…she was very impatient with my mum because she was fumbling…she said, “How’s she managing?” and I said, “Basically the hearing aids were in a drawer”. “You must make her wear them!”. And I felt “Fine. I’ll pin her down, ram the hearing aids into her ears, but what I can’t do is stop her taking them out three minutes later!” There’s this assumption because somebody is losing their capacity that other people can tell them what to do….no it’s a hundred times worse…they are a hundred times more stubborn than they would be normally…’.

Nadia relates a similar situation with her dentist. Both Nadia and I laughed, me in empathy, as we recognised the situation she described:

> ‘And all the professionals. It’s little things, like you go to the dentist…And she’ll say to him, to me, “You need to see that he does it”. It’s everything – he ought to floss his teeth more [laughter]…I mean there’s no answer, you can’t solve it can you?’.

I can picture my dad’s teeth in his latter years, blackened and falling out. No-one, not even the most patient carer could get a toothbrush anywhere near his mouth! His beaming smile to the dentist, a sense of shame and failure to his family. Friends and other professionals could also be unaware of the complexities of caring for a PLWD and give sound but impossible to enact advice. Wendy again:

> ‘All kinds of people, professionals who should have known better and friends who were saying “You must make her do power of attorney”, “Well no I can’t. Cos if I drag her protesting to the solicitors, they’ll show me the door no time flat!”.

Written and online support materials could also be a source of frustration. A number of carers criticised dementia specific pamphlets and advice:

> ‘…the only other thing I had was a pamphlet from ***. I opened it, it said “Don’t argue with the person”. I closed it again and never looked at it. If someone is saying “I’m not taking my tablets”, you have to argue with them!’ (Wendy).

A number of carers expressed frustration with dementia groups or services which foregrounded memory retention through ‘old’ music. Some PWLD suffering from apathy did not respond well to these and there was irritation that it was assumed that ALL PWLD like music and singing when they did not. Services were often deemed ill-equipped to meet the needs of PLWD with more complex challenging behaviours such as sexual disinhibition, wandering or aggression. Carers often cited the dignity of the person they cared for or embarrassment at their behaviour as reasons for avoiding attendance at dementia specific or other services.

In most instances, carers had to accompany the PLWD to activities or services. Some carers and PLWD had been offered more than one option regarding dementia services, but if the presentation of the dementia, for example apathy was one of the key features, or the services/activities on offer were just not appropriate for the person, there were very few alternatives. Tanya and Sam, who live in the west of the county, were signposted to a local third sector organisation, which Tanya describes as ‘wonderful’, but there was nothing that Sam wanted to do, nor did she think that there was anything for ‘blokes to do’ and Tanya continued to worry about him sitting at home doing nothing. They attended activity sessions a few times but:

> ‘It wasn’t for Sam. He wasn’t going to do painting or singing, it was the last thing he wanted to do.’.

Tessa and Ian living mid Northumberland were also signposted to local voluntary initiatives – a dementia café and a singing group. Like Tanya and Sam, these options were not something that Ian enjoyed and moreover his communication difficulties brought additional pressure to social settings. Tessa’s interpretation of the café as ‘more for chatty women’ implied, in a similar manner to Tanya, that the service was gender coded for women and not men:

> ‘There is a dementia café, and he just said, “I don’t want to be here”, and he can’t communicate round the coffee table. I think it’s more for chatty women really. So that was a no go…then they said there’s a singing group in ***, but he doesn’t sing, doesn’t want to go, and you know… “he’s never been into community things”’ (Tessa).

PLWD who enjoyed activities or services could find that the providers, and even medical professionals became unable to cope as the dementia progressed. Tina’s experience offers a useful comparison highlighting the differing outcomes when a professional has experience or conversely lacks appropriate dementia training:

> ‘The consultant…used to be wonderful because the consultant’s mum had dementia. He was really good. It was hilarious. He used to turn up with a bag of doughnuts and other things. He did Mum’s first cataract with no problems, bribing her and everything, and he didn’t rush it, he knew it was going to take loads of time. He did distraction therapy; he did doughnut therapy…Then he left. It broke my heart…and the new lad, and he is young, came in and he was terrified of Mum. And our appointment was at the beginning of the afternoon. We got seen at 4.30pm – she was crawling the walls, and she knocked some instruments on the floor…and it took a lot of arguing to get him to see her again. We had a proper meeting, and we discussed all sorts of sensible things – like they would ask people with dementia what is the best time for you…and he was very interested. He said “I know nothing about how to speak to people with dementia. We didn’t do any on our training”’.

Lack of training and knowledge also played a part in the breakdown of dementia support activities, but often the medical impairment became the driving factor in ‘disabling’ the person with dementia from continuing. Two carers supporting their loved ones to access these services or activities expressed anger and sadness that the person they cared for could no longer attend. Norman, who had enjoyed singing in the local choir in his small, rural village for a number of years began to have difficulties as his dementia progressed. His wife Winnie spoke of her sadness when the choir leader phoned her to say that she didn't think Norman should sing at their next concert and Eloise, was furious when a local walking group asked her mother to leave:

> 'but my mam…was in a walking group, they rejected her. They kicked her out…I think it was billed as some sort of ageing well, healthy ageing walking group or something. I said what is it only people who are completely compos mentis who are allowed to age well?.

Support groups, often voluntary and sometimes with minimal training can find themselves struggling to meet the needs of all the people attending with increasingly complex support needs. The impact of medical impairments and the disabling of the PLWD due to lack of training and dementia specific knowledge of paid staff (Smith et al, 2019, De Silva and Mukherjee, 2014, Jack-Waugh et al, 2018) correlates with the problems identified earlier in the chapter.

5.5.3 Paid and Voluntary Sector Care Services in the home

> 'I mean it's easier if it's the same person, but it never is really…I think sometimes the carers haven't got the knowledge that they really should have for dementia…Dad gets young girls going in, and they're really nice but they haven't got a clue what to do' (Una).

Only a third of participants (9) had any paid care within their own homes at any time during their caring role. Paid carers were usually considered good but could lack advanced skills in dementia care. The PWLD occasionally reacted badly to a paid carer. Routine, as evidenced above, is often very important to someone with dementia, and by extension therefore, their carer. Whether paying for care, or using voluntary care services, care was often unreliable, with arrangements being broken or hastily rearranged and continuity of staff was rare. Several carers expressed reluctance to have paid care workers in their home. A familiar refrain from participants was that it was often 'more hassle than it was worth'.

Whilst I was interviewing Olivia, a volunteer carer arrived to take her husband for a walk – at the wrong time. Olivia and her husband liked her, but Olivia was clearly frustrated at the lack of reliability and punctuality:

> '[she] is a volunteer for **** who's just started. She comes 2 hours a week and takes him for a walk and takes him for a cup of tea and she was supposed to come at 10:30 this morning it's on my calendar 10:30 till 12:30. I'd hoped she would come between 2 and 4 but she said she could do 10:30 to 12:30 and she never turned up and she

> appears to have turned up now! She’s a lovely lady obviously heart in the right place, but she's a scatterbrain’.

Katherine eventually had to stop the paid carer who had been employed to sit with her mum after several visits were shortened or rearranged with little notice. Katherine was aware of the immense pressure on carers to go from one job to another:

> ‘I had a lady used to come twice a week to sit with my mum…er from **** care company, it didn’t work out. Er she’d phone, can I come at 12 o’clock instead of half past one, on her rota she was putting down 11 o’clock when she’d never been here at 11 o’clock, not saying she was bad or anything but the pressure on them, they’ve got to be at their next call and it was constantly like that and she let me down a couple of times, when I’d signed an agreement that she’d come on a Monday and a Friday at them specific times, and I had to stop it, I had to stop it.’.

If a carer had had difficulty trying to persuade the PLWD to accept any help, being let down by a potential source of help, after they had reluctantly agreed made the situation even worse, and effectively made subsequent attempts impossible:

> ‘I don’t know whether it was NHS or Social Services, but there is a sort of re-skilling service and we arranged much against mum’s desire for somebody to come and visit her just to try and go through one or two of the things to help and they bloody well didn’t turn up and didn’t ring to say they weren’t coming. Mum took offense and said, “they’re never darkening my door again”. So that was the end of that avenue of help…’ (Wendy).

Theresa had been told at a local support group about a new service which would see a volunteer come and take the PLWD out for an afternoon. Theresa had thought this would be ideal for her husband, but she had heard nothing more about the scheme and did not know whether it was going to happen or not. Most carers who were caring for someone in the later stages of dementia had considered respite or paid care options or had accessed them. The majority of those who had arranged paid care explicitly articulated that it was often ‘more hassle than it’s worth’. There were several reasons why carers felt this way. It might be because the person did not like it:

> ‘I had a befriender; they came out one afternoon a week. And after two or three, he didn’t want to go “why should I have to go” so I thought, “I’m only doing it for you” so we stopped.’ (Tessa).

Or, as discussed earlier in the chapter, the PLWD would be angry with the carer for leaving them, and/or exhibit challenging behaviours when the carer returned:

> ‘I’m trying to put more on them [paid carers] and they’ve had a few goes at doing it [showering his wife]…I’ve got back and there’s been a mess everywhere and there’s been 4 or 5 bath towels and a carer at one point said “I had to get in the shower with

> her" to stop her from coming out…and I've actually taken this up with them [the care agency]…' (Quinn).

The extreme anxiety suffered by Eric's wife Shirley has left him unable to access paid care or informal care leaving Eric with no option but to be in almost constant attendance. He described trying to snatch a few hours to himself to enjoy a hobby:

> 'So, I left the house at 2 o'clock got back at 4 but by the time you've driven to **** you've only got an hour basically and it's not long enough. But I don't feel like I can prise any longer out of her because she doesn't like it. She puts up with it, it's the lesser of two evils for her I think it's better than her having somebody to take her out while I go out'.

Olivia recounted problems she encountered after Harry had to go into a residential unit whilst she was in hospital. This had led to her reluctance to use respite care again:

> 'I thought about it [further respite care] but I thought is it worth it? And the last time I was in hospital…he didn't settle he was devilish to deal with when I got home it took me about a fortnight to get him back to normal'.

When asked if he had considered respite or further paid care options, Quinn related problems he had already encountered:

> 'I've thought about it…I've looked at one or two things …its biting the bullet …I just don't know…it's bad enough I find sometimes going out on a Tuesday afternoon and leaving her by herself cos she gets really, really angry…she won't speak to me, and she'll swear at us and…long pause…so she can be quite difficult'.

In addition, when Quinn imagined trying to take Maureen his wife to an activity for people with dementia locally, the anxiety borne of experience, prevented him from trying:

> 'It's terrible. It's a fight to get her in the car and it's a fight to get her seatbelt on and it's a fight to get in the car afterwards'.

It can be hard for both carer and cared alike to accept help which they might previously have eschewed, and accepting help from volunteer or paid support workers, particularly when they come into the home can be especially challenging. Xena was wary of accepting it because she felt her husband would not like it:

> '[when social worker visits]…she said "maybe you could get somebody to bath him?"…he certainly wouldn't want that at all…and she kept sort of, not insisting….I said "he doesn't want it, I can manage him"…and then things turned a bit and she said "if you don't need any help, I'll cross you off the list…'.

It may also be that Xena did not want someone coming into the house, a position echoed by a number of other carers:

> 'I'm very independent… [re carers coming into the house]. I just feel it would be intrusive, sorry, but I do' (Nettie).

Most participants were grateful and generally positive about the help their loved one had received, but often the best outcome was an acceptance of the situation, and thus an acceptance of help:

> 'To start with he was really worried about it you know. I just got someone in for an hour a week and he was really apprehensive about it, but after the first few times, well, he was ok. He didn't like it particularly, but he accepted it' (Tanya).

Outside care brought into the home does not always bring the additional help anticipated. Care provision was not person centred either in terms of the PLWD or the family carers needs. Shortages in health and social care staff (House of Lords Library, 2022, Carers UK, 2021b) exacerbated by difficulties in accessing rural areas (Craig and Manthorpe, 2000, Public Health England, 2019) contribute to difficulties for care agencies in providing continuity of care at the right time. Recent reports highlight social care contracts being handed back to councils as private companies cannot fulfil them (Sharman, 2019). As evidenced, even when good formal carer and support services were available, uptake was dependent on how the PLWD's impairment would affect their responses to it.

5.5.4 Respite or Replacement Care – I only want a short break, but I can't get it

Respite was rarely offered to carers and difficult to obtain regardless of dementia stage, geographical area, or financial ability. Availability in local care homes was limited, could not be booked in advance, and was restricted to a specific number of days. Private care in one's own home had restrictions on the number of days one could book. For example, overnight care on an ad-hoc basis was mostly unavailable. Several carers had family members who provided occasional support e.g., allowing a carer a weekend away, but many had no support at all. Only five had accessed respite; of these, one had been because the carer was in hospital and one carer had respite only once a year. One participant had arranged a weeks' care from a private care agency to enable a family holiday. Carers who had managed to access respite sometimes described the PWLD being angry with them when they came back. There were high levels of guilt among carers if the PWLD was unhappy after being in respite. and thus arranging respite was, as with other formal care options, 'more hassle than it was worth'.

One person felt that paid carers were too young and another worried that they did not have the skills to cope. Families couldn't have just 'anyone' in their house. Several family carers did not know how to find paid care or arrange respite, and those who did or had, spoke of having to do it themselves. Doing it themselves could be an intimidating prospect for some carers, who had no experience in arranging it, and little or no knowledge of local care provision.

Katherine decided to use a private care agency, who would provide care at home for her mother if she was away. This had worked well, albeit it had been an anxious decision and experience to instigate. But familiarity and routine for her mother was the dominating factor in arranging home care. However, even private care organisations can have limited flexibility when carers need shorter break options, and family or informal care is still needed to provide this, as recounted by Katherine here:

> '…they only do a minimum of 4 days ...so for me to have even one night out I haven't been able to do it this year, one day out…I haven't been able to do it'.

Planning ahead is also problematic when trying to organise respite care, as Olivia, hoping to arrange one night care in order to see her daughter graduate was told that she could not book it in advance:

> But I can't organise it because I tried the place at **** that he goes to on a Tuesday because they have a care home and I thought he will know that place. But they can't tell me until the week before…'.

Una had relied on her sister to come up and look after her dad in order for her to have a holiday. But Una felt that she couldn't always ask her to do that. When she spoke to someone at the Mental Health team, about respite, she was told that there was not a lot of places. This was similar to Leonard and Maggie:

> '[We] had a discussion…with [their care manager] … she said that we'd find it easier…to do it ourselves rather than letting her do it'.

Utilising the CA to assess capabilities and conversion factors (Sen, 2010a, Robeyns, 2005,) rather than resource-based conceptions of justice (Dworkin, 2002, Rawls, 1971, 1999) enables understanding of the difficulties carers face sourcing appropriate replacement care. Most carers I interviewed had the financial means to pay for respite or for additional help, but attention to conversion factors allows us to analyse the individual circumstances which prevent conversion of resources and capabilities to outcomes. In order to access respite, there are environmental and social resource-based considerations: is there a variety of paid care options including replacement care at home and varied and suitable day and residential facilities, which have flexible short- and long-term choices, and sufficient staff to ensure safety and well-being of PLWD? There are also personal and relational considerations: Will the PLWD agree to go (or if lacking capacity, respite is arranged in their/the carer best interest), what level of emotional difficulty will the carer experience, including, sadness, anxiety and guilt, will the person be angry with the carer when they get back from a break, potentially undoing some of the benefits to well-being accrued through time away, leading to a zero-sum outcome for both carers and PLWD. It is also important to remember that replacement care can only occur when the PLWD has agreed:

> ‘It may be that the best way to meet a carer’s needs is to provide care and support directly to the person that they care for, for example, by providing replacement care to allow the carer to take a break. It is possible to do this as long as the person needing care agrees.’ (GOV.UK, 2016).

The ‘more hassle than it’s worth’ philosophy expressed by several carers illustrates why resource-based assessments of freedom *from* or *to* is not enough. Accessing respite is predicated on what carers are actually able to do. Further consideration of replacement care and residential care will be discussed in chapter six.

5.6 Spatial Injustice – The Problem of Holidays

Holidays amplified changes in the PLWD often causing acute anxiety as unfamiliar places and disruptions to routines discomforted and bewildered them. Carers struggled with the associated stigma and embarrassment (Goffman, 1976, Kim et al, 2019, Leder,1990) as the PLWD reacted to a strange environment. Carers and cared for often become restricted to the home or to within a few miles of it (Kitchen, 1998).

Barriers at passport control, security and other built environment designs have been highlighted in recent research on PLWD and airport travel (Peterson et al, 2022). Poor planning and design often results from a lack of understanding of the needs of people with disabilities and their carers (Kitchen, 1998). Krissie described the new airport passport electronic scanning systems as ‘a nightmare’. Neville articulated similar difficulties:

> ‘and then you have things like the automatic passport scanner thingies …we came back in March from somewhere and er and she just couldn’t get the scanner bit cos it goes in and it [en]closes you so you can’t help them …so I was waiting and so she could see that I was through already …so all the guards saying “what are you waiting there for?”, “I’m waiting for my wife”. “Well can you not go through”, and I said, “no I’m waiting for my wife she’s got dementia”, ‘oh alright’.

The convergence of medical impairment, social and environmental disabling aspects in addition to embarrassment of the carer apparent in the narratives of several other carers had led to the cessation of holidays altogether. Dementia can cause delusions in some people affected. Winnie narrated a story of embarrassment and fear which has left her having nightmares and in fact has given away a holiday they had booked abroad to friends, such is the fear of trying to go away again:

> ‘We had been to Morocco. Oh dear, can you imagine, he stood up in the coach and …he said “I’ve got to get out, I’ve got to get out” …oh dear me. It’s when it goes from me seeing it, to the rest of the world seeing it….and he crossed the line there…letting the rest of the world see his delusions…I’m still having nightmares about getting home from the airport… I cancelled the holiday we were supposed to have this week… [that last holiday] was too much for him’.

Winnie and Norman had done a huge amount of travelling throughout their marriage and being unable to face going away again was a sad loss. Quinn also explained the impact of the medical aspects of the disease which made future travel with his wife untenable:

> ‘…We’ve been on a couple of holidays together, the last one was er…[sighs] three years ago….and after that I thought “no that’s it, never again” [laughter]…washing sheets in a hotel bedroom... [and]…in terms of interacting socially with other people….that’s another of the reasons we stopped going on holiday…..Inevitably on holiday you socialise with other people and Maureen could be extremely rude to people…..Having to change clothes, wash things while you’re away on holiday, being worried about whether she is going to soil the bedding….so that’s the thing about social inclusion, there are so many barriers when people have got dementia’.

Only two carers were able to continue with holidays. This remained possible because of the way the dementia symptoms presented in the PLWD, they had help from other family members or friends, and they were able to cope with any embarrassment or discrimination faced. These factors were crucial in evaluating how easily a carer could convert abilities and resources into real opportunities:

> ‘I know everybody’s not the same they’ve got different types of dementia but really for god’s sake have some fun. [Third sector organisation] told me “don’t do anything new, don’t do this, don’t do that, don’t take her to any different environments” you know what a load of old shite, pardon me, what shit…when did we get married, the second time in 2009 the official wedding was in New York, so I took me mam and me sister and by this time mam was 2 years into a diagnosis. Everybody was going you’re insane you can’t do this you can’t do that you can’t do the other. I said “Well, me mother loves cities, she used to love to go to London, she used to go to Paris all the time, loves the city” …and she had a bloody whale of a time.’ (Eloise).

The contrast in Quinn’s and Eloises’s narratives are stark. Personal and social *relational* conversion factors must be accounted for in order to fully comprehend carers’ capabilities.

5.6.1 Spatial restrictions at home and in the community

Spatial limitations were also apparent at home. Carers often lacked privacy – either because the PWLD followed them around including into toilets and bathrooms, watched what they did on computers or listened to personal phone calls. Paid care in the home could also be experienced as an invasion of privacy as the home resembled a mini care home:

When Krissie got a rare break from caring she compared it to ‘being let out of jail free’. Her joy at having time to read a book was palpable:

> ‘It’s like, my god! If I sit and want to read a book, I can sit and read a book!’.

As their caring role became increasingly tied to the house and of greater intensity, maintaining friendships and activities, became extremely difficult, leading to isolation. Katherine not only described loneliness, but specific difficulty maintaining contact with her own friends:

> ‘It’s quite lonely. Lonely for me cos I don’t really see any of my friends. I just speak to like my mum’s friends and that now…’.

Spatial restrictions even meant attending a family funeral was logistically too difficult for Flora to manage. She could not leave her husband for the length of time required to attend, but nor could she manage his challenging behaviours if took him with her. Carers expressed spatial injustices through sadness at the loss of retirement plans:

> ‘I thought we would just potter on here happily doing everything we’ve always done and that’s what I still try and do you see…And I thought we’d trundle all over the place … cos that’s what we’ve always done, and have friends round and things…but it’s obvious more things are difficult. …partly I resent the disruption into my life,…but coping with it …’ (Winnie).

Olivia and Krissie also expressed a sadness at the shrinking of a future which would now never happen - plans to travel, spend time with friends and family. Krissie succinctly articulates this sense of both time and space limitation and disruption as the realisation that such freedom has now come to an end:

> ‘I mean the life we thought we were going to have retired – we have had it. We’ve gone to different places, but we still didn’t think we were going to basically stop.’.

The detriments to carers accumulate through the relational practice of caring. Laudable attempts to shift discussion of people with dementia as a burden (Sabat et al, 2011, Kitwood, 1997) have, however, led to downplaying of the material disadvantages carers experience (La Fontaine and Oyebode, 2014, Tolhurst et al, 2017). Wolf and De-Shalit (2007) have utilised a CA framework to theorise ‘corrosive disadvantage’ as individuals *and* couples experience social, temporal, and spatial limitations. Spatial restrictions contributed to the increased social exclusion and loneliness outlined earlier in the chapter. Holidays exemplified the multiple barriers carers faced as impairments and hostile social and built environments in conjunction, ‘disabled’ both the carer and PLWD. Spatial injustices can be understood through the interlocking of the social and space (Harvey, 1973, Soja, 2009, Lefebvre, 1991, Marcuse, 2009). Reducing spatial aspects to considerations of resources and outcomes (Marcuse, 2009, Rawls, 1999) or fair decision making and opportunities (Nozick, 1974, Young, 1990) is insufficient to conceptualise how carers and people with disabilities are disadvantaged by a society which spatially influences both design and planning of community spaces (Kitchin,1998) but nor can spatial injustices fully capture the disabling through impairment (Shakespeare, 2014).

5.7 - Toilets and Incontinence: Moving towards the Late Stages of Dementia Care.

Incontinence is an issue which eventually affects most people with dementia. It is often a complex and particularly challenging aspect of dementia care (Murphy et al, 2021). Embarrassment and stigma associated with incontinence and practical difficulties can often be the tipping point between remaining at home and entering residential care (Murphy et al, 2022). Carers, in this research, of those already in residential care, or who had died acknowledged incontinence as one of the factors which influenced a decision for the PLWD to move to a care home facility. Where the PLWD was still living at home, carers identified incontinence or personal care as a potential tipping point leading to residential care. The term 'incontinence' might be somewhat misleading, as inability to control urinary or fecal output may not always be the primary issue (Murphy et al, 2021. 2022). The PLWD may forget where the toilet is, be unable to communicate when they need to go, have difficulties undoing clothing or forget basic hygiene such as wiping and hand washing. Confusion might be especially prevalent at night. Over three quarters of participants reported toileting problems experienced by the PLWD. Challenges were experienced both at home and in the community.

Multiple structural and design aspects of many public or customer toilets can be disabling factors for people with additional needs including dementia. For example, toilets may have two doors for entry and egress, disorientating a PWLD, who may leave by a different door to the one that they have come in. Taps may have confusing multiple operating designs – push, twist, wave hand. Mirrors can cause confusion to some people with dementia who fail to recognise themselves. Signs which are too small or use unclear language or design, a lack of colour contrasts between doors and door frames, toilet base and toilet seat can all add to difficulties for a PLWD (Bell, McLaughlin, Hull and Morrison, no date, Marshall, 2019).

Unfamiliar places began to be avoided as dementia progressed as carers could not know if the toilets would be suitable for the PLWD's needs. A lack of large accessible unisex toilets caused Tanya problems:

> '…One of the difficulties is that if you're out and about…it's difficult to take that person to the toilet, if they're of a different sex…Increasingly we've got unisex toilets

> which would make it, would have made my life so much easier. I mean the number of times he'd go to the toilet, and I'd be standing outside, and he didn't appear, and I'd wonder what happened to him. I couldn't go into the gent's toilet to ask. Sometimes when it was clear it was a small toilet and there wasn't anyone else there, then I'd shout through the door'.

Toileting became very 'planned'; did you have enough incontinence pads with you, enough time to get ready, had the person gone to the toilet before you left:

> '…We're going to miss the bus because I'm having to sort out the bathroom' (Wendy).

Carers often have a mental map of where toilets were in their community, which ones were closed or inaccessible. Trips out were planned around toilet options:

> 'I'm lucky, because I know where they are [public toilets] …I mean we always check before we go out…I'll say to him…"do you want to go?" and I usually go into a disabled loo with him, but the one behind the library in *** has been closed and is not available…' (Nadia).

Having a car was often advantageous in managing incontinence; being able to carry pads, wipes, and a change of clothes. It also enabled the carer and the PLWD to leave and go home more quickly if necessary:

> Quinn - '…we've once been in a really public situation within a café, and she didn't make it to the toilet, and she was soaking wet …She's had a couple of accidents in the car or just outside the car erm we had to leave a cricket match at *** halfway through couple of years ago – England versus West Indies
>
> LM - 'Oh no … [both laughing]'
>
> Quinn - 'West indies had just come into bat'
>
> LM - 'You're remembering it so well … '[both laughing]
>
> Quinn - 'and she said "I need to go to the toilet"
>
> LM - 'Not now!'
>
> Quinn - 'Went to the toilets, and she came back soaking wet so we packed up at that point and went home …I now carry a change of clothes wherever we go and the other thing ...a recent step forward …she wears disposable pants but that's just in the last month…'.

Despite referral to the incontinence service, Quinn was buying the disposable pants as the incontinence service would only provide pads, which were poorly fitting, and Maureen refused to wear them:

> 'I got in touch with the incontinence team when she first started having problems …it must be a year ago at least … they won't supply disposable pants …they'll only supply pads, but she wouldn't wear those…they sent a sample of washable ones but

> she just wouldn't entertain them at all …and the ones they sent were about two sizes too big. They did send some smaller ones, but she just wouldn't entertain them'.

Incontinence services are frequently unknown to carers or there are delays in referrals, pad provision is often inadequate; insufficient quantity, poor quality or inappropriate product type, leads to families purchasing products themselves (Murphy et al, 2022). Our family experienced the same difficulties as Quinn and we also had to buy pads.

There is still a discomfort prevalent in society that makes bodily functions taboo and hidden. Exposing oneself to shame and embarrassment by needing 'help to toilet' can be excruciating to older people unused to such a situation (Murphy et al, 2021). The stigma associated with age, failure of body and mind can be epitomised in incontinence or bodily decrepitude (Gilliard and Higgs, 2011). Stigma associated with bodies, carework is linked to low value and esteem (Twigg, 2000) and as 'dirty work' (Jervis, 2001). This social aspect begins to dominate as the first signs of incontinence emerge – having an 'accident' - epitomises the euphemistic language used to describe urinary and faecal leakage by participants. Stigma associated with incontinence and cognitive decline can lead to profound embarrassment and discomfort for both carer and cared for. Thus, the 'bladder leash' (Cooper et al, 2000, Kitchen and Law, 2001) ties carers and PWLD to the house as community access becomes too demanding. When incontinence becomes a daily reality, multiple factors contribute to this spatial and social exclusion and injustice. Injustices can be resource based; quality of incontinence service, financial ability to access the most appropriate products, afford washing bills and the cost of new clothes, environmental and practical; availability of accessible toilets, capacity to carry pads and changes of clothes on outings (this may mean access to a car), social and personal; the capability to manage embarrassment and stigma, impairments which challenge – the PLWD may be aggressive, refuse to change dirty clothes, urinate or defecate in the wrong places. These multiple constraining factors limited carers' ability to convert resources into capabilities.

'Accidents' could cause embarrassment to both carer and PLWD when they were outside the home:

> 'There were times which were quite embarrassing… I used to try and get him into the car quickly…Yes, there were embarrassing times, yes.' (Carol).

Problems at home were equally distressing:

> '…he would wet his pyjamas and sometimes he didn't realise …I think that was the dementia I think, so he'd be wet, so I would get up and change him completely…I didn't tell anybody …because it was personal and I didn't want him to look demeaned in any way, you know?' (Carol.)

Going to new places or on holiday, as we have already seen earlier in the chapter caused particular challenges. Incontinence brought additional obstacles. Neville described the logistical awkwardness of supporting someone to go to the toilet on a plane, and Theresa explained why she would no longer attempt a holiday:

> ‘We don’t go anywhere; we don’t go on holiday…I mean we’ve lived here forty-five years and he’s confused enough in his own home. But I think if we went anywhere and we were staying away from home, I think that could be a real problem’.

Supporting the PLWD at home can become increasingly difficult. Carers frequently had to get up at night to assist or direct the person to the toilet or change their pad. Carers often use a variety of techniques to manage the situation themselves including placing pictures or signs on doors and keeping lights on at night. But even these measures did not always work:

> ‘I’ve stuck big things on his bedroom [signs and pictures] …we leave the light on in the loo all night…but…sometimes he doesn’t know where the toilet is, even with the light on…and he’ll come into my bedroom and “it’s not this one” I say “it’s the other one with the blue sticker on” (Winnie).

Getting paid help at home to manage personal care issues (as has already been discussed earlier in the chapter) was at times a source of discomfort and additional challenge to some carers but providing intimate care to an opposite sexed PLWD could prove equally problematic. Eloise providing personal care to her mother, was able to manage by getting into the shower with her. Her husband, caring whilst Eloise was away, had faced considerable difficulty and embarrassment:

> ‘he’s like shouting outside the door “right go into the shower now”, she’s like da da da doesn’t mean anything to her…’.

Kenneth’s experience illustrated the ways personal care posed different challenges to each of his parents:

> ‘I found it easy to adapt, but my mother found it difficult…especially with me having to do some of her personal hygiene…but she was adamant she would rather have me do it than have a stranger come in…but that did upset her that I had to come in and do that sort of thing…my Dad, I think he found it difficult to adapt which was probably the male/macho thing that I had to come in and do things…’.

Over half the participants recognised that incontinence, or personal care was likely to be a tipping point between managing themselves at home and requiring help or residential care. The justifications for recognising this tipping point were distaste at the thought of personal care provision, discomfort at providing care for an opposite sexed parent, physical inability to provide personal care and exhaustion due to night care responsibilities:

> 'I know it sounds awful, but if it got to the stage where he was incontinent, that would be a real tipping point for me because I'm not good with things like that at all. I would never have made a nurse' (Theresa).

Nadia described the physical limitations to the type of care she could realistically provide:

> 'I don't think I would cope if he gets to a point where I…I mean I can help him shower now, but if I had to start changing him, he's a big man…'.

Quinn perhaps can be seen as on the threshold of this most acutely dreaded decision. As outlined earlier in the chapter, Quinn had already had to accept paid carers coming into the house to provide [generally unsuccessful] personal care for Maureen. His sense of duty in desiring to continue caring for his wife was juxtaposed with a sense of doubt which sustained and prolonged hours of caring had brought. He was beginning to acknowledge that his ability to cope was reaching the end point:

> 'The only thing that's changed that view [his sense of duty] is that sometimes she's up during the night… quite frequently…erm…like I've had to change her bed at five in the morning, she's had an accident. And then you just get so tired, you lose your patience…and at that point you just start doubting yourself…whether you are up to it, …it's just…your needs aren't really recognised…'.

Kenneth's narrative underscored the eventual unfeasibility of continued care at home as he tried to support his mother, caring for his father after continence difficulties became insurmountable:

> 'He had to go into residential care because it was too much for me mother. Mother was getting up at night and finding he'd defecated in the wardrobe'.

The ability to access appropriate public toilet spaces is crucial for maintaining social and community inclusion and mobility and this is especially so for people with disabilities and for women (Greed, 2003, 2013, Stanwell Smith, 2010, Kitchen, 1998, Kitchen and Law, 2001, Bichard and Knight, 2012, Ramster et al, 2018). Stanwell Smith (2010) would even argue that 'Toilet provision has been called the barometer of civilisation'. Despite government reports underscoring the importance of public toilet provision (House of Commons, 2008) there have been swingeing cuts to public toilet provision over the last decade (BBC, 2016c), with the Royal Society for Public Health (2019) highlighting the negative consequences to public health as a result. Some authorities have set up community toilet schemes (Public Toilets UK, 2015) in response to these closures. Northumberland has a limited community toilet scheme (Northumberland County Council, 2022b) but unlike many other local authorities has been able to retain county wide public toilet provision, increased the number of Changing Places Toilets; specially adapted toilets crucial to people with multiple and complex needs including PLWD and their carers (Changing Places Toilets, 2022, Northumberland County Council, 2022c), and have committed to a 1.3-million-pound investment in renovating current toilet provision (Smith, 2022b).

Appropriate public toilet facilities and suitable incontinence pad provision can reduce the social disabling of PLWD and their carers by helping them to access their local communities and manage continence issues for longer. But dementia impairments can prove too challenging even with these provisions.

5.8 Conclusion and Chapter Summary

> '…ubiquitous variations in conversion opportunities between different people…make the informational focus on functionings and capabilities essential for thinking about social arrangements, and social realizations, both in setting up the institutional structure and in making sure it functions well and with adequate use of humane and sympathetic reasoning' (Sen, 2010a, p.261).

This chapter identified a range of factors which combined to create personal, social, and spatial injustices for carers of PLWD. Rural disadvantage showed most carers had limited access to appropriate support and formal care services, lacked nearby family support, and experienced stigma and discrimination through their relationship with the PLWD. The burden of care fell almost exclusively on one person, and injustices for this carer grew as the PLWD became more impaired. Impairments, especially behaviours which challenged such as sexual disinhibition, wandering, aggression and incontinence combined with other environmental and social factors to create myriad challenges for the carer. Holidays and short breaks often ceased, friends faded away and many carers faced social isolation and detriment to their well-being.

Social justice and care literatures were insufficient to address the ways in which carers conversion prospects were limited relative to their standing with others. Ethics of care literature (Porter, 1999, Gilligan, 1993, Noddings, 1982, Tronto, 1994) explained the messy relational aspects of care which reasoning alone failed to address, but reason *and* emotion (Sen, 2010) were required by carers to negotiate the ethical dilemmas they faced and the complexities of interconnected responsibilities within the relationships.

Applying a model of conversion factors presupposes that people have diverse abilities in order to convert their resources into worthwhile options (capabilities) or functionings (eventualities). Most participants had diverse abilities, but these decreased in relation to the deterioration of the PLWD's cognitive function, rendering conversion of financial and social capital into functionings unlikely:

> ‘…a richer person with a disability may be subject to many restraints that the poorer person without the physical disadvantage may not have’ (Sen, 2010a, p. 253).

If injustices faced by carers and cared for were addressed by increased resources and the removal of structural and financial barriers to healthcare, one might still be spatially restricted by the type of medical impairment. If negative representations of dementia (Bond et al, 2004) and concomitant stigma associated with it were ameliorated through education, training and awareness raising, the personal circumstances of the carer and PLWD - dementia impairments, carer ontological frameworks of duty, obligation, guilt, might still preclude conversion of capabilities into well-being. Downplaying the difficulties carers experience as individuals and through the caring relationship risks acknowledging how impairments and barriers intersect to create social exclusion (Shakespeare et al, 2017). As Quinn acknowledged:

> ‘Social inclusion? ...there comes a point where you can’t be included…’.

Recognising this eventuality in order to address carer injustices and the impact on their well-being requires rejection of idealist theories of justice (Rosenberg, 2014, Shakespeare et al, 2017) and a foregrounding of realist theories (Danermark and Gellerstedt, 2004). The pre-dominance of post-structuralist and social constructivist theoretical frameworks have led to a neglect of material and realist approaches (Thomas, 2004) which might better address the actual difficulties carers and PLWD encounter and help to identify the means to ameliorate them.

The capability approach offers a framework to examine dementia care with a realist rather than idealist lens, utilising both philosophical and empirical methodologies and drawing together relational aspects from an ethics of care with individual standpoints of justice and well-being. Capabilities not just through our understanding of ‘how societies and individuals together constitute capabilities’ (Smith and Seward, 2009, p. 214), but how individual capabilities are also constituted through relational caring practices.

Chapter 6. Caring for a Relative in the Later Stages of Dementia

6.1 Introduction

> ‘But by definition, care is the sort of value that cannot simply be aggregated and extended to just anyone – its value lies in it being wrapped up in relations of recognition and attentiveness.’ (Barnett, 2005, p. 597).

This chapter examines the final stages of dementia caring as the PWLD’s cognitive and physical health continues to deteriorate. Practical caring challenges discussed in chapter five increase and carers at this stage began to contemplate residential care options. Personal factors dominated at this juncture, as carers wrestled with psychological and emotional drivers especially guilt, obligation and a continuing grieving process intensified by the loss or fear of loss of recognition of the PLWD. Several carers experienced ‘dementia grief’ (Blandin, 2017) as cognition and memory declined diminishing the ‘philosophical person’, whilst the physical person remained. Carers were thus often grieving and living (Stroebe and Schut, 1999) as they faced this dual bereavement. Other carers were clear that personhood was maintained and expressed anger at any suggestion that recognition might have been lost. Carers identified potential factors such as recognition, incontinence, safety, or impact on carer health and well-being as leading to tipping points between PLWD continuing to live at home or requiring residential care. Several described caring situations in which the tipping point, by their own definitions, had already been reached, yet the PLWD was still at home. How carers adapted to loss or potential loss of recognition shaped their ability to apprehend when their capacity to care appropriately and safely had been reached, enabling relinquishment of primary care of their partner or parent to a residential facility.

This was the stage of dementia which frightened carers (and PLWD) the most. Fear and the stigma associated with care homes compounded distress and anxiety. Choosing an appropriate residential facility was an agonising decision for most carers. Options were often limited. It was also a lonely decision, with little help from professionals to support them in making it. Financial considerations were a factor for several carers.

Carers whose loved one was already in residential care frequently expressed relief, experienced increased well-being and discovered that the quality, of care home provision, exceeded expectations. At the time the interviews were conducted, five PLWD were currently living in residential care homes, three were carers for someone who had been in residential care (one in hospital) but had now died. For carers where the PLWD was still living at home, (19) the majority had considered that future residential care of the PLWD might be needed, but discussions with the person or with other family members were often cursory and limited; future arrangements lacked real detail or had involved any specific advanced planning.

This chapter will be divided into three sections. Section one will examine carers approaches to identity and recognition and how this relates to their ability to care at home and consideration of residential care. The next section will consider the stigma and guilt associated with residential care and the practicalities of finding appropriate care home provision. Part three will focus on life after the PLWD moves into permanent residential care.

6.2 Identity and Recognition - Do they still know who you are?

> ‘I have noticed that at the mention of dementia, memory loss, or Alzheimer’s, everyone, almost without exception, responds with some version of the same question: “Does she recognize you?” There are variants, of course: “Does she still know who you are?” …’ (Taylor, 2008, p.313).

When my dad was diagnosed with dementia, ‘Does he know who you are?’ was a question I became used to hearing, a question I puzzled over and like Janelle Taylor (2008), I found the question ‘…both ubiquitous and quite difficult to answer’ (p.315). I varied my responses to this question as years went by. In the earlier days, I would reply ‘Yes’, although I wasn’t sure that this was true. Later I would answer ‘No’ or sometimes ‘I don’t know’. Latterly, borne of a frustration at being asked so many times, I took to saying, ‘Why does it matter?’

Most participants I interviewed had been asked the question ‘Do they still know who you are?’ - often many times. Only five participants said they had not been asked this question or couldn’t remember being asked it. These carers were generally caring for someone younger or in the earlier stages of dementia.

Participants identified several different elements and interpretations to this question. Firstly, it was a question used to judge what stage of dementia the person had reached. Tessa had also been asked the question many times:

> LM - ‘Have you been asked a lot “Does he know who you are”’
>
> Tessa - ‘Oh yes!... It doesn’t bother me at all. They don’t know what stage he is at…it defines the stage he is at – he’s really bad, he doesn’t know who you are’.

Closely related to this was an assumption that lack of recognition was, like incontinence and safety, another potential marker for entry into residential care:

> ‘If Mum had Alzheimer’s and was wandering and didn’t know who I was and that, yes, I probably would have her in care because there would be no reason to try and keep some stability [stability at home]’ (Katherine).

Tanya also noted recognition loss as a factor linked to potential need for residential care but in addition, highlighted both the pressure carers' felt to care for the PLWD at home and the value of the person associated with recognition ability. Loss of recognition Tanya said, would '…have made it more acceptable for me perhaps to put him in care.' Eric similarly regarded lack of recognition as a stage denoting entry to care home but acknowledged that this might be specific to his capacity to manage this stage:

> '…she still does recognise me. It would be difficult; I can imagine that would be a very difficult stage to reach. I don't know if I could cope with that'.

Una, like Katherine, concurred that safety might be a determining factor in opting for residential care, however she saw loss of recognition of herself and family as indicative of being inherently unsafe:

> 'If he didn't recognise us, then he would be at a stage where he couldn't be left in the house himself...it would change everything because he would probably have to go into a care home if he was getting that bad, but at the minute he seems to recognise us'.

A separate strand to this question distinguished by carers was that it was the *expected* question; people knew to ask it, perhaps as above to gauge dementia stage, or as Kenneth postulated 'It's probably the only question they can think of to ask…they've got to say something'. For a few carers', this was not only a question they had been asked, but a self-reflexive question, which acknowledged loss of recognition as the most feared outcome of the dementia progress:

> '…If she didn't have a clue what was happening and who I was…I think that's the most scary thing, not recognising you. Mum's never displayed any kind of signs of that erm currently, but I think that's probably...that would maybe be a turning point' (Laura).

Most carers expressed anger or sadness at the loss, or the fear of future loss, of recognition and identity of the PLWD they cared for, and several expressed frustrations at the inevitable question and were insistent that recognition remained. Enquiry about her mum's capacity for recognition provoked an angry response from Katherine:

> LM - 'Is it something you have been asked…" Does she recognise you; does she know who you are?"'
>
> Katherine - 'Oh, all the time!... [laughter]
>
> LM - 'How do you feel being asked it all the time?'
>
> Katherine - 'My blood pressure goes sky high. It just annoys us. Of course, she bloody knows us!'.

Katherine’s response may be two-fold; frustration at assumptions that dementia is necessarily always about memory loss and thus lack of recognition, or angry insistence of extant recognition is fear of its eventual loss and inevitability of residential care ‘[if she] didn’t know who I was and that, yes, I probably would have her in care...’. Carol expressed a comparable insistence when asked the same question:

> ‘They’re ALWAYS saying that [laughter]...And he DOES know me, and he knows my daughter…’.

For one family recognition as a value and as a reciprocal process was explicitly crucial to the maintenance of their relationships. Without it, their husband and father’s life had no meaning or value. This understanding led to a decision to have a do not resuscitate (DNR) in place:

> ‘The boys said, “Mum, what’s the point in letting Dad live on, not knowing who we are?”. And it’s true. So yeah, some people might think I’m really, really hard, but it’s the right thing to do. [putting a DNR in place]’ (Nettie).

For participants who had already reached a point where substantial cognitive decline had impacted the ability of the PLWD to recognise them, most concurred that it had been an important factor in decisions to seek residential care. For a few carers recognition or non-recognition did not directly affect their capacity to continue caring at home. Even when a partner failed to recognise their wife or husband, some carers were able to maintain a pragmatic approach of acceptance which aided them in sustaining a caring relationship whilst the PLWD remained at home:

> Theresa ‘A wee while ago he got his hat and coat on and I said, “where are you going?” “I’m going to look for my wife.” He says, “I don’t know whether she’s dead or not but I’m going to go and look for her.” And I says, “I’m your wife!” And then he sort of looks at me”.
>
> LM ‘And do you think whether he recognises you or not is important in terms of whether you care for him or not?’
>
> Theresa ‘No, I don’t think that would make any difference.’.

Eloise was unconcerned about memory or identity loss and expressed anger when people encouraged PLWD to try and remember; living in the moment and enjoying life was more important than whether her mother recognised her. The dementia presentation and the prior turbulent relationship she had had with her mother were both influential in her capacity to confront misrecognition with sanguinity:

> ‘Who cares? Doesn’t matter that she doesn’t know who she is, who I am. It doesn’t matter. But sometimes I see people and they’re constantly, there’s reminiscence books and I’m thinking “bloody hell, what’re you doing?” It is like electrocuting someone,

> it's like sticking a wet finger into a lightbulb and turning it on and off. That's what they're doing, and I really don't agree with it'.

A few carers also managed to accept a lack of recognition by the PLWD, because a 'sense' of the person was still retained, or because they accepted that unidirectional recognition was enough:

> '…right up until the end, even though I wasn't always sure my mother could have said to somebody "This is my daughter Wendy". She used to fudge it by saying "This is my very good friend" …she knew I was special to her.' (Wendy).

6.2.1 Do you recognise the PLWD?

> 'When everyone keeps asking me "Does she recognize you?" I believe the question really is—or should be—Do you, do we, recognize her? Do we grant her recognition?' (Taylor, 2008, p.315).

A question that I was never asked about my parents was 'Do *you* recognise *them*'? For some carers I spoke to, changes in the PLWD were so profound that this might have been a more apposite question than 'Do *they* know who *you* are'? My mum had a lifelong phobia of snakes, yet she was pictured in the care home happily holding a snake, brought in to show residents. Does this matter? One day when she was in hospital, mum woke up suddenly and said, 'Am I supposed to know who I am?' This was a perplexing and intriguing question. I answered, 'I don't really know, but you are Laura. Who do you think I am?' There was a long pause while she contemplated this question, perhaps equally as perplexed by it as I had been with hers, then 'Are you Mrs Flesh? or, Mrs Bond?' I told her I'd settle for Mrs Bond, and we both laughed. Did this matter, did it affect how I felt as a daughter, as a carer that mum didn't know my name, or even who she was herself? I think it did…and it didn't. One does become accustomed to the changes wrought by dementia, the erosion of memory, sometimes personality traits and concomitant issues with identity and recognition. The importance of caring for mum was not lost to me as her cognition failed – after all I was still visiting her in hospital and care home, bringing gifts and cards and trying to make her laugh, make her comfortable and see to her needs. My mum looked like my mum, and I was caring for her, she was embodied and that mattered to me, but the loss of continuity through shared memories and personality traits mattered too, and at times this hurt. Becoming inured to a new situation does not preclude a persistence of sadness and of grief, and all this whilst having to continue to care.

If recognition is indeed a reciprocal action involving two or more people in the act of recognition (Butler, 2016), and thus identity is how we view ourselves by the recognition or misrecognition by others, dementia symptoms and presentations can leave carers bereft of a sense of who they are and who the person they are caring for is. Embodied selfhood (Kontos et al, 2017) challenges notions that the 'self' is only located in the brain. Interdependence and reciprocity through caring and acknowledgement that corporeality and engagement of our senses are central to relational capacities and retention of selfhood.

Most of the participants at some point during the interview, articulated the alterations in behaviours and patterns from recognisable to unrecognisable of the PWLD they cared for. This was usually illustrated by obfuscation of the present individual through talking about and situating the person permanently in the past, to a particular point in their life course 'We've frozen them in time' (Wendy) or as an explicit acknowledgement of the changes wrought by dementia in the person they cared for:

> 'There are five people in the room – one is you and the other four are mum, and you don't know which one you are going to get' (Wendy).

Una explained how the changes wrought by dementia had affected her dad in relation to multiple aspects of his identity – as a man, as a father and through his career:

> 'But he's totally not the guy, or Dad or the man who was a paramedic and that...well really over the last five years, he hasn't been him'.

Theresa during our conversation also expressed how fundamental the changes had been to her husband – using their marriage to illustrate the 'otherness' of the person she is now with, unrecognisable to her:

> LM '…it's the person that you've been with for years and years?'
>
> Theresa - 'Hmmm, who's no longer the same person…In one of my worst fettles, I think "Ee, if I'd known this, I'd never have married him [laughter]…that's just when I'm having a bad day'.

Several carers conveyed a sense that the person, had in essence, gone and the grieving process had already begun:

> 'I mean when we first got the diagnosis, you know you start to like to grieve. Because we're all a similar age to our friends….and I think a couple of years ago, you would think "I wonder which one of us will go first?" Well, I got the answer to that one – he may not go first, but I'm going to lose him first' (Krissie).

An exchange between Wendy and I during her interview captured some of the spatial, temporal and metaphysical complexity, which carers found difficult to express, of a relative who has philosophically 'gone' but is simultaneously a person with needs, embodied and present:

> Wendy - ‘I think people are making that assumption that…their wants and desires stop when they’re diagnosed and that’s not true…
>
> LM - ‘I think that’s really interesting and one of the things I think is quite important...people talk like my dad would have wanted this, as if he’s already dead…’
>
> Wendy - ‘Yes!’
>
> Libby - ‘But he’s sitting here! … [lots of laughter].

A few carers described important and continued recognition through caring practices which brought pleasure to both themselves and the person they cared for. Eloise recounted simple daily activities, such as showering, which provoked howls of laughter from her mum, and Kenneth described walks with his mother:

> ‘I’d go to the gym 6.30am every morning, then I’d go to mother’s for 8 o’clock with the newspaper…I’d say “Get your shoes on Mum, we’re going to the beach, and her face would just light up…middle of winter, didn’t matter…[laughter]’.

These articulations were rare in participants narratives. Often the presentation of the dementia symptoms precluded pleasure in the everyday. Dementia presents challenges to personhood (Kitwood, 1990, 1993, Kitwood and Bredin, 1992). By foregrounding a person-centred approach, Kitwood (1997) argues personhood can be maintained through a caring relationship, if PLWD are valued and recognised. Loss of recognition can result in a ‘reduced mode of being’ (Taylor, 1994, p.25). Carers voiced divergent responses to these conceptions of self and personhood. Dementia effects had left some carers feeling that they were caring for a stranger, particularly if they had a stronger sense of identity as fixed (Lawler, 2014). Other carers accepted profound personality changes and loss of recognition and a retention of personhood of the PLWD through acceptance of identity as ‘successive selves’ (Parfit, 1987) rather than a fixed, innate personality or through embodied caring practices (Kontos, 2004, Hughes, 2014, Gilliard and Higgs, 2011). Person-centred approaches may relegate the carer to a subservient position in the relationship, if personhood requires recognition, then the carer personhood within the relationship may diminish their ‘mode of being’ (Tolhurst et al, 2017).

A coping mechanism used by over a third of participants was to disconnect the PLWD from the disease, by utilising a possessive pronoun such as hers/his ‘…that’s **his** dementia’ (Carol) or the definite article ‘**the** dementia’ (Neville) when they talked about the illness. This personification of the dementia as a discrete entity to the person they were caring for was a common linguistic device in carers’ narratives. One participant had even written a poem entitled ‘Mr Dementia Moves In’ which explicitly situated ‘The Dementia’ as another person (See Appendix L).

Krissie invoked a violent metaphor illustrating the effect that *the* dementia had had on her husband:

> 'There's no love left; the dementia destroyed all that – he's the physical embodiment of the disease'.

For Kenneth, the dementia was responsible for the transformation of his father:

> 'It [Dementia] turned my dad into a different person'.

Personifying the dementia in this way may be linked to the psychological process involved in developing a coping mechanism similar to Illness Personification Theory (Shahar and Lerman, 2013, Schattner et al, 2008). The anger and frustration which many of the carers admitted they had expressed to the PLWD left them with profound feelings of guilt. Being angry at 'Mr Dementia' allowed them to deflect the anger and sorrow they felt from the person they cared for to the dementia itself:

> 'Individuals tend to ascribe humanlike characteristics to illness-related symptoms in a way that is relevant to the self.' (Tsur, 2022, p. 2518).

Krissie's assertion that her husband was now an embodiment of the disease, precluded a retention of his personhood through embodiment or through psychological continuity. Anger at 'the dementia' is perhaps the only way to manage complex emotional responses to this philosophical impasse – a relationship with the dementia rather than the person may allow the carer to be angry. The dualistic nature of mind and body, how we can be both embodied – i.e., our physical bodies made up of material atoms and molecules, but also how our notions of identity are socially constituted or constructed within the context of the culture/era within which we live, are at the heart of philosophising about ourselves, individuals and relational and the person whom we care for. Any account of 'self' struggles to explain both the individual and the relational, the mind and the body, or perhaps the material and the philosophical. When caring for a PLWD, these profoundly unsettling notions of who we are and who they are, are at the heart of this *particular* caring relationship. Carers would agree that '…our relations are part of what constitutes our identity.' (Held, 2006, p.14) but also that memory matters, and narrative identities shaping who we are, our relationships and the stories of our lives are profoundly disrupted by dementia. 'Alzheimer's steals the person away' (Miller, W. Feedback, 2021).

6.2.2 Identity within the Relationship

> '…by attaining a certain level of dementia an individual might cease to possess those characteristics which allow us to regard them as a person.' (Sweeting and Gilhooly, 1997, p. 99).

As highlighted in chapter four, carers were aware of an alteration in relationship from spousal or parent/child to that of carer. This alteration affected carers both at an individual level of identity and as the relational dyad. Flora highlighted the profound changes to her relationship and the hurt and sorrow as mutual care, and recognition faded:

> Flora 'the dynamics have changed" ...the love's still there, but it's different because you are caring for them and it's not the same as it used to be. He doesn't look after me.'
>
> LM - '…It's not reciprocated, it's not kind of looking after each other?'
>
> Flora - 'That's right it's a one-way street'
>
> LM - 'It's one-way caring?'
>
> Flora - 'That's hurtful for me. I find that hard to deal with'.

Xena mourned the loss of intimacy with her husband which was compounded by uncertainty whether he knew she was his wife:

> 'I do miss cuddles', …I mean I can get plenty cuddles off friends and what have you but you know, it's lovely but it's not quite the same…I don't know who he thinks I am …I think he still knows I'm his wife …' (Xena).

Spending a large proportion of one's time with someone who you find it hard to recognise and who does not recognise you is perhaps peculiarly disorientating. Several carers acknowledged changes to their own 'identity' as they adapted to a new role, and to the changes wrought be dementia to the person they cared for. Tina recounted a characteristic of psychological adaptation and unambiguously described how this had changed her:

> 'I think it changes you, you get harder. I'm quite shocked sometimes. I used to lie awake being desperately worried about mum…but you have to learn to shut it off, and I worry often that I seem to have shut off a lot of things now. I sometimes wonder, is it the first kind of symptoms in me, or is it a side effect of closing down, that I'm always a little distant from emotions'.

Quinn expressed a certain ambivalence to his acceptance of the loss of recognition and acknowledged psychological adjustments which had enabled him to face the situation, if not with equanimity, then with a black humour. Quinn conjectured that he had continued with long established rituals because it appeared the right thing to do rather than being intrinsically important to either himself or his wife. Caring practices serve to retain or preserve something which may be lost:

> '…I think that the recognition thing could diminish the relationship …I'm not even sure of my own thoughts on this …it's almost slightly easier…because you can become ...[long pause]…more dispassionate and you're not quite as emotionally involved …I know erm the first time Maureen didn't recognise it was Christmas and she forgot my birthday …I found at the time a little upsetting…I can't deny it…but as time goes on …you accept it. It's our twentieth anniversary today actually [laughter]
>
> LM – 'And I've dragged you here!'
>
> Quinn – 'We had a lovely card this morning ...had to prompt her to open it…she's not really bothered so she's not missing out or anything! I more or less had to tease the envelopes open myself and try and get her involved…so it wasn't for her it was just…you're almost keeping up appearances …'.

The spousal relationship can be especially problematic as the spousal identity moves from one of intimate relationship to a carer based one. The partner of the PLWD often rejects the carer label (Hellstrom, 2013) and the carer becomes the keeper of their shared life story as the PLWD becomes unable to articulate it to themselves or others (Hellstrom, 2013). Conversely a carer can also feel bereft at the loss of their carer role. Several carers expressed extreme fear and reluctance to relinquish their one-to-one carer role. Their identity as a person who cared had led to very strong feelings of duty and obligation.

Drawing on relationality and interdependence in both ethics of care and disability studies (Kittay, 1999, Holstein, 2013, Clare and Shakespeare, 2004) and on the importance of reciprocity in identity literature (Butler, 2016, Taylor, 1994) highlights the potential for profound effects on carer/cared for relationships as a result of memory loss. Carers had little, if any specific support to enable them to cope with this profoundly challenging stage in dementia care. The impact on carer well-being was predicated on the personal capacity to manage emotional distress associated with loss of recognition of the person they cared for. Several carers had clearly struggled with relational identity challenges when they felt that they had to collude with therapeutic lying (O'Conner et al, 2017, Kirtley and Williamson, 2016) in order to minimise distress to the PLWD - for example agreeing that their parents were still alive when they were not or that one was a first wife rather than the second. This has the potential to be profoundly bewildering for the carer. If one does not 'therapeutically lie', one may well cause the PLWD profound suffering as the narrative they have at that moment in time is 'true' for them, and negation of it impossible to grasp. Yet this reinforces the non-reciprocity of identity recognition of themselves. When my dad on being given a Father's Day card responded, 'I'm not a dad', I had no option, it felt, other than to agree with him in order to maintain his own reality at that point. But this rejection of who one is oneself, in order to facilitate a calmer environment for the PLWD, can have profound implications for carer well-being. It is at this point that grieving, whether anticipatory or present seems the wrong word. It is not just a profound sadness, but a real hurt and deeply disorientating.

Only a few carers were able to view loss of recognition with a degree of sanguinity by separating a sense of self out with, or distinct from the relationship. Eloise was perhaps the only carer who articulated genuine acceptance and unconcern at her mum's cognitive decline. Like Taylor, reciprocity was not required:

> 'I don't need my mother to tell me my name, or how I am related to her. I already know these things. And I know, furthermore, that she suffers cognitive losses—that's just what it means to have dementia.' (Taylor, 2008, p. 317).

6.2.3 Anticipatory Grief

> 'Recalling yesterday, dreaming about tomorrow: these mental coordinates extend a miraculous thread on which to peg our lives, allowing us to weave irretrievable sensory data into something more substantial: a tale of who we are and where we are going. Time's script gives us history, identity, accumulating meaning, reasons to stay alive.' (Blyth, 2017, p.61).

Some carers as seen above concurred with Hughes (2014) that identity can be protected through the relational act of caring '…at least in part, what I am as a person can be held by others. My relationships, in a sense sustain me. Even if I can't remember, they can.' (p.72), but despite this, several expressed fear, and an anticipatory grief at future recognition loss. Carol expressed a frank and raw dread that her husband might eventually not recognise them. 'That would upset me terribly, it would…oh, I hope that never happens.' (Carol). Nadia articulated a similar fear which captured a temporal aspect as the ability to recognise became a precarious and precious capacity:

> '*** [their daughter] will be arriving on Tuesday…she's only decided ten days ago, because I let her know, I said "I think you ought to come see Quentin, before he gets any worse". Cos it would be awful if he couldn't remember who she was'.

Many carers had already encountered moments of non-recognition or fluctuating misrecognition whilst several accepted that this was now a permanent feature of their caring relationship. Shock and sadness were common responses:

> '…He said "eh, who are you" ...I was horrified! I thought "This is awful" and it took me quite a long while to get over it, and that was the first time. It's very hard when you first encounter it. "Do you really not know, d'you honestly not know who I am?"' (Winnie).

Chapter four discussed ‘dementia grief’ (Blandin and Pepin, 2017) and ‘anticipatory grief’ (Alzheimer’s Society, 2021, Fulton, 1987) as carers and PLWD came to terms with dementia diagnosis. Dementia grief, or loss of the philosophical person, whilst still living pre-supposes a bereavement process prior to physical death. A common observation people made when I told them that both my parents were in care homes and were living with dementia, was a suggestion that I must already have done my grieving, and that when they died, I would suffer less bereavement. I was never sure how I felt about this and now, after both parents have died, I am still unclear. Several carers had experienced similar comments on grieving whilst the person they cared for was still alive. This observation may link to notions of ‘social death’ (Sweeting and Gilhooly 1997), a death prior to physical death. Fulton (1987) argues that ‘anticipatory grief’ can be a way for relatives (particularly children) to grieve in advance of physical death, parents who are old.

For some the slow realisation that the person they knew was slipping away allowed for some psychological adaptation as discussed above. Tessa connected this accustomisation to an aspect of grieving:

> ‘Yes, I don’t say I’ve done my grieving, but I know what they mean. You’re slowly inured to it. It’s not a shock. It’s a gradual process’ (Tessa).

Kenneth whose parents had both died, his Mum shortly before I interviewed him, expressed surprise that he had not experienced grieving:

> LM ‘someone said to me, when my Mum and Dad die that I will have done my grieving, because they have dementia….is that something you felt that you had done, your grieving…?
>
> Kenneth ‘It’s a funny thing. I’ve actually thought about grieving quite a lot and I don’t think I ever have…I’m the eldest son, arranged the funerals…basically gone in, done my bits and pieces…and then got on with it…
>
> LM ‘Is that just because…
>
> Kenneth [interrupting] ‘It’s the way I am…I’ve no idea!’.

Anticipating her dad’s loss of recognition, Una accepted that this would change the relationship to a uni-directional flow of care but that her dad would be grievable in some tangible or philosophical way:

> ‘I would still go [to visit her dad in a care home] even if he didn’t know us, because I would still know it was my dad…….and I think, “Yes, he’s not the dad he was” but you would still grieve if anything happened to him’.

Katherine pinpointed the close relationship created through the caring experience as being a specific aspect of potential loss and bereavement she expected to feel most acutely:

> ‘When Mum dies it will be hard for us, I think… because I’m so involved in it [caring]…it’s part of my routine…’.

In Chapter 4 we saw the importance carers ascribed to the reasons that they those to care. Paramount was a sense of duty and obligation associated with spousal carers and marriage vows ‘in sickness and in health’, or parental carers children repaying a debt of care to parents who had previously cared for them. Identity, and mutual recognition of ‘self’ and ‘selves’ appears to be one of the underpinning factors influencing the decision of carers to look for residential care for the PLWD. Derek Parfit (1987) raises philosophical issues of identity and obligation in relation to ‘selves’ or ‘successive selves’ over time. Identity of both the maker and receiver of a promise matters. But have carers made promises that:

> ‘I, and all my later selves, shall help…you and all your later selves’? (Parfit, 1987, p.327).

Brock (1988) and Parfit (1987) foreground the importance of memory or psychological continuity to retain personhood and identity. Richard Denton, who produced programmes with Johnathan Miller, living with Alzheimer’s disease, explained to Miller’s son William in the radio broadcast Lost Memories (Radio 4, 4/8/21) that ‘personhood comes from the brain, and it comes from memory…’ (Miller, 2021) whereas Kitwood (1993, 1997, 1990), Kontos et al (2017) argue that it is embodiment and the relational act of caring which is crucial for retention of personhood.

Several carers, like Krissie, expressed sadness for a future, including the retirement plans which had come to naught. Loss, as described by Matthews is the loss of both past and future. Some carers who could no longer share memories with the PLWD or plan for the future found this loss of continuity, of time and of sense of selves removed a crucial an irreplaceable thread of their lives:

> ‘Because it depends for its continued existence on recall, then there is a sense in which people with severe dementia have lost some of their identity as persons, so that they are ‘no longer the people they once were’. This is the element of truth in the Locke–Parfit view, and it fully explains, in my opinion, the devastating sense of loss that those who love someone with dementia usually feel: they have indeed lost something precious about the person they love. The sense of loss is all the greater just because some elements of the person still survive. Severe dementia is a fate which, for those who love the demented person, is in some ways *worse* than death, because at least, when someone is literally dead, we can remember them as they were in the full richness of their individuality and are not presently faced with what we may see as a diminished version of them.’ (Matthew, 2006, p.176).

Foregrounding a relational approach (Held, 2006, Kittay, 1999), particularly, perhaps to a long spousal relationship (Clare and Shakespeare, 2004) is important to appreciate the positioning of the self and other and the potential power differentials in order to assess 'interaction styles that promote well-being' (Clare and Shakespeare, 2004, p. 228). Other relational concepts such as 'couplehood' (Helstrom et al, 2007) or 'shared identity' (Molyneeaux et al, 2012, Davies, 2011a) are also useful when exploring the impacts of caring, but whilst significant, sole focus on the relational at the expense of the individual may diminish either individual in the caring dyad. Kitwood (1997), by prioritising the PLWD through a person-centred approach, may understate both the relational and the individuality of carers, leave them to feel they are complicit in the disabling process, leading to a malignant social psychology (Davis, 2004). Whilst Kitwood's centring of retained personhood of the PLWD has done much to improve and prioritise better care for them, it has perhaps been at the expense of the carer. Minimising the actual difficulties carers face risks unfairly deprioritising them, isolating them from families and the wider community leading to poorer health and well-being outcomes.

Understanding the carers' views on identity and recognition is a crucial factor in ascertaining how the emotional impact on themselves will impact their ability to deliberate complex decisions and challenges and how they see themselves and the PLWD:

> 'In practice, the ability to recognise others appears to be the most important determinant of whether or not social death occurs'. (Sweeting and Gilhooly, 1997, p. 98).

Whether supporting someone to stop driving, to access help or enter residential care, these decisions are often based on perceptions of PLWD as we think they *were* (Dworkins, 1993) rather than who they are *now* (Dresser, 1986). Advance planning through health and welfare LPA's or through other advanced statements can be problematic if a person's previous wishes are in conflict with their needs and desires in the present, as a PLWD. Jaworska, (1999) argues that the dichotomy between Dworkin and Dresser can be overcome by focussing on 'value' rather than rational decision making.

As dementia robs people of their memories, cognition and renders profound changes to personalities and identities, carers lose more than just their relationship, perhaps work, or social contacts and spatial freedoms:

> 'If some of the things I value most are accessible to me only in relation to the person I love, then she becomes part of my identity.' (Taylor, 1994, p.34).

Kenneth retained a sense of the value of his relationship with his Mum right to the end, highlighting the importance of physical contact:

> '…You've only got to touch someone on the hand, and that's contact…My mother died after a week in a coma…now you couldn't say it wasn't worth going to see her at that point…I would go and talk to her, touch her hands…'.

Embodied care, the power of care through caring as a practice bought value to Kenneth's last few days with his mum and helped him to retain his sense of her through the actual caring.

6.3 Stigma Revisited - 'Putting Them in Care'

The pejorative use of the word 'put' in carers' narratives could be correlated to issues of value and recognition of the PLWD, as discussed above- 'I'll put him in a home when he doesn't really realise what's going on' (Tessa). Implicit in most carers accounts was a clear aversion to residential care and negative perceptions of residential care

This was usually expressed by using the small word '*put*':

> 'I've no intention of *putting* Shirley in a home before it's absolutely unavoidable' (Eric).
>
> 'I don't think he's at the stage where I want to *put* him in somewhere for a week. I think that will be wrong for him…well I think the last resort would be for him to go in somewhere as far as I'm concerned….' (Krissie).

Using humour when contemplating future residential care needs as a 'threat' or 'repercussion' served to underline the negative association of residential care:

> 'Actually, I have said to him when he's been off on one, and he says, "What are you going to do about it?", I says "I'm the bugger that's going to pick your nursing home!"' (Krissie).
>
> 'I've said to Leonard you know, if he ends up like his mother, he's definitely going into a home!... (laughter) (Maggie).

Tanya's narrative (Tanya had been considering care options before her husband had died of a non-dementia related illness) encapsulated three different strands of thought; lack of recognition as directly attributable to a decision for her husband to move into a residential facility, the acceptability of 'putting' them into care when they no longer recognised the carer, and the influence of wider societal attitudes in this process:

> Tanya '…I was looking for it you know, has he come to that point when he doesn't know who I am?
>
> LM '…and how would you have felt if he didn't, would that have changed how…?'
>
> Tanya 'I think it would'
>
> LM 'Yes? How do you think it would have changed it?
>
> Tanya 'I think it'd have made it more acceptable for me perhaps to put him in care'

> LM 'Ok, so the recognition is the tipping point perhaps as well?
>
> Tanya 'That's what I said to myself yes. I don't know if it would have come to that, I don't know. And I mean I'm just quoting what has been inbred in me, that's what I've absorbed from the culture'.

Flora recognised negative connotations associated with the language used to discuss care homes and speculated whether changing it might be beneficial:

> 'I do think if we thought about it in a different way that would, yeah, '*putting* them away' sounds like you're locking them up in a mental home or something'.

Language matters when we are discussing people with dementia, care work and care homes (Gendron et al, 2016). Stigma and discrimination are perpetuated by dehumanising language and negative stereotyping (Goffman, 1976, Bond et al, 2004, Bruens, 2014). Many carers used the word '*put*' in a pejorative manner, expressing clearly very negative associations of care homes. Negativity and stigma appeared to be dependent on three key factors:

> a) Failure – the carer (and often extended family or wider society) understood the person they cared for moving into residential care as a failure of their care. I often heard comments from friends and colleagues such as 'we used to look after our old people at home', or 'care homes don't exist in other countries'. The implication being that we don't respect our old people, and that as a carer you have not done enough and are morally a failure. The Living Well with dementia agenda, (Department of Health, 2009) promotes a positive message which tries to negate some of the stigma associated with dementia and old age, by foregrounding independence, capability, and agency (McParland et al, 2017, Lloyd, 2012). To be seen to age well, individuals are expected to manage their ageing through eating well, exercising and community participation and thus challenge notions of burden. Care home admission thus appears as a failure to 'age well'. Moving from an agentic third age, to a 'frailed old age', or 'fourth age' of almost wholly negative connotations of dependency, illness, decrepitude, and death (Gillieard and Higgs, 2010, 2011, Higgs and Gilleard, 2016) is viewed as failure and so valueless.
>
> b) value **-** if the person with dementia now needs to be looked after in a residential setting, this indicates that they have lost their value as a person. Their inability to recognise or be recognised, reduces them to an object who can be 'put'. They are objects of pity and horror. (Butler, 2016, Kristeva, 1982, Sontag, 2004). Grenier, Lloyd, and Phillipson's (2017) description of the transferral from 3rd to 4th age as a 'black hole' or event horizon, or Bury's concept of biographical disruption (1982)

> might express something of the fear, stigma linked to identity and recognition discussed above and the fear and failure with which care home entry is associated and situated. Another common reaction if I told people my parents had dementia was 'If I ever get like that, shoot me'.
>
> c) finality – it is the end of the road, the place of no return where one remains hidden from our communities. No-one would choose this, they must be 'put' there. 'the nursing home has become a new space – a new void- within society…every bit as terrifying as the workhouse…' (Gilleard and Higgs, 2010, p.125).

The bio-medical domination of understanding dementia which came to predominate throughout the second half of the 20th century created a 'tragedy discourse' which has come to permeate societal and media narratives fuelling the notion that dementia is the worst thing possible, with discourses often describing the disease in terms of 'catastrophe' (McDade and Bateman, 2017) a 21st century epidemic (Lock, 2013) or a 'ticking time-bomb' (Torre, 2013).

Does continued focus on the personhood of the person with dementia risk failing to consider the ageing self in other contexts, and other experiences?:

> 'The focus on dementia raises the issue of how aspects of the self-specific to old age but not specifically linked to illness or disability play out in everyday life and what such work can contribute to a fuller analysis of self across the life-course' (Degnan, 2012, p. 104).

Grieving in advance, as discussed above, presupposes that PLWD are now non-persons, who are no longer grievable. As people experience the biographical disruption (Bury, 1982) of moving into care, there is a concomitant disruption in grievability as they move from being persons who are grievable to persons who are not (Butler, 2016, p22). To have value it is assumed there must be recognition. As people with dementia lose their 'identity' through memory loss and cognitive degeneration, they lose their recognisibility and thus their valuability.

This tragedy discourse associated with a diagnosis of dementia result in the stigmatisation of the person with the diagnosis and their family – particularly the main carer, often the partner. The perspective of dementia being the worst thing one could suffer from creates the normal/other dichotomy and when we sense difference, then a person can be stigmatised, tainted, and discounted. In a recent Guardian opinion piece, Polly Toynbee said the following:

> ‘Who doesn’t live in dread of losing their mind before their body gives out? The prospect of joining the swelling ranks of those with dementia who are warehoused in miserable nursing homes appals most people. So does the thought of being an intolerable burden to their family. But campaigners scrupulously avoid talking about the wider social landscape, the rocketing numbers of those with dementia outliving their brains at vast personal and social cost’ (Toynbee, 2018).

Toynbee’s description of PLWD is laced with negativity and valuelessness, entrenching the stigma associated with having dementia and needing to be cared for – ‘miserable’, ‘dread’, ‘burden’. Thus, as memory loss and cognitive difficulties progress, the person with dementia and their informal carers can feel increasingly isolated:

> ‘Negative ideas… practically dehumanise people who suffer from dementia, neglecting their personhood, and excluding them from society’ (Bond et al, 2004).

As dementia progresses, it can be increasingly difficult for people to stay at home. Moving to a care or nursing home is thus viewed with dread, with care homes, as evidenced by Toynbee above, perceived both as modern-day poor houses and abject pity. Pressure on the carer to continue to look after the PLWD at home is multi-factorial – that care at home is best dominates familial, health and social narratives, is financially expedient and internalised by personal expectations of duty and obligation.

6.4 Guilt Revisited – Capability to Care and the Impact on Carer Well-being

> ‘That point of not managing any more was tough for me to admit. Very tough.’ (Enid).

Recognising that they might find it difficult to know when the point has been reached where they may no longer be able to care for the PLWD at home, was couched in ‘protective’ terms such as ‘he is veering towards possibly having to go into a home…’ (Una) or ‘well he’s not that bad yet….’ (Winnie). Or as Nadia reflects:

> ‘[a friend told Nadia not to leave it too late before thinking about care] ‘She actually nearly wore herself into the ground and I hope I’ll be more sensible than that. But I don’t know. I don’t know. I mean, I’m not at that point yet’.

The manager of the care agency who provide support for Quinn’s wife Maureen, had broached the subject of long-term care or respite. And Quinn says:

> ‘….I think it’s inevitable that you do think about these things ..even if only in fleeting moments…and I must admit I have gone online and looked up the cost of er residential care …and I keep saying ..yes at some point …I’m not sure when that point is …I….[long pause]…I think I could accept it more if it was perhaps my parents or an older person but again for Maureen, who’s still 59 now erm …[long pause]…I just wonder how she would fit into that situation’.

For most carers the dementia symptoms and/or their feelings of guilt in combination made contemplation of residential care something to be resisted and feared. However, for a few carers the dementia presentation itself made planning for a future involving residential care much easier. The quality of the care home itself rather than the decision for their loved one to go there being the predominating issue. For Tricia, her mum's dementia symptoms in addition to concordant family decision making, made the final choice of care home an easy one:

> 'I think we've been really lucky and part of that will be to do with how mum is, and the fact that she's been very accepting and she's made it very easy for us'.

Although still at home, Eloise has accepted that her mum may in the future need to have full time care. Her Mum already attends a day care centre which she enjoys and easily fits in 'like the people at the day centre said "I wish everybody was like her, she's game for anything…"' And despite having a very problematic relationship with her mother as a child, she now describes her mum 'now she's like a sweet little old lady' (Eloise). Eloise's only worry is finding the right place for her mum when the time comes:

> 'I actually went to look round a care home. I was more depressed I think than I ever….I could feel this overwhelming sadness of the locked dementia unit, and these people were really far gone. I mean they were like almost comatose and I thought….I just suddenly pictured my mam in there and I thought "my god, she'd be like this bright butterfly in the middle of people who are locked in" and I thought "no!"….whereas downstairs she was chatting on with the people who were just old and they were very nice but the trouble is with the people who were just old sometimes they get really freaked by people with dementia'.

Eloise's narrative underscores the relevance of dementia symptoms in outlook for eventual residential care needs as well as highlighting the attitudes of other people as a factor. Katherine similarly describes her mother in very positive terms who responds well to social stimuli and activities. Future care homes would have to provide the opportunity for her mum to continue to enjoy socialising, and it is this which concerns her, rather than the ability of her mum to adapt to a care setting:

> '…[she] loves her clothes…she's funny and that's where I think of her being in a home, she would just be sitting there…that's what I don't like. Er I'd like to walk into one of those places and see them walking around with their strollers, doing activities and that, like baking…you know things like that…'.

Laura recognised that the changes which MS and now dementia have wrought in her mum have led her to being cared for in her own home in a way which precludes notions of independence and dignity – words which are very often used to discuss aspects of caring for people with dementia and other cognitive issues. This realisation enabled her to view the situation through her own eyes rather than her mother's:

> Laura 'I think mum's at the stage now where she doesn't think about being independent if I'm honest…And I don't think she thinks about it…I don't think dignity is a huge thing for mum either…
>
> LM 'But maybe more so for you?'
>
> Laura 'Yeah'.

In marked contrast is the difficulty experienced by carers who care for someone with particularly challenging behaviours. Carers expressed overwhelming guilt at the thought of their loved one going into residential care or described harrowing scenes when this had in fact taken place. Enid, caring for Karl for over six years who has multiple health issues as well as dementia told of her difficulty in getting her husband to accept that they both needed help:

> '...Karl diagnosed with the cancer and everything, …he had a heart attack so he was in hospital, and he's sitting in the bed going…cos the nurses were saying "do you need help"? Karl's going "No, I'm fine. I'm fine". I said, "We're not, we need help, I NEED HELP, YOU NEED HELP".

After Karl went into the local care home for palliative care, his anger directed at Enid was both verbal and physical:

> 'I had Karl accuse me of "you put me here, for your convenience, you don't want me at home with you". Let's say I've had a range of… explosion of emotions from him levelled at me in violence'.

Pressure to remain caring for the person at home as evidenced above can be directly attributable to guilt on the part of the carer at being unable to cope, fear at the anger or resentment that the PLWD might express towards them or that the person might be unhappy. This can exacerbate the guilt that carers live with and when the reality indeed resulted in their worst fears, the emotional toll was overwhelming.

Wendy, six months after her mum's death, was still visibly distressed when she described the pressure she had faced when decisions were being made that led to her mum going to live in a care home. At this stage her mum was wandering, phoning Wendy constantly, often at night, making it difficult for her to work. A disagreement between her mum's consultant and her social worker as to whether she required residential care left Wendy distraught:

> 'so, mum had broken her hip…hospital consultant said she couldn't live independently anymore and they'd have to find a home for her…and at that stage they brought a social worker in …she bustles into mum's room and I explain that the consultant says that mum can't live on her own anymore, she'll have to go into a home. The social

> worker said, “we’ll see about THAT”… now at this point I’d admitted to myself that my own mental and physical health was suffering …the consultant was giving me permission to lay down the burden a bit, and to have this bloody social worker telling me that she was going to try and keep mum at home…Honestly, if I was lying in a ditch, I would have nothing more to do with social services. They have really caused me more heartache, pain, and anger …and I felt particularly with the one that you know wanted me to keep mum at home …she wasn’t acting in my best interests OR mum’s best interests. She was saving budget – and that was a very strong feeling.”.

This narrative helps to explain both the guilt carers express and the complexity of decision making involved due to the number of factors – the dementia presentation – in this case safety issues re wandering, anxiety, the toll on the carer – she has suffered both physical mental breakdown of her own health, the financial imperative driven by social workers mindful of squeezed budgets and the normative assumption of care at home being best for the PLWD conspires to create situations of immense complexity.

A few carers expressed reservations or sometimes a strong mistrust of social services which led to a reluctance to seek help from them:

> ‘**** today said if you need any help, I could get you in touch with a social worker. But I thought I don't want a social worker involved, what does it say about social workers and rottweilers? you can get your kids off a rottweiler, you can't get them back off a social worker’ (Krissie).

Dread of an intervention from social workers is commonly expressed as a fear that children might be taken away (Family Lives, 2021). For Krissie, the fear was that intervention would lead to her husband being ‘taken away’ to a care home. Understanding the above can act as an explanatory framework for carers who have not yet reached the tipping point between home care and residential care – or in fact recognise that the tipping point has been reached, but they may refute this to avoid scenes as described above. Several carers, as we saw earlier in chapter were also fearful of what might happen should they become unable to cope or if their own health prevented them from being able to provide care. For two carers who were needing surgery in the near future this was not a hypothetical situation but a real consideration causing them anxiety

Nadia, who may need knee surgery said:

> ‘[if she had to go ahead with surgery] I mean the psychiatric nurse says “Well, he’d just have to go into care”. Just like that! Well, you can imagine...’.

Neville, awaiting ankle surgery had no confidence that something appropriate would be available:

> ‘I think er…what would happen to Brigitte now if I wasn’t there, I really don’t know, I haven’t a clue what would happen to her. She would have to go into something…I can’t see any other way she could live…I don’t see any facilities that are there that would be able to take her’.

Lack of advance planning (see chapter 4 regarding LPAs) was apparent across the majority of narratives, yet even when professionals and friends had addressed the future needs of the PLWD and anticipated that care at home might become untenable, the individual presentation of the dementia symptoms, and the lack of appropriate care homes rendered good decision-making moot. Eric’s situation is particularly poignant. His wife Shirley, as evidenced earlier in chapters four and five, exhibits extreme anxiety and distress when Eric is away or when anyone else comes to the house, including other family members. Eric is sanguine about his own feelings should the situation arise:

> ‘It wouldn’t have bothered me personally if she was in a care home. I’d get some respite. I don’t think it would be unduly distressing for me personally, but it would be for Shirley, though you never know do you until you’re in that situation’.

But Eric’s strong sense of duty and obligation to his wife, and regard for her emotional well-being, means he is extremely reluctant that she ever goes into residential care, yet he knows that this is predicated on him remaining well. He, and other people have tried to talk to his wife about some advance decision making, but such is her fear and her difficulty in understanding that nothing has been put in place:

> Eric ‘I actually worry about becoming unwell because of getting older’.
>
> LM ‘This is it, this is reality isn’t it, because if you broke your leg tomorrow and needed to go into hospital, what would happen?
>
> Eric ‘we’ve said this to Shirley. Dr *** has said it to Shirley, the CPN said it, our friends have said it, everybody says it. But because of her condition it doesn’t go in, and she’s frightened to death of course of ending up in a home, or even respite care…’.

Xena expressed a similar sense of obligation and the likely distress which respite, or care would cause her husband. She is also cognisant of the risks to herself, and the necessity of staying safe and well:

> ‘…Snowy, icy weather. I feel like I don’t want to go out in case I fall. Not for me, but there’d be nobody to look after him…and I know he would hate to go into anywhere respite…so that then…what’s going to happen?’.

Nadia articulated the difference in the feelings of guilt experienced when the PLWD was in hospital; manageable, or in residential setting; much worse:

> ‘It’s like giving up yourself. I would feel that…I had not failed…I know that I’ve done my best as long as I could, but I wouldn’t want to give in…I didn’t really mind leaving him in the hospitals, but I felt so bad leaving him last night at the care home. I just felt awful’.

The separation between health and social care needs perhaps underscores the difficulties carers face; health or nursing aspects are accepted, care by others is not. A comment from Nettie’s GP highlights the lengths to which carers (particularly partners) will go in order to continue caring for the PLWD at home:

> ‘I’ll hang on as long as I possibly can. The doctor knows that. He says “you know, you spouses…you’re all the same…to the detriment of your own health, you’ll hang on as long as you can”. But of course, you will. I don’t want to put him into care’ (Nettie).

Carol was very reluctant for her husband to go into residential care and admitted that she would still prefer to have him at home. But, she was also aware of the demands that were placed on health services when her husband was still at home – emergency callouts to paramedics etc. In her case, health care professionals made the decision that he could no longer stay at home. Although Carol clearly still felt guilt and anxiety, she visits every day, there was perhaps a slight sense of relief in her narrative about the decision being made others:

> ‘It was the hospital that said “look, he needs to have permanent care in a care home”, and it was taken out of my hands’.

Her anxiety and worry about the situation were about telling her husband, how to do it, or whether he understood.

> ‘I didn’t know how to tell him… I just didn’t know how to explain…I think I was more worried about him and how he would fit in…Even now I haven’t really told him that he’s going to be there permanently. I’m not sure if he understands…he doesn’t tell me whether he is unhappy or not, I have to guess…you know, he’s just there and he seems to accept what’s going on’ (Carol).

Tanya described how she felt about respite care and how she had considered and rejected full time residential care in terms of duty and obligation:

> LM ‘Did you ever have days where you thought “oh you know, I can’t manage this anymore?”’
>
> Tanya ‘I thought about it, but I rejected it. I don’t know if it would have got to such a stage when I… but no. I didn’t want to leave him there forever [respite care] It was bad enough for a week. I felt as if I was denying him or letting him down’.

Carers can be driven by guilt – as a sense of failure to meet the obligations and duty they feel they owe to their loved one, or by guilt that the person that they love is experiencing distress and discomfort, even when they are clearly unable to provide the necessary care, guilt as they may be perceived as putting their own needs before the needs of the PLWD – pressure from health or social care practitioners, or conversely, the practitioners think that residential care is the best option, but the carer rejects this assessment and wants to carry on even to the detriment of their own health.

Guilt expressed by carers involved feeling that they had let the person down if they were unable to care. Guilt was also experienced as a result of the PLWD actions or words or by other people. A recent paper by Gallego-Alberto et al, (2022) highlights the lack of research into dementia carer guilt and recommends support strategies to help carers should include specific interventions to address feelings of guilt. Drawing on Capability Approach literature can emphasise the importance of considering personal characteristics and thus what is actually feasible (Sen, 2010a). This might include focus on social and environmental factors and our personal circumstances which impact on the opportunities actually open to us and our capability to identify and act on them. The CA specifically considers justice in relation to well-being and what we actually value. Carers struggling to meet the demands of their caring responsibilities in juxtaposition with their desire to meet duty and expectation and retain the identity of themselves, the person they love and their relationship, can battle to distinguish what they value most. And this is amplified by a narrative of care at home as best (Wiles et al, 2011, Davey et al, 2004, Means, 2007) which may be to the detriment of their well-being (Williams, 2007) and their relationship (Wendell, 1996). Tessman (2014) stresses the moral dilemmas people face when finding themselves in places of moral conflict where neither rational nor intuitive value judgements can help us decide on an action:

> ‘Even following the best possible action-guiding advice does not enable us to escape from all of our problems…What I have tried to do is to characterize the plight of the moral agent who, in making such a commitment, in joining “I must” with “I can’t,” experiences the difficulty of a moral life that includes inevitable failure’. (Tessman, 2014 p. 255-6).

The CA with its emphasis on reducing injustice, rather than proscribing perfectly just solutions (Sen, 2010a, Tessman, 2014) may better placed to help evaluate between different actions by deliberating the ability of carers to assess what they value and how they might convert resources or capabilities into outcomes. It must also be acknowledged that some carers valued their capability to care for the PLWD over utilising other capabilities which might have enhanced their wellbeing (Horrell et al, 2015). Economic and social capital may not translate into actual respite or paid at home care, nor a network of family and friends to share the care burden. Robeyns (2005) underscores the contextual ways that economic, social, cultural, and personal factors can intersect to deny people real choices. Sen (2010a) calls this disadvantage ‘coupling’. Coupling may be a particularly useful phrase to describe the relational implications of care to carers as well as it’s understanding of increased detriment by the addition of multiple factors:

> ‘… the basic fact that our societies are aging, and more and more such nursing facilities are needed to take care of a growing number of very old, frail, and dependent individuals, whose families have increasingly left behind traditional nuclear family structures where the generations lived together and the women typically stayed at home and took care of the children and the elderly. These demographic and family-related changes are again complexly connected to the accelerating individualization and consumer culture of free choice in the West, where we place great emphasis on self-realization and less emphasis on being attached to groups founded in solidarity and self-sacrifice.’ (Simonsen, 2017, p. 177).

Comparisons between different carers draws attention to the divergent factors which might affect the decisions made and the guilt suffered – the impairment of the PLWD, the strength of duty felt by the carer, the health and well-being of the carer, financial considerations, and societal attitudes. These factors are in addition to challenges in finding local, appropriate residential facilities.

6.5 Finding a care home - Practicalities

> ‘If to be human is to be limited, then the role of caring professions and institutions…ought to be aiding people in their struggle with those limits’. (Gawande, 2015, p. 260).

Finding appropriate care for the PLWD when it became clear that the carer could no longer provide support appropriate to the person needs often comes after a crisis or unexpected event, which means that families have little time to consider suitable residential care options (Alzheimer’s Society, 2022f). Choosing the right place for a loved one is often dependent on local availability – in Northumberland this realistically often means a very limited choice, sometimes considerable distances from the family. In our own case, my mum’s first care home was 10 miles away, her second and last, 40 miles away.

Discussions about care homes during the interviews were mostly focussed on the emotional impact of moving from home to care home, but some carers did outline concerns about the financial implications of long-term care. Several carers expressed anger at what they perceived as real injustice in dementia care costs and worry about future their financial situation. Two carers indicated they had made financial ‘adjustments’ to minimise future outgoings. The care system was viewed as grossly unfair, with social and health services viewed primarily as a gatekeeper to budget holders, and therefore, it was ‘all about the money'. This was seen as a real injustice. Self-funding carers and PLWD felt they were 'left to get on with it'. Qualifying for continuing health care funding (CHC) is dependent on the person requiring 'nursing' not 'care'. Dementia is usually classed as a social care need only rather than a health one, and this has financial implications for the PLWD, carers and families (Alzheimer's Society, 2022g and 2022h). This is an all or nothing scenario – if you qualify for CHC your care or nursing costs will be paid, but if you don't, and the vast majority of PLWD do not, then the entire care costs will be borne by the person. The application forms and assessment process are very difficult to complete and understand (Alzheimer's Society, 2022g).

Wendy had faced considerable financial difficulties:

> 'until she was awarded CHC mum paid for everything ..and again that has put me in a worse position ….because then, money that I would have inherited has been spent on care homes, which is fine, I don't begrudge it at all but you know……but there was a time when she ran out of money ...although there was money it wasn't in the accounts that I could touch …the care home wanted their fees …I couldn't access any money…that was stressful … I couldn't afford to talk to a solicitor I couldn't afford the deputeeship fees…fortunately mum's CHC kicked in and the care home I think was owed 8 or 9 thousand pounds… and they agreed to staged payments, like a payment plan.'.

Tricia, whose mum had been in residential care for five years, was worried about what would happen when the money (from selling her mum's house) ran out. This is a concern for many carers who fear that their relative might be forced to leave a care home and move to a cheaper one when they are unable to self-finance and become reliant on local authority funding (Care Home.co.uk, 2022).

Carers and families are usually given a list of care homes in the area, and they will have to arrange visits to them, when choosing prospective care. Not all homes will have vacancies or be able to look after someone in late-stage dementia. PLWD may require nursing or specialist care, and this can limit choice even further. Occasionally, in a crisis, the PLWD may even have to go into residential care out with the area. Care home places will need to increase by an estimated 71,215 by 2025 and 189,043 by 2035 (Kingston et al, 2017), yet according to the latest CQC report spaces have decreased (CQC, 2022).

Tanya said that she would look at an inspection report for a home online or talk to somebody who might have had a relative living in the home:

> '…and of course I'd look myself and see the reception and the feel of the place, but...it could be hiding all sorts of things that you don't know about'.

Katherine was aware of the limited spaces available locally:

> LM 'Where would your Mum go in an emergency, for respite?'
>
> Katherine '*** or *** but trying to get them in there would be an absolute nightmare'.

Tessa similarly felt that when or if the need arose (despite being financially able to pay for care):

> 'I think you are at the mercy of what is available aren't you?'.

Tanya articulated the fear that many carers had about residential care, even when she had no criticism of the respite care her husband received:

> '…From a carers point of view "Do you really know this organisation, are you really confident about leaving him there…?" because they paint a picture of how wonderful they are if you go round…and you see all of the good things, but do you really know? You don't, and that was always in the back of my mind'.

Nettie, whose husband was currently in respite care was able to provide some more detailed criticism of residential care itself:

> 'It's the whole layout of the buildings as well. Because a hospital, it's [set up] so that staff can see everybody you know…And then in a care home, everybody has their own little room. And so they're shut off and there's a long corridor…Henry made a beeline into the dining room, and they said, "We eat at half past four", anyhow the young man said [to Nettie] "I'm sorry, you can't stay in the dining room when we're serving meals". And I thought "for god's sake, I've just got him here!"'.

This was also my experience. Residential care had individual private rooms in contrast to the care my mum received on the dementia ward at the local emergency hospital which was in a circular room of bays with a central nursing hub which allowed some privacy for the patients, but also visibility for the nurses.

Utilising care and space literatures (McEwan, and Goodman, 2010), Milligan, 2001, Milligan and Wiles, 2010, Gessler, 1992) can illustrate the importance of the places in which care takes place and attention to therapeutic landscape theorising (Gessler, 1992, McLean, 2007) can identify spaces which are detrimental or beneficial to both carer and PLWD.

6.5.1 Life after the PLWD goes into Residential Care - Continuing Guilt

'Nothing chews at a man's soul more ravenously than guilt.' (Toltz, 2009, p.94).

Although going into residential care could provide some relief for the carer and allow them to re-establish better relationships as a result, for some the guilt remained profound and unassuaged, even after many years:

> 'I still feel guilty…thinking honestly of that day when I agreed [to residential care for her mother] was because I couldn't face it anymore. That was when she wouldn't let

> the police in, and things and she was ringing me saying “there’s people trying to break in”. And to a certain extent, I think I let it run because I saw it as a way out. Somebody else would have to do something….and it got to the stage where I just couldn’t do it on my own anymore. And I think that’s why I feel so guilty, which is why I take her out, why I visit the house [care home]’ (Tina).

Kenneth, who had cared for both parents with dementia, described the guilt he still felt when reflecting on the decision that his dad went into residential care, whilst his Mum remained at home. Kenneth blamed himself for the decision:

> ‘I probably overstepped the mark over what I should have been doing to be quite honest….I mean….putting him into care….he didn’t want to be there and he was adamant he wasn’t staying there….I was trying to look after my mother, but I found pure guilt the fact that it was my Dad who worked all his life and paid for the house….me mother didn’t really contribute to it moneywise, he paid for it so he and me mum could live in it…that’s terrible, it’s a horrible situation to be in’.

Carol visited her husband every day and wished she could have continued to carry on looking after him at home, although she acknowledged it was becoming untenable. Her description of coming home after her husband moved into the care home is vivid, capturing the sadness, loneliness, and permanency:

> ‘When I took Colin finally [to the care home] …it was the 10th of April, and this is the date when he’s going to be always permanently there. And when I came home, gosh the house seemed so empty, you know, and his armchair was empty. It was a horrible feeling, just being alone. The house felt so big and cold you know…’.

Tina and Kenneth both expressed continuing guilt after the PLWD entered residential care. They also expressed the sense of burden in relation to visiting as being entirely their responsibility, with no-one else going in to visit:

> ‘[Third sector organisation] did say “you shouldn’t be going in so much”, but thing is, when people say that, everybody else has family, brothers, sisters. Other people have other people who go in…’ (Tina).

Kenneth, although there was some immediate relief when his father went into a local care home, continued to care for his mother and the distress she experienced on his own:

> ‘….I mean I’m not putting my brother down here, because like I say, he worked full-time, but I was the one who went into the care home every day to visit me Dad….my mother started going in everyday but after a while it was really cutting her up so we cut it down to once a week….cos she was coming out in floods of tears all the time…so I did all the day to day visits to the care home.’.

The guilt and distress Wendy articulated in section three above was compounded when her mother suffered intense anxiety and unhappiness upon going into the care home:

> ‘When she first went into the care home she was terribly anxious….it was cruel…and erm really awful for both of us…she was crying every time I left…she didn’t want to be there so distressed…’.

Davis (2004) argues that by rejecting Kitwood’s assumptions of retained personhood, carers can be absolved of guilt for being unable to cling to an identity which has gone and allows them to grieve earlier in the dementia care process. Gallego-Alberto et al (2022) highlight the complex nature of guilt in dementia caregivers ‘…guilt appears not only to originate at the cognitive level of the person who suffers it, but it is clearly shaped by the caregiver’s social context and interpersonal relationships.’ (p. 1300). They recommend psycho-therapeutic interventions with caregivers which recognise the carers own values.

Additional consideration must be given to the temporal aspect of caring for those who have been caring for the longest time. Tina, caring for almost twenty years - her mother had been in a care home for so long, that people expressed surprise when she talked about her, or assumed that she was already dead ‘…sometimes people say, “oh when did she die”?’. Tina described a sense of guilt and lack of emotion juxtaposed with jealousy which she felt when hearing that someone else’s older relative had died after only a short time of living with dementia:

> ‘….and you feel dreadful. I mean how can you be jealous of somebody’s parents dying, but people have two or three neat little years, and it’s sort of a tidy dementia and I think it changes you. You get harder. I’m quite shocked sometimes. ….. I’m always a little distant from emotions…I feel I’ve shut down a little bit’.

Acknowledging that care homes can be best is often anathema to many people because of the negative stigma surrounding the place of death, the ‘modern day poorhouse’. But for some carers, who have had positive experiences of care, this negativity drives people to remain caring for the PLWD at home long past a time when this is beneficial either to themselves or the person they care for (Egdell, 2013, Gessler, 1992, Milligan, 2003).

6.5.2 The benefits of Residential Care

Despite considerable fear and anxiety and guilt when someone with dementia permanently moved into a residential home, or when carers contemplated such a decision, the actual experience for most of the carers was positive. Negative experiences were few and related to staffing levels or structural issues within the care system rather than a criticism of the care in of itself. ‘[carers] are busy people…they’re busy getting drinks, changing the nappy or whatever. I sympathise. I can see it’. (Nadia). Participants were usually very positive about paid care workers who they thought did a good job, and they were angry at the poor pay, lack of training and perceived low status and value attributed to those working in the care sector.

A third of carers had seen their loved one move into residential care – for several this was permanent over a long period, for others it was a shorter interval of weeks, or for respite, and as the PLWD neared the end of their life. These carers often described a ‘crisis’ or ‘tipping point’ where care at home was considered untenable by medical professionals, or by the family/family carer themselves. Yet family carers were often continuing to care at home even after ‘tipping points’ had clearly been reached:

> ‘It does worry me this keeping people at home for as long as possible. I look at some people that come to the Alzheimer’s support group and the majority of them will be somebody [living at home] with a spouse, and they’re trying to keep it all going. And you just look at how some people struggle and think “is this really the best way for both people?”. For both the person with dementia and the person… that’s caring. It takes a massive toll on them I think…’ (Tricia).

Tessa also questions the resistance people have towards residential care, but in addition posits the specific benefit in a reduction of social isolation experienced at home:

> ‘there’s a sort of foolish resistance to going into a care environment, but I think it’s quite supportive and you’ve got friends…people to talk to. It can be ever so lonely sitting at home’.

Eloise expresses a specific objection to a prolongation of the current orthodox position of ‘care in place’. Eloise’s mother lives with her and she cares for her full-time, but here she recognises that this may come to an end if she no longer is able to provide the necessary care and she questions whether people living at home (on their own) are happy:

> ‘Why do they insist on having people living at home like independently? Can you imagine the anxiety? It actually really upsets me…I think they’re better off in a home actually…Why do people torture themselves? If Mam gets a medical ailment that I can’t deal with, she will have to go into a home…’.

Her pragmatic attitude was in marked contrast to the profoundly challenging decision-making process of anger, guilt, sadness, which dominated the narratives of other participants. Most carers had negative preconceptions of care homes as discussed above but had found the experience of residential care to be compassionate, with thoughtful and staff caring for their relative:

> ‘[The care home] is really kind and caring…it’s been excellent’ (Carol).

Beverley was extremely anxious prior to her mother going into a residential care home but admitted that her mum had settled in well and that she enjoyed the company. Again, her dementia symptoms were such that she remained a happy person:

> ‘She was always the party girl my mother…she still laughs and laughs with you’.

Wendy, despite the initial difficulties her mum had experienced when moving into residential care, praised the quality of care her mother received :

> ‘They [carers at the care home] were wonderful, really in a way it was the best thing that could happen to mum…Now mum’s died er I do have these lovely times to think about and they are taking over from the traumas [when her mum was at home] …’.

Several carer enjoyed a rediscovery of pleasure from caring when quality time with their relative was re-established after they went into residential care. This is something I identify with strongly and for some people this positive aspect of residential care remains largely hidden and unacknowledged. Carers often sounded surprised at the good care they observed. Despite the difficulties he experienced supporting his mum to visit the care home to see his dad, and the obligations he felt to do so alone, Kenneth was impressed with the quality of care his dad received. Enid expressed relief that much of the decision making which had caused her stress was now taken by care home staff instead of herself. Beverley recognised that her mum had more company in the care home and was less lonely than she had been at home, something that Una, with her experience of care homes through her job, also speculated might benefit her dad when he could no longer stay at home.

Tricia and her family, uniquely within this research had decided their mum would go into a care home at a much earlier stage, as a result they were able to involve their mother in the decision process. ‘I don't know whether legally you could have said she had capacity, but she was still sort of aware of what you were talking about.’ They made their decision against advice from social services who thought Tricia’s mother was able to continue living at home with help. The siblings had all separately provided care and support over a number of years and paid help had also been acting together with their mum to make a best interest decision, in light of previous attempts by them all to try and support their mum at home. It also highlights how much easier it is to make decisions with someone whose dementia presents in an equanimous way – no aggression, anger, apathy and therefore less guilt:

> ‘You could tell in lots of ways she was way less stressed than she had been at home because she was not having to make any decisions, she was not having to think about preparing meals, she wasn't having to think about getting her washing done… The staff are great, she's got a lovely room, she loves her room, but she doesn't spend any time in her room on her own during the day she says “why would I? Why would I sit on my own in my room? I've spent the last however many years being on my own at home” and the whole benefit for her being there is that she’s seeing people, that she's got company…’(Tricia).

Accepting the inevitable can be hard for carers. Insisting that your loved one will never go into to care can set up a pathway from which deviation is guilt laden and harder to cope with, and is often based on a lack of understanding about the potential challenges they might face:

> 'Because I always said Karl would never go into a care home, but I've learnt to say not to say never… cos you don't know what's going to come'. (Enid).

Relinquishing their caring role often had surprising benefits, and several carers reported an increase in well-being, through a freedom to socialise and reconnect with family and friends:

> '…now I'm making newer friends and reconnecting with old ones…I didn't realise that's what I had given up, because we used to do things together.' (Enid).

Or because they had additional quality time to spend with their relative: as care staff took over the practicalities of day to day caring, Wendy appreciated and cherished the time it freed up to spend with her mum:

> 'It seems a bad thing when somebody eventually goes into a care home, but actually the care home staff are doing the hard bit. They're doing the persuading to eat, and they're giving the medication and taking to the toilet, so you've got time for the quality time, and you can chat and have cake, and it's not the end of the world'.

Tina described simple games at her mum's care home resulting in impromptu shared fun and laughter. This is something I have also observed and experienced. One of the most moving moments of the interviews I conducted was Wendy's recounting of this precious moment of joy, which had helped to relieve Wendy of the guilt expressed earlier:

> Wendy 'There was one day I was leaving…you could see the effort in her face and she said, "I love you". Well, I went home and wept buckets, but that was worth it…if I hadn't gone to see her, I would never have got that…I know, I'm sorry, I'm tearing you up!
>
> LM - 'We both are!' [tearful]
>
> Wendy - 'We should have had tissues'
>
> LM - 'I should have thought of that! [both laugh].

Drawing on the relational understanding of ethics of care literature, the agency and autonomy of carers of PLWD must be considered in relation to the person they care for. Kittay's critiques of theories of justice and autonomy highlights the inherent problem of the lauding of independence '…there is much that is problematic in an approach that extols independence as the route to a dignified life…' (Kittay, 2011, p.51). Sacks (2020) underscores the prevalence of 'I' rather than 'we' over the last fifty years in the West, where hyper individualism has dominated over social connections or social capital (Puttnam, 1995). There are boundaries to personal autonomy in any society, but foregrounding conceptions of relational autonomy

(Mackenzie, and Stoljar, 2000) or relational or collective capabilities (Ibrahim, 2020) may both protect independence and demarcate limits.

An ethic of care can address the importance of dependence and our care towards another's needs when the needs of carers are ignored (Kittay et al 2005) or diverge:

> 'The potential for conflicts of interests between givers and receivers [of care] …An ethic of care requires that attention is paid to ways of resolving these' (Lloyd, 2012, p.134).

CA with the addition of a relational ethic of care may be a useful framework. The multiple impairments resultant in late-stage dementia and 'coupling' of disadvantage (Sen, 2010a) to carer and PLWD create 'corrosive disadvantages' (Wolf and De-Shalit, 2007) which become almost impossible to mitigate whilst the PLWD remains at home. The CA is also a framework broad enough to accommodate other important social theories and conceptions which highlight injustice, disadvantage, and discrimination: stigma, (Goffman, 1963, 1976) medical impairment and social disability models (Barnes and Mercer, 2004, Oliver, 1983, 2004, Thomas, 2004, Shakespeare, 2014, Burchardt, 2004) personhood (Kitwood, 1993, 1997, Kitwood and Bredin, 1992), spatial injustice (Kitchin, 1998) and social exclusion (Walsh, Scharf and Keating, 2017).

6.6 Conclusion and Chapter Summary

> 'Our culture is imbued with the belief that we can fix just about anything and make it better; or, if we can't, that it's possible to trash what we have and to start all over again. Grief is the antithesis of this belief: it eschews avoidance and requires endurance and forces us to accept that there are some things in this world that simply cannot be fixed' (Samuel, 2018, p. xxi).

For most participants, residential care was something which if not always dreaded, was viewed with sadness, guilt and perhaps failure. A few carers had already experienced their loved one entering a residential home, and some acknowledged the inevitability of their loved one eventually needing nursing or residential care, but only three carers expressed a positive or pragmatic attitude towards residential care solutions. Negative emotions were compounded by expectations placed on families by societal narratives which view residential care as abhorrent and the deleterious connotations of 'putting' someone in a care home. Often as the carer narratives unfolded, stigma associated with care homes and the debilitating emotion guilt at 'putting' the PLWD into a residential care home were critical factors which hampered carers in distinguishing the significant junctures which precluded continuing to care at home. Carer well-being was significantly affected at this stage, often socially isolated, facing internal and external pressure to continue caring and struggling with acute guilt and anticipatory grief. Lack of intimacy, physical contact, reciprocal care often with little or outside or family help for many years clearly had profound and potentially damaging implications for the carers' physical and mental health. The impact on health and well-being of those caring for the longest was of particular concern and deserves greater attention.

The majority considered being recognised as a crucial marker of the point at which residential care was required. Carers who worried less about recognition, had accepted eventual residential care at an earlier stage and who had fewer adverse opinions about care homes, were able to consider care options with more equanimity:

> 'To have one's elderly mother put into a residential home is not necessarily to signal that one does not care for her; it is in fact to make sure that someone does care for her, ideally under proper working conditions and not at the cost of an experienced loss of autonomy on the caregiver's side.' (Simonsen, 2017, p. 188).

The loss of this understanding of both who we are and who the person we are caring for is, cannot be underestimated. Loss of cognitive function is viewed very negatively in a society which does not like forgetfulness (Post, 1995). Challenges to sense of self and their position within one of the longest and most important relationship of their lives were profound. The 'physical' person, for which the carer was legally, financially, and morally responsible for and as such recognisable, could be in collocation with the loss of the philosophical person who may be unrecognisable. Changing from a kind, loving individual to an aggressive or apathetic person or continuity of self through shared memories lost as cognition faded. In addition, the carers sense of their own identity became indistinct as the word 'carer' became their new identity, and mutual recognition with their spouse or parent was lost. This was often profoundly disorientating for the carer. A third of carers appeared to cope with this situation by utilising a technique of 'personifying' dementia – this could be explicit 'Mr Dementia' or implicit 'that's been took away from him' – as if 'dementia' was and entity which had specific powers to remove things from the person. How the carer coped with these profound changes was crucial in understanding their decision making as the PLWD entered the later stages of illness:

> '…choices are always made within limits of what are seen as feasible. The feasibilities in the case of identities will depend on individual characteristics and circumstances that determine the alternative possibilities open to us' (Sen, 2007, p. 5).

Some participants had reached points where these difficulties no longer upset them through acceptance or psychological adaptation. For those carers where recognition or memory loss had not caused such profound changes in the person they cared for, fear of it was palpable, and the biggest dread that they had. One or two carers seemed sanguine about the changes wrought by dementia, or which might happen later in the PLWD's illness – sometimes in part due to positive changes in the person they cared for, or an ability to still find connections, however changed they might be from their previous relationship to the person.

Theories of justice are mostly inadequate to provide answers to the multiple problems carers of PLWD face:

> 'I think people can picture the individual issue you might have to deal with, but what they can't imagine is the one thing on top of another on top of another, and the relentlessness of it' (Quinn).

Focussing on challenging injustices of carers through the CA is a better way to identify problems which might have solutions rather than an overarching universal strategy. Utilising an ethic of care to examine the relational impacts on carer, cared for and the duties and responsibilities of our social institutions is important to understand carer well-being. Promoting the 'I' over the 'we', individual freedom agendas collude with carer psychology to promote stay at home at expense of carer well-being and absolving of societal responsibility.

Chapter 7. Conclusion

7.1 Introduction

> ‘You know how when people talk of First World problems, they forgot to mention Alzheimer’s and dementia?’ (Toltz, 2016, p. 8).

Understanding and providing dementia care will continue to be an important facet of our contemporary and future societies. The UK has faced a burgeoning ‘crisis of care’ which began with the privatisation of the care sector in 1990 (Centre for Health and the Public Interest, 2016) and has continued due to increased demand for adult social care (Bottery and Mallorie, 2023, National Audit Office, 2021) and chronic underfunding of services (Phillipson, Calasanti, & Scharf, 2021) particularly since the introduction of austerity measures in 2010 (Institute of Health Equity, 2020, Johns, 2020). Sustained financial pressures, with cuts from central government and increases in fees to private, for profit, providers for residential and home care provision reported in a recent King’s Fund report (Bottery and Mallorie, 2023) has led:

> ‘…local authorities to ‘ration’ social care to those in the greatest need. In October 2022, the Local Government and Social Care Ombudsman said it was seeing ‘more cases where councils are failing to provide care, or are limiting care, while using cost as the justification’. It ascribed this to ‘under-resourced system unable to consistently meet the needs of those it is designed to serve’. (Bottery and Mallorie, 2023, no page).

Yet private care profits have also fallen since 2015, with many providers facing significant cost pressures (exacerbated by the Covid 19 pandemic) with fees inadequate to ensure services are of acceptable quality and enable them to retain and train staff. Local authorities have reported contracts being handed back and some care providers ceasing to operate (Bottery and Mallorie, 2023). Care service provision is likely to remain challenging to local authorities over the coming decades impacting PLWD and their families in Northumberland.

This thesis used a feminist standpoint approach to examine the lives of carers of people living with dementia in Northumberland. In depth qualitative interviews allowed me to discover what carers did, why they did it and the places and spaces within which they provided this care.

Literature reviewed in this thesis was influenced by a personal standpoint and from the data gathered in the empirical research. The literatures were key to understanding the narratives of the carers I interviewed, not just to situate them and their stories within extant literature, but to probe and tease out the literature and the data in order to extrapolate new or underexplored areas of research, to acknowledge existing theories and concepts, and to try and make sense of the multiple factors – social, spatial, personal, and psychological which affected caregivers' lives.

I foregrounded care and capability approach literatures as normative frameworks in which to situate carers lives. An ethic of care underscored the relational aspect of care, without which carers lives cannot be understood. The Capability Approach considered the 'beings' and doings' or human functionings, and the capabilities or opportunities to achieve these functionings. By differentiating between functionings, that which makes our lives intrinsically valuable, and capabilities, that which is actually possible, one can attempt to identify areas where carers lives (and the person they care for) can be improved. Social justice theories such as the social primary goods (Rawls, 1971) spatial, or social disability models were useful to identify some key aspects of dementia caring but were unable to capture the complexity and interconnectedness of human relations, carer psychology, changing needs of carers in different times and places and the interpersonal impact of disability and impairment. The CA provided a more fruitful framework to examine other factors – moral and relational aspects to freedom and caring.

7.2 Key Findings

The empirical findings were divided into three chapters. Each chapter addressed social, environmental, and personal factors affecting carers and PLWD in early, mid, and late-stage dementia caring. As this research only provided a snapshot of dementia care, rather than a longitudinal study, dividing the empirical chapters into three stages of care seemed apposite.

7.2.1 Early Stages of Care

Social and structural factors dominated in the early stages. Carers identified key deficits in post-dementia diagnosis support for the PLWD and themselves. Carers foregrounded development of a dementia care pathway with better signposting and support early in the diagnostic stage, effectual needs assessments with regular follow up, pro-active communication from health and social care services and mentoring by someone experienced in dementia care. Carers highlighted onerous benefit and financial responsibilities. The majority of participants did not believe they had a choice whether to be a carer or not. Dohmen argues that 'the caregiver decides for himself/herself whether and when he/she takes care of another or not' (2014, p. 50). Most carers I interviewed would disagree. Having a 'choice' to care for a relative with dementia is a naïve expectation. Most proffered a strong sense of duty toward their relative and this in conjunction with legal, financial, health and social care systems which place obligations on one person – usually the spouse or child of the PLWD, they were firmly embedded in a caring role early after the diagnosis.

Carers expressed a range of emotional responses to the diagnosis of their relative with dementia. Often an initial sense of shock was superseded by loss and grief for the person and their shared past and future.

Driving cessation was a site of carer and PLWD conflict and complex carer decision-making (Breen et al., 2007). The relational aspect of driving cessation found multiple factors affecting how this situation was handled and resolved. Carers found themselves as de facto assessors of capability, being obligated to observe and report decline in executive function and resultant loss of ability. Carers expressed anger and frustration at the numerous quandaries they faced, including confronting someone about problem driving, safety concerns for the PLWD, themselves and other road users, guilt if the person refused to disclose diagnoses to the DVLA, and sadness at the loss of independence and identity associated with driving cessation.

7.2.2 Mid Stages of Care

The mid stages of care saw growing social exclusion and spatial injustices. Carers in Northumberland often lacked support from family and friends and access to appropriate services including respite and paid care. PLWD who had complex needs were poorly served. Carers cited a lack of knowledge and sufficient awareness among both professionals and lay people of dementia symptoms, impairments, and caring issues. Even when paid support was available, some carers found it brought little benefit and was often ‘more hassle than it was worth’.

Rurality impacted the distance to hospitals and other services which were compounded by poor public transport options. Cognitive decline, medical impairments including incontinence and behaviours which challenge in the PLWD, led carers to experience increasing relational stigma and discrimination. Carers were often socially isolated, spatially limited and began to suffer detriments to their health and well-being. Holidays and short breaks were often restricted or came to an end. Carers’ narratives drew attention to key areas for improvements in health and care services: development of EOD services, more dementia specific services, additional paid care options (in particular respite provision) providing a range of care on both a regular and ad-hoc basis.

The combination of social, personal, and environmental factors was often acute at this stage. Concerns associated with incontinence highlighted the multitude of interconnected problems that carers faced.

7.2.3 Late Stages of Care

Personal factors dominated the late stages of care. For two carers whose relatives had mild and unchallenging impairments, supportive family and a sanguine approach to recognition loss and eventual residential care, caring was manageable with continued social inclusion and spatial freedom.

Cognitive decline in the PLWD resulting in significant memory loss and sometimes personality changes, caused many carers acute distress. How carers coped with anticipatory grief associated with loss of recognition or mis-identity impacted their decision-making capacities as caring at home became untenable and residential care became necessary. A strong desire to fulfil their duty and obligation, negative association of care homes and concomitant stigma of 'putting' someone in a home, led to extreme and anguished feelings of carer guilt which had an increasingly damaging effect on their health and well-being. Well-being may not thus be the goal for some carers when meeting their duty and obligation offers a way to assuage some of the guilt.

The latest World Alzheimer Report (2022) highlights the problems and challenges that carers face arguing that:

> '…much more needs to be done to make sure that carers are able to carry their duties without sacrificing their financial, social, and mental wellbeing.' (Alzheimer's Disease International, 2022, p. 27).

A societal narrative which emphasises staying at home, care homes as last resort and underestimates the challenges derived from actual impairments, compounds the guilt and resultant impact on well-being of carers of PLWD.

7.3 Philosophical and Conceptual Framework

> 'Divergent problems cannot be killed; they cannot be solved in the sense of establishing a "correct formula"; they can, however, be transcended' (Schumacher, 1977, p. 126).

Acknowledging and spotlighting carer standpoints is a way of addressing those types of problems which are not easily measured or solved. These problems might be considered 'divergent' (Schumacher, 1977), 'wicked' (Bache et al, 2015) or 'wild' (Roberts, 2022). Caring for PLWD and the people who care for them is what we do and *should* do –

minimising injustices, promoting greater well-being, and recognising the *relational* nature of care. *How* we identify these injustices and what we can do to mitigate them needs a realist lens to identify feasible and pragmatic options.

Focus on carer burden (Sabat et al, 2011) and a medical model of disability in early literature (Hasler, 1993) has often been at the expense of a more social disability model (Oliver, 1983) which promotes the personhood, rights, citizenship, choices, and opportunities of PLWD (Kitwood, 1997). Promoting social inclusion of people with dementia has underestimated the relational impact on the carer and further has promoted the individual rights of the PLWD over those of the carer, thus resulting in expanding injustices which are negatively impacting the well-being of family or informal carers of PLWD in Northumberland. Freedom and agency of carers (actual freedom to do and be what they value) is constrained through their relationship to the PLWD, psycho-social and environmental factors resulting in conversion deficits.

CA offers the practical means to assess practicability and achievability of function. As Sen recognises the impossibility of developing an overarching theory of justice, precisely because justice is a divergent problem, examination of injustices and the impact on well-being through a capability approach offers us a method to identify and remedy instances where remedy is possible. Freedoms or duties and responsibilities of carers are divergent problems for which we cannot devise an all-embracing solution, but we can help carers to convert their capabilities into the best that they can be and do. Value for the participants in this research included the act of caring. Even when that caring had become tiring and often onerous carers continued to provide succour and support to the PLWD often mitigating even the most difficult of circumstances ‘abjection – even the profound abjection of the fourth age – can be redeemed through caring’. (Gilliard and Higgs, 2011, p139).

The CA may offer opportunities to examine both the PLWD and their main carer as well as their relationship in addressing limitations on freedom, individual and shared injustices, and impact on well-being and developing policies and practices which support the PLWD, the carer *and* the relationship.

Recent research by Herron and Rosenberg (2019) draws attention to the need for a relational approach to address the challenges faced by carers in rural communities from care at home policies which have adverse outcomes for carers health and well-being. They identified key deficiencies in health and care services: lack of sufficient, timely home care hours, respite, navigating the care system, diverging needs of partners in the caring dyad and how carer and cared for needs change over time:

> 'Solutions to these issues must take into account the dynamic nature of care and the importance of rural contexts' (Herron and Rosenberg, 2019, p. 354).

These deficiencies echo the narratives of participants in this research.

Sen's conversion factors may begin to identify some problems and difficulties which carers face in rural Northumberland and ascertain which policy changes could be made when one acknowledges the abilities of the carer and the temporal nature of the caring role. This temporal aspect – how long the person has been caring for and how the dementia symptoms or presentation evolve over time means a constant re-evaluation of conversion factors as the situation changes. Examining the spatial limitations, social exclusions, and personal factors, including how carers cope with changes to identity and recognition of the PLWD, anticipatory grief and feelings of guilt will be required throughout the period of dementia caring.

Utilising a conversion factor allows the capability framework to analyse both equality of outcome and equality of opportunity. For example, a carer living in rural Northumberland may have a similar caring role and access to the same resources as a carer in an urban town, but in order to attend a community facility with the person they care for, the rural dweller may have to get a bus – cost and additional time. If the person they care for uses incontinence pads, they may need access to a suitable toilet at regular intervals, making a journey of this kind challenging, complex or impossible. A taxi may be needed to reduce the journey time and thus the need for toilet facilities. Dementia impairment resulting in behaviours which challenge might further diminish the carer's ability to support the PLWD to access the facility. Someone living nearby can walk there and use the toilet facilities at home before and after. Thus, appraising a person's well-being cannot rest solely on the resources they have, but on how they are able to convert these resources into functionings.

The CA may not be able to address all abilities to convert resources into outcomes, but it may identify the inadequacy of dementia specific responses, the profound impact on well-being of carers especially guilt associated with 'letting the person down' and pinpoint a time when capabilities cannot be realised and residential care has become the best option for some people. A gradual, planned, expected, prioritised, and normalised progression from home to care home for those PLWD and their carers who are identified as having the least ability to convert resources into functionings may enable these carers to reduce and manage overwhelming sense of guilt.

7.4 Policy Implications – Addressing Carer Injustices in Northumberland

This research highlighted numerous social, environmental, and personal difficulties experienced by carers of PLWD in Northumberland. Some deficits in dementia care support can only be addressed through policy change at government level. This research project does not make suggestions for changes at this level, but it does concur that:

> 'The entire home care policy is built on the assumption that there is (or should be) a 'family caregiver' or 'informal carer' available at home to provide care and basically act as a privatised safety net' (England, 2010, p.140).

It also notes that long promised changes to address inequities in care funding have been shelved, the introduction of a UK wide dementia strategy has been postponed (Department for Health and Social Care, 2022a) and there is currently no dementia strategy for Northumberland. Effective and comprehensive strategies at both local and national government level are urgently needed to address some of the financial and structural health and social care injustices experienced by carers and PLWD and the resulting significant impact on their well-being (Reiheld, 2015).

A recent report by Alzheimer's Disease International (2022) which found that 37% of PLWD and 36% of informal carers of PLWD in higher income countries had had no post-diagnosis support, declared that post diagnosis dementia care should be classed as a human right. Contributions to the report from the Pridem project at Newcastle University (2022) underscored the need for improved post diagnosis support and care through a dementia specialist nurse based in GP practices. This has the potential to improve communication, provide continuity and the specialist single point of contact for advice at and after diagnosis which were highlighted as deficient by most participants in this research. It might also be an opportunity to discuss advance plans and advise on completion of a health and welfare LPA.

The recent Northumberland Joint Health and Well-being Strategy (NJHWBS) 2018-2028 (NCC, 2018b) states '…over the last few years, there has been an unprecedented increase in the demand on health and social care.' (p. 9). To address this, the strategy has a focus on fairness and equity, joined up health and social care provision, ill health prevention and promotion of well-being, quality care and value for money as key aims utilising a fair opportunity approach. The strategy foregrounds local assets and community-based, non-clinical interventions or solutions, such as social prescribing: befriending, volunteering, and physical activity to build personal resilience and enable people to stay healthier and at home for longer. Dementia or dementia specific support is not discussed in the NJHWBS and although the strategy states it will take measurements to assess carer well-being and help carers back into the labour market as long-term goals, it is unclear how local communities will be able to provide enough specialised support to address the needs of carers and PLWD.

Emily remarked during her interview that it was unrealistic to expect people in local communities to have the skills and expertise needed to appropriately support PLWD who have behaviours which challenge. Carers in this research drew attention to the need for enhanced training and awareness raising for professionals, communities, and families regarding complex dementia symptom presentations and how to respond to them resulting in better support and advice to carers. In addition, they suggested awareness raising at a community level in order to address stigma and discrimination of PLWD and their carers, value of care work and workers (Fawcett Society, 2022).

The strategy stresses the growing pressures on resources from an ageing population increasingly living with chronic and/or multiple health conditions. An Older Person report underlines the acute problems Northumberland will face in the future:

> 'By 2039 the total population is projected to rise to 321,764, an increase of 1.8% since 2014. Over the same time period the population aged 65 and over is expected to rise by 51.9%...' (Northumberland County Council, 2017, p. 3).

(See Table 2 in Appendix A for a map of Northumberland with projected increases in population over 65).

With the current dearth of appropriate support and replacement care options for carers of PLWD in Northumberland articulated by participants in this research, it is unclear how the NJHWBS aims will be met. Resources and investment in services to support mid to late-stage dementia care, especially those with the most challenging behaviours will need to be considered and both Emily and carer participants drew attention to the need for additional, suitable, and flexible care and respite options.

The strategy calls attention to problems associated with rural living in Northumberland, with a paucity of public transport, difficulties accessing health and care services, an ageing population with higher health needs and a lack of community resources leading to social and spatial isolation. Most carers I interviewed were living rurally or semi rurally in Northumberland and did highlight problems with access to health, social care and transport leading to increasing levels of loneliness and social exclusion.

Driving cessation is an especially complex problem, with multiple factors affecting the ways in which carers, and sometimes clinicians, struggled to support a PLWD to cease driving. Rural living, with its high car dependency and poor public transport is a key factor in assessing the challenges of stopping driving for PLWD and their carers. The NJHWBS accepts that rural dwellers are strongly car reliant due to public transport deficiencies:

> '…low population density in rural Northumberland makes practical and affordable public transport difficult to provide. At the same time, accessible and affordable transport is a lifeline for many rural residents. Rural areas are very car dependent, as public transport is perceived as inadequate.' (NCC, 2018b p. 17).

This is an area which deserves further investigation, earlier intervention, and development of guidelines for carers and clinicians.

This thesis can only be considered as a starting point for how a CA framework might be useful at looking at policies rather than providing detailed ideas of policy development but utilising the framework to develop a robust carer assessment tool might be an apposite preliminary step. Guidance for the Care Act (Legislation.Gov.UK, 2014) and the Health and Care Act (Legislation.Gov.UK, 2022) states:

> 'The importance of achieving a balance between the individual's wellbeing and that of any friends or relatives who are involved in caring for the individual. People should be considered in the context of their families and support networks, not just as isolated individuals with needs. Local authorities should take into account the impact of an individual's need on those who support them and take steps to help others access information or support' (Department for Health and Social Care, Care and Support Statutory Guidance, 2022b, no page).

In order to achieve this balance, carer assessments must be constantly re-evaluated in light of the changing cognitive and physical decline of the PLWD, the impact of this on the carers ability and agency to convert capabilities into functionings and additionally the changing circumstances of the carer themselves- their health, work commitments, other family commitments, physical and emotional well-being. As PLWD live longer and often longer at home, the CA framework must be adapted to incorporate fluctuations and a temporal aspect to capability theorising. Lloyd-Sherlock's (2002) prescient observation that the CA lacks sufficient analysis of the complexities of capabilities throughout the life course, particularly as we age, is an important consideration for carers of PLWD, and may be especially pertinent to spousal carers. Continual reassessment of the social, personal, and environmental factors affecting each individual and in relation to each other requires us to ask questions, to analyse, to review, to adapt and to do this again:

> 'To ask how things are going and whether they can be improved is a constant and inescapable part of the pursuit of justice.' (Sen, 2010a, p. 86).

Carer assessment as currently undertaken in Northumberland, has a list of questions to assess the needs of carers. (See Appendix M). Current carer support guidelines from

Northumberland County Council and Northumbria Healthcare (2018, see Appendix K) suggest:

> '…we would usually recommend that you first contact Carers Northumberland. They can give you advice to help you decide whether a formal carer's assessment would be worth your while at present…Obviously the person themselves will need to agree to this'.

Emily concluded that mostly carers assessments in Northumberland were not 'worth your while' as there was little available for carers. Emily argued that only if carers had access to a *meaningful* carer assessment which identified carer needs, addressed them, regularly reviewed them, and actually delivered, could carer well-being be improved.

Advancing and modelling a new carer assessment with a set of conversions, which address aspects of dementia care raised by participants in this research may offer new opportunities to better meet carer need. Some basic capabilities may need to be agreed upon in order to operationalise (Burchardt and Vizard, 2011, 2014) and assessment and discussion at earlier stages, whilst the PLWD is capable of more complex cognition, with both carer, cared for and perhaps wider family may identify functionings which contribute to their well-being and which environmental, social and personal factors may affect their ability to convert capabilities. For example, if a PLWD agreed in early stages that maintaining family relationships was crucial to their carer's well-being, this might reduce carer guilt at a later date if they prioritised time away with other family members. An assessment tool would need to consider myriad relational factors which affect carer capability - driving cessation, incontinence, medical impairments, rurality, understanding carers duty/guilt/psychological responses to identity and recognition, financial situation, and likelihood of eventual residential care etc. Assessment by a dementia specialist linked to GP practice, as discussed above, might allow for continuity when reassessing carers needs as a single point of ongoing contact. The CA has been debated by academics for twenty years, but now is the time to focus on '…using it to study the problems that need addressing' (Robeyns, 2017, p. 211).

7.5 Limitations of Research

This research was a small-scale examination of carers lives in Northumberland and the findings may not be extrapolated to a larger study. Recruiting participants relied on carers, already recognised as such, responding to my requests. As many people do not regard themselves as carers and additionally many PLWD have not been diagnosed, the participants may not be representative of the Northumberland populace, or more broadly nationally.

The Covid 19 pandemic had profound effects on our health and care systems. When I was conducting most of the interviews in 2018/19, I could not have imagined the situation which was about to change so dramatically – with lockdowns, isolation, inability to visit relatives in hospital and care homes. The effects on carers and PLWD both at the time and how they view caring now, may have undergone profound change as a result. I would have liked to have held follow up focus groups or second interviews with participants and with further time and funding, analysis of these experiences through a post-Covid lens would make for an important post-doctoral study.

I think it is important to acknowledge the current lack of any effective medical treatment for an illness whose trajectory encompasses inevitable and serious cognitive decline and eventual death. We should not minimise the immensity of this illness nor make glib assertions that simple changes to care practices, environmental improvements or reduction in the stigma associated with dementia, old age and residential care can easily solve the multiple difficulties which many carers of PLWD face. Tanya succinctly expresses this feeling when asked about improvements to the current system of help and support:

> ‘I would only want to know about it [an improved pathway of care] if there were *clear help*…because I already knew what the [dementia] pathway was, and to me it was just grim the whole way’ (Tanya).

Caring for someone with dementia effectively, whilst maintaining one’s own physical and emotional well-being, particularly in the later stages was dependent on numerous social, environmental, medical, and personal factors. There were points during care for my parents, particularly when they were still at home which were completely overwhelming, and I felt that no-one or nothing could have helped. Eric stressed the complexity of dementia impairments which lead to the difficulty in providing appropriate services or help. Even with excellent GP support and a supportive care group, Eric was unable to get time for himself for a few hours – there was no paid support which offered continuity, *or* which his wife would countenance, his wife was angry with him if he went out and she couldn’t cope with visits to or from children and grandchildren, shutting him off from familial support and comfort. Eric argued that the unpredictability of dementia can add to this difficulty in providing appropriate services. Such is the challenge of some dementia care, it is important to note that several carers could not think of *anything* that would have made a difference:

> LM ‘Is there anything [which would make a difference]?’
>
> Flora ‘To be honest, I don’t know… nothing sticks out to me’.

7.6 Contributions of the Research

Drawing on auto-ethnographical experiences helped me to bring empathy and understanding to the in-depth qualitative interviews. The interviews produced powerful and valuable data which encapsulated the caring experiences of the participants. The participants represented a reasonably diverse demographic cross section. Feminist ethics of care helped to underline the relational nature of the caring experiences in contrast to dominant individualist philosophy. It highlighted the spatial, social, and personal limitations carers experienced through their caring role.

The CA has been criticised for being too individualistic (Lloyd, 2012, Held, 2006) and Nussbaum does indeed espouse a liberal individualism (2006). Yet, individual freedom and choice matters (Mill, 2008, Fukuyama, 2022). Promoting a group identity of ‘carers’, assumes a similarity of group experiences which obscures the individual experiences. Sen, however, is cognisant of the particularities of injustice and disadvantage wrought to individuals and families through disability trying to realise capabilities and foregrounds a conversion factor which highlights ‘the difficulty in converting incomes and resources into good living *precisely* because of disability.’ (Sen, 2010a, p.258). Disability can be socially constructed but medical impairment exists outside of that construction.

The relational ethics of care centres on our understanding of the ubiquitous nature of dependency and acknowledgement of this dependency is crucial to our understanding of care and care relations. Bringing together both the importance of the individual freedom of carers (and people living with dementia) to realise well-being through a capability approach, whilst recognising the centrality of caring relations can help identify carer injustices in Northumberland and develop policies to alleviate it.

Deficits in research have been identified in both formal and paid care (Morgan et al, 2011) as well as the support needs of informal unpaid caregiving (Innes et al, 2011) and rural living people with dementia and their carers (Clarke and Bailey, 2016, Herron and Rosenberg, 2019). A guide to rural communities supporting people with dementia has only recently been published (Alzheimer’s Society, 2018b). The Northumberland Joint Health and Well-being Strategy 2018-2028 identifies specific problems in rural areas pertaining to access to health and related services including the distance to reach appropriate services, public transport – resulting in high driving dependency, and social isolation and exclusion especially for older people.

A more recent publication ‘Remote and Rural Dementia Care’ (Innes et al, 2020) is the first book dedicated to studies of dementia in rural areas. It brings together good practice and research in a specific rural dementia volume. The book identifies deficits in research including ongoing support for the PLWD after diagnosis, rural inclusion - focussing on employment, social and cultural activities and other community services, support around driving cessation and post driving. (Farmer, Morgan and Innes, 2020)

These deficits are all areas with which my own research concurs. Rachel Herron, reviewing the book highlights the lack of research on informal carers of PLWD in rural areas (Herron, 2021) This thesis is an opportunity to add informal caregivers accounts to this rural dementia care literature. Psychological and emotional factors which affected carers – guilt, identity and personhood, duty, and obligation within the spatial and social challenges inherent in rural communities needs supplementary research.

7.7 Recommendations for Future Research

Assessing injustice of carers of PLWD and the impact on their well-being may be a ‘wicked problem’ (Bache et al, 2015) but the CA can offer an alternative ethical and evaluative approach to tackle the complexities of carer and PLWD’s lives. Further cross disciplinary collaboration – particularly between Human Geography, Sociology, Politics, Ethics and Psychology would bring epistemological exchange, driving opportunities for conceptual and theoretical development. CA theorising needs to include a temporal aspect, with consideration of caring throughout the life course, to better understand the lives of PLWD and their carers. Incorporating a more robust relational approach, drawn from feminist ethics of care literature might support this.

Focusing on the psychological drivers which motivate and affect carers deserves special attention to highlight difficulties that carers experience. Dementia carer guilt is profound, enduring and under researched (Gallego-Alberto et al, 2022, 2019). Interventions to support carers as dementia progresses with issues pertaining to guilt, recognition, and identity, are crucial for carer well-being. Psychological interventions show some promising results (Mahmoudi et al, 2017). Carers identified as having the most intractable and multiple problems may benefit from targeted early intervention.

Guilt in relation to a carers sense of duty to care for a PLWD at home for as long as possible is compounded by societal narratives and local and national policies foregrounding this as the best option. Negative perceptions of residential care heightened through critical media reports (Toynbee, 2018) and more recently through care home excess deaths – particularly those with dementia (ONS, 2022) and limited visiting rights due to Covid 19 is likely to have exacerbated carer fears of residential options and guilt and a sense of failure if the PLWD can no longer be cared for at home. In particular, the high care home death rate, limitations on care home visits by relatives may have contributed to an even stronger aversion to residential care than was evidenced in this research. The stigma associated with residential care and concomitant pressure to care for the PLWD at home may now be even greater. Implications for offshore care of UK PLWD in Thailand, alluded to in chapter one (Johnston and Pratt, 2022), and resultant issues with carer visiting, may be especially prescient. Post Covid research in this area will be an important undertaking.

7.8 Concluding Remarks

> '…there may remain contrary positions that simultaneously survive and which cannot be subjected to some radical surgery that reduces them all into one tidy box of complete and well-fitted demands…' (Sen, 2010a, p.46).

Caring for someone with dementia is natural, ethical, complex, and demanding. This thesis has investigated the caring practices of carers in Northumberland, what they can actually do and be and the impacts on their well-being. It is both about the relational, espoused through an ethics of care and the individual freedom of people. The CA offers a framework rather than a fully-fledged theory. It is perhaps why I was drawn to the Capability Approach as it has the capacity to encompass a plurality of theoretical positions in a simple and effective formula. It can consider the multiplicity of care and injustice aspects – spatial and environmental, personal, and social – to assess well-being and develop practical ways to help people. It can capture aspects from mid-range theories such as Goffman's Social Stigma Theory, Social Model of Disability, identity, and grief. These can be examined in line with the conversion factors – stigma theory may help explain the difficulty for carers personal conversion factors, the social model of disability might identify environmental and spatial conversion deficits, whilst the medical model of impairment might explain personal challenges and psycho social conversion insufficiencies. A feminist ethics of care brings a relational dimension which brings care as a normative ethical position, whilst CA offers a practical framework to examine the actual freedom of individual carers.

The literature on the ethics of care and CA both examine well-being, individual and relational freedoms and seek to diminish injustices. Critical Realism and feminist standpoint theory offered theoretical perspectives to conduct this enquiry. CA supplies both a realist ontology and epistemological approach and standpoint the epistemological enquiry.

Dementia care is a ‘wicked’ problem. Identifying injustices and unfairness is often obvious, finding solutions to tackle these injustices is frequently less so. But addressing the needs of PLWD and their families as well as future service provision will be of critical importance over the coming decades (Wittenburg et al, 2019).

Appendix A

Table 1
Projected number of older people with dementia receiving care and projected costs of dementia care in England, 2015–2040

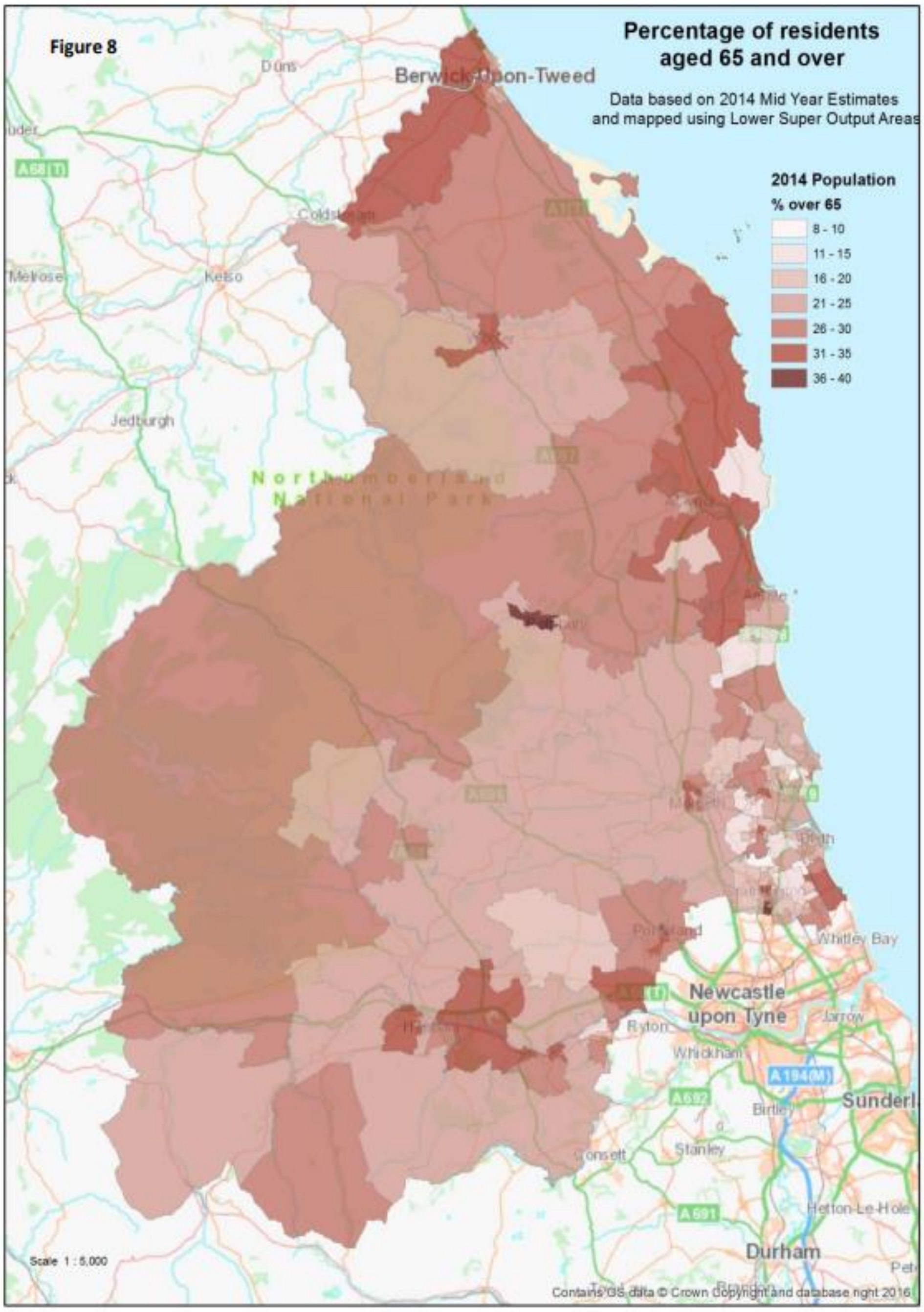
	2015	**2040**	**2015–40 (% increase)**
Prevalence of dementia			
Number of people aged 65+	9,710,000	15,293,000	57%
Number of people aged 85+	1,297,000	3,083,000	138%
Number of older people with dementia	651,000	1,351,000	108%
Prevalence of dementia	6.7%	8.8%	32%
Mild dementia	110,000	167,000	52%
Moderate dementia	237,000	276,000	16%
Severe dementia	303,000	909,000	199%
Care recipients with dementia			
No care	120,000	170,000	42%
Unpaid care only	193,000	348,000	81%
Formal care only	21,000	37,000	71%
Both	65,000	131,000	100%
Care home residents	251,000	667,000	166%

	2015	2040	2015–40 (% increase)
Total annualised costs (£ million)			
Health care costs	3,530	10,310	192%
Social care costs	9,780	39,170	300%
Unpaid care	9,500	30,120	217%
Other costs	151	528	249%
Total	22,970	80,130	249%
Average costs (£ per person per year)			
Health care costs	5,440	7,630	40%
Social care costs	15,060	28,970	92%
Unpaid care	14,620	22,270	52%
Other costs	233	390	68%
Total	35,110	58,860	68%

Note: Numbers may not add exactly due to rounding.
(Wittenburg et al, 2020)

Table 2

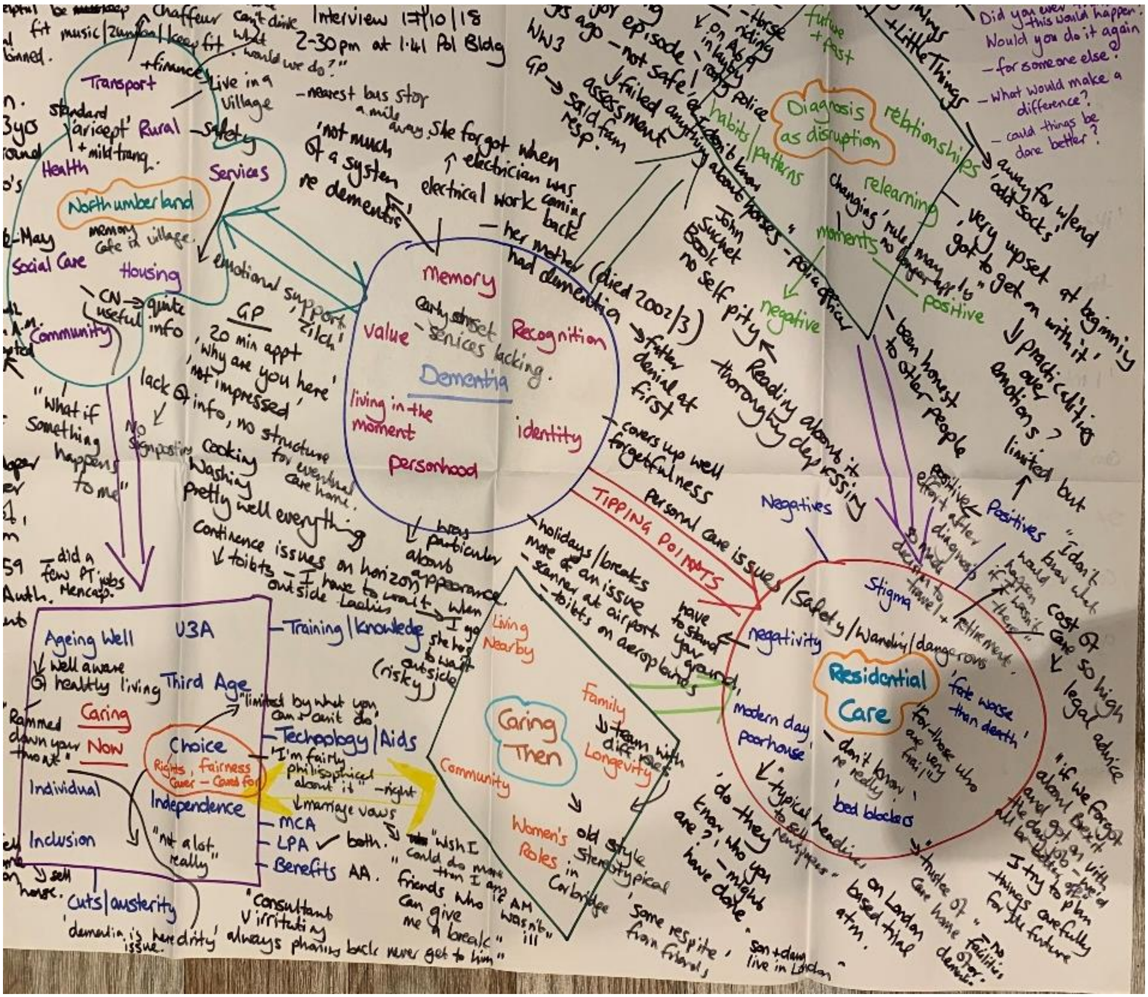
Age profile of Northumberland



(Northumberland County Council, 2017, p. 8)

Appendix B

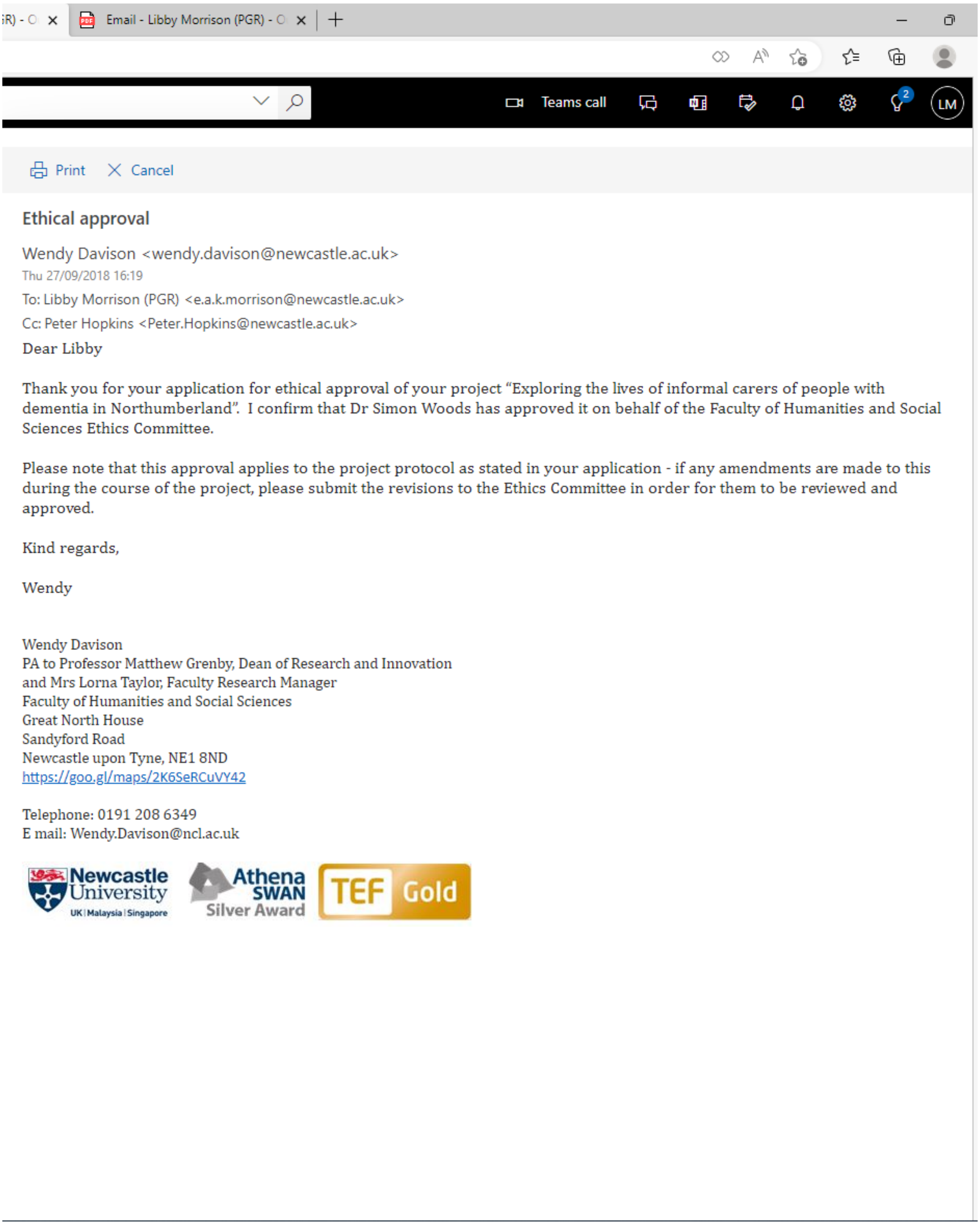
PCP Poster Example



(Some identifying information has been cropped out)

Appendix C

Ethics Approval



Ethical approval

Wendy Davison <wendy.davison@newcastle.ac.uk>
Thu 27/09/2018 16:19
To: Libby Morrison (PGR) <e.a.k.morrison@newcastle.ac.uk>
Cc: Peter Hopkins <Peter.Hopkins@newcastle.ac.uk>

Dear Libby

Thank you for your application for ethical approval of your project "Exploring the lives of informal carers of people with dementia in Northumberland". I confirm that Dr Simon Woods has approved it on behalf of the Faculty of Humanities and Social Sciences Ethics Committee.

Please note that this approval applies to the project protocol as stated in your application - if any amendments are made to this during the course of the project, please submit the revisions to the Ethics Committee in order for them to be reviewed and approved.

Kind regards,

Wendy

Wendy Davison
PA to Professor Matthew Grenby, Dean of Research and Innovation
and Mrs Lorna Taylor, Faculty Research Manager
Faculty of Humanities and Social Sciences
Great North House
Sandyford Road
Newcastle upon Tyne, NE1 8ND
https://goo.gl/maps/2K6SeRCuVY42

Telephone: 0191 208 6349
E mail: Wendy.Davison@ncl.ac.uk

Appendix D

Participant Information Sheet

Participant Information Sheet for One to One Interviews

Exploring The Lives of Informal Carers of People with Dementia in Northumberland, at Home, in the Community or in Residential Settings.

Introduction

I am a first year PHD student researcher from Newcastle University. I am funded by the Economic Social Research Council via the University to do this work. I have a collaborative partner, Co-ordinating for Age, Wooler, which is able to offer advice and support throughout the three-year project. I am interested in researching the lives of informal (also called family) carers in Northumberland looking after someone with dementia. For example, you may be a wife or husband, a son or daughter, or a friend or neighbour of the person you care for. I would like to do a number of interviews with informal carers about their experiences. As someone who might be interested in participating in an interview, this information sheet aims to tell you about how the interviews will be structured, how the information gathered will be used and stored, and to get your feedback on this information about the interview process before you agree to take part in the project. Please keep this information sheet for future reference. Feel free to share the information sheet with other people. If you would like this information sheet in larger print, different font, electronic format or an accessible version, I would be happy to provide this.

Who am I?

My name is Libby Morrison. I came to Newcastle University as a mature student six years ago to study politics, and gained a BA in Politics in 2016. Prior to this, for nearly twenty years, I was a support worker and paid carer for people with learning difficulties. As part of my degree, I was involved in a project examining the difficulties and barriers carers and the person they care for face when trying to access facilities in their local communities in Northumberland. I completed an MA in Human Geography in September 2017. The research undertaken for the dissertation element of the Masters involved interviewing paid carers at a North East residential care home, where I explored the shifting landscapes of care. Having cared for both my parents who have dementia for the last ten years, I am particularly interested in the experiences of informal carers of people with dementia.

What am I planning to do?

During 2018 and 2019, I aim to interview around twenty to thirty informal carers of people with dementia. The person who is being cared for may still be living in their own home, in the home of a family member, or in a residential or nursing setting. I am working with a number of local organisations to help me reach out to potential carers who might like to be part of this research project. I also hope to interview a number of service providers and to hold three informal discussion groups (or a follow-up interview) with carers after the interview stage has been completed. If you take part at the first interview stage, you are under no obligation to take part in any follow-up interview or discussion group.

If I agree to be interviewed, what will it involve?

If you agree to be interviewed, it is anticipated that you will take part in an interview lasting approximately one hour. Sometimes interviews are shorter than this, and sometimes they take a little longer, but certainly no more than 90 minutes. The interviews can take place somewhere that you are comfortable - this could be in your own home, in a local café or library, a meeting room can be specifically booked, at a local service provider venue. I am aware of the difficulties that informal carers can experience in arranging time away from the person they care for, therefore interviews will be scheduled to fit in with your timetable rather than mine. I would hope for the interview to be free flowing and more in the style of an informal conversation, rather than a formal interview. There will not be set interview questions, but I will explore with you a number of themes about your caring experiences. With your agreement, I would like to record the interview so that I can listen to it again, and transcribe it, in order to help me remember all that was discussed. I will also take written notes during the session, usually on flip chart.

Sometimes when we share aspects of our lives, such as a caring role, this can raise difficult issues and potentially provoke emotional responses. If you would like someone to be available to support you during or after the interview, for example a friend, family member or support worker, please let me know. With your agreement, I can also signpost you to organisations which offer support to carers.

What will happen to the information collected?

I will analyse all the data collected at interviews, using the written notes, recordings and transcriptions, and this information will be used as a basis for a follow-up interview or discussion group (a separate participant information sheet and consent form will be provided if you agree to take part) and become part of my research and final thesis. The notes, transcription and recordings will be stored safely on the University's secure computer networks and/or in locked filing cabinets. All details which might identify you or the person you care for, will be changed to anonymise your contribution, Your personal details will not be used in the final thesis.

What will the outcomes of the project be?

I hope to gain a clearer understanding of the lives of informal carers of people with dementia in Northumberland, their day-to-day lives, the impact on the whole family, the places they go to and the services they access. This information might be used to shape local policy in Northumberland, raise awareness of the issues informal carers of people with dementia face in Northumberland, and form the basis for further research.

What happens next?

If, after discussion and feedback on the content of this information sheet, and what the research will entail, you are happy to take part in this part of the project, I will give you a written consent form to complete and sign. After participating in the research, I will also provide you with a debriefing sheet which will outline the key points contained in these information sheets, contact details, and information on where to get help or advice on any issues which might have arisen during the research process. If you decide not to take part, I thank you for the time you have taken to read the information contained in this participant sheet. The contact details for myself, for my supervisors at university and for my collaborative partner are provided at the end of this information sheet. If you have any questions, issues you would like to discuss further, or would like additional information now or at a later date, please feel free to contact either myself or my supervisors.

Contact Details

Researcher **Libby Morrison** PHD Candidate, School of Geography, Politics and Sociology, Newcastle University Email: e.a.k.morrison@newcastle.ac.uk	**Collaborative Partner** **Co-ordinating for Age, (C4A)** Glendale Gateway Trust, Wooler, Northumberland Web address: https://www.wooler.org.uk/the-age-pages/partners/624-the-glendale-gateway-trust
Supervisors **Prof. Peter Hopkins** Professor of Social & Political Geography, School of Geography, Politics & Sociology Newcastle University Email: peter.hopkins@ncl.ac.uk **Prof. Thomas Scharf** Professor of Social Gerontology, Institute of Health & Society' Newcastle University, Email: thomas.scharf@ncl.ac.uk	**Dr. Michael Richardson** Lecturer in Human Geography, School of Geography, Politics & Sociology, Newcastle University Email: michael.richardson@ncl.ac.uk

Last updated: August 2018

Appendix E

Consent Form 1

Exploring The Lives of Informal Carers of People with Dementia in Northumberland at Home, in the Community or in Residential Settings.

Informed Consent Sheet for Adults – One to One Interviews

1.	I have read and understood the information about the project, as provided in the Information Sheet dated __________________.	☐
2.	I have been given the opportunity to ask questions about the project and my participation.	☐
3.	I voluntarily agree to participate in the project.	☐
4.	I understand I can withdraw at any time without giving reasons and that I will not be penalised for withdrawing nor will I be questioned on why I have withdrawn.	☐
5.	The procedures regarding confidentiality have been clearly explained (e.g. use of names, pseudonyms, anonymisation of data, etc.) to me.	☐
6.	If applicable, separate terms of consent for interviews, audio, or other forms of data collection have been explained and provided to me.	☐
7.	The use of the data in research, publications, sharing and archiving has been explained to me.	☐
8.	I understand that other researchers will have access to this data only if they agree to preserve the confidentiality of the data and if they agree to the terms I have specified in this form.	☐
9.	I, along with the Researcher, agree to sign and date this informed consent form.	☐

I, the undersigned, confirm that (please tick box as appropriate):

Participant:

____________________ ____________________ ______________
Name of Participant Signature Date

Researcher:

____________________ ____________________ ______________
Name of Researcher Signature Date

Last Updated: July 2018

Consent form 2

Exploring The Lives of Informal Carers of People with Dementia in Northumberland, at Home, in the Community or in Residential Settings.

Audio Recorded Material

Informed Consent Sheet for Adults – One to One Interviews
I, the undersigned, confirm that (please tick box as appropriate):

1.	I have read the information sheet about audio recorded material	☐
2.	I have had a chance to ask questions about the audio recorded sessions	☐
3.	Only the researcher will have access to the recorded material and only the researcher and her supervisors will have access to the transcribed material as set out in the information and debriefing sheets	☐
4.	I understand that all audio recorded material will be securely stored on the university hard drive and password protected	☐
5.	I, along with the Researcher, agree to sign and date this informed consent form.	☐

Participant:

________________________ __________________________ __________
Name of Participant Signature Date

Researcher:

________________________ ________________________ ___________
Name of Researcher Signature Date

Last Updated: July 2018

Appendix F

Mental Health First Aid Certificate

Certificate of Attendance

MHFA England

Libby Morrison has attended the **Adult MHFA Two Day** course and is now **a Mental Health First Aider**. This course teaches in depth skills for providing first aid to people who may be experiencing mental health issues such as depression, anxiety and psychosis.

Dates of attendance

Start Date: **10/09/2018**

End Date: **13/09/2018**

Course delivered by

Bridget Woodhead

Mental Health First Aid (MHFA) England is a community interest company working to increase mental health awareness and skills across society. Our range of courses are designed to empower people to support their own mental health and that of the people they connect with in life.

By giving people the facts about mental health and the practical skills to support wellbeing, we work towards building healthier communities free from stigma.

Simon Blake OBE
MHFA England Chief Executive

MHFA England CIC
49-52 East Road, Old Street
London, N1 6AH

www.mhfaengland.org
info@mhfaengland.org

020 7250 8062
CIC Registration Number: 702139

1087436411

Appendix G

Example follow up email to care home manager after introduction by collaborative partner.

Hi **** It would probably be helpful to you if I gave you a little information about myself and my project. I am a first year PHD student researching the lives of informal carers of people with dementia in Northumberland. I am particularly interested in the experiences of carers as the person they care for moves from home to a residential care setting. This research follows on from a project I did at undergraduate and then master's degrees. I am a mature student with two grown up daughters. Both my parents have dementia and are now in residential care homes. I supported them at home for many years.

I am hoping to interview carers over the course of the next year, starting October 2018, after I have been given ethical approval from the university. At this stage, I was hoping to come up to visit ****to have an informal chat with you about how I might contact carers who have family members resident at the care home. This would only be once I have the go ahead from the university, and if yourself and staff at **** are happy for me to do this, - for example I could have information sheets about the project which could go on notice boards, in newsletters, emails, social media or I could arrange to visit carers for informal chats.

I have reasonable flexibility over the next few weeks - I could come up on Mon 20th, Thursday 23rd or Frid 24th at any time. The following week I can do Thurs 30th or Frid 31st at any time. Are any of these dates good for you? It would be great to meet you and talk through with you what might be possible.

Thanks very much. I really appreciate your time regarding this.

Kind regards,

Libby

Libby Morrison

PHD Student

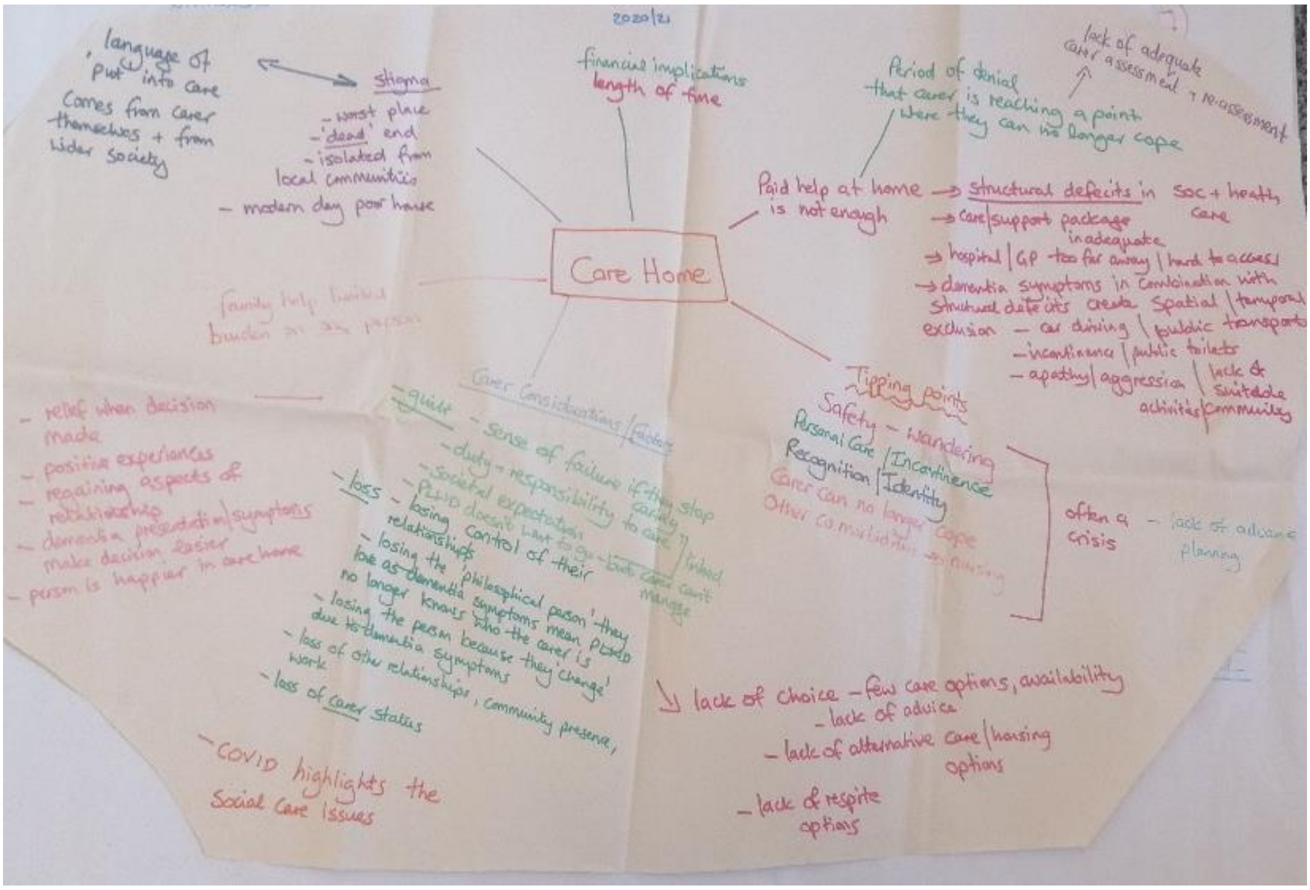
School of Geography, Politics and Sociology

Newcastle University

e.a.k.morrison@newcastle.ac.uk

Appendix H

Example of Mind Map – coding and analysis



Appendix I

Demographics

	Carer Pseudonym	Sex	Location	Age Range	Caring For (Pseudonym)	Length time caring	Ethnicity	Occupation	Education	Cared for person lives/d	Car Driver	Diagnosis
1	Quinn	M	Central Northumberland	60-70	Wife Maureen	5years	British	Retired Professional	Degree	At home with Quinn	yes	AD
2	Wendy	F	West Northumberland	60-70	Mum Beryl	7.5 years (died 6 months ago)	White British	Self-employed	Degree	In Own home, Care Home,	no	AD
3	Eloise	F	Central/South Northumberland	50-60	Mum Frances	12 years	White British	Professional	Masters	Lives in Eloise's home	yes	AD
4	Winnie	F	North Northumberland	70-80	Husband Norman	3 years	White British	Retired Professional	Masters	At home with Winnie	yes	Lewy Bodies
5	Kenneth	M	Central/South Northumberland	50-60	Dad and Mum Lorna and Len	Dad 2 years died 2014 Mum 3 years died 2018	White British	Retired Service Person	Secondary level	In their own homes, whilst alive, Dad in care home latterly	yes	Dad – VD Mum – AD + VD
6	Neville	M	West Northumberland	60-70	Wife Brigitte	8 years	White British	Retired Manager	Degree	At home with Neville	yes	AD
7	Una	F	North Northumberland	50-60	Dad Vince	4 years	British	NHS Worker	Nursing Training	In their own home	yes	Probably AD
8	Katherine	F	North Northumberland	40-50	Mum Elizabeth	7 years	White British	Self-Employed	Cert Ed,	Lives with Katherine	yes	Progressive Dysphasia Dementia
9	Leonard (married to Maggie)	M	North Northumberland	60-70	Mum Kay	13 years (lived with)	Didn't say	Retired Public Sector	O'level	Lives with Leonard and his wife	yes	Dementia – unclear diagnosis
10	Maggie (married to Leonard)	F	North Northumberland	60-70	Mother-in-law	As above	As above	Retired Office Worker	HND	Lives with Maggie and her husband	yes	As above
11	Carol	F	North Northumberland	70-80	Husband Colin	20yrs	English	Retired teacher	Degree	At home, husband now in Care Home since April 2018	yes	VD

12	Laura	F	North Northumberland	30-40	Mum Denise	26yrs (was a YC for many years)	British white	Administrator	Degree	Mum lives Seahouses	yes	MS - now a neurological diagnosis, linked to MS
13	Tessa	F	Central Northumberland	70-80	Husband Iain	7 years	British born SA	Retired/housewife	Diploma	At home with Tessa	yes	AD
14	Enid	F	North Northumberland	60-70	Husband Karl	6 years	White British	Retired Childcare	Nurse Training	In Residential Care since April 2018	yes	Unclear – husband could not cope with assessment
15	Xena	F	South Northumberland	70-80	Husband Charlie	4 years	White British	Health Sector	Left school 16	At home with Xena	no	AD
16	Izzy	F	West Northumberland	30-40	Dad Joe	2 years	British	Business Manager	Higher levels	At home with Izzy	yes	AD
17	Tina	F	North Northumberland	60-70	Mum Vera	17 years	White British	Retired Public Sector	PG Degree	Mum in Res Care, Alnwick	yes	AD
18	Nadia	F	West Northumberland	80-90	Husband Quentin	10years	European WB	Retired Public Sector	Training College	At home with Nadia	yes	Mixed – VD and AD
19	Tanya	F	West Northumberland	70-80	Husband Sam	8 years	WB	Public Health	MA	Husband died 2015	yes	Parkinson's and dementia
20	Eric	M	North Northumberland	70-80	Wife Shirley	7 years	WB	Retired Professional	O levels, Further training	At home with Eric	yes	AD and Small Vessel Disease
21	Theresa	F	North Northumberland	60-70	Husband Connell	2.5 years	WB	Retired civil servant	O Levels	At home with Theresa	yes	AD
22	Beverley	F	North Northumberland	50-60	Mum Betty	8 years	WB	Unemployed	GCSE's	In Res Care	no	AD and VD
23	Tricia	F	Borders, Scotland	50-60	Mum Penny	7 years	British	Rural Worker	Degree	Care Home in Northumberland	yes	Dementia – possibly AD
24	Flora	F	North Northumberland	70-80	Husband Ernie	20 years	WB	Retired Administration	None Left school 15	Private Rent with Flora	Yes, but no car	VD and AD
25	Olivia	F	North Northumberland	70-80	Husband Harry	6 years	WB	Retired Third Sector	O levels	At home with Olivia	no	AD
26	Nettie	F	North Northumberland	70-80	Husband Henry	7 years	WB	Retired Public Sector	Left school 15	At home with Nettie	yes	VD and Fronto Temporal
27	Krissie	F	North Northumberland	70-80	Husband Neil	2 years	WB	Retired Sales	Sec Modern	At home with Krissie	yes	AD and VD
28	Emily	F	Professional Manger from Third Sector									

Key Information from Coding and Analysis of interviews 2019-2022

	Carer Pseudonym	Children	Help from family or Friends	Paid Care at Home	Respite/ or Residential Care	Dementia/carer Services	GP/Health	Social services	Key Issues
1	Quinn	yes	One or two long term friends help very little family help	Yes, in house twice a week	No respite	Nothing suitable for her – EOD. Information from CN	V little help. Assessment unhelpful	Self-funders – told to 'do it themselves'	Incontinence Challenging behaviour Lack of help for EOD Lack of time/space for himself
2	Wendy	No	V little help from friends or family	No	No respite 2.5yrs in residential care	Information from CN	Mixed	Very angry with them Particularly CM	Health issues herself Unhappy with soc services, lack of care options Financial problems
3	Eloise	No	Some family help, no friends help	No	No	Information from CN Day centre 5 days a week	GP excellent	CM for 2 months	Upbeat Lives at home with mum Mum's dementia easy to cope with
4	Winnie	yes	No family help but neighbours good	No	No	Information from CN	Not discussed	No	Incontinence Challenging behaviour Driving Spatial/temporal limitations
5	Kenneth	yes	Very little help.	Fortnightly help round house	Dad in residential care And had respite	Community centre CN registered	Frustrated with GP, long time to diagnose discharged	Soc worker dipped in and out	Caring both parents Driving Lack of help Poor diagnostics Incontinence Lack of info
6	Neville	yes	No family help. A few friends – harder to rely on them as she gets worse	Help in house occasionally	No	Art class for PWLD Information from CN	Critical of GP	No help	Challenging behaviour Safety/wandering Spatial/temporal limits No support after diagnosis Nothing for EOD Continence issues beginning
7	Una	yes	Some family help. Friends have backed off	No	No frustrated at lack of help	Third sector org provides dinner and day care	No issues raised	Hard to contact – lack of continuity	Respite Stigma Embarrassment Benefits/difficulties of rural village Loneliness/isolation Training/experience of carers
8	Katherine	yes	Not much – loss of friends, family not much help	No	Private care organisation has been used for respite, short break	Third sector organisation – dinner and day care	GP surgery good. Unhappy hospital care	CM – Nice but narrow minded. Very little offered	Isolation Identity loss Space/time Lack of choice Lack of awareness about dementia Poor hospital care Lack of joined up services Respite/care Continence issues beginning
9 and 10	Leonard and Maggie	yes	No family help. One or two neighbours	Help with personal care twice a week	No – have been offered, but can't take	Third sector day-care organisation - twice a week	Good	Good	Challenging Behaviour Guilt Respite – poor options

					it as no short breaks available – told to arrange themselves				Space/time Lack of choice incontinence
11	Carol	yes	Friends have been good. One family member is good	No, when he was at home	Now in residential care – very good	Not discussed	Good	No CM	Rural good place to manage. Help with finances lacking Having to call paramedics – embarrassment Incontinence Verbal embarrassment, guilt
12	Laura	No	Some limited family help. No friends help.	6 calls per day paid carers	Has had respite – bad experience Uncle and aunt pop in if K is away	Third sector day care weekly but not really her mum's age group	GP – lack of continuity Nurses good	Latest CM is good – pro-active	Young carer Huge guilt/obligation Anxious Multiple challenging support needs Burden Toilet/catheter Space/time
13	Tessa	yes	Very little help. Responds to one old friend	No paid care	No respite	Husband does not want to attend the limited options available. Information from CN and other third sector providers	Not discussed	No	Isolation spatially restricted by the illness not the environment Wandering Guilt Apathy
14	Enid	No	One family member a little help. No friends help	Yes, previously Had day-care.	In residential care since April 2018	Information from CN	GP good	Disagreements with social services and third sector organisation	Housing Finances Choices/rights Women's roles Battles re money and care
15	Xena	yes	Family member pays for some help, No friends help. No	Yes 2 hrs	No respite	Husband does not want to attend care options available. Information from CN	Access issues. GP good	No	The illness itself is the problem Reluctance to accept help GP issues Isolation Spatial injustice
16	Izzy	No	No family help, Neighbours keep an eye	No	No	Information from CN	Long delays with follow ups	No	Working and caring Driving Increasing anxieties No one else to help Safety issues mounting

17	Tina	yes	No family help or friends	None whilst she was still at home	Now in residential care	Information from CN	GP – access issues	Named worker	Length of time in care home Exhaustion – 17 years of caring The presentation of the illness – aggression, delusions
18	Nadia	yes	No family help.	Paid help in house	No	Information from CN	GP – easier to get appt as reg as carer. GP not sympathetic	CPN – always cancelling appts	Driving Women's work Length of time Tied to house Toilets Presentation of illness
19	Tanya	yes	No – didn't want family to help	Yes – care agency	Yes, respite, then residential care last 2 months of life	Very little for men Information from CN	GP – access issues Sees Parkinson's nurse	CPN	Driving Lack of pathway Toilets Time to herself Lack of appropriate services
20	Eric	yes	No family help Occasionally a friend takes her out	No	No	Support group Information from CN	GP excellent, continuity with GP, who treats them as a couple not as an individual	No – had some previous contact, but not much use	Lack of a break His wife won't accept being away from him so no-one can help. Family visits cause his wife distress, which then limits his contacts with them. The illness itself rather than the support Driving His MH severely affected
21	Theresa	yes	A little family help. No friends help	No	No	support group	See GP every 3 months – good service	No	Living in quite Isolated place Toilet issues She doesn't recognise him Wanders Embarrassment His illness, not the environment is the problem
22	Beverley	yes	Some family help. No friends help.	Yes, at weekends when she was still at home	In residential care	Support group, third sector organisation Information from CN	GP good	Did have one previously	Recognition loss Very neg re care home But her mum is happier, less isolated

23	Tricia	yes	Family all help. No friends help	2 x a day for a month prior to going into residential care	In residential care	Support group	Not discussed	Did have a CM in another part of the country but not in Nbland	What will happen when funds run out Good family decision making – joined up, pragmatic approach. Mum's dementia presented in a way which made this easier Very positive approach
24	Flora	yes	No family or friends help	No	No	Support group, third sector organisation Information from CN	GP – access issues, no continuity	No	MH is poor relation in NHS She has multiple caring difficulties over a prolonged period of time No one checks in on her Toilet Lack of car
25	Olivia	yes	No family or friends help	No	Respite once, when she was in hospital	Support group, third sector organisation, respite local residential care home Information from CN	GP – access issues ring back service, no continuity	No. Did have one and MH worker, both signed off	Her own health is v bad Financial costs Lack of clear pathway Toilet Driving Wandering/safety Bus difficulties due to his behaviour
26	Nettie	yes	No family or friends help.	No	Once a year respite	Information from CN	GP – access issues	Yes, re contacted after violent incident – CPN	Violence Aggression Inappropriate sexual behaviour Difficulties dealing with above Transport Driving Stigma embarassment
27	Krissie	yes	No family helps. 1 neighbour occasionally helps.	No	No	Support group. Information from CN.	GP – access issues	CPN	Aggression Wandering Driving The actual disease Lack of info or joined up services Loneliness isolation

Red = interview with professional in third sector

Black = interviews with carers of PLWD

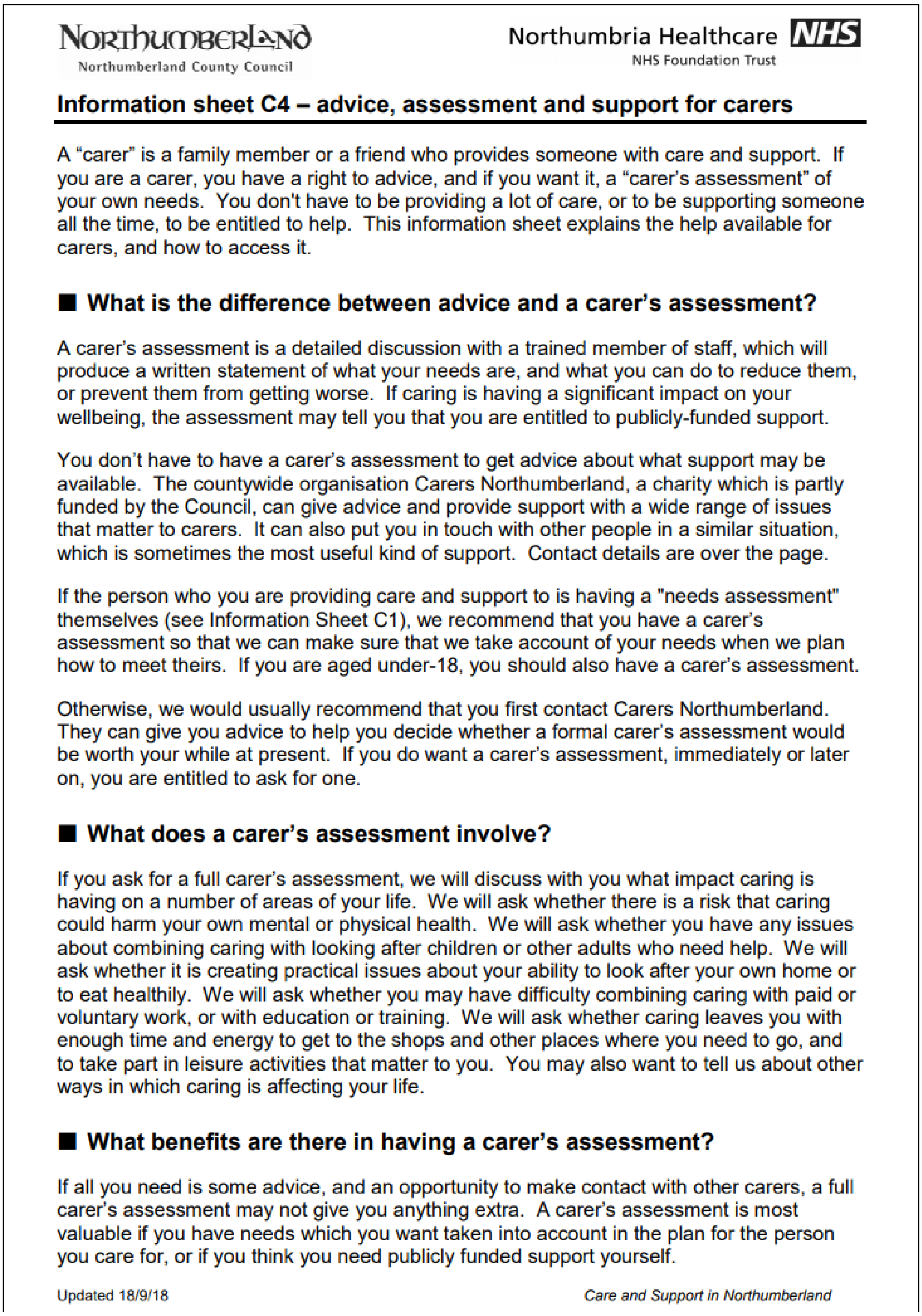
Appendix J

Table 4 – How Participants were recruited.

Who was contacted	Carers Northumberland	Local Third Sector Organisation	Local Third sector support Organisation	Direct contact	Residential Care provider	Manager in Third Sector
Method of recruitment	Newsletter	Email/Newsletter after Collaborative Partner introduction	Contacted after collaborative partner suggestion and through online research	Word of Mouth	Introduction through collaborative partners	Recruited through previous professional contact
Number of Participants	10	5	8	3	1	1

Appendix K

Carers Assessment Information



Northumberland
Northumberland County Council

Northumbria Healthcare NHS
NHS Foundation Trust

Information sheet C4 – advice, assessment and support for carers

A “carer” is a family member or a friend who provides someone with care and support. If you are a carer, you have a right to advice, and if you want it, a “carer’s assessment” of your own needs. You don't have to be providing a lot of care, or to be supporting someone all the time, to be entitled to help. This information sheet explains the help available for carers, and how to access it.

■ What is the difference between advice and a carer’s assessment?

A carer’s assessment is a detailed discussion with a trained member of staff, which will produce a written statement of what your needs are, and what you can do to reduce them, or prevent them from getting worse. If caring is having a significant impact on your wellbeing, the assessment may tell you that you are entitled to publicly-funded support.

You don’t have to have a carer’s assessment to get advice about what support may be available. The countywide organisation Carers Northumberland, a charity which is partly funded by the Council, can give advice and provide support with a wide range of issues that matter to carers. It can also put you in touch with other people in a similar situation, which is sometimes the most useful kind of support. Contact details are over the page.

If the person who you are providing care and support to is having a "needs assessment" themselves (see Information Sheet C1), we recommend that you have a carer’s assessment so that we can make sure that we take account of your needs when we plan how to meet theirs. If you are aged under-18, you should also have a carer’s assessment.

Otherwise, we would usually recommend that you first contact Carers Northumberland. They can give you advice to help you decide whether a formal carer’s assessment would be worth your while at present. If you do want a carer’s assessment, immediately or later on, you are entitled to ask for one.

■ What does a carer’s assessment involve?

If you ask for a full carer’s assessment, we will discuss with you what impact caring is having on a number of areas of your life. We will ask whether there is a risk that caring could harm your own mental or physical health. We will ask whether you have any issues about combining caring with looking after children or other adults who need help. We will ask whether it is creating practical issues about your ability to look after your own home or to eat healthily. We will ask whether you may have difficulty combining caring with paid or voluntary work, or with education or training. We will ask whether caring leaves you with enough time and energy to get to the shops and other places where you need to go, and to take part in leisure activities that matter to you. You may also want to tell us about other ways in which caring is affecting your life.

■ What benefits are there in having a carer’s assessment?

If all you need is some advice, and an opportunity to make contact with other carers, a full carer’s assessment may not give you anything extra. A carer’s assessment is most valuable if you have needs which you want taken into account in the plan for the person you care for, or if you think you need publicly funded support yourself.

Updated 18/9/18 *Care and Support in Northumberland*

■ What support are carers entitled to?

You are entitled to support if you have difficulties in any of the areas of life which we ask about that are having a significant impact on your wellbeing.

Often the most important way to make life easier for you will be to adjust the care and support arrangements for the person you care for. This might mean providing some extra support so that you have time during the day to get some rest or do other things or it may just mean arranging the person's services in a way that doesn't create difficulties for you.

If you are providing a lot of support, or if there are a lot of other things going on in your life, you may need some longer breaks from caring. We will discuss with you how this might best be arranged, and what replacement care will be needed for the person you care for. Obviously the person themselves will need to agree to this. We will also arrange replacement care if you have other plans or commitments which mean that you won't be able to provide care during some periods of time.

Finally, some carers may find that caring leaves them with so little time that they need support with other basic tasks in their lives to enable them to carry on. If necessary we can assist with this. If caring is taking over your life to the extent that you don't have time to deal with your own basic needs, we will want to discuss with you how sustainable this is.

■ Personal budgets and direct payments

Flexibility is often very important for carers. So carers may find it particularly beneficial to take direct control of any funding for support with their needs.

If we agree that you need publicly funded support, we will tell you what we estimate it will cost and whether you will have to contribute (Information Sheet C8 has more information about charges). We will also do the same if we agree to fund care and support for the person you care for. If you decide that you want to control some or all of the money yourselves, we will help you to make the necessary arrangements, and we will agree with you a final figure for how much money you will need. This is called a "direct payment". For instance you can use a direct payment to arrange replacement care directly, to let you take breaks from caring at the times when they will be most beneficial for you. Usually a direct payment for replacement care will be paid to the person you look after, while payments for any support that you need yourself will be paid to you. If the person you look after can't manage the money themselves, you may be able to manage it on their behalf.

Even if you choose to ask us to arrange services for you, we will tell you how much these are costing – this is known as a "personal budget".

■ Contacting Carers Northumberland

Carers Northumberland (www.carersnorthumberland.org.uk) can be contacted at:

- 107-109 Station Road, Ashington, Northumberland, NE63 8RS
- Phone: 01670 320025
- Email: info@carersnorthumberland.org.uk

Appendix L

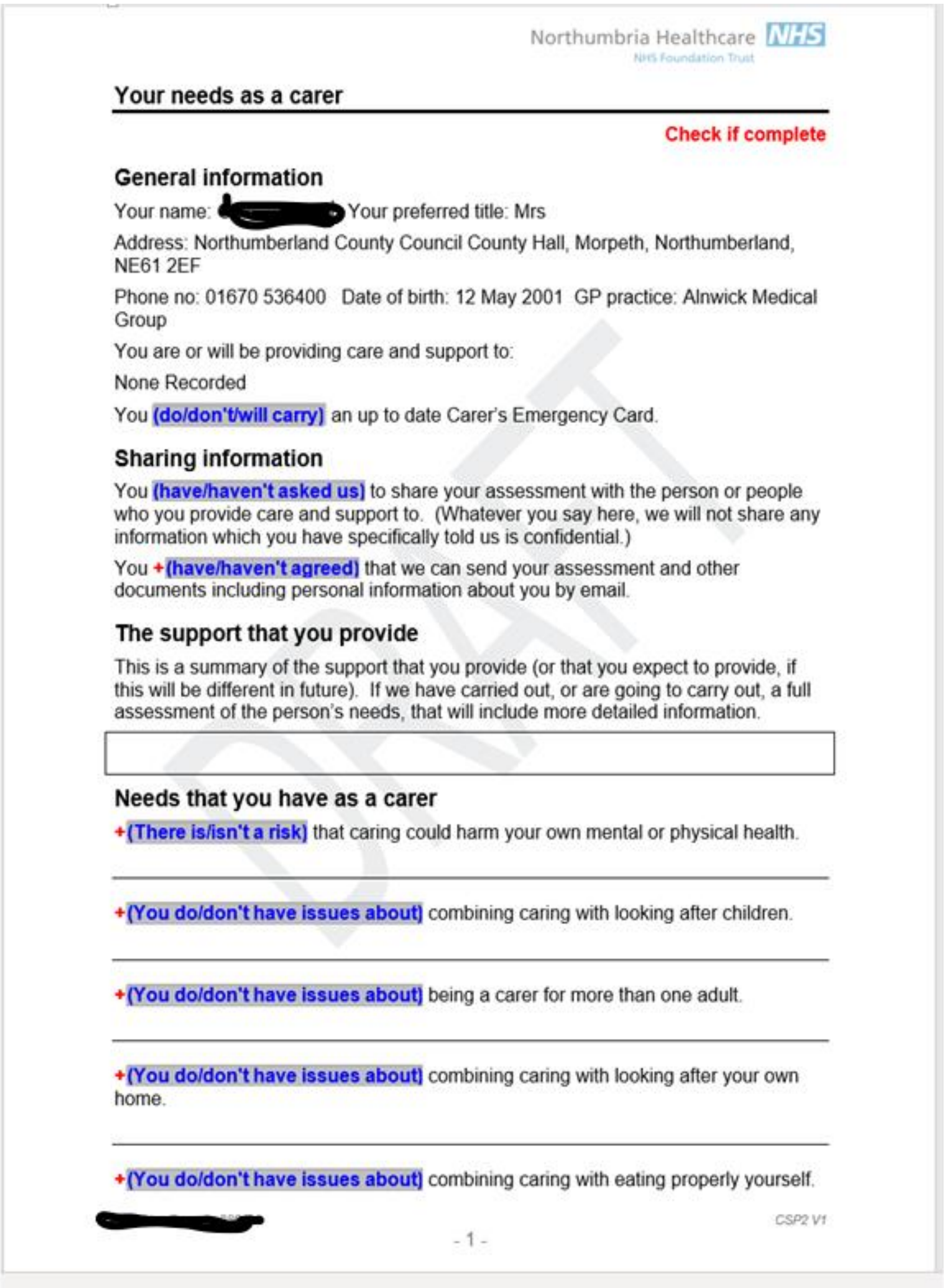
‘Mr Dementia Moves In’ – (Winnie)

Mr Dementia has just moved in,
Uninvited I might add and
What makes me really mad
Is he occupies the best chair in the house
And clearly has no intention of going!
He claimed he spoke to that other person (ie. me)
Who said he should pour himself a cup of tea
Join the ‘other people’ and watch TV.
He even plonked his boots on the sitting room table!
Mind, he’s a rotten house guest
Getting up and having a shower (and me get out of bed)
You can imagine what I said at half past three in the morning!
It’s hard not to shout, when he’s up and about
Getting dressed at four, ready to walk out the door
But doesn’t know just where and why he’s going.
There’s just him and me, but he sets breakfast for three
Lays out three forks, one knife, five table mats and one plate
Causing chaos wherever he goes,
Leaving his clothes all over the place
And piles of unopened letters
At the bottom of the bedroom wardrobe.
I try to hint that he’s not welcome
And the sooner Mr Dementia leaves the better
But he has a thick skin, and forever asking
Me where he put his bag and wallet.
After a while, I get used to his losing things.
I go for walks, go shopping – anything to forget about him
But he’s waiting for me, standing there
When I get back wondering where

He put his blasted bag and wallet.
I have to get used to the silences, him always sleeping
Not speaking, always there, half there
The proverbial elephant in the room
Our harbinger of doom – Mr Dementia!
How bad will it get? No-one knows yet
It's funny how I've got more used to him now
Living alongside, always there, wondering where
He's put that confounded bag and wallet?

Appendix M

Blank Carer Assessment Form



Northumbria Healthcare **NHS**
NHS Foundation Trust

Your needs as a carer

Check if complete

General information

Your name: [redacted] Your preferred title: Mrs

Address: Northumberland County Council County Hall, Morpeth, Northumberland, NE61 2EF

Phone no: 01670 536400 Date of birth: 12 May 2001 GP practice: Alnwick Medical Group

You are or will be providing care and support to:

None Recorded

You **(do/don't/will carry)** an up to date Carer's Emergency Card.

Sharing information

You **(have/haven't asked us)** to share your assessment with the person or people who you provide care and support to. (Whatever you say here, we will not share any information which you have specifically told us is confidential.)

You +**(have/haven't agreed)** that we can send your assessment and other documents including personal information about you by email.

The support that you provide

This is a summary of the support that you provide (or that you expect to provide, if this will be different in future). If we have carried out, or are going to carry out, a full assessment of the person's needs, that will include more detailed information.

Needs that you have as a carer

+**(There is/isn't a risk)** that caring could harm your own mental or physical health.

+**(You do/don't have issues about)** combining caring with looking after children.

+**(You do/don't have issues about)** being a carer for more than one adult.

+**(You do/don't have issues about)** combining caring with looking after your own home.

+**(You do/don't have issues about)** combining caring with eating properly yourself.

[redacted]

Northumbria Healthcare NHS
NHS Foundation Trust

+(You do/don't have issues about) making sure you have enough time for your own family life and friendships.

+(You do/don't have issues about) combining caring with paid or voluntary work.

+(You do/don't have issues about) combining caring with education or training.

+(You do/don't have issues about) getting out to the shops and other places where you need to go.

+(You do/don't have issues about) finding time for leisure activities that matter to you.

+(You do/don't also have) other issues because of caring.

Information which you have told us in confidence

You **+(do/don't have)** additional confidential comments.

Support from us

After taking account of the other sources of support available to you, we have decided that you **+(also need/don't need)** further support for which we may be responsible, involving either adjustments to the care and support arrangements for the person you care for, or direct support for you.

Disagreements

There are **+(Disagreements/No disagreements)** about this plan.

Bibliography

Ackerly, B. A. and True, J. (2020) *Doing Feminist Research in Political and Social Science, ProQuest Ebook Central* [Online]. http://ebookcentral.proquest.com/lib/ncl/detail.action?docID=6234560. (Accessed: 5 September 2022).

Adams, T.E., Holman, J.S. and Ellis, C. (2014) *Autoethnography*. New York: Oxford University Press.

Addison, M., Breeze, M. and Taylor, Y. (2022) *The Palgrave Handbook of Imposter Syndrome in Higher Education,* Springer International Publishing AG, Cham. Available at: ProQuest Ebook Central. https://ebookcentral.proquest.com/lib/ncl/detail.action?docID=6951417 (Accessed: 16 September 2022).

Adler, G. and Rottunda, S.J. (2017) ‘Ethical Considerations for the Driver with Dementia’, in Catic, A. (ed.) *Ethical Considerations and Challenges in Geriatrics*. Springer, Cham. pp. 75-85. [Online]. https://doi.org/10.1007/978-3-319-44084-2_7 (Accessed: 10 June 2022).

Agarwal, B. and Panda, P. (2007) 'Toward Freedom from Domestic Violence: The Neglected Obvious', *Journal of Human Development,* 8(3), pp. 359-388. [Online]. Available at: DOI: 10.1080/14649880701462171 (Accessed: 8 June 2022).

Age UK (2022a) *Northumberland Age UK.* Available at: https://www.ageuk.org.uk/northumberland/ (Accessed: 1 June 2022).

Age UK (2022b) *Attendance Allowance.* Available at: https://www.ageuk.org.uk/information-advice/money-legal/benefits-entitlements/attendance-allowance/ (Accessed: 7 June 2022).

Age UK (2019) *Breaking Point, The Social Care Burden on Women.* Available at: https://www.ageuk.org.uk/contentassets/c3dac0771e614672b363c5fe7e6f826e/breaking-point-age-uk.pdf (Accessed: 19 April 2022).

Age UK (2016) *The Internet and Older People in the UK – Key Statistics*. Available at: https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/active-communities/rb_july16_older_people_and_internet_use_stats.pdf, (Accessed: 8 January 2023).

Albert, K., Brundage, JS., Sweet, P. and Vandenberghe, F. (2020) 'Towards a Critical Realist Epistemology?', *Journal for the Theory of Social Behaviour*, 50(357– 372). [Online]. Available at: https://doi.org/10.1111/jtsb.12248 (Accessed: 7 September 2022).

Allen, F., Cain, R. and Meyer, C. (2020) 'Seeking Relational Information Sources in the Digital Age: A Study into Information Source Preferences Amongst Family and Friends of Those with Dementia', *Dementia*, 19(3), pp. 766–785. [Online]. Available at: DOI: 10.1177/1471301218786568 (Accessed: 27 June 2022).

Alston, P. (2018) 'Statement on Visit to the United Kingdom, by Professor Philip Alston, United Nations Special Rapporteur on Extreme Poverty and Human Rights', [Online]. Available at: www.ohchr.org/Documents/Issues/Poverty/EOM_GB_16Nov2018.pdf (Accessed: 14 June 2022).

Alzheimer's Disease International (2022*) World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support.* Available online: https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf (Accessed: 12 October 2022).

Alzheimer's Research UK (2022a) *Mild Cognitive Impairment*. Available at: https://www.alzheimersresearchuk.org/dementia-information/types-of-dementia/mild-cognitive-impairment/ (Accessed: 7 November 2022).

Alzheimer's Research UK (2022b) *Dementia Statistics Hub Numbers of People in the UK.* Available at: https://www.dementiastatistics.org/statistics/numbers-of-people-in-the-uk-2/ (Accessed: 6 January 2023).

Alzheimer's Research UK (2022c) *ARUK CCG Map.* Available at: https://visualisation.polimapper.co.uk/?dataSetKey=aruk-ccg-map#con_over=Northumberland (Accessed: 14 April 2022).

Alzheimer's Research UK (2022d) *Dementia Statistics Hub Care Services.* Available at: https://www.dementiastatistics.org/statistics/care-services/ (Accessed: 20 April 2022).

Alzheimer's Research UK (2022e) *Why are Women Bearing more of the Impact of Dementia.* Available at: https://www.alzheimersresearchuk.org/blog/why-women-are-bearing-more-of-the-impact-of-dementia/ (Accessed: 27 June 2022).

Alzheimer's Research UK (2016) *Symptoms.* Available at: https://www.alzheimersresearchuk.org/about-dementia/types-of-dementia/alzheimers-disease/symptoms/ (Accessed: 3 June 2022).

Alzheimer’s Society (2023) *What Causes Young Onset Dementia?* Available at: https://www.alzheimers.org.uk/about-dementia/types-dementia/what-causes-young-onset-dementia (Accessed: 6 January 2023).

Alzheimer’s Society (2022a) *Research into New Treatments.* Available at: https://www.alzheimers.org.uk/about-dementia/treatments/drugs/NICE-guidance-summary#content-start (Accessed: 25 April 2022).

Alzheimer’s Society (2022b) Receiving a Dementia Diagnosis. Available at: https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/dementia-diagnosis/receiving-diagnosis, (Accessed: 9 November 2022).

Alzheimer’s Society (2022c) *Replacement Care (respite care) in England***.** Available at: https://www.alzheimers.org.uk/get-support/help-dementia-care/replacement-care-respite-care-england (Accessed: 25 April 2022).

Alzheimer’s Society (2022d) *Safeguarding and Dementia.* Available at: https://www.alzheimers.org.uk/get-support/legal-financial/safeguarding (Accessed: 7 June 2022).

Alzheimer’s Society (2022e) *Driving and Dementia.* Available at: https://www.alzheimers.org.uk/get-support/staying-independent/driving-dementia (Accessed: 9 June 2022).

Alzheimer’s Society (2022f) *‘How do you Know if Someone Needs to Move into a Care Home?*’. Available at: https://www.alzheimers.org.uk/get-support/help-dementia-care/care-homes-decision, (Accessed: 18 August 2022).

Alzheimer’s Society (2022g) *Alzheimer's Society's view on NHS Continuing Healthcare***.** Available at: https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/nhs-continuing-healthcare, (Accessed: 14 November 2022).

Alzheimer’s Society (2022h) Paying for Care and Support in England. Available at: https://www.alzheimers.org.uk/get-support/legal-financial/care-home-fees#content-start, (Accessed: 9 November 2022).

Alzheimer’s Society (2021) *Feelings after Diagnosis of Dementia*. Available: https://www.alzheimers.org.uk/get-support/help-dementia-care/feelings-after-diagnosis-dementia (Accessed: 27 June 2022).

Alzheimer’s Society (2018a) *What is mixed dementia*? Available at: https://www.alzheimers.org.uk/blog/what-is-mixed-dementia (Accessed: 6 January 2023).

Alzheimer’s Society (2018b) *Dementia Friendly Rural Communities Guide.* Available at: https://www.alzheimers.org.uk/sites/default/files/2019-07/AS_DF_NEW_Rural_Guide_Online_09_07_19.pdf (Accessed: 19 April 2022).

Alzheimer’s Society (2017) *Turning Up the Volume.* Available at: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/turning_up_the_volume_unheard_voices_of_people_with_dementia.pdf (Accessed: 6 June 2022).

Alz.Org (2018a) *Stages of Alzheimer’s.* Available at: https://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp (Accessed on 3 June 2022).

Alz.Org (2018b) *Korsakov’s Syndrome.* Available at: https://www.alz.org/dementia/wernicke-korsakoff-syndrome-symptoms.asp#treatments (Accessed: 3 June 2022).

Aminzadeh, F., Byszewski, A., Molnar, F.J. and Eisner, M. (2007) Emotional Impact of Dementia Diagnosis: Exploring Persons with Dementia and Caregivers’ Perspectives, *Aging & Mental Health*, 11(3), pp. 281-290. [Online]. DOI: 10.1080/13607860600963695 (Accessed: 27 June 2022).

Anderson, E. (2010) ‘Justifying the Capabilities Approach to Justice’, in Brighouse, H. and Robeyns, I. (ed) *Measuring Justice: Primary Goods and Capabilities*, pp. 81–100. [Online]. DOI: 10.1017/CBO9780511810916.004 (Accessed: 8 June 2022).

Andrews, E.S. (2017) ‘Institutionalising Senile Dementia in 19th Century Britain’, in Higgs, P and Gilleard, C. (ed) *Ageing Dementia and the Social Mind*, Chichester: Wiley Blackwell, pp. 69-82.

Arendt, H. (1958) The Human Condition, Chicago: University of Chicago Press.

Arneson, R.J. (2010) ‘Two Cheers for Capabilities’, in Brighouse, H. and Robeyns, I. (ed) *Measuring Justice: Primary Goods and Capabilities*. Cambridge: Cambridge University Press, pp. 101-127.

Asthana, S., Halliday, J. and Gibson, A. (2009). ‘Social Exclusion and Social Justice: A Rural Perspective on Resource Allocation’, *Policy & Politics,* 37(2), pp 201-214.

Atkinson, R. (1998) *The Life Story Interview*. London: Sage.

Babb, J. (2012) *Empirical Political Analysis,* Harlow: Pearson Education Ltd.

Bache, I. and Scott, K. (2018) *The Politics of Wellbeing Theory, Policy and Practice*. Palgrave MacMillan. [Online]. Available at: https://link.springer.com/book/10.1007/978-3-319-58394-5 (Accessed: 8 June 2022).

Bache, I., Reardon, L. and Anand, P. (2015) 'Wellbeing as a Wicked Problem: Navigating the Arguments for the Role of Government. *Journal of Happiness Studies,* February 2015, pp. 1-20.

Baier, A. C. (2018) The Need for More Than Justice. in (ed) Held, V. *Justice and Care, Essential Readings in Feminist Ethics.* London: Routledge, pp. 47-60.

Baier, A. (1987) 'Hume: The Woman's Moral Theorist?' in Kittay, E.F. and Meyers, D (ed). *Women and Moral Theory.* USA: Rowman & Littlefield, pp.37-55.

Baldwin, C. (2005) 'Narrative, Ethics and People with Severe Mental Illness', *Australian & New Zealand Journal of Psychiatry*, 39(11–12), pp. 1022–1029. [Online]. DOI: 10.1080/j.1440-1614.2005.01721.x. (Accessed: 9 January 2023).

Barad, K. (2007) *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning*. New York, USA: Duke University Press.

Barbour, R.S. (2008) *Introducing Qualitative Research: A Student's Guide to the Craft of Doing Qualitative Research*. Los Angeles, CA; London: Sage Publications.

Barnes, C. and Mercer, G. (2004) *Implementing the Social Model of Disability: Theory and Research.* Leeds: The Disability Press. Available at: https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-implementing-the-social-model-chapter-3.pdf (Accessed: 14 June 2022).

Barnett, C. (2005) 'Who Cares', in Cloke, P., Crang, P. and Goodwin, M. (ed) '*Introducing Human Geographies'*. London: Routledge, pp. 588-601.

Barry, B. (1995) *Justice as Impartiality*. Oxford: Oxford University Press.

Bartlett, R. (2016) 'Scanning the Conceptual Horizons of Citizenship', *Dementia,* 15 (3), pp. 453–46.

Bartlett R. (2014). 'Citizenship in action: the lived experiences of citizens with dementia who campaign for social change'. *Disability & Society* 29: 1291–1304. Available at: DOI:10.1080/09687599.2014.924905. (Accessed: 9 January 2023).

Bartlett, R. and O’Connor, D. (2010) *Broadening the Dementia Debate: Towards Social Citizenship*. Bristol: The Policy Press.

Bayles, K.A. and Tomoeda, C.K. (2007) *Cognitive-Communication Disorders of Dementia.* Abingdon: Plural Publishing Inc.

BBC (2022) *Our Dementia Choir Sings Again*. Available at: https://www.bbc.co.uk/programmes/m001d0pf (Accessed: 27 December 2022).

BBC Radio 4 (2017) *The Today Programme* - 16 August. [Online]. Available at: http://www.bbc.co.uk/programmes/b090vdb9#play (Accessed: 16 August 2017).

BBC (2016a) *Dementia Now Leading Cause of Death*. Available at: https://www.bbc.co.uk/news/health-37972141 (Accessed: 24 June 2022).

BBC (2016b) *Too Many Delay Seeking Dementia Diagnosis, Charity Says*. Available at: https://www.bbc.co.uk/news/health-36286016 (Accessed: 27 June 2022).

BBC (2016c) *Public Toilets Wiped out in Parts of UK.* Available at: https://www.bbc.co.uk/news/uk-36405414 (Accessed: 15 July 2022).

Behuniak, S.M. (2010) ‘Towards a model of dementia: power as compassionate care’, *Journal of Ageing Studies*, 24(4), pp.231-240.

Behuniak, S. M. (2011) “The living dead? The construction of people with Alzheimer's disease as zombies,” *Ageing and Society*. Cambridge University Press, 31(1), pp. 70–92. [Online]. Available at: DOI: 10.1017/S0144686X10000693 (Accessed: 22 August 2022).

Bell, J. (1993) *Doing Your Research Project*. Open University Press: Buckingham.

Bell, D., McLaughlin, J., Hull, M. and Morrison, L. (no date) *How To Improve the Accessibility of Public and Customer Toilets*. Available at: https://static1.squarespace.com/static/5d25e9848ff6870001951193/t/5d499dd5a45265000138dfbe/1565105641444/Accessible+Spaces+WEB+Final.pdf (Accessed: 15 July 2022).

Benhabib, S. (1987) ‘The Generalized and Concrete Other: The Kohlberg Gilligan Controversy and Feminist Theory’ in Benhabib, S. and Cornell, D. (ed). *Feminism as Critique: Essays on the Politics of Gender in Late-Capitalist Societies*. Cambridge: Polity. Feminism as Critique Oxford.

Berger, F.R. (1984) *Happiness, Justice and Freedom.* London: University of California Press.

Berlin, I. (1969) *Four Essays on Liberty.* Oxford: Oxford University Press.

Bernard, H. R., & Ryan, G. (1998). ‘Text analysis: Qualitative and quantitative methods’ in H. R. Bernard (ed). *Handbook of methods in cultural anthropology*. Walnut Creek, CA: Alta Mira Press, pp. 595–645.

Besio, K. (2009) ‘Autoethnography’, in Kitchin, R. and Thrift, N. (ed) *International Encyclopedia of Human Geography*. Elsevier, pp. 240-243. [Online]. Available at: https://doi.org/10.1016/B978-008044910-4.00405-3. (Accessed: 18 February 2022).

Bhandary, A. (2019). *Freedom to Care: Liberalism, Dependency Care, and Culture* (1st ed). Routledge. [Online]. Available at: https://doi.org/10.4324/9780429283093 (Accessed: 13 June 2022).

Bhaskar, R. (2017) *The Order of Natural Necessity*. Createspace Independent Publishing Platform.

Bhaskar, R. (2011) *Reclaiming Reality.* Abingdon, Oxon:Routledge.

Bichard, J-A. and Knight, G. (2012) ‘Improving Public Services Through Open Data: Public Toilets’. *Proceedings of the Institution of Civil Engineers*. Municipal engineer. 165 (3), pp.157–165.

Binder, M. (2014) ‘Subjective Well-Being Capabilities: Bridging the Gap Between the Capability Approach and Subjective Well-Being Research’, *Journal of happiness studies*, 15(5), pp. 1197–1217.

Birt, L., Poland, F., Csipke, E. and Charlesworth, G. (2017) ‘Shifting Dementia Discourses from Deficit to Active Citizenship’, in Gilleard C., and Higgs, P. (ed). *Ageing, Dementia and the Social Mind.* Oxford: Wiley Blackwell, pp.24-36.

Blackstock, K., Innes, A., Cox, S., Smith, A. and Mason, A. (2006) ‘Living with dementia in rural and remote Scotland: Diverse experiences of people with dementia and their carers’. *Journal of rural studies*. 22(2), pp.161–176.

Blandin, K. & Pepin, R. (2017) ‘Dementia Grief: A Theoretical Model of a Unique Grief Experience’. *Dementia.* 16(1), pp. 67–78.

Blyth, C. (2017) *On Time*. London: William Collins.

BMJ (2021) *Patients have struggled to access general practice during the pandemic, Healthwatch reports,* Available online: Patients have struggled to access general practice during the pandemic, Healthwatch reports | The BMJ, (Accessed 5 March 2022).

Boise, L., Morgan, D.L., Kaye, J. and Camicioli, R. (1999) 'Delays in the diagnosis of dementia: Perspectives of family caregivers', *American Journal of Alzheimer's Disease,* 14(1), pp. 20–26. [Online]. Available at: DOI: 10.1177/153331759901400101 (Accessed: 29 June 2022).

Bok, D. (2010) *The Politics of Happiness*. Princeton: Princeton University Press.

Bond, J., Corner, L. and Graham, R. (2004) 'Social Science theory on dementia research: normal ageing, cultural representation and social exclusion', in Innes, A., Archibald, C. and Murphy, C. (ed) *Dementia and Social Inclusion: Marginalised Groups and Marginalised Areas of Dementia Research, Care and Practice*. London and Philadelphia: Jessica Kingsley Publishers, pp 220-36.

Booth, R. and Duncan, P. (2022) *Dementia patients in England facing 'national crisis' in care safety*. Available at: https://www.theguardian.com/society/2022/dec/28/dementia-patients-in-england-facing-national-crisis-in-care-safety (Accessed: 1 January 2023).

Booth, P. (2012) 'Introduction'*….and the Pursuit of Happiness, Well Being and the Role of Government',* London: Profile Books Ltd.

Bottery, S. and Mallorie, S. (2023) *The King's Fund: Social Care 360* Available at: https://www.kingsfund.org.uk/publications/social-care-360, (Accessed: 6 July 2023).

Bottery, S. (2022) *Reform of adult social care: some progress, but nowhere near enough.* Available at: https://www.kingsfund.org.uk/blog/2022/05/reform-adult-social-care-some-progress-nowhere-near-enough (Accessed: 1 January 2023).

Bowlby, S. (2012) 'Recognising the Time—Space Dimensions of Care: Caringscapes and Carescapes', *Environment and Planning A: Economy and Space,* 44(9), pp. 2101–2118. [Online]. Available at: DOI: 10.1068/a44492 (Accessed: 23 June 2022).

Bowlby, S., et al. (2010) *Interdependency and Care over the Lifecourse*, Taylor & Francis Group. *ProQuest Ebook Central*. [Online]. Available at: https://ebookcentral.proquest.com/lib/ncl/detail.action?docID=481002 (Accessed: 9 January 2023).

Boyatzis, R.E. (1998) *Transforming qualitative information: thematic analysis and code development.* Thousand Oaks, CA: Sage Publications.

Bozalek, V. and Hooyman, N.R. (2012) 'Ageing and Intergenerational Care: Critical/Political Ethics of Care and Feminist Gerontology Perspectives', *Agenda,* 94(26), pp. 37-47.

Bradley, T. (1986) ‘Poverty and Dependency in Village England’, in Lowe, P., Bradley, T and Wright, S. *Deprivation and Welfare in Rural Areas.* Norwich: Geo Books.

Braun, V. and Clarke, V. (2013) *Successful Qualitative Research: A Practical Guide for Beginners.* London: SAGE.

Braun, V. and Clarke, V. (2006) ‘Using Thematic Analysis in Psychology’. *Qualitative Research in Psychology*. 3(2), pp77–101.

Brighouse, H. and Robeyns, I. (2010) *Measuring justice: primary goods and capabilities*. Cambridge [England] New York: Cambridge University Press.

Brison, S.J. (2017) Personal Identity and Relational Selves, in (ed). Garry, S.J. Khader and A. Stone *The Routledge Companion to Feminist Philosophy*. Abingdon: Routledge, pp. 218-230.

Britten, K. (1969) *John Stuart Mill.* London: Constable and Company Ltd.

Brock, D.W. (1988) ‘Justice and the Severely Demented Elderly’. *Journal of Medicine and Philosophy* 13(1), pp. 73– 99.

Brooker, D. (2007) *Person Centred Dementia Care: Making Services Better*, London and Philadelphia: Jessica Kingsley Publishers.

Bruens, M. (2014) Dementia: Beyond Structures of Medicalisation and Cultural Neglect, in Baars, J., Dohmen, J., Grenier, A. and Phillipson, C. *Ageing, Meaning and Social Structure.* Bristol: Policy Press, pp 81-96.

Bryant, A. and Charmaz, K. (2007) *‘The SAGE handbook of grounded theory’*. London: SAGE.

Bubeck, D. (2002) ‘Justice and the Labor of Care’, in Kittay, E. F. and Feder, E. K.(ed) *The Subject of Care: Feminist Perspectives of Dependency*. Oxford: Rowman and Littlefield Publishers, pp. 160-185.

Bubeck, D. (1995). ‘Introduction’, in *Care, Gender, and Justice.* Oxford: Oxford University Press. [Online]. Available at: https://oxford-universitypressscholarship-com.libproxy.ncl.ac.uk/view/10.1093/acprof:oso/9780198279907.001.0001/acprof-9780198279907-chapter-1 (Accessed: 29 July 2021).

Burchardt, T. and Vizard, P. (2011) ‘Operationalizing’ the Capability Approach as a Basis for Equality and Human Rights Monitoring in Twenty-first-century Britain’, *Journal of Human*

Development and Capabilities, 12(1), pp. 91-119. [Online]. Available at: DOI: 10.1080/19452829.2011.541790 (Accessed: 1 August 2022).

Burchardt, T. and Vizard, P. (2014). 'Using the Capability Approach to Evaluate Health and Care for Individuals and Groups in England', in: Ibrahim, S. and Tiwari, M. (ed) *The Capability Approach*. London: Palgrave Macmillan. [Online]. Available at: https://doi.org/10.1057/9781137001436_7 (Accessed: 1 August 2022).

Burchardt, T. (2004) 'Capabilities and Disability: The Capabilities Framework and the Social Model of Disability, *Disability & Society*, 19(7), pp. 735-751. [Online]. Available at: DOI: 10.1080/0968759042000284213 (Accessed: 17 October 2022).

Burr, V. (2004) *Social constructionism*. 2nd ed. Hoboken: Taylor and Francis.

Bury M. (1982) 'Chronic illness as biographical disruption', *Sociology of Health and Illness*. 4(2) pp.167-82. [Online]. Available at: DOI: 10.1111/1467-9566.ep11339939. PMID: 10260456 (Accessed: 9 January 2023).

Butler, J. (2016) *Frames of War – When is Life Grievable.* London: Verso.

Butler, J. (2004) *Undoing gender*. Abingdon: Routledge.

Butler, J. (1993) *Bodies that matter: on the discursive limits of "sex".* New York: Routledge.

Butler, J. (1990) *Gender trouble: feminism and the subversion of identity*. New York: Routledge.

Byszewski, A.M., Molnar, F.J. and Aminzadeh, F. (2010) 'The Impact of Disclosure of Unfitness to Drive in Persons with Newly Diagnosed Dementia: Patient and Caregiver Perspectives', *Clinical Gerontologist*, 33(2), pp. 152-163. [Online]. Available at: DOI: 10.1080/07317110903552198 (Accessed: 14 June 2022).

Cahill, S. (2018) *Dementia and Human Rights*. Bristol University Press. [Online]. Available at: DOI: 10.46692/9781447331384 (Accessed: 1 November 2022).

Campbell, L., Gray, N., Meletis, Z., Abbott, J. and Silver, J. (2006) 'Gatekeepers and Keymasters: Dynamic Relationships of Access in Geographical Fieldwork', *Geographical Review*, 96(1), pp.97-121.

Card, Claudia (1990) 'Caring and Evil', *Hypatia* 5(1), pp101-108.

Carduff, E., Finucane, A., Kendall, M., Jarvis, A., Harrison, N., Greenacre, J., and Murray, S.A. (2014) ‘Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources’, *BMC Family Practice,* 15(1), p.48-48.

Care Home.co.uk (2022) *Who pays for care home fees when savings run out?* Available at: https://www.carehome.co.uk/advice/who-pays-for-a-care-home-when-the-money-runs-out?faq=2 (Accessed: 18 August 2022).

Carers Northumberland (2022a) *Annual Report 2021-2022.* Available at: https://img1.wsimg.com/blobby/go/4ab9dc9c-ac15-450e-8164-b7dc02250af2/Annual%20Report%202021%20-2022%20(5).pdf (accessed: 6 January 2023).

Carers Northumberland (2022b) *Carers Northumberland Services.* Available at: https://carersnorthumberland.org.uk/our-services (Accessed: 1 June 2022).

Carers Trust (2022a) *About Caring.* Available at: https://carers.org/about-caring/about-caring (Accessed: 18 February 2022).

Carers Trust (2022b) *Pushed to the Edge.* Available at: https://carers.org/downloads/resources-pdfs/pushed-to-the-edge.pdf (Accessed: 14 April 2022).

Carers Trust (2022c) *How Employers Can Help Carers.* Available at: https://carers.org/working-and-learning/how-employers-can-support-carers (Accessed: 3 June 2022).

Carers Trust (2014) *Husband, Partner, Dad, Son, Carer.* Available at: https://carers.org/resources/all-resources/83-husband-partner-dad-son-carer (Accessed: 8 January 2023).

Carers UK (2022) *10 facts about women and caring in the UK on International Women’s Day*. [Online]. Available at: https://www.carersuk.org/news-and-campaigns/features/10-facts-about-women-and-caring-in-the-uk-on-international-women-s-day (Accessed: 29 June 2022).

Carers UK (2021a) *Breaks or Breakdown – Carers Week 2021 Report.* Available at: https://www.carersuk.org/for-professionals/policy/policy-library/breaks-or-breakdown-carers-week-2021-report (Accessed: 5 January 2022).

Carers UK (2021b) *State of Caring Report 2021.* Available at: https://www.carersuk.org/policy-and-research/policy-library/ (Accessed: 24 February 2022).

Carers UK (2021c) *Carers UK Breaks Factsheet.* Available at: https://www.carersuk.org/images/Factsheets/2021-22_factsheets/Carers_UK_breaks_factsheet_2021-22-2.pdf (Accessed: 5 January 2022).

Carers UK (2020a) *Carers Week 2020 Research Report.* Available at: https://www.carersuk.org/images/CarersWeek2020/CW_2020_Research_Report_WEB.pdf (Accessed: 1 March 2022).

Carers UK (2020b) *Caring Behind Closed Doors – 6 Months On.* Available at: caringbehindcloseddoorsoct20v6.pdf (Accessed: 21 February 2022).

Carers UK (2019) *Facts About Carers Policy Briefing August 2019*. Available at: https://www.carersuk.org/images/Facts_about_Carers_2019.pdf, (Accessed: 9 November 2022).

Carers UK (2014) *Carers Assessments*. Available at: https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment (Accessed: 2 June 2022).

Carpenter, B.D., Xiong, C., Porensky, E.K., Lee, M.M., Brown, P.J., Coats, M., Johnson, D. and Morris, J.C. (2008), ‘Reaction to a Dementia Diagnosis in Individuals with Alzheimer's Disease and Mild Cognitive Impairment’, *Journal of the American Geriatrics Society,* 56, pp. 405-412. [Online]. Available at: https://doi.org/10.1111/j.1532-5415.2007.01600.x (Accessed: 27 June 2022).

Carr, D. B. and O’Neill, D. (2015) ‘Mobility and safety issues in drivers with dementia’, *International Psychogeriatrics*. Cambridge University Press, 27(10), pp. 1613–1622. [Online]. Available at: DOI: 10.1017/S104161021500085X (Accessed: 9 January 2023).

Casey, D. A., Antimisiaris, D., and O'Brien, J. (2010) ‘Drugs for Alzheimer's disease: are they effective?’, *P & T: a peer-reviewed journal for formulary management, 35* (4), pp. 208–211.

Castells, M. (1978) ‘*City, Class and Power’*, London: MacMillan Press Ltd.

Centre for Health and the Public Interest (2016) *The failure of privatised adult social care in England: what is to be done?,* Available at: CHPI-SocialCare-Oct16-Proof01a.pdf, (Accessed: 4 October 2023).

Chakravartty, A. (2017) ‘Scientific Realism’, *The Stanford Encyclopaedia of Philosophy,* Summer Edition, Edward N. Zalta (ed). [Online]. Available at:

https://plato.stanford.edu/archives/sum2017/entries/scientific-realism/ (Accessed: 22 September 2022).

Changing Places (2022) *What are Changing Places Toilets.* Available at: https://www.changing-places.org/ (Accessed: 3 June 2022).

Charmaz, K. (2015) 'Grounded Theory', in Smith, J.A. (ed.) *Qualitative Psychology – A Practical Guide to Research Methods*. London: Sage, pp. 53-84.

Charmaz, K. (2014) *Constructing Grounded Theory*. 5th edn. London: Sage.

Chaudhuri, S. (2017) Witches, Activists, and Bureaucrats: Navigating Gatekeeping in Qualitative Research, International Journal of Sociology, 47(2), pp. 131-145. [Online]. Available at: DOI: 10.1080/00207659.2017.1300469 (Accessed: 9 January 2023).

Chisale, S. (2018). '*Ubuntu* as care: Deconstructing the gendered *Ubuntu*'. *Verbum et Ecclesia, 39*(1). [Online]. Available at: DOI :https://doi.org/10.4102/ve.v39i1.1790 (Accessed 30 July 2021).

Cipriani, G., Lucetti, C., Nuti, A. and Danti, S. (2014) 'Wandering'. *Psychogeriatrics,* 14 pp. 135-142. [Online] Available at: https://doi.org/10.1111/psyg.12044 (Accessed: 13 December 2022).

Citizens Advice (2022) *Citizens Advice Northumberland.* Available at: https://www.citizensadvicenorthumberland.org.uk/ (Accessed: June 2022)

Clare, L. and Shakespeare, T. (2004) 'Negotiating the Impact of Forgetting'. *Dementia,* 3(2), pp. 211–232. [Online]. Available at: https://doi.org/10.1177/1471301204042338 (Accessed: 9 January 2023).

Clark, T., Foster, L., Sloan, L. and Bryman, A. (2021) *Bryman's Social Research Methods,* 6th edn. Oxford: Oxford University Press.

Clarke, A.E. (2012) 'Feminism, Grounded Theory and Situational Analysis Revisited', in Hesse-Biber, S. (ed.) *The Handbook of feminist research: Theory and praxis,* 2nd edn. Thousand Oaks, London: Sage, pp. 388-412.

Clarke, C. L. and Bailey, C. (2016) 'Narrative citizenship, resilience and inclusion with dementia: On the inside or on the outside of physical and social places', *Dementia*, 15(3), pp. 434–452. [Online]. Available at: DOI: 10.1177/1471301216639736 (Accessed: 9 January 2023).

Clarke, V. and Braun, V. (2017) ‘Thematic analysis’, *The Journal of Positive Psychology*, 12(3), pp. 297-298. [Online]. Available at: DOI: 10.1080/17439760.2016.1262613 (Accessed: 15 September 2022).

Clement, G. (1996) *Care, Autonomy and Justice: Feminism and the Ethic of Care*. Boulder, CO: Westview Press.

Coenen, A. (2016). Brain Disorders Associated with Dementia. *Manasa, 5*(1), pp. 57-75.

Cohen, L. (2006) ‘Introduction’ in *Thinking About Dementia, Culture, Loss and the Anthropology of Senility*. London: Rutgers University Press, pp. 1-19.

Collard, D. (2006) ‘Research on Well-Being: Some Advice from Jeremy Bentham’, P*hilosophy of the Social Sciences*, 36(3), pp. 330–354.

Collier, A. (1999) *Being and Worth*. London: Routledge

Conlon, C., Carney, G., Timonen, V., and Scharf, T. (2015) ‘‘Emergent reconstruction’ in grounded theory: learning from team-based interview research’, *Qualitative Research*, 15(1), pp. 39–56. [Online]. Available at: DOI: 10.1177/1468794113495038 (Accessed: 9 January 2023).

Conradson, D. (2003) ‘Geographies of care: spaces, practices, experiences’, *Social & Cultural Geography*, 4, pp. 451-454.

Cook, I. (2005) ‘Participant Observation’, in Flowerdew, R. and Martin, D. (ed.) *Methods in Human Geography,* 2nd edn. Harlow: Pearson Education Ltd, pp. 167-188.

Cooper, A., Law, R., Malthus, J., and Wood, P. (2000) ‘Rooms of Their Own: Public Toilets and Gendered Citizens in a New Zealand City, 1860–1940’. *Gender, Place and Culture*. 7, pp.417–433.

Corbin, J. and Strauss, A. (2008) *Basics of Qualitative Research*, 3rd edn. London: Sage.

Corbin, J. and Morse, J.M. (2003) ‘The Unstructured Interactive Interview: Issues of Reciprocity and Risks When Dealing with Sensitive Topics’, *Qualitative Inquiry*, June, pp. 335-354.

CQC (2022) *State of Care*. Available at: https://www.cqc.org.uk/publication/state-care-202122/ (Accessed: 17 November 2022).

Craig, G and Manthorpe, J. (2000) *Fresh fields Rural social care: research, policy and practice agendas,* Available at: https://www.quickonthenet.com/2005/7460/docs/freshfields.pdf, (Accessed: 8 January 2023).

Crenshaw, K. (1991) ‘Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color’, *Stanford Law Review*. 43(6), pp.1241–1299.

Crotty, M. (1998) *The Foundations of Social Research: Meaning and Perspective in the Research Process*. London: Sage Publications.

Cutchin, M.P. (2007) ‘Therapeutic Landscapes for Older People: Care with Commodification, Liminility and Ambiguity’, in Williams, A. (ed.) *Therapeutic Landscapes,* pp. 181-198. Aldershot: Ashgate Publishing Ltd.

Dalton, J., Thomas, S., Harden, M., Eastwood, A., and Parker, G. (2018) ‘Updated Meta-Review of Evidence on Support for Carers’, *Journal of Health Services Research & Policy.* 23(3) pp. 196-207. [Online]. Available at: DOI:10.1177/1355819618766559 (Accessed: 2 November 2022).

Danermark, B. and Gellerstedt, L.C. (2004) ‘Social Justice: Redistribution and Recognition—A Non-reductionist Perspective on Disability’, *Disability & Society,* 19(4), pp. 339-353. [Online]. Available at: DOI: 10.1080/0968759041000l689458 (Accessed: 15 August 2022).

Daniels, N. (2010) ‘Capabilities, Opportunity and Health’, in H. Brighouse and I. Robeyns (ed.), *Measuring Justice: Primary Goods and Capabilities*, pp. 131-149. Cambridge: Cambridge University Press.

Dankoski, M. E. (2000) ‘What makes research feminist?’, *Journal of Family Therapy* 2(1), pp. 3–19.

Davey, D. A. (2013) ‘Alzheimer’s Disease, Dementia, Mild Cognitive Impairment and the Menopause: A ‘Window of Opportunity’?’, *Women’s Health,* pp. 279–290. [Online]. Available at: DOI: 10.2217/WHE.13.22 (Accessed: 27 June 2022).

Davey, J., Nana, G., Joux de, V. and Arcus, M. (2004) ‘Accommodation Options for Older People in Aotearoa/New Zealand*’, NZ Institute for Research on Ageing/Business and Economic Research Ltd, for Centre for Housing Research*. Aotearoa/New Zealand.

Davies, J.C. (2011): ‘Preserving the “us Identity” through Marriage Commitment While Living with Early-stage Dementia.’ *Dementia* 10(2), pp. 217-34.

Davis, D. H.J. (2004) ‘Dementia: Sociological and Philosophical Constructions’, *Social Science & Medicine* (1982) 58(2) pp. 369-78.

Degnan, C. (2012) *Ageing Selves and the Everyday Life in the North of England.* Manchester: Manchester University Press.

De Graff, J. and Batker, D.K. (2011) *What's The Economy for Anyway.* New York: Bloomsbury Press.

Dementia Engagement and Empowerment Project (DEEP) (2016) *Our Dementia, Our Rights*. Available at: http://www.innovationsindementia.org.uk/wp-content/uploads/2018/01/Our-dementia-Our-rights-booklet.pdf, (Accessed: 1 November 2022).

Dementia Statistics Hub (2022) *People in the UK.* Available at: https://www.dementiastatistics.org/statistics/numbers-of-people-in-the-uk-2/ (Accessed: 21 February 2022).

Dementia UK (2020) *Lasting Power of Attorney.* Available at: https://www.dementiauk.org/get-support/legal-and-financial-information/lasting-power-of-attorney/ (Accessed: 2 June 2022).

Dementia UK (2019) *The Carers Assessment.* Available at: https://www.dementiauk.org/wp-content/uploads/2019/07/Carers-Assessment-new-style-WEB.pdf#:~:text=If%20you%20provide%20care%20to%20a%20friend%20or,and%20then%20receive%20support%20dependent%20upon%20their%20needs (Accessed: 6 June 2022).

Department for Transport (2016) *Older Car Drivers Factsheet.* Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/706517/older-car-drivers-factsheet.pdf (Accessed: 10 June 2022).

Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy*. London: DH Publications.

Department of Health and Social Care (2022a) *About Adult Social Care Reform.* Available at: https://engage.dhsc.gov.uk/social-care-reform/about-the-reforms/ (Accessed: 1 January 2023).

Department of Health and Social Care (2022b) *Care and Support Statutory Guidance*. Available online: https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#other-areas (Accessed: 2 January 2023).

Department of Health and Social Care (2021) *People at the heart of care adult social care reform, Policy Paper*. Available at: https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper/people-at-the-heart-of-care-adult-social-care-reform#executive-summary (Accessed: 1 January 2023).

De Silva, D.K. and Mukherjee, S. (2014) *Staff training in dementia for care homes.* Available at: https://www.gmjournal.co.uk/staff-training-in-dementia-for-care-homes#:~:text=In%20particular%2C%20a%20lack%20of%20training%20in%20dementia,social%20activity%20being%20available%20in%20the%20care%20home., (Accessed: 19 January 2023).

De Vos, M. (2012). The Unbearable Lightness of Happiness Policy in IEA '*....and the Pursuit of Happiness, Well Being and the Role of Government',* 7, London: Profile Books Ltd.

Dias, D. (2018) *The Ten Types of Human*. London: Windmill Books (Penguin Random House).

Dickerson, A. (2022) *Transportation planning for dementia, in Alzheimer's Disease International Report 2022,* pp. 211-212. [Online]. Available at: https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf (Accessed: 12 October 2022).

Diener, E. (2009) *The Science of Well-Being: The Collected Works of Ed Diener*. Dordrecht: Springer.

Direct Line (2016) *Millions of Motorists Fail to Disclose Medical Conditions.* [Online]. Available at: https://www.directline.com/media/archive-2016/millions-of-motorists-fail-to-disclose-medical-conditions (Accessed: 10 June 2022).

Dohmen, J. (2014) 'My Own Life: Ethics, Ageing and Lifestyle', in Baars, J., Dohmen, J., Grenier, A. and Phillipson, C. *Ageing, Meaning and Social Structure, Connecting Critical and humanistic Gerontology* (ed). Bristol: Policy Press, pp 31-54.

Domenech, M. and Tirado, F.J. (1997) 'Rethinking Institutions in the Societies of Control', *International Journal of Transdisciplinary Studies,* 1(1).

Donaghy, P.C. and McKeith, I.G. (2014) 'The Clinical Characteristics of Dementia with Lewy Bodies and a Consideration of Prodromal Diagnosis', *Alzheimer's Research & Therapy.* [Online]. Available at: https://doi.org/10.1186/alzrt274 (Accessed: 9 January 2023).

Donovan, R. and Williams, A. (2007) 'Home as Therapeutic Landscape' in Williams, A. (ed) *Therapeutic Landscapes.* Aldershot: Ashgate Publishing Ltd, pp. 199-218.

Dorling, D. (2015) ‘Inequality and the 1%’, London: Verso

Downs, M., Clare, L. and Mackenzie, J. (2006) ‘Understandings of Dementia: Explanatory Models and Their Implications for the Person with Dementia and Therapeutic Effect’, in Hughes, J., Louw, S. and Sabat, S (ed) *Dementia: Mind, Meaning and the Person*. Oxford: Oxford University Press.

Dresser, R. (1986) ‘Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law’, *Arizona Law Review* 28(3), pp. 373-405.

Driver, Julia. (2005) ‘Consequentialism and Feminist Ethics’, *Hypatia*, 20(4), pp. 183–199. [Online]. Available at: https://doi.org/10.1111/j.1527-2001.2005.tb00543.x (Accessed: 9 January 2023).

Drydyk, J. (2012) *A Capability Approach to Justice as a Virtue. Ethical Theory and Moral Practice,* 15(1), pp. 23-38. [Online]. Available at: http://www.jstor.org/stable/41474504 (Accessed: 31 August 2021).

Dubois, J.-L. and Rousseau, S. (2008) ‘Reinforcing households' capabilities as a way to reduce vulnerability and prevent poverty in equitable terms’, in Comim, F., Qizilbash, M., and Alkire, S. (ed) *The Capability Approach: Concepts, Measures and Applications*. Cambridge: Cambridge University Press, pp. 421–436. [Online]. Available at: DOI: 10.1017/CBO9780511492587.014 (Accessed: 9 January 2023).

Dworkin, A. (1981) *Pornography: Men Possessing Women.* London: Women's Press.

Dworkin, R. (2002) *Sovereign Virtue: the theory and practice of equality*. Cambridge, Mass; London: Harvard University Press.

Dworkin, R. (1993) *Life's Dominion: An Argument About Abortion, Euthanasia and Individual Freedom.* New York: Knopf.

Edwards, G. (2014) ‘Standpoint theory, realism and the search for objectivity in the sociology of education’, *British Journal of Sociology of Education, 35*(2), pp. 167–184. [Online]. Available at: http://www.jstor.org/stable/43818145 (Accessed: 8 September 2022).

Egdell, V. (2013) ‘Who cares? Managing obligation and responsibility across the changing landscapes of informal dementia care,’ *Ageing and Society,* 33(5), pp. 888–907.

Egdell, V. and Robertson, P.J. (2021) 'A critique of the Capability Approach's potential for application to career guidance', *International journal for educational and vocational guidance,* 21(2), pp. 447–463.

Egdell, V. and Beck, V. (2020) 'A Capability Approach to Understand the Scarring Effects of Unemployment and Job Insecurity: Developing the Research Agenda', *Work, Employment and Society*, 34(5), pp. 937-948.

England, K. (2010) 'Home, Work and the Shifting Geographies of Care', *Ethics Policy Environment,* 13 (2) pp. 131-150.

England, K. (1994). 'Getting Personal: Reflexivity, Positionality, and Feminist Research∗' *The Professional Geographer*, 46(1), pp. 80–89. [Online]. Available at: https://doi.org/10.1111/j.0033-0124.1994.00080.x (Accessed: 9 January 2023).

England, K. and Dyck, I. (2014) 'Masculinities, Embodiment and Care', in Gorman-Murray, A. and Hopkins, P. *Masculinities and place*. Taylor & Francis Group, pp. 285-297.

Engster, D. (2021) 'Just add care and stir? The limits of mainstream liberal theory for taking on dependency care', *Critical Review of International Social and Political Philosophy*, [Online]. Available at: DOI: 10.1080/13698230.2021.1922862 (Accessed: 4 August 2021).

Engster, D (2007) *The Heart of Justice, Care ethics and Political Theory*. Oxford: Oxford University Press.

Engster, D. and Hamington, M. (2015) *Care ethics and political theory*. Oxford: Oxford University Press.

Falvey, M., Forest, M., Pearpoint, J. and Rosenberg, R. (1997) *All my Life's a Circle – Using the Tools, Circles, Maps and Path.* Toronto: Inclusion Press.

Family Lives (2021) *Social Services and Your Family*. Available at: https://www.familylives.org.uk/advice/your-family/social-services-and-your-family/social-services-and-your-family#:~:text=Families%20often%20feel%20anxious%20at%20the%20prospect%20of,will%20remove%20their%20children%20from%20the%20family%20home. (Accessed: 7 June 2022).

Farmer, J., Morgan, D. and Innes, A. (2020) 'Conclusion: Navigating 21st-Century Remote and Rural Dementia Care and a Future Research Agenda,' in Innes, A., Morgan, D., and

Farmer, J. (ed.) *Remote and Rural Dementia Care: Policy, Research and Practice*. Bristol University Press, pp. 285–298. [Online]. Available at: DOI: 10.46692/9781447344964.015. (Accessed: 14 June 2022).

Farrington, J. and Farrington, C. (2005) 'Rural accessibility, social inclusion and social justice: towards conceptualisation', *Journal of Transport Geography*, 13(1), pp. 1–12.

Fawcett Society (2022) *Value Care Work*. Available at: https://www.fawcettsociety.org.uk/value-care-work#:~:text=Caring%20experience%20is%20particularly%20concentrated%20in%20women%20aged,is%20estimated%20to%20be%20%C2%A377%20bn%20per%20year (Accessed: 29 June 2022).

Finch, J. (1993) *Negotiating family responsibilities*. London/New York: Tavistock/Routledge.

Firestone, S. (1979) *The Dialectic of Sex: The Case for Feminist Revolution*. London: Women's Press.

Fischer, F. (2019) 'Knowledge Politics and Post-truth in Climate Denial: On the Social Construction of Alternative Facts', *Critical Policy Studies*, 13(2), pp. 133-152, [Online]. Available at: DOI: 10.1080/19460171.2019.1602067 (Accessed: 23 September 2022).

Fisher, B. and Tronto, J. (1990) 'Toward a Feminist Theory of Caring', in Abel, E. K. and Nelson, M. (ed.), *Circles of care*, pp. 35−62. Albany State University: New York Press.

Flatschart, E. (2017) 'Feminist Standpoints and Critical Realism. The Contested Materiality of Difference in Intersectionality and New Materialism', *Journal of Critical Realism*, 16(3), pp. 284-302. [Online]. Available at: DOI: 10.1080/14767430.2017.1313650 (Accessed: 9 January 2023).

Foley, D. J., Heimovitz, H. K., Guralnik, J. M. and Brock, D. B. (2002) 'Driving life expectancy of persons aged 70 years and older in the united states', *American Journal of Public Health,* 92, pp. 1284–1289. [Online]. Available at: https://ajph.aphapublications.org/doi/full/10.2105/AJPH.92.8.1284 (Accessed: 14 June 2022).

Foster, J.E. and Handy, C. (2008) 'External Capabilities', in *Arguments for a Better World: Essays in Honor of Amartya Sen: Volume I: Ethics, Welfare, and Measurement*. Oxford University Press. [Online]. Available at:

https://oxford.universitypressscholarship.com/view/10.1093/acprof:oso/9780199239115.001.0001/acprof-9780199239115-chapter-20 (Accessed: 10 November 2021).

Foucault, M. (1977) *Power/Knowledge: Selected Interviews and other Writings.* New York: Pantheon.

Frankfurt, H. (1999) *Autonomy, Necessity and Love. In Necessity, Volition, and Love*. Cambridge: Cambridge University Press.

Friedan, B. (1982) *The Feminine Mystique*. Harmondsworth: Penguin.

Fukuyama, F. (2022) *Liberalism and its Discontents*, London: Profile Books.

Fulton, R. (1987) The Many Faces of Grief. *Death Studies*, 11, pp. 243-56.

Future Care Capital (2019) *Data that Cares*, Available at: https://futurecarecapital.org.uk/wp-content/uploads/2020/03/Data-that-cares-full-report-single.pdf, (Accessed: 4 October 2023).

Gallagher, J. (2022*) Alzheimer's Drug Lecanemab Hailed as Momentous Breakthrough, BBC News*. [Online] Available at: https://www.bbc.co.uk/news/health-63749586, (Accessed: 8 December 2022).

Gallego-Alberto, L., Losada, A., Cabrera, I., Romero-Moreno, R., Pérez-Miguel, A., Pedroso-Chaparro, M.D.S. and Márquez-González, M. (2022) ‘"I Feel Guilty". Exploring Guilt-Related Dynamics in Family Caregivers of People with Dementia’, *Clinical gerontologist,* 45(5), pp. 1294–1303.

Gallego-Alberto, L., Márquez-González, M., Romero-Moreno, R., Cabrera, I., & Losada, A. (2019). Pilot study of a psychotherapeutic intervention for reducing guilt feelings in highly distressed dementia family caregivers (Innovative practice). *Dementia*, 147130121988676. doi:10.1177/1471301219886761 (Accessed: 19 January 2023).

Galvin, R., Bråthen, G., Ivashynka, A., Hillbom, M., Tanasescu, R. and Leone, M. A. (2010) ‘EFNS guidelines for diagnosis, therapy and prevention of Wernicke encephalopathy’, *European Journal of Neurology*, 17, pp.1408-1418. [Online]. Available at: DOI: 10.1111/j.1468-1331.2010.03153.x (Accessed: 6 January 2023).

Gatrell, C. (2009) ‘Safeguarding subjects?: A reflexive appraisal of researcher accountability in qualitative interviews’, *Qualitative Research in Organizations and Management: An International Journal,* 4(2), pp. 110-122. [Online]. Available at: DOI: http://dx.doi.org/10.1108/17465640910978382. (Accessed: 9 January 2023).

Gawande, A. (2015) *Being Mortal.* London: Profile Books.

Gendron, T.L., Welleford, A.E.,Inker, J. and White, J.T. (2016) 'The Language of Ageism: Why We Need to Use Words Carefully', *The Gerontologist*, 56(6), pp. 997–1006. [Online]. Available at: https://doi.org/10.1093/geront/gnv066. (Accessed: 9 January 2023).

Gessler, W. (1992) 'Therapeutic Landscapes, Medical Geographic Research in Light of the New Cultural Geography', *Social Science and Medicine*, 34(7), pp. 735-746.

Geuss, R. (2008) Philosophy and real politics. Princeton: Princeton University Press.

Gibson, B. (2007) 'Accommodating Critical Theory', in *The SAGE Handbook of Grounded Theory*, SAGE Publications Ltd, pp. 436-453. [Online]. Available at: https://dx.doi.org/10.4135/9781848607941 (Accessed: 21 Apr 2022).

Giddens, A. (1991) *Modernity and Self-Identity: Self and Society in the late modern age*. Cambridge: Polity Press.

Gilleard, C.J. and Higgs, P. (2011) 'Frailty, Disability and Old Age: A Re-appraisal', *Health*, 15(5), pp. 475-90.

Gilleard, C.J. and Higgs, P. (2010) 'Aging without Agency: Theorizing the Fourth Age', *Aging and Mental Health*, 14(2), pp. 121-8.

Gilligan, C. (1993) *In a Different Voice*. London: Harvard University Press.

Gillman, L. (2016) 'Critical Realist and Postpositivist Realist Feminisms: Towards a Feminist Dialectical Realism', *Journal of Critical Realism*, 15(5), pp. 458-475. [Online]. Available at: DOI: 10.1080/14767430.2016.1191005 (Accessed: 20 September 2022).

Glaser, B.G. (1992) *Basics of Grounded Theory Analysis*. Mill Valley, CA: Sociology Press.

Glaser, B. and Strauss, A. (1967) *The Discovery of Grounded Theory: Strategies for qualitative research.* New Brunswick: Aldine de Gruyter.

Glaser, B. and Strauss, A. (1965) *Awareness of dying (Observations).* Chicago: Aldine Pub.

Glendale Gateway Trust (no date) Available at: https://www.glendalegatewaytrust.org/ (Accessed: 18 March 2015).

Goffman, E. (1976) *Stigma*. Harmondsworth: Pelican Books.

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. Prentice-Hall, Englewood Cliffs: New Jersey.

Gorman-Murray, A. and Hopkins, P. (2014) *Masculinities and place*. Taylor & Francis Group.

Gorski, P.S. (2013) ‘"What is Critical Realism? And Why Should You Care?"’, *Contemporary Sociology,* 42(5), pp. 658–670.

Gouws, A. and Zyl, M. (2015). ‘Towards a feminist ethics of ubuntu: Bridging rights and ubuntu’, in *Care Ethics and Political Theory.* Oxford University Press. [Online]. Available at: https://oxford-universitypressscholarship-com.libproxy.ncl.ac.uk/view/10.1093/acprof:oso/9780198716341.001.0001/acprof-9780198716341-chapter-10 (Accessed: 30 July 2021).

Government Office for Science (2016) *Future of Ageing.* Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/816458/future-of-an-ageing-population.pdf#:~:text=%20The%20UK%20population%20is%20ageing.%20In%20mid-2014%2C,will%20have%20a%20major%20effect%20on%20the%20UK (Accessed: 11 March 2022).

Gov.UK (no date, a) *Work Preparation Support for Carers*. Available at: https://www.gov.uk/moving-from-benefits-to-work/help-for-parents-and-carers (Accessed: 29 June 2022).

Gov.UK (no date, b) *Deputies Responsibilities.* Available at: https://www.gov.uk/become-deputy/responsibilities (Accessed: 7 June 2022).

Gov.UK (no date, c) *Dementia and Driving.* Available at: https://www.gov.uk/dementia-and-driving (Accessed: 9 June 2022).

Gov.UK (2022) *Reported road casualties Great Britain: older drivers factsheet 2020.* Available at: https://www.gov.uk/government/statistics/reported-road-casualties-great-britain-older-driver-factsheet-2020/reported-road-casualties-great-britain-older-drivers-factsheet-2020 (Accessed: 10 June 2022).

Gov.UK (2016) *Factsheet 8 the Law for Carers.* Available at: https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets#factsheet-8-the-law-for-carers (Accessed: 7 November 2022)

Gray, J. (1983). *Mill on Liberty: A Defense.* London: Routledge and Kegan Paul.

Gray, T. (1991). *Freedom.* Basingstoke: MacMillan.

Greed, C. (2013) *Clara Greed on the importance of global public toilet provision Southbank Centre*. Available at: https://www.youtube.com/watch?v=wMcxGqH5bcg (Accessed: 23 May 2017)

Greed, C. (2003) *Public Toilets – Inclusive Urban Design.* Oxford: Elsevier.

Green, S., Davis, C., Karshmer, E., Marsh, P. and Straight, B. (2005) 'Living Stigma: The Impact of Labeling, Stereotyping, Separation, Status Loss, and Discrimination in the Lives of Individuals with Disabilities and Their Families', *Sociological inquiry*, 75(2), pp. 197–215.

Grenier, A., Lloyd, L. and Phillipson, C. (2017) 'Precarity in Late Life: Rethinking Dementia as a Frailed Old Age', in *Ageing, Dementia and the Social Mind.* Cardiff: Wiley, Blackwell, pp. 142-154.

Groenhout, R. (2014) 'Virtue and a Feminist Ethics of Care', in Timpe, K. and Boyd, C.A *Virtues and Their Vices*. [Online]. Oxford: Oxford University Press. Chapter 22. Available at: https://doi.org/10.1093/acprof:oso/9780199645541.003.0023 (Accessed: 1 February 2022).

Groenhout, R.E. (2003) *Theological echoes in an ethic of care*. Notre Dame, Ind: Erasmus Institute.

Grossman, M. (2017) *Stages of Dementia – The 3-Stage and the 7- Stage Models.* Available at: https://www.kindlycare.com/stages-of-dementia/ (Accessed: 19 March 2018).

Guest, G., MacQueen, K. M. and Namey, E. E. (2012). 'Introduction to Applied Thematic Analysis'. In *Applied Thematic Analysis*. London: Sage, pp. 3-20.

Gunnarsson, L., Martinez Dy, A. and Van Ingen, M. (2016). 'Critical Realism, Gender and Feminism: Exchanges, Challenges, Synergies', *Journal of Critical Realism,* 15(5), pp. 433–439.

Habibi, D. (1998). 'J. S. Mill's Revisionist Utilitarianism', *British Journal for the History of Philosophy,* 6(1), pp. 89-114.

Haidt, J. (2013) *The Righteous Mind.* London: Penguin.

Hamington, M. (2004) *Embodied Care: Jane Addams, Maurice Merleau-Ponty, and Feminist Ethics.*

Hampsher-Monk, I. (1992). *A History of Modern Political Thought.* Oxford: Blackwell.

Haraway, D. (1988). 'Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective'. *Feminist Studies,* 14(3), pp. 575–599.

Harding, R. (2017) *Duties to Care: Dementia, Relationality and Law*. Cambridge: Cambridge University Press (Cambridge Studies in Law and Society). [Online]. Available at: DOI: 10.1017/9781316160688 (Accessed: 9 January 2023).

Harding, S.G. (2004) *The Feminist Standpoint Theory Reader: Intellectual and Political Controversies*. New York: Routledge.

Hartsock, N. (2004) 'The Feminist Standpoint: Developing the Ground for a Specifically Feminist Historical Materialism', in Harding, S. (ed) The Feminist Standpoint Theory Reader, London: Routledge, pp. 35-53.

Hartsock, N. (1997) 'Standpoint Theories for the Next Century', in *Politics and Feminist Standpoint Theories* (ed.) Kenney and Kinsella, Haworth Press: London, pp. 93-101.

Hartsock, N. (1983) *Money, Sex, and Power: Towards a Feminist Historical Materialism*. New York: Longman.

Harvey, D. (1973) *Social Justice and the City.* London: Edward Arnold.

Hasler, F. (1993) 'Development's in the Disabled People's Movement', in J. Swain et al (ed) *Disabling Barriers, Enabling Environments*, London: Sage.

Hayek, F.A. (1991). 'Freedom and Coercion' in Miller, D. *Liberty.* Oxford: Oxford University Press.

Healthwatch Northumberland (no date) *Dementia*. Available at: https://healthwatchnorthumberland.co.uk/your_health/dementia/ (Accessed: 17 November 2022).

Held, V. (2006) *The Ethics of Care*. Oxford: Oxford University Press.

Hellstrom, I. (2014) 'I'm his wife not his carer!" – Dignity and Couplehood', in Lars-Christer Hyden, Hilde Lindemann and Jens Brockmeier (ed.). *Beyond Loss – Dementia, Identity, Personhood*. Oxford University Press: Oxford, pp. 53-66.

Hellström, I., Nolan, M., and Lundh, U. (2007) 'Sustaining `Couplehood': Spouses' Strategies for Living Positively with Dementia', *Dementia,* 6(3), pp. 383–409. [Online]. Available at: https://doi.org/10.1177/1471301207081571 (Accessed: 9 January 2023).

Hendricks, J. and Hatch, L.R. (2008) 'Theorising Lifestyle: Exploring structure and agency in the life course', in V. Bengston, M. Silverstein, N. Putney and D Gans (ed.) *Handbook of Theory of Ageing*, New York: Springer, pp. 435-454.

Hennink, M. (2014) *Focus Group Discussions Understanding Qualitative Research.* Oxford: Oxford University Press.

Herron, R. V. (2022) “Anthea Innes, Debra Morgan, and Jane Farmer. Remote and Rural Dementia Care: Policy, Research and Practice. Bristol, UK: Policy Press, 2020.,” *Canadian Journal on Aging / La Revue canadienne du vieillissement*. Cambridge University Press, 41(1), pp. 143–144. doi: 10.1017/S0714980820000471. (Accessed: 9 January 2023).

Herron, R.V. and Rosenberg, M.W. (2019) ‘Dementia in rural settings: examining the experiences of former partners in care’, *Ageing and Society*. Cambridge University Press, 39(2), pp. 340–357. [Online]. Available at: DOI: 10.1017/S0144686X17000952 (Accessed: 9 January 2023).

Herzkovits, E. (1995) ‘Struggling Over Subjectivity: Debates about the “Self” and Alzheimer’s Disease’, *Medical Anthropology Quarterly*, 9, pp. 146-164.

Heywood, A. (1999) *Political Theory an Introduction*, (2nd edn.). Basingstoke: Palgrave.

Higgs, P. and Gilleard, C. (2017) ‘Ageing, Dementia and the Social Mind: Past, Present and Future Perspectives’, *Ageing, Dementia and the Social Mind.* Cardiff: Wiley, Blackwell, pp. 1-6.

Higgs, P. and Gilleard, C. (2016) *Personhood, Identity and Care in Advanced Old Age*, Bristol: Policy Press.

Hird, M.A., Egeto, P., Fischer, C.E., Naglie, G. and Schweizer T.A. (2016) ‘A systematic review and meta-analysis of on-road simulator and cognitive driving assessment in Alzheimer’s disease and mild cognitive impairment’, *Journal of Alzheimer’s Disease*, 53(2): pp. 713–29.

Hoag, R.W. (1986) ‘Happiness and Freedom’, *Philosophy and Public Affairs,* 15(2), pp. 188-199.

Hoffmann, N. and Metz, T. (2017) ‘What can the capabilities approach learn from an ubuntu ethic? A relational approach to development theory’, *World Development,* 97. pp. 153-164.

Holland, D. (2022) *Scale of Bus Route Cuts to Northumberland and North Tyneside Revealed 2 March,* Northumberland Gazette. Available at: https://www.northumberlandgazette.co.uk/news/transport/scale-of-bus-route-cuts-to-northumberland-and-north-tyneside-revealed-3589650 (Accessed: 10 June 2022)

Holloway, W. and Jefferson, T. (2007) ‘*Doing Qualitative Research Differently*’, London: Sage.

Holmes, C. and Amin, J. (2016) ‘Dementia’, in *Psychiatric Disorders,* pp. 687-690.

Holstein, M. (2013) ‘A Looming Dystopia: Feminism, Aging, and Community-Based Long-Term Care.’ *International Journal of Feminist Approaches to Bioethics*, vol. 6, no. 2, 2013, pp. 6–35. Available at: *JSTOR*, www.jstor.org/stable/10.2979/intjfemappbio.6.2.6. (Accessed 2 Aug. 2021).

Holstein, M. (2010) ‘Ethics and Old Age: The Second Generation’, in Dannefer, D. and Phillipson, C. (eds) The Sage Handbook of Social Gerontology, London: Sage Publications, pp 630-640.

Hopkins, P. (2007a) ‘Thinking Critically and Creatively about Focus Groups’, *Area, 39*(4), 528–535. [Online] Available at: http://www.jstor.org/stable/40346074 (Accessed: 9 January 2023).

Hopkins, P. (2007b) ‘Positionalities and Knowledge: Negotiating Ethics in Practice’, *Acme: An International e-Journal for Critical Geographies,* 6(3), pp. 386-394.

Hopkins, P. and Pain, R. (2007) ‘Geographies of Age – Thinking Relationally’, *Royal Geographic Society,* 39(3), pp. 287-294.

Horrell, B., Stephens, C. and Breheny, M. (2015) ‘Capability to Care: Supporting the Health of Informal Caregivers for Older People’, *Health psychology.* 34(4), pp. 339–348.

House of Commons (2008) *The Provision of Public Toilets.* Available at: https://publications.parliament.uk/pa/cm200708/cmselect/cmcomloc/636/636.pdf (Accessed 3 June 2022).

House of Lords Library (2022) *Staff shortages in the NHS and social care sectors.* Available at: https://lordslibrary.parliament.uk/staff-shortages-in-the-nhs-and-social-care-sectors/#:~:text=In%20June%202022%2C%20the%20House%20of%20Commons%20Health,that%20almost%20every%20healthcare%20profession%20was%20facing%20shortages. (Accessed: 14 December 2022).

Hoy, C.M. (1984) ‘*A Philosophy of Individual Freedom, The Political Thought of F.A.Hayek’,* Wesport, Conneticut: Greenwood Press.

Hughes, J.C., Louw, S.J. and Sabat, S.R. (2006) Dementia: Mind, Meaning, and the Person. Oxford; New York: Oxford University Press.

Hughes, J. C. (2014) *How We Think about Dementia: Personhood, Rights, Ethics, the Arts and What They Mean for Care*, London: Jessica Kingsley Publishers.

Hughes, J.C., Louw, S.J. and Sabat, S.R. (2005) 'Seeing Whole', in J.C. Hughes, S.J. Louw and S.R. Sabat (ed) *Dementia: Mind, Meaning, and the Person*. Oxford: Oxford University Press. Available at: https://doi.org/10.1093/med/9780198566151.003.0001 (Accessed 9 January 2023).

Hume, D. (1978) *A treatise of human nature* in Bigge, L. A. and Nidditch, P. H. (ed) (2nd edn.). Oxford: Oxford University Press. Oxford Scholarly Editions Online (2014). [Online] Available at: DOI:10.1093/actrade/9780198245872.book.1(Accessed: 13 October 2022).

Hundleby, C. (1997) 'Where Standpoint Stands Now', pp. 25-43 in *Politics and Feminist Standpoint Theories* (ed.) S.J. Kenney and H. Kinsella, Haworth Press: London

Ibrahim, S. (2020) 'Individualism and the Capability Approach: The Role of Collectivities in Expanding Human Capabilities', pp. 206–226. in Chiappero-Martinetti, Osmani, and Qizilbash, (eds) *The Cambridge Handbook of the Capability Approach,* Cambridge: Cambridge University Press,

Imison, C., Curry, N., Holder, H., Castle-Clarke, S., Nimmons, D., Appleby, J., Thorlby, R. and Silvia Lombardo (2017) *Shifting the Balance of Care Great Expectations*, Nuffield Trust, pp. 1-139.

Innes, A., Morgan, D. and Farmer, J. (2020) *Remote and Rural Dementia Care: Policy, Research and Practice*. Bristol University Press. [Online] Available at: DOI: 10.46692/9781447344964.

Innes, A., Morgan, D.G., and Kosteniuk, J.G. (2011). 'Dementia care in rural and remote settings: a systematic review of informal/family caregiving', *Maturitas, 68(1),* pp. 34-46.

Innes, A, Sherlock, K., Smith, A., Mason, A. and Cox, S. (2005) 'Diversity in the experience of the provision of health and social care to people with dementia across Scottish rural communities', *Health and Social Care in the Community,* 13(4), pp. 354-365.

Institute of Health Equity (2020) *Health Equity in England: The Marmot Review 10 Years On,* Available at: https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on, (Accessed: 6 July 2023).

Integrated Care System North East and Cumbria (2022) *North East and North Cumbria Integrated Care Partnership: Draft Integrated Care Strategy*. Available at: https://northumberland.moderngov.co.uk/documents/s12450/07.1ICP%20Integrated%20Care%20Strategy%20DRAFT%2020221021.pdf, (Accessed: 11 November 2022).

Israel, E. & Frenkel, A. (2018) 'Social justice and spatial inequality', *Progress in human geography,* 42(5), pp. 647–665.

Jack-Waugh, A., Ritchie, L. & MacRae, R. (2018) 'Assessing the educational impact of the dementia champions programme in Scotland: Implications for evaluating professional dementia education', *Nurse education today*, 71 pp. 205–210.

Jaggar, A. (2017) 'Other Worlds are Possible But Which Are Gender Just?', Lecture at Conference: 'Law, Society and Care', Manchester Metropolitan University, 21 July 2017.

James, I. A., and Caiazza, R. (2018) 'Therapeutic Lies in Dementia Care: Should Psychologists Teach Others to be Person-Centred Liars?', *Behavioural and cognitive psychotherapy, 46*(4), pp. 454–462. [Online] Available at: https://doi.org/10.1017/S1352465818000152 (Accessed: 15 August 2022).

Jaworska, A. (1999) 'Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value', *Philosophy & Public Affairs,* Spring, 1999, 28(2). pp. 105-138.

Jervis, L.L. (2001) 'The pollution of incontinence and the dirty work of caregiving in a U.S. nursing home', *Medical Anthropology Quarterly* 15, pp. 84–99.

Jett, K., Tappen, R. and Rosselli, M. (2005) 'Imposed versus involved: Different strategies to effect driving cessation in cognitively impaired older adults', *Geriatric Nursing,* 26(2). pp. 111–116.

Johns, M. (2020) *IPPR North:10 Years of Austerity,* Available at: https://www.ippr.org/files/2020-06/10-years-of-austerity.pdf, (Accessed: 6 July 2023).

Johnston, C. and Pratt, G. (2022) 'Anticipating a Crisis: Creating a Market for Transnational Dementia Care in Thailand' *Annals of the American Association of Geographers,* 112(7). pp. 2064-2079, DOI: 10.1080/24694452.2022.2041389 (Accessed: 15 December 2022).

Jones, C. and Richardson, M. J. (2020) Justice. *In Social Geographies, An Introduction*. The Newcastle Social Geographies Collective; Pain, R; Hopkins, P, ed. London: Rowman and Littlefield International.

Kaufman, S. (2006) 'Dementia-Near Death and Life Itself', in *Thinking About Dementia, Culture, Loss and the Anthropology of Senility*, London: Rutgers University Press.

Keating, N. (2008) 'Revisiting rural ageing', in N. Keating (ed.) *Rural Ageing: A Good Place to Grow Old?*, pp. 121-130). Bristol University Press. [Online] Available at: DOI:10.46692/9781847424037.013 (Accessed: 5 October 2022).

Keller, J. and Kittay, E.F. (2017) 'Feminist Ethics of Care', in (eds) Garry, A., Khader, S.J. and Stone, A. *The Routledge Companion to Feminist Philosophy*. pp540-555.

Kelly, P. (2009) 'J.S. Mill on Liberty' in Boucher, D. and Kelly, P, '*Political Thinkers from Socrates to the Present'.* Oxford: Oxford University Press.

Kenney, S.J. and Kinsella, H. (1997) *Politics and feminist standpoint theories*. New York: Haworth Press.

Kesby, M., Kindon, S. and Pain, R. (2005) 'Participatory Approaches AND Diagramming Techniques' in Flowerdew, R. and Martin, D. (ed.) *Methods in Human Geography*, 2e, Pearson Education Ltd: Harlow, pp. 144-166.

Kiely, A. (2018) *Why is Dementia Different for Women?* Available at: https://www.alzheimers.org.uk/blog/why-dementia-different-women (Accessed 8 June 2022).

Kim, S., Werner, P., Richardson, A., and Anstey, K. J. (2019) Dementia Stigma Reduction (DESeRvE): Study protocol for a randomized controlled trial of an online intervention program to reduce dementia-related public stigma. *Contemporary clinical trials communications*, *14*, 100351. [Online] Available at: https://doi.org/10.1016/j.conctc.2019.100351 (Accessed: 11 March 2022).

Kings Fund (2019) *Cancer or dementia: the social care system is unfair to people with either condition.* Available at: https://www.kingsfund.org.uk/blog/2019/09/cancer-dementia-unfair-social-care-system (Accessed: 6 June 2022).

Kingston, A., Commas-Herrera, A. and Jagger, C. (2018) 'Forecasting the Care Needs of the Older Population in England Over the Next 20 Years: Estimates From the Population Ageing and Care Simulation (PACSim) Modelling Study', *Lancet Public Health* 2018 (3), pp. 447–55 [Online]. Available at: http://dx.doi.org/10.1016/ S2468-2667(18)30118-X (Accessed: 17 October 2022).

Kingston, A., Wohland, P., Wittenberg, R., Robinson, L., Brayne, C., Matthews, F.E. and Jagger, C. (2017) 'Is late-life dependency increasing or not? A comparison of the Cognitive

Function and Ageing Studies (CFAS)' *The Lancet.* 390(10103), pp.1676-1684, Open Access Published: August 15, 2017 [Online] Available at: DOI: https://doi.org/10.1016/S0140-6736(17)31575-1(Accessed 3 August 2022).

Kirtley, A. and Williamson, T. (2016). 'What is Truth? An Inquiry About Truth and Lying in Dementia Care. *Mental Health Foundation*.

Kitchen, R. (1998) 'Out of Place, Knowing One's Place: Space, Power and the Exclusion of Disabled People', *Disability and Society*. 13(3), pp. 343-356.

Kitchin, R. and Law, R. (2001) 'The Socio-spatial Construction of (In)accessible Public Toilets', *Urban Studies (Routledge)*. 38(2), pp. 287-298.

Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris*, 24(1), pp. 49-58.

Kittay, E.F. (2002) 'When Caring is Just and Justice is Caring', in Kittay, E. F. and Feder, E. K.(eds) The Subject of Care: Feminist Perspectives of Dependency, Rowman and Littlefield Publishers: Oxford, pp. 257-276,

Kittay, E.F. (1999) *Love's Labor*. Abingdon, Oxon: Routledge.

Kittay, E.F. and Meyers, D.T. (1987) *Women and moral theory*. Totowa, N.J.: Rowman & Littlefield.

Kittay, E.F., Jennings, B. and Wasunna, A.A. (2005) 'Dependency, Difference and the Global Ethic of Long-Term Care', *Journal of Political Philosophy*, 13(4), pp. 443-469.

Kitwood, T. (1997) *Dementia Reconsidered: The Person Comes First.* Buckingham: Open University Press.

Kitwood, T. (1993) 'Person and Process in dementia', *International Journal of Geriatric Psychiatry*, 8(7), pp 541-546.

Kitwood, T. (1990) 'The Dialectics of Dementia: With Particular Reference to Alzheimer's Disease'. *Ageing and society*. 10(2), pp. 177–196.

Kitwood, T. and Bredin, K. (1992) Towards a Theory of Dementia Care: Personhood and Well-being. *Ageing and society*. 12 (3), pp. 269–287.

Kohl, E. and McCutcheon, P. (2015) 'Kitchen table reflexivity: negotiating positionality through everyday talk', *Gender, Place and Culture: a Journal of Feminist Geography*, 22(6), pp. 747–763. [Online]. Available at: https://doi.org/10.1080/0966369X.2014.958063

Kontos, P.C. (2004) ‘Ethnographic reflections on selfhood, embodiment and Alzheimer's disease’. *Ageing and society.* 24(6), pp. 829–849.

Kontos, P., Miller, KL. and Kontos, A.P. (2017) ‘Relational Citizenship: supporting embodied selfhood and relationality in dementia care’, in Higgs, P and Gilleard, C, *Ageing, Dementia and The Social Mind*, pp7-23, Chichester; Wiley Blackwell.

Kopelman, M.D., Thomson, A.D., Guerrini, I. and Marshall, E.J. (2009) ‘The Korsakoff Syndrome: Clinical Aspects, Psychology and Treatment’, *Alcohol and Alcoholism*, 44(2), pp. 148–154.

Kristeva, J. (1982) Powers of Horror: An Essay on Abjection. New York: Columbia University Press.

Kubler-Ross, E. and Kessler, D. (2014) *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss.* London: Simon and Schuster.

Kuhn, T.S. (1996) *The structure of scientific revolutions*. (3rd edn). Chicago, IL: University of Chicago Press.

Kvale, S. (2010) *Doing Interviews*, London: Sage.

Kymlicka, W. (2002) *Contemporary Political Philosophy*, Oxford: Oxford University Press.

La Fontaine, J. and Oyebode, J. R. (2014) ‘Family relationships and dementia: a synthesis of qualitative research including the person with dementia’. *Ageing and Society*, 34(7), pp. 1243–1272. [Online]. Available at: https://doi.org/10.1017/S0144686X13000056

Latour, B. and Woolgar, S. (1986) *Laboratory Life: The Construction of Scientific Facts*, (2nd ed.), Princeton: Princeton University Press.

Lawler, S. (2014) *Identity: sociological perspectives*. Second edition. Cambridge: Polity.

Laws, J. (2009) ‘Reworking Therapeutic Landscapes: The Spatiality of an Alternative Self-Help Group’, *Social Science and Medicine*, 69, pp. 1827-1833.

Lawson, V. (2007) ‘Presidential Address: Geographies of Care and Responsibility’, *Annals of the Association of American Geographers*, 97(1), pp. 1-11.

Layard, R. (2011) ‘*Happiness’*. London: Penguin.

Lazris, A. (2015) *A Review of Dementia Drug Therapy.* Available at: https://www.dementia.org/dementia-drug-therapy-review (Accessed 2 June 2022).

Leder, D. (1990) The Absent Body. Chicago: University of Chicago Press.

Lefebvre, H. (1991) *The Production of Space*, Oxford: Blackwell Publishing.

Legislation.Gov.UK (2022) *The Health and Care Act 2022*. Available at: https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted (Accessed 2 January 2023).

Legislation.Gov.UK (2014) *The Care Act.* Available at: https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted (Accessed: 29 June 2022).

Lewis, F., Schaffer, S.K., Sussex, J., O'Neill, P. and Cockcroft, L. (2014) The Trajectory of Dementia in the UK – Making a Difference, Available at: https://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/OHE-report-Full.pdf, (Accessed: 9 November 2022).

Link, D.G. (2019) 'Women's Brains Should Be on Our Minds'. *Journal for nurse practitioners*. 15(6), pp. 461–462. Available at: https://doi.org/10.1016/j.nurpra.2019.03.009, (Accessed: 24 June 2022).

Link, B. and Phelan, J. (2001) 'Conceptualizing Stigma', *Annual Review of Sociology*, pp. 363-385.

Link, B., Yang, L., Phelan, J. and Collins, P. (2004) 'Measuring mental illness stigma', *Schizophrenia Bulletin*, 30, pp. 511–41.

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S.G., Dias, A., Fox, N., Gitlin, L.N., Howard, R., Kales, H.C., Kivimäki, M., Larson, E.B., Ogunniyi, A., et al. (2020) 'Dementia prevention, intervention, and care: 2020 report of the Lancet Commission'. *The Lancet* (British edition). 396 (10248), pp. 413–446 [Online] Available at: https://doi.org/10.1016/S0140-6736(20)30367-6

Lindemann, H. (2019) *An Invitation to Feminist Ethics*. New York: Oxford University Press.

Lindemann, H. (2009) 'Holding One Another (well, wrongly, clumsily) in a Time of Dementia'. *Metaphilosophy,* 40, pp. 416-424. [Online]. Available at: https://doi-org.libproxy.ncl.ac.uk/10.1111/j.1467-9973.2009.01592.x (Accessed 10 August 2021)

Lloyd, L. (2012) *Health and Care in Ageing Societies – A New International Approach,* Bristol: Policy Press.

Lloyd-Sherlock, P. (2002) ‘Nussbaum, Capabilities and Older People’, *Journal of International Development*, 14, pp. 1163-1173.

Lock, M. (2013) The Alzheimer Conundrum’, Woodstock: Princeton University Press.

Lo, C.O. (2014) Enhancing Groundedness in Realist Grounded Theory Research. *Qualitative psychology* (Washington, D.C.). 1 (1), 61–76.

Longhurst, R. (2010) ‘Semi-structured Interviews and Focus Groups’, in Clifford, N, French, S. and Valentine, G. (ed.) *Key Methods in Geography*, London: Sage, pp. 103-115.

Luengo-Fernandez, R., Leal, J. and Gray A. (2015) ‘UK research spend in 2008 and 2012: comparing stroke, cancer, coronary heart disease and dementia’. *BMJ Open* 2015, 5(e006648). [Online]. Available at: DOI: 10.1136/bmjopen-2014-006648 (Accessed: 6 June 2022).

Lukes, S. (2005) *Power: A Radical View*, (2nd edn.), New York: Palgrave.

Lyman, K. (1989) ‘Bringing the Social Back in: A Critique of the Biomedicalisation of Dementia’, *The Gerontological Society of America,* 29(5), pp. 597-597.

MacAskill, W. (2016) *Doing good better: effective altruism and a radical new way to make a difference.* London: Guardian Books: Faber & Faber

MacCallum, G.C. (1991) ‘Negative and Positive Freedom’ in Miller, D. *Liberty.* Oxford: Oxford University Press.

Machielse, A. and Hortulanus, R. (2014) ‘Social Ability or Social Frailty? The balance between autonomy and connectedness in the lives of older people’, in Baars, J., Dohmen, J., Grenier, A. and Phillipson, C. *Ageing, Meaning and Social Structure, Connecting critical and humanistic gerontology* (ed), pp 119-138, Bristol: Policy Press.

MacIntyre, A.C. (1985) *After virtue: a study in moral theory*. London: Duckworth.

Mackenzie, C. and Stoljar, N. (2000) *Relational Autonomy, Feminist Perspectives on Autonomy, Agency and The Social Self*. New York: Oxford University Press.

MacNicol, J. (2006) *Age Discrimination: An Historical and Contemporary Analysis*. Cambridge: Cambridge University Press. DOI: 10.1017/CBO9780511550560. (Accessed: 21 September 2022)

Mahmoudi, M., Mohammadkhani, P., Ghobari Bonab, B.and Bagheri, F. (2017). Effectiveness of cognitive-behavioural group therapy on guilt feeling among family caregivers of patients with Alzheimer's disease. *Practice in Clinical Psychology*, 5(3), 203–210. doi:10.18869/acadpub.jpcp.5.3.203 (Accessed: 19 January 2023).

Mallon, R. (2019) 'Naturalistic Approaches to Social Construction', *The Stanford Encyclopedia of Philosophy* (Spring 2019 Edition), Edward N. Zalta (ed.), Available at: https://plato.stanford.edu/archives/spr2019/entries/social-construction-naturalistic/ (Accessed: 22 September).

Marcuse, P. (2009) *Spatial Justice, Derivative but Causal of Social Injustice*. Available at: https://planningdesigntudelft.files.wordpress.com/2014/07/spatial-justice-marcuse-2009.pdf (Accessed 3 June 2022).

Marshall, M. (2019) 'Toilet Talk; Accessible Design For People with Dementia', *Hammond Care*. Available at: https://www.dementiacentre.com/resources/61-toilet-talk-accessible-design-for-people-with-dementia, (Accessed: 17 August 2022).

Marshall, P. (2012) 'Toward an Integral Realism. Part 1: An Overview of Transcendental Realist Ontology', *Journal of Integral Theory and Practice,* 7(4), pp. 1–34.

Martinez, R. (2016) *Creating Freedom, Power Control and the Fight for Our Future*. Edinburgh: Canongate Books Ltd.

Massey, D. (2004) 'Special Issue: The Political Challenge of Relational Space', *Geographies of Responsibility,* Source: Geografiska Annaler. Series B, Human Geography, 86 (1) pp. 5-18.

Matthews, E. (2006) 'Dementia and the identity of the person', in Hughes, J.C., Louw, S.J., and Sabat, S.R. (ed), *Dementia: Mind, Meaning, and the Person*, *International Perspectives in Philosophy & Psychiatry*. pp. 163–178 Oxford. [Online]. Available at: https://doi.org/10.1093/med/9780198566151.003.0010 (Accessed 26 July 2022).

Mauthner, N. and Doucet, A. (2003) 'Reflexive Accounts and Accounts of Reflexivity in Qualitative Data Analysis', *Sociology*, 37(3), pp.413-431.

Mauthner, N. and Doucet, A. (1998) 'Reflections on a voice-centred relational method. Analyzing maternal and domestic voices', in Edwards, R., and Ribbens McCarthy, J. (ed.) *Feminist dilemmas in qualitative research: Public knowledge and private lives*. London: Sage, pp. 119-146.

Mayr, E. (1961) 'Cause and Effect in biology; kinds of causes, predictability and teleology are viewed by a practicing biologist', *Science*, 134(3489), pp. 1501-1506.

McAdams, D (2001) ‘The Psychology of Life Stories’, *Review of General Psychology*. 5(2), pp. 100–122.

McCloskey, H.J. (1971) *John Stuart Mill a Critical Study.* London: MacMillan and Co Ltd.

McDade, E. and Bateman, R.J. (2017) *Stop Alzheimer’s Before it Starts.* (Nature). Available at: https://www.nature.com/news/stop-alzheimer-s-before-it-starts-1.22274 (Accessed: 3 June 2022).

McDowell, L. (2004) ‘Work, workfare, work/life balance and an ethic of care’, *Progress in Human Geography The Progress in Human Geography lecture,* 28 (2), pp. 145-163.

McEwan, C. and Goodman, M.K. (2010) ‘Place, Geography and the Ethics of Care: Introductory Remarks on the Geography of Ethics, Responsibility and Care, in *Ethics, Place and Environment* 13(2), pp.103-112.

McKie, L., Gregory, S. and Bowlby, S. (2002) Shadow Times: The Temporal and Spatial Frameworks and Experiences of Caring and Working. Sociology (Oxford). 36 (4), 897–924.

McKinstry, B., Campbell, J. and Salisbury, C. (2017) Telephone first consultations in primary care *BMJ* 2017, 358(j4345), [Online]. Available at: doi:10.1136/bmj.j4345 (Accessed: 7 June 2022).

McLaren, M. (2001) ‘Feminist Ethics: Care as a Virtue’, in (ed.) Des Autels, P. and Waugh, J. (2001) *Feminists doing ethics*. Lanham, MD: Rowman and Littlefield Publishers.

McLaughlin, J. (2003) *Feminist social and political theory: contemporary debates and dialogues.* Basingstoke: Palgrave Macmillan.

McLean, A. (2007) ‘The Therapeutic Landscape of Dementia Care: Contours of Intersubjective Spaces for Sustaining the Person’, in Williams, A. (ed.) *Therapeutic Landscapes,* Aldershot: Ashgate Publishing Ltd, pp. 315-332.

McMillan, J. (2006) ‘Identity, Self and Dementia’, in Hughes, J.C., Louw, S.J., and Sabat, S.R. (ed) *Dementia: Mind, Meaning, and the Person*. Pages 63–70 Oxford: Oxford University Press. Available at: https://doi.org/10.1093/med/9780198566151.003.0004 (Accessed: 9 January 2023).

McParland, P., Kelly, F. and Innes, A. (2017) ‘Dichotomising dementia: is there another way?’, in Higgs, P. and Gilleard, C. *Ageing, Dementia and The Social Mind.* Chichester: Wiley Blackwell, pp. 83-94, Means, R. (2007) ‘Safe as Houses? Ageing in Place and Vulnerable Older People in the UK’, *Social Policy and Administration*, 41, pp. 65-85.

Mesterton, J., Wimo, A., By, A., Langworth, S., Winblad, B., and Jönsson, L. (2010) ‘Cross sectional observational study on the societal costs of Alzheimer's disease’. *Current Alzheimer research*, *7*(4), pp. 358–367. [Online]. Available at: https://doi.org/10.2174/156720510791162430

Metz, T. (2016) ‘Recent philosophical approaches to social protection: From capability to ubuntu’. *Global Social Policy,* 16(2), pp. 132–150. [Online]. Available at: https://doi-org.libproxy.ncl.ac.uk/10.1177/1468018116633575 (Accessed: 9 January 2023).

Metz, T. (2013) ‘The Western Ethic of Care or an Afro-communitarian Ethic? Specifying the Right Relational Morality’, *Journal of Global Ethics*, 9(1), pp. 77-92. [Online]. Available at: DOI: 10.1080/17449626.2012.756421 (Accessed: 30 July 2021).

Metz, T. and Gaie, J.B.R. (2010) ‘The African Ethic of *Ubuntu/Botho*: Implications for Research on Morality’, *Journal of Moral Education*, 39(3), pp. 273-290. [Online]. Available at: DOI: 10.1080/03057240.2010.497609 (Accessed: 30 July 2021).

Milbourne, P. (2012) ‘Growing Old in Rural Places’, *Journal of Rural Studies,* 28(3), pp.15-317.

Milbourne, P. and Doheny, S. (2012) ‘Older People and Poverty in Rural Britain: Material Hardships, Cultural Denials and Social Inclusions’, *Journal of Rural Studies,* 28, pp. 389-397.

Mill, J.S. (2008a) Utilitarianism in ‘*On Liberty and Other Essays'*, Oxford: Oxford University Press.

Mill, J.S. (2008b) On Liberty in ‘*On Liberty and Other Essays'*, Oxford: Oxford University Press.

Miller, J. and Glassner, B. (2004) ‘The Inside and the Outside – Finding Realities in Interviews’, in Silverman, D. *Qualitative Research – Theory, Method and Practice*’, London: Sage, pp. 125-139.

Miller, W. (2021) ‘Johnathan Miller Lost Memories’, *Radio 4,* Available at: https://www.bbc.co.uk/sounds/play/m000yt7f (Accessed: 28 August 2021)

Miller, W. (2021) Radio 4 Feedback - 27/08/2021 - BBC Sounds Available at: https://www.bbc.co.uk/programmes/m000z1kc (Accessed: 27 August 2021).

Milligan, C. (2003) ‘Location or dis-location? Towards a conceptualization of people and place in the care-giving experience’, *Social & Cultural Geography*. 4, pp. 455-470.

Milligan, C. (2001) *Geographies of Care: Space, Place and the Voluntary Sector.* Aldershot: Ashgate.

Milligan, C. (2000) ‘Bearing the Burden Towards a Restructured Geography of Caring’, *Royal Geographical Society,* 32(1), pp. 49-58.

Milligan, C. and Conradson, D. (ed.) (2011) ‘*Landscapes of Voluntarism’*. Bristol: The Policy Press.

Milligan, C. and Thomas, C. J. (2016) 'Dementia and the social model of disability: does responsibility to adjust lie with society rather than people with dementia?', *Signpost*, 21(3), pp. 5-16. [Online]. Available at: https://issuu.com/bangoruniversity/docs/volume21number3spring2016 (Accessed: 11 August 2022).

Milligan, C. and Wiles, J. (2010) ‘Landscapes of Care’, *Progress in Human Geography,* 34(6), pp. 736-754.

Mitchell, D. (2008) ‘New Axioms for Reading the Landscape: Paying Attention to Political Economy and Social Justice’, in (ed.) Wescoat, J.L. and Johnston, D.M. *Political Economies of Landscape Change*. [Online]. Dordrecht: Springer Netherlands. pp. 29–50. (Accessed: 5 October 2022).

Molyneaux, V. J., Butchard, S., Simpson, J., and Murray, C. (2012) ‘The co-construction of couplehood in dementia’, *Dementia*. 11(4), pp. 483–502. [Online]. Available at: https://doi.org/10.1177/1471301211421070. (Accessed: 23 September 2021).

Moran, J. (2018) ‘Aristotle on Eudaimonia (‘Happiness’)’, *Think*. Cambridge University Press, 17(48), pp. 91–99. [Online]. Available at: DOI: 10.1017/S1477175617000355 (Accessed: 13 October 2022).

Morgan, D., Innes, A. and Kosteniuk, J. (2011) ‘Dementia Care in Rural and Remote Settings: A Systematic Review of Formal or Paid Care’, *Maturitas,* 68(1), pp. 17-33. [Online]. Available at: https://doi.org/10.1016/j.maturitas.2010.09.008. (https://www.sciencedirect.com/science/article/pii/S037851221000352X) (Accessed: 22 January 2023).

Morse, J. M. (1997) 'Perfectly Healthy, But Dead: The Myth of Inter-rater Reliability', *Qualitative Health Research*, *7*(4), pp. 445-447.

Mruck, K. and Mey, G. (2007). 'Grounded Theory and Reflexivity', in *The SAGE Handbook of Grounded Theory.* SAGE Publications Ltd, (pp. 514-538). [Online]. Available at: https://dx.doi.org/10.4135/9781848607941

Mukaetova-Ladinska, E.B. (2017) 'Silent lives: why do we fail community-dwelling people with dementia?' *Age Ageing.* 46(3), pp. 341-343.

Murphy, C., De Laine, C., Macaulay, M. and Fader, M. (2022) 'A qualitative study of continence service provision for people living with dementia at home in the UK: Still inadequate?', *PLoS ONE,* 17(5): e0268900. [Online]. Available at: https://doi.org/10.1371/journal.pone.0268900 (Accessed: 17 August 2022).

Murphy, C., De Laine, C., Macaulay, M., Lennie, K.H. and Fader, M. (2021) 'Problems faced by people living at home with dementia and incontinence: causes, consequences and potential solutions', *Age and Ageing*, 50(3), pp. 944–954. [Online]. Available at: https://doi.org/10.1093/ageing/afaa262 (Accessed: 17 August 2022).

National Audit Office (2021) *The Adult Social Care Market in England*, Available at: https://www.nao.org.uk/wp-content/uploads/2021/03/The-adult-social-care-market-in-England-Summary.pdf, (Accessed: 6 July 2023).

National Institute on Aging (2018) *Blood, brain metabolites could be earlier biomarkers of Alzheimer's disease.* Available at: https://www.nia.nih.gov/news/blood-brain-metabolites-could-be-earlier-biomarkers-alzheimers-disease (Accessed 14 March 2018).

NEF, (2012) *Wellbeing and the Role of Government, NEF Response.* Available at: http://www.neweconomics.org/publications/entry/well-being-and-the-role-of-government (Accessed: 23 April 2016).

New, C. (1998) 'Realism, Deconstruction and the Feminist Standpoint'. *Journal for the Theory of Social Behaviour*, 28, pp. 349-372. [Online]. Available at: https://doi.org/10.1111/1468-5914.00080 (Accessed: 20 September 2022).

Newcastle University (2022) *People with dementia could be missing out on post-diagnosis care*. Available at: https://www.ncl.ac.uk/press/articles/latest/2022/09/dementiapost-diagnosiscare/#:~:text=A%20new%20report%20has%20found,recognised%20as%20a%20human%20right (Accessed: 17 November 2022).

NHS (2022) *Who is considered a carer?* Available at: https://www.england.nhs.uk/commissioning/comm-carers/carers/ (Accessed: 11 March 2022).

NHS (2021) *Is There a Cure for Dementia?* Available at: https://www.nhs.uk/conditions/dementia/cure/ (Accessed: 25 April 2022).

NHS (2020) *What Are the Treatments for Dementia?* Available at: https://www.nhs.uk/conditions/dementia/treatment/ (Accessed: 25 April 2022).

NHS (2019) *Carers Breaks and Respite Care.* Available at: https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carer-breaks-and-respite-care/ (Accessed: 20 September 2022).

NHS Digital -Government Statistical Service (2022) *Personal Social Services Survey of Adult Carers in England 2021-2022*. Available at: https://files.digital.nhs.uk/28/2342AD/PSS_SACE_Report_2021-22.pdf (Accessed: 11 November 2022).

NICE (2022) *Supporting Carers.* Available at: https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/niceimpact-dementia/ch5-supporting-carers (Accessed: 21 April 2022).

Nichols-Casebolt, A. (2012) 'Data Management: Acquisition, Sharing, and Ownership', *Research Integrity and Responsible Conduct of Research, Building Social Work Research Capacity,* May, pp. 95–112, Oxford Academic [Online]. Available at: https://doi.org/10.1093/acprof:oso/9780195378108.003.0006 (Accessed: 26 Sept. 2022).

Noddings, N. (2003) *Caring: A Feminine Approach to Ethics & Moral Education*. (2nd edn.) Berkeley: University of California Press.

Noddings, N. (1982) *Caring: A Feminine Approach to Ethics and Moral Education.* Berkley: University of CA Press.

Nolan, M. and Grant, G. (1992) ‘Respite care: challenging tradition.’, *Br J Nurs*. 1992 May 28-Jun 10;1(3), pp. 129-31. [Online]. Available at: DOI: 10.12968/bjon.1992.1.3.129. PMID: 1617276.

Nolan, M., Lundh, U, Grant, G. and Keady, J. (2003). *Partnerships in Family Care: understanding the caregiving career*. Buckingham: Open University Press.

Nordberg,K. (2020) ‘Spatial Justice and local capability in rural areas’, *Journal of Rural Studies,* 78, pp. 47-58.

Northumberland County Council (2022a) *Dementia Awareness 'How many people are affected in Northumberland?* Available at: https://www.northumberland.gov.uk/Care/Support/Care-support-for-adults.aspx (Accessed: 14 April 2022).

Northumberland County Council (2022b) *Use our Loo*. Available at: https://www.northumberland.gov.uk/Highways/Street.aspx (Accessed: 15 July 2022).

Northumberland County Council (2022c) *Public Toilets.* Available at: https://www.northumberland.gov.uk/Highways/Public-toilets.aspx (Accessed: 15 July 2022).

Northumberland County Council (2018a) *Know Northumberland Population and Health Bulletin, March 2018.* Available at: https://www.northumberland.gov.uk/NorthumberlandCountyCouncil/media/Northumberland-Knowledge/Know%20bulletins/26-Population-and-Health-Bulletin-Mar18.pdf (Accessed: 14 April 2022).

Northumberland County Council (2018b) *Joint Health and Well-being Strategy 2018-2028.* Available at: https://www.northumberland.gov.uk/NorthumberlandCountyCouncil/media/Health-and-social-care/Public%20Health/Northumberland-CC-Health-and-Wellbeing-17-12-19-2.pdf (Accessed: 9 November 2022).

Northumberland County Council (2017) *Northumberland Knowledge: Northumberland population Older people - age profile June 2017.* Available at: https://www.northumberland.gov.uk/NorthumberlandCountyCouncil/media/Northumberland-Knowledge/NK%20people/Demographics/Older-people-age-profile-Northumberland-2017-docx.pdf (Accessed: 11 November 2022).

Northumberland County Council (2013) *Past Trends and Future Change –Northumberland's Age Profile.* Available at: https://www.northumberland.gov.uk/NorthumberlandCountyCouncil/media/Northumberland-Knowledge/NK%20people/Demographics/Age%20structure/Past-trends-and-future-change.pdf (Accessed: 3 June 2022).

Northumberland County Council (2012) *Know Northumberland – 2011 Census* Available at: https://www.northumberland.gov.uk/NorthumberlandCountyCouncil/media/Northumberland-Knowledge/NK%20people/Census/KnowNland2011CensusKeyStatisticsNewsletter.pdf (Accessed: 6 January 2023).

Northumberland County Council (2007) *Northumberland's population is out of balance the ageing population of Northumberland 2006 and 2021 an Infonet Briefing.* Available at: https://www.northumberland.gov.uk/NorthumberlandCountyCouncil/media/NorthumberlandKnowledge/Document%20library/NorthumberlandAgeingPopulation2006And2021.pdf (Accessed: 3 June 2022).

Northumberland County Council and Northumbria Healthcare (2018) *'Information sheet C4 – advice, assessment and support for carers'.* Available online: https://www.northumberland.gov.uk/NorthumberlandCountyCouncil/media/Health-and-social-care/Care%20support%20for%20adults/Information-sheet-C4-_advice-assessment-and-support-for-carers-Sep-18.pdf (Accessed: 5 January 2023).

Nozick, R. (1974) *Anarchy, State and Utopia.* Oxford: Blackwell.

Nussbaum, MC (2013), *Political Emotions: Why Love Matters for Justice*. Cambridge: Harvard University Press. Available from: ProQuest Ebook Central. (Accessed: 25 October 2022).

Nussbaum, M. C. (2011) '*Creating Capabilities',* London: Harvard University Press.

Nussbaum, M.C. (2011) *Creating Capabilities: The Human Development Approach*. Cambridge, Mass: Belknap Press of Harvard University Press, pp.1-45.

Nussbaum, M. (2006) *Frontiers of Justice: Disability, Nationality, Species Membership*. Cambridge MA: Harvard University Press.

Nussbaum, M. (2004) 'Mill Between Aristotle and Bentham', *Daedalus,* 133(2), pp. 60-68.

Nussbaum, M. (2002) 'Education for Citizenship in an Era of Global Connection', *Studies in Philosophy and Education*, 21(4/5), pp. 289-303.

Nussbaum, M. (2001) 'Adaptive Preferences and Women's Options', *Economics and Philosophy*, 17, pp. 67-88.

Nussbaum, M. (2000) *Women and Human Development: The Capabilities Approach*. New York: Cambridge University Press.

Nussbaum, M. (1999) *Sex and Social Justice,* New York: Oxford University Press.

Oakley, A. (1981) 'Interviewing Women: A Contradiction in Terms', in Roberts, H. (ed.) *Doing Feminist Research*, London: Routledge, pp. 30-61.

O’Brien, J. and O’Brien, C.L. (1998) *A Little Book About Person Centred Planning*. Toronto: Inclusion Press.

O'Brien, J. and Thomas, A. (2015) ‘Vascular dementia’, *The Lancet,* 386(10004), pp. 1698-1706.

O’Connell, B. (2019) ‘Questions raised over bus services across Northumberland’, 20 October, *Northumberland Gazette* [Online]. Available at: https://www.northumberlandgazette.co.uk/news/politics/questions-raised-over-bus-services-across-northumberland-816966 (Accessed: 10 June 2022).

O'Connor, E., James, I. A. and Caiazza, R. (2017). ‘A response framework with untruths as last resort’, *Journal of Dementia Care*, 25(4), pp. 22–25.

Office for Improvements and Disparities (2022) *Dementia Profile Northumberland CCG.* Available at: https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#page/1/gid/1938132811/pat/44/par/E40000009/ati/166/are/E38000130/iid/247/age/1/sex/4/cat/-1/ctp/-1/yrr/1/cid/1/tbm/1 (Accessed: 14 April 2022).

Office for National Statistics (2022) *Deaths involving COVID-19 in the care sector, England and Wales: deaths registered between week ending 20 March 2020 and week ending 21 January 2022*. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsregisteredbetweenweekending20march2020andweekending21january2022 (Accessed: 18 January 2023).

Office for National Statistics (2021) *Coronavirus and the social impacts on unpaid carers in Great Britain.* Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/datasets/coronavirusandthesocialimpactsonunpaidcarersingreatbritain (Accessed: 24 February 2022).

Office for National Statistics (2019). *More than one in four sandwich carers report symptoms of mental ill-health*. Available at https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/articles/morethanoneinfoursandwichcarersreportsymptomsofmentalillhealth/2019-01-14 (Accessed 15 February 2022).

Office for National Statistics (2018) *Trends in self-employment in the UK*. Available at: https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/articles/trendsinselfemploymentintheuk/2018-02-07 (Accessed: 29 June 2022).

Office for National Statistics (2013) *Full story: The gender gap in unpaid care provision: is there an impact on health and economic position?* Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/articles/fullstorythegendergapinunpaidcareprovisionisthereanimpactonhealthandeconomicposition/2013-05-16 (Accessed: 29 June 2022).

Oleson, V.L. (2007) ‘Feminist Qualitative Research and Grounded Theory: Complexities, Criticisms, and Opportunities’, in Bryant, A., and Charmaz, K. (ed.) *The SAGE Handbook of Grounded Theory*, London: SAGE, pp. 417-435.

Oliver, C. (2012) ‘Critical realist grounded theory’. *The British Journal of Social Work*. 42 (2), pp. 371–387.

Oliver, M. (2004) ‘The Social Model in Action: if I had a Hammer, in Barnes, C. and Mercer, G. (eds) *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press.

Oliver, M. (1983) *Social Work with Disabled People*. Basingstoke: Palgrave Macmillan.

Oliver, P. (2013) *Writing Your Thesis*. SAGE Publications, Limited. *ProQuest Ebook Central*, [Online]. Available at: https://ebookcentral.proquest.com/lib/ncl/detail.action?docID=1534973 (Accessed: 20 September 2022).

O’Neill, O. (2018) ‘Liberal Justice: Kant, Rawls and Human Rights,’ *Kantian Review*. Cambridge University Press, 23(4), pp. 641–659. [online]. Available at: DOI: 10.1017/S1369415418000432.

O'Neill, O. (1996) *Towards Justice and Virtue: A Constructive Account of Practical Reasoning*. Cambridge; New York: Cambridge University Press.

Oshana, M. (2015) *Personal Autonomy and Social Oppression* (ed) New York: Routledge.

Owen, T. and Meyer, J. (2012) *Promoting Voice, Choice and Control for Older People Living in Care Home’s*. York: Joseph Rowntree Foundation.

Owens, J., Entwistle, V. A., Craven, L. K., and Conradie, I. (2022). ‘Understanding and investigating relationality in the capability approach’. *Journal for the Theory of Social*

Behaviour, 52(1), pp. 86– 104. [Online]. Available at: https://doi.org/10.1111/jtsb.12310 (Accessed: 22 September 2022).

Page, K. S. et al. (2019) ‘Development of a Multidimensional Measure to Examine Fear of Dementia’, *The International Journal of Aging and Human Development*, 89(2), pp. 187–205. [Online]. Available at: DOI: 10.1177/0091415018784737. (Accessed: 1 April 2022).

Pain, R. and Francis, P. (2003) ‘Reflections on Participatory Research’. *The Royal Geographical Society*, 35 (1), pp. 46-54.

Pain, R., Whitman, G. and Milledge, D. (2010) *Participatory Action Research Toolkit: An Introduction to Using PAR as an Approach to Learning, Research and Action.* Available on-line: https://www.dur.ac.uk/resources/beacon/PARtoolkit.pdf (Accessed: 9 January 2023).

Parfit, D. (1984) *Reasons and persons*. Oxford: Clarendon Press.

Parker, M., Barlow, S., Hoe, J. and Aitken, L. (2020) ‘Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia,’ *International Psychogeriatrics*. Cambridge University Press, 32(5), pp. 611–634. [Online]. Available at: DOI: 10.1017/S1041610219002229. (Accessed: 27 June 2022).

Pateman, C. (1987) ‘Feminist Critiques of the Public/Private Dichotomy’, in Philips, A. (ed) *Feminism and Equality*, Oxford: Blackwell, pp. 103-126.

Peterson, C.M., Birkeland, R.W., Barsel, S., Statz, T.L., Gaugler, J.E. and Finlay, J.M. (2022) ‘Sick with stress’: perspectives on airport travel from persons living with dementia and their travel companions’, *Disability & Society*, [Online]. Available at: DOI: 10.1080/09687599.2022.2070060 (Accessed: 11 August 2022).

Phillipson, C., Calasanti, T., & Scharf, T. (2021). Series editors’ preface. In B. Simmonds (Author), *Ageing and the Crisis in Health and Social Care: Global and National Perspectives* (Ageing in a Global Context, pp. V-Vi). Bristol University Press. [Online] Available at: doi:10.46692/9781447348726.001 (Accessed: 16 October 2023).

Pierik, R. and Robeyns, I. (2007) ‘Resources Versus Capabilities: Social Endowments in Egalitarian Theory’, *Political Studies*, 55, pp. 133–152.

Pogge, T. (2010) ‘A Critique of the Capabilities Approach’, in Brighouse, H. and Robeyns, I. (ed.), *Measuring Justice: Primary Goods and Capabilities.* Cambridge: Cambridge University Press, pp17-60.

Porter, E. (1999) *Feminist Perspectives on Ethics*. London: Longman.

Post, S. G. (1995) *The Moral Challenge of Alzheimer Disease*. Baltimore: Johns Hopkins University Press.

Pratt, A. C. (2013) '… the point is to change it': Critical realism and human geography', *Dialogues in Human Geography*, 3(1), pp. 26–29. [Online]. Available at: DOI: 10.1177/2043820613485048. (Accessed: 16 September 2022).

Prince, M.,Comas-Herrera, A., Knapp, M., Guerchet, M. and Karagiannidou, M. (2016) *World Alzheimer report 2016: improving healthcare for people living with dementia: coverage, quality and costs now and in the future. Alzheimer's Disease International (ADI) London,UK.* Available at: http://eprints.lse.ac.uk/67858/1/Comas-Herrera_World%20Alzheimer%20report_2016.pdf (Accessed: 3 June 2022).

Prunty, M. M. and Foli, K. J. (2019). Guilt experienced by caregivers to individuals with dementia: A concept analysis. *International Journal of Older People Nursing*, 14(2), e12227. doi:10.1111/opn.12227. (Accessed: 19 January 2023).

Public Health England (2019) *An evidence summary of health inequalities in older populations in coastal and rural areas Executive summary and main messages.* Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/824717/Health_Inequalities_in_Ageing_in_Rural_and_Coastal_Areas-Messages_and_summary.pdf (Accessed: 9 November 2022).

Public Health England (2017) *Commissioning for Value Mental health and dementia pack, NHS Northumberland CCG.* Available at: https://www.england.nhs.uk/wp-content/uploads/2017/07/cfv-northumberland-mhidp.pdf (Accessed 11 November 2022).

Public Toilets UK (2015) *A Matter of Urgency.* Available at: http://fombl.org.uk/Community+Toilet+Schemes+PTUK.pdf (Accessed: 3 June 2022).

Punch, K. (2006) *Developing Effective Research Proposals*. London: Sage Publications Ltd.

Punch, K. (2005) *Introduction to Social Research Quantitative and Qualitative Approaches* (2nd edn.), London: Sage Publications Ltd.

Putnam, H. (2004) *Ethics without Ontology*. Cambridge MA.: Harvard University Press.

Putnam, R.D. (2000) Bowling alone: the collapse and revival of American community. New York: Simon & Schuster.

Putnam, R. D. (1993) *Making democracy work: Civic traditions in modern Italy*. Princeton, NJ: Princeton University Press.

Qizilbash, M. (2012) 'The Capability Approach: It's Interpretation and Limitations', in Panzironi and Gelber (ed.), *The Capability Approach: Development Practice and Public Policy in the Pacific Region*, London: Routledge, pp. 9-22.

Quinton, A. (1989) *Utilitarian Ethics.* London: Duckworth and Co Ltd.

Ramster, G., Greed, C. and Bichard, J.-A. (2018) 'How Inclusion can Exclude: The Case of Public Toilet Provision for Women'. *Built environment* (1978). 44 (1), pp. 52–76.

Rao, S.R., Gupta, M. and Salins, N. (2021) 'The Concept of Respite in Palliative Care – Definitions and Discussions', *Palliative Medicine,* Available online: https://doi.org/10.1007/s11912-021-01015-z (Accessed: 7 January 2022).

Rapley, T.J. (2001) 'The Art (fulness of Open-ended Interviewing: Some Considerations on Analysing Interviews', *Qualitative Research*, 1(3), pp.303-323.

Rapoport, M.J., Chee, J.N., Carr, D.B., Molnar, F., Naglie, G., Dow, J., Marottoli, R., Mitchell, S., Tant, M., Herrmann, N., Lanctôt, K.L., Taylor, J.P., Donaghy, P.C., Classen, S. and O'Neill, D. (2018) 'An international approach to enhancing a national guideline on driving and dementia', *Current Psychiatry Reports*, 20(3), pp.16.

Rapoport, M., Hyde, A. and Naglie, G. (2020) 'Transportation Issues in Dementia,' in Innes, A., Morgan, D., and Farmer, J. (ed.) *Remote and Rural Dementia Care: Policy, Research and Practice*. Bristol University Press, pp. 213–240. [Online]. Available at: DOI: 10.46692/9781447344964.011. (Accessed: 14 June 2022).

Rauch, J. (2021) *The Constitution of Knowledge*. Brookings Institution: Washington.

Rawls, J. (1999) *A Theory of Justice: Revised Edition.* Cambridge: Harvard University Press.

Rawls, J. (1993) *Political Liberalism*, New York: Columbia University Press.

Rawls, J. (1971) *A Theory of Justice.* Oxford: Oxford University Press.

Rees, J.C. (1989) *John Stuart Mill's On Liberty.* Oxford: Clarenden Press.

Reeves, C. (2010) 'A Difficult Negotiation: Fieldwork Relations with Gatekeepers', *Qualitative Research,* 10(3), pp. 315–31.

Reiheld, Alison (2015) ‘Just Caring for Caregivers: What Society and the State Owe to Those Who Render Care’, *Feminist Philosophy Quarterly*. 1(2).

Reisberg, B., Ferris, S.H., De Leon, M.J. and Crook, T. (1982) ‘The global deterioration scale for assessment of primary degenerative dementia’, *Journal of Psychiatry*, 139, pp.1136-1139.

Reiss, A. B., Glass, A. D., Wisniewski, T., Wolozin, B., Gomolin, I. H., Pinkhasov, A., De Leon, J., and Stecker, M. M. (2020) ‘Alzheimer's Disease: Many Failed Trials, So Where Do We Go From Here?’ *Journal of Investigative Medicine: The Official Publication of the American Federation for Clinical Research*, 68(6), pp. 1135–1140. [Online]. Available at: https://doi.org/10.1136/jim-2020-001297

Richardson, M.J. (2015) ‘Embodied Intergenerationality: Family Position, Place and Masculinity’, *Gender, Place & Culture*, 22(2), pp. 157-171, [Online]. Available at: DOI: 10.1080/0966369X.2013.855710

Riley, J. (1998) *Mill on Liberty*. London: Routledge.

Roberts, R. (2022) Wild Problems: A Guide to the Decisions That Define Us, Kindle Edition, EPUB: John Murray Press.

Robeyns, I. (2017) *Wellbeing, Freedom and Social Justice: The Capability Approach Re-examined*. Cambridge: Open Book Publishers.

Robeyns, I. (2005) ‘The Capability Approach: A Theoretical Survey’, *Journal of Human Development*, 6(1) pp. 93-117.

Robeyns, I. and Byskov, M. (2020) ‘The Capability Approach’, *The Stanford Encyclopedia of Philosophy* (Fall 2021 Edition), Zalta, E. N. (ed.), Available at: https://plato.stanford.edu/archives/fall2021/entries/capability-approach/ (Accessed: 10 June 2022).

Robinson, F. (2011) *The Ethics of Care: A Feminist Approach to Human Security,* Philadelphia: Temple University Press.

Robinson, F. (1997) ‘Globalizing Care: Ethics, Feminist Theory, and International Relations’, *Alternatives: Global, Local, Political.* 22(1), pp. 113–133.

Robinson, L, Clare, L. PhD and Evans, K. (2005) ‘Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples’, *Aging & Mental Health*, 9(4), pp. 337-347, [Online]. Available at: DOI: 10.1080/13607860500114555 (Accessed: 27 June 2022).

Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S., Samsi, K. and Manthorpe, J. (2011) 'The Transition to Dementia – Individual and Family Experiences of Receiving a Diagnosis: A Review,' *International Psychogeriatrics*. Cambridge University Press, 23(7), pp. 1026–1043. [Online]. Available at: DOI: 10.1017/S1041610210002437. (Accessed: 27 June 2022).

Romero-Moreno, R., Losada, A., Marquez, M., Laidlaw, K., Fernández-Fernández, V., Nogales-González, C. and López, J. (2014). Leisure, gender, and kinship in dementia caregiving: Psychological vulnerability of caregiving daughters with feelings of guilt. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences,* 69(4), pp. 502–513. doi:10.1093/geronb/gbt027 (Accessed: 19 January 2023).

Rose. G. (1997). 'Situating Knowledges: Positionality, Reflexivities and Other Tactics', *Progress in Human Geography,* 21(3), pp. 305–320. [Online]. Available at: https://doi.org/10.1191/030913297673302122 (Accessed: 9 January 2023).

Rosenburg, M. (2014) 'Health Geography 1: Social Justice, Idealist Theory, Health and Healthcare', *Progress in Human Geography*, 38(3), pp.466-475.

Rovelli, C. (2022) Interview with Alexis Papazoglou for IAI TV 19 July 2022, [Online] Available at: https://iai.tv/articles/consciousness-is-irrelevant-to-quantum-mechanics-auid-2187&utm_source=reddit&_auid=2020 (Accessed: 22 September 2022).

Rovelli, C. (2016) *Seven Brief Lessons in Physics.* London: Penguin.

Rowbotham, S. (1992) *Women in Movement: feminism and social action.* New York: Routledge.

Rowles, G.D. (1978) *Prisoners of Space.* Colorado: Westview Press.

Royal College of Psychiatrists (2019) *Driving with Dementia or Mild Cognitive Impairment, Consensus Guidelines for Clinicians.* Available at: https://www.bgs.org.uk/sites/default/files/content/resources/files/2019-01-11/Driving%20with%20dementia%20or%20MCI%20-%20Consensus%20guidelines%20for%20clinicians%2011.1.19.pdf (Accessed: 9 June 2022).

Royal Society for Public Health (2019) *Taking the Piss, The Decline of the Great British Public Toilet*. Available at: https://www.rsph.org.uk/static/uploaded/459f4802-ae43-40b8-b5a006f6ead373e6.pdf (Accessed: 15 July 2022).

Ruddick, S. (2004) ‘Maternal Thinking as a Feminist Standpoint’, in Harding, S. (ed) *The Feminist Standpoint Theory Reader*. London: Routledge, pp. 161-167.

Ruddick, S. (1980) ‘Maternal Thinking’, *Feminist Studies*, 6(2) pp. 342-367.

Ruger, J.P. (2010) *Health and social justice*. Oxford; New York: Oxford University Press.

Russell, B. (2010) *History of Western Philosophy* Abingdon, Oxon: Routledge.

Ryan, A. (1970) *The Philosophy of John Stuart Mill.* London: MacMillan.

Sabat, S.R. (2021) ‘Cognitive and Social Strengths of People Living with Dementia: Discoveries Through Harré’s Method’, *Journal for the Theory of Social Behaviour*. 51(2), pp. 232–248.

Sabat, S. R. and Cahill, S. (2018) ‘Foreword’, in *Dementia and Human Rights*. Bristol University Press, pp. xi-xiv. [Online]. Available at: DOI: 10.46692/9781447331384.001. (Accessed: 9 January 2023).

Sabat, S. R., Johnson, A., Swarbrick, C., and Keady, J. (2011). ‘The 'Demented Other' or Simply 'A Person'? Extending the Philosophical Discourse of Naue and Kroll Through the Situated Self’, *Nursing Philosophy*, 12(4), pp. 282–292. [Online]. Available at: https://doi.org/10.1111/j.1466-769X.2011.00485.x (Accessed: 10 June 2022).

Sacks, J. (2020) *Morality.* London: Hodder and Stoughton Ltd.

Said, E. (2003) *Orientalism*. London: Penguin.

Sahraoui, N. (2019). ‘Introduction: From the Empirical Study of Care Labour to Feminist Care Ethics’, in *Racialised Workers and European Older-Age Care. Thinking Gender in Transnational Times*. Cham: Palgrave Macmillan. [Online]. Available at: https://doi.org/10.1007/978-3-030-14397-8_1 (Accessed: 5 September 2022).

Salecl, R. (2020) 'Denial of Illness', in *A Passion for Ignorance: What We Choose Not to Know and Why*. Princeton: Princeton University Press, pp. 75-95. [Online]. Available at: https://doi-org.libproxy.ncl.ac.uk/10.1515/9780691202020 (Accessed: 20 June 2022).

Samuel, J. (2018) *Grief Works.* Random House UK: Penguin Life.

Sandel, M. (2009) *Justice – What’s The Right Thing To Do*? London: Allen Lane Penguin Books.

Sandel, M. (1998) *Liberalism and the Limits of Justice*. New York: Cambridge University Press.

Sanderson, H (2000) *Person Centred Planning, Key Features and Approaches*. Available at: http://www.familiesleadingplanning.co.uk/documents/pcp%20key%20features%20and%20styles.pdf (Accessed: 17 February 2022).

Sander-Staudt, M. (2006) The Unhappy Marriage of Care Ethics and Virtue Ethics. Hypatia. 21 (4), pp. 21–39.

Satsangi, M. (2013) 'Synthesizing Feminist and Critical Realist Approaches to Housing Studies', *Housing, Theory and Society*, 30(2), pp. 193-207, [Online]. Available at: DOI: 10.1080/14036096.2012.743484 (Accessed: 20 September 2022).

Sayer, A. (1992) *Method in Social Science: Revised 2nd Edition* (1st edn.). Routledge. [Online]. Available at: https://doi.org/10.4324/9780203163603 (Accessed: 16 September 2022).

Sayer, R.A. (2005) *The moral significance of class*. Cambridge: Cambridge University Press.

Scanlon, T. (1998) *What we Owe to Each Other*. Cambridge, MA: Harvard University Press.

Scharf, T. and Bartlam, B. (2008) 'Ageing and social exclusion in rural communities', in Keating, N. (ed.), *Rural Ageing: A Good Place to Grow Old?* Bristol University Press, pp. 97-108. [Online]. Available at: DOI:10.46692/9781847424037.011 (Accessed: 9 January 2023).

Scharf, T. and Bartlam, B. (2006) *Rural Disadvantage – Quality of Life and Disadvantage Amongst Older People – a Pilot Study*, Commission for Rural Communities.

Schattner, E., Shahar, G. and Abu-Shakra, M. (2008) 'I Used to Dream of Lupus as Some Sort of Creature: Chronic Illness as an Internal Object', *American Journal of Orthopsychiatry*, 78(4), pp. 466–472.

Schmidtz, D. (2020) 'Robert Nozick, Anarchy, State, and Utopia' in Levy, J.T. *The Oxford Handbook of Classics in Contemporary Political Theory*, (ed). Political Science, Political Theory, International Relations [Online]. Available at: DOI: 10.1093/oxfordhb/9780198717133.013.23. (Accessed: 10 February 2022).

Schumacher, E.F. (1977) *A Guide for the Perplexed*. New York: Harper and Row.

Seligman, M. and Csikszentmihalyi, M. (2000) ‘Positive psychology: An introduction’. *American Psychologist, 55*(1), pp. 5–14.

Sen, A. (2021) *Home and Humanity,* Lecture at Edinburgh International Book Festival, 23/8/21 4-5pm. Available at: https://www.edbookfest.co.uk/media-gallery/item/amartya-sen-home-and-humanity (Accessed: 23 August 2021).

Sen, A. (2010a) *The Idea of Justice.* London: Penguin.

Sen, A. (2010b) ‘The Place of Capability in a Theory of Justice,’ in Brighouse, H. and Robeyns, I. (ed.) *Measuring Justice: Primary Goods and Capabilities*. Cambridge: Cambridge University Press, pp. 239–253. [Online]. Available at: DOI: 10.1017/CBO9780511810916.011 (Accessed: 8 September 2022).

Sen, A. (2007) *Identity and Violence.* London: Penguin.

Sen, A. (2001) *Development as freedom*. Oxford ; New York: Oxford University Press.

Sen, A. (1992) *Inequality Re-examined,* Cambridge, MA: Harvard University Press.

Sen, A. and Williams, B. (1982) *Utilitarianism and Beyond.* Cambridge: Cambridge University Press.

Sevenhuijsen, S. (1998) *Citizenship and the Ethics of Care*. London: Routledge.

Shahar, G. and Lerman, S. F. (2013) ‘The Personification of Chronic Physical Illness: Its Role in Adjustment and Implications for Psychotherapy Integration’, *Journal of Psychotherapy Integration,* 23(1), pp. 49–58. [Online]. Available at: https://doi.org/10.1037/a0030272

Shakespeare, T. (2014) *Disability Rights and Wrongs Revisited*. London: Routledge.

Shakespeare, T., Zeilig, H. and Mittler, P. (2017) ‘Rights in Mind: Thinking Differently about Dementia and Disability’, *Dementia,* 1, pp. 1–14. [Online]. Available at: DOI:10.1177/147130121770150 (Accessed: 11 August 2022).

Sharman, L. (2019) *Double the number of providers handing back care contracts to councils.* Local Gov Report. Available at: https://www.localgov.co.uk/Double-the-number-of-providers-handing-back-care-contracts-to-councils/46864 (Accessed: 23 December 2022).

Shields, C.J. (2006) *Aristotle*. London: Routledge.

Shim, B., Barroso, J. and Davis, L. L. (2012) ‘A Comparative Qualitative Analysis of Stories of Spousal Caregivers of People with Dementia: Negative, Ambivalent, and Positive

Experiences', *International Journal of Nursing Studies*, 49(2), pp. 220–229. [Online] Available at: https://doi.org/10.1016/j.ijnurstu.2011.09.003 (Accessed: 14 June 2022).

Shweder, R.A. and Haidt, J. (1993) 'The Future of Moral Psychology: Truth, Intuition, and the Pluralist Way', *Psychological science*, 4(6), pp. 360–365.

Shweder, R., Much, N.C., Mahapatra, M. and Park, L. (1997) 'The Big Three of Morality' (Autonomy, Community and Divinity), and the Big Three Explanations of Suffering', in Brandt, A. and Rozin, P. *Morality and Health*, (ed.), New York: Routledge, pp. 119-69.

Silverman, D. (2022) *Qualitative Research in the Wake of a Pandemic, Limits and Opportunities,* Leeds University Business School Public lecture, 10am 25/2/22 Available at: https://www.eventbrite.co.uk/mytickets/2636602939 https://universityofleeds.zoom.us/j/82508786748?pwd=d1lnSDlXR1BhTFpVMVRwUkZJWHJ5UT09. (Accessed: 25 February 2022).

Silverman, D. (2013) *Doing Qualitative Research.* (4th edn.), London: Sage Publications.

Simonsen, P. (2017) 'Who Cares?: The Terror of Dementia in Ian McEwan's Saturday', in Chivers, S. and Kriebernegg, U. (ed.), *Care Home Stories: Aging, Disability, and Long-Term Residential Care*. pp. 175–190. Transcript Verlag. [Online]. Available at: http://www.jstor.org/stable/j.ctv1xxs09.18 (Accessed 9 January 2023).

Singer, P. (2015) *The Most Good You Can Do: How Effective Altruism is Changing Ideas about Living Ethically*. New Haven, CT: Yale University Press.

Skeggs, B. and Loveday, V. (2012) 'Struggles for value: value practices, injustice, judgment, affect and the idea of class', *The British journal of sociology*, 63(3), pp. 472–490.

Skoropski, J. (1989) *Liberty John Stuart Mill*. London: Routledge.

Slaughter, S., Cole, D., Jennings, E. and Reimer, M. A. (2007) 'Consent and Assent to Participate in Research from People with Dementia', *Nursing Ethics*, 14(1), pp. 27–40. [Online]. Available at: https://doi.org/10.1177/0969733007071355 (Accessed: 14 June 2022).

Slote, M. (2015) 'Care ethics and liberalism'. in Engster, D. and Hamington, M. (ed.), *Care Ethics and Political Theory*. Oxford University Press: Oxford, pp. 37–50.

Slote, M. (2011) *The Impossibility of Perfection: Aristotle, Feminism, and the Complexities of Ethics*. Oxford University Press: Oxford Scholarship. [Online]. Available at: https://oxford.universitypressscholarship.com/view/10.1093/acprof:oso/9780199790821.001.0001/acprof-9780199790821 (Accessed: 14 June 2022).

Slote, M. (2007) *The Ethics of Care and Empathy*. New York: Routledge.

Slote, M. (2001) *Morals from motives*. Oxford: Oxford University Press.

Slote, M. (1998) 'The Justice of Caring'. *Social Philosophy & Policy.* 15(1) pp.171–195.

Smart, J.C.C. and Williams, B. (1973) *Utilitarianism, For and Against.* Cambridge: Cambridge University Press.

Smirthwaite, G. and Swahnberg, K. (2016) 'Comparing Critical Realism and the Situated Knowledges Approach in Research on (In)equity in Health Care: An Exploration of their Implications', *Journal of Critical Realism*, 15(5), pp. 476-493, [Online]. Available at: DOI: 10.1080/14767430.2016.1210427 (Accessed: 20 September 2022).

Smith, A. (1976) *The Theory of Moral Sentiments*. (London: T Cadell, 1790) republished Oxford: Clarendon Press.

Smith, D.M. (2000) *Moral Geographies: Ethics in a World of Difference*. Edinburgh: Edinburgh University Press.

Smith, I. (2022a) 'Rail Ticket Offices in Northumberland at Risk of Closure Claims Union', 23 May, *Northumberland Gazette* [Online]. Available at: https://www.northumberlandgazette.co.uk/news/people/rail-ticket-offices-in-northumberland-at-risk-of-closure-claims-union-3704757?itm_source=parsely-api (Accessed: 10 June 2022).

Smith, I. (2022b) 'Revealed: The 19 public toilets in Northumberland set for full refurbishment in £1.35m project: Improvements to public toilets in Northumberland are in the pipeline', *Northumberland Gazette* [Online]. Available at: https://www.northumberlandgazette.co.uk/news/politics/council/revealed-the-19-public-toilets-in-northumberland-set-for-full-refurbishment-in-ps135m-project-3550502, (Accessed: 15 July 2022).

Smith, M.L. and Seward, C. (2009) 'The Relational Ontology of Amartya Sen's Capability Approach: Incorporating Social and Individual Causes', *Journal of Human Development and Capabilities,* 10(2), pp. 213-235, [Online]. Available at: DOI: 10.1080/19452820902940927 (Accessed: 15 August 2022).

Smith, S.J., Parveen, S., Sass, C. *et al.* (2019) 'An audit of dementia education and training in UK health and social care: a comparison with national benchmark standards'. *BMC Health Serv Res* 19 (711) pp. 2-9. Available at: https://doi.org/10.1186/s12913-019-4510-6 (Accessed: 23 December 2022).

Smithson, J. (2000) ‘Using and analysing focus groups: Limitations and possibilities’, *International Journal of Social Research Methodology,* 3(2), pp.103-119, [Online]. Available at: DOI: 10.1080/136455700405172 (Accessed: 14 June 2022).

Social Care Institute for Excellence (2020) *Decision Making Capacity in Dementia.* Available at: https://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/capacity (Accessed: 17 February 2022).

Soja, E. (2011) ‘Response to Kurt Iveson – Social or Spatial Justice, Marcuse and Soja on the Right to the City’, *City,* 15(2), pp 260-262.

Soja, E. (2010) *Seeking Spatial Justice.* Minnesota: Minnesota University Press.

Soja, E. (2009) ‘*The City and Spatial Justice’*. Spatial Justice Conference, Nanterre, Paris Available at: http://www.jssj.org/wp-content/uploads/2012/12/JSSJ1-1en4.pdf. (Accessed: 3 June 2022).

Sontag, S. (2004) *Regarding the Pain of Others*. London: Penguin.

Stafford, W. (1998) *John Stuart Mill.* Basingstoke: MacMillan Press Ltd.

Stalker, K. (2012) ‘Theorising the Position of People with Learning Difficulties within Disability Studies’, in Watson, N., Roulstone, A. and Thomas, C. (ed.) *Routledge Handbook of Disability Studies*. London: Routledge.

Stalker K. (1996) *Developments in Short-term Care: Breaks and Opportunities*. United Kingdom: Jessica Kingsley.

Stanley, L. and Wise, S. (1993) *Breaking Out Again – Feminist Ontology and Epistemology*. London: Routledge.

Stanwell Smith, R. (2010) ‘Public Toilets Down the Drain? Why Privies are a Public Health Concern’, *Public Health*, 124(11) pp. 613-616.

Stockdale, A. (2011) ‘Ageing in the UK – Opportunities for Rural Research, *Population, Space and Time,* 17, pp. 204-221.

Strauss, A. and Corbin, J. (1997). *Grounded theory in practice*. Thousand Oaks: Sage Publications.

Stroebe, M. and Schut, H. (1999) ‘The dual process model of coping with bereavement: Rationale and description’, *Death Studies* 23, pp. 197–224.

Sweeting, H. and Gilhooly, M. (1997) ‘Dementia and the Phenomenon of Social Death’, *Sociology of Health & Illness*, 19, pp. 93-117. [Online]. Available at: https://doi.org/10.1111/j.1467-9566.1997.tb00017.x (Accessed: 10 August 2022).

Tanner, D. (2013). ‘Identity, selfhood and dementia: messages for social work’, *European Journal of Social Work,* 16(2), pp. 155–170. [Online]. Available at: https://doi.org/10.1080/13691457.2011.611795 (Accessed: 14 June 2022).

Tarrant, A. (2010) ‘Constructing a Social Geography of Grandparenthood: A New Focus for Intergenerationality’, *The Royal Geographic Society,* 42(2), pp. 190-197.

Taylor, C. (1994) ‘The Politics of Recognition’, in A. Gutmann (ed.), *Multiculturalism: Expanded Paperback Edition.* Princeton University Press, REV-Revised, pp. 25–74. [Online]. Available at: https://doi.org/10.2307/j.ctt7snkj.6 (Accessed 3 August 2022).

Taylor, C. (1991). What’s Wrong with Negative Liberty in Miller, D. (ed.) *Liberty,* Ch7 pp. 141-162, Oxford: Oxford University Press.

Taylor, C. (1989) *Sources of the self: the making of the modern identity*. Cambridge: Cambridge University Press.

Taylor, C. (1985) *Human Agency and Language, Philosophical Papers,* Cambridge University Press: Cambridge.

Taylor J. S. (2008) ‘On Recognition, Caring, and Dementia’, *Medical Anthropology Quarterly*, *22*(4), pp.313–335. [Online]. Available at: https://doi.org/10.1111/j.1548-1387.2008.00036.x (Accessed: 10 August 2022).

Taylor, S.A.P. (2001) ‘Place Identification and Positive Realities of Aging’, *Journal of Cross-Cultural Gerontology*, 16, pp. 5-20.

Ten, C.L. (1980) *Mill on Liberty*. Oxford: Oxford University Press.

Terzi, L. (2020) ‘Capability and Disability,’ in Chiappero-Martinetti, E., Osmani, S., and Qizilbash, M. (ed.) *The Cambridge Handbook of the Capability Approach*. Cambridge: Cambridge University Press, pp. 544–561.

Terzi, L. (2010) ‘What metric of justice for disabled people? Capability and disability’, in Brighouse, H. and Robeyns, I. (ed.) *Measuring Justice: Primary Goods and Capabilities*. Cambridge: Cambridge University Press, pp. 150–173. [Online]. Available at: DOI: 10.1017/CBO9780511810916.007

Tessman, Lisa. (2014) ‘Conclusion’, in *Moral Failure: On the Impossible Demands of Morality*. New York: Oxford University Press. Oxford Scholarship, pp. 253-256. [Online]. Available at: https://oxford.universitypressscholarship.com/view/10.1093/acprof:oso/9780199396146.001.0001/acprof-9780199396146-chapter-9?print=pdf (Accessed: 14 June 2022).

Thomas, C. (2004) ‘Developing the Social Relational in the Social Model of Disability: a theoretical agenda’, in Barnes, C. and Mercer, G. (ed.) *Implementing the Social Model of Disability: Theory and Research.* Leeds: The Disability Press, pp. 32-47. [Online]. Available at: https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-implementing-the-social-model-chapter-3.pdf (Accessed: 14 June 2022).

Thomas, C. and Milligan, C. (2018) ‘Dementia, Disability Rights and Disablism: Understanding the Social Position of People Living with Dementia’, *Disability & Society*, 33(1), pp. 115-131. [Online]. Available at: DOI: 10.1080/09687599.2017.1379952, (Accessed: 11 August 2022).

Thornberg, R. (2012) ‘Informed Grounded Theory’, *Scandinavian Journal of Educational Research*, 56(3), pp. 243-259. [Online]. Available at: DOI: 10.1080/00313831.2011.581686 (Accessed: 4 May 2022).

Tolhurst, E., Weicht, B. and Kingston, P. (2017) ‘Narrative Collisions, sociocultural pressures and dementia: the relational basis of personhood reconsidered’. in Higgs, P. and Gilleard, C. (ed.) *Ageing, Dementia and the Social Mind*. Cardiff: Wiley Blackwell, pp. 37-51.

Toltz, S. (2016) *Quicksand.* London: Hodder and Stoughton.

Toltz, S. (2009) *A Fraction of the Whole.* UK: Penguin Random House.

Torre, de la J. C. (2013) ‘Vascular Risk Factors: A Ticking Time Bomb to Alzheimer's Disease’, *American Journal of Alzheimer's disease and other dementias*, 28, 10.1177/1533317513494457. [Online]. Available at: https://www.researchgate.net/publication/243969739_Vascular_Risk_Factors_A_Ticking_Time_Bomb_to_Alzheimer%27s_Disease (Accessed 14 June 2022).

Transport for the North (2022) *Transport Related Social Exclusion in the North of England.* Available at: https://transportforthenorth.com/wp-content/uploads/Transport-related-social-exclusion-in-the-North-of-England.pdf (Accessed: 29 September 2022).

Travel in Urban and Rural Areas (2010) *Personal Travel Factsheet*, Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/230556/Travel_in_urban_and_rural_areas_personal_travel_factsheet___March_2010.pdf (Accessed: 8 January 2023).

Tronto, J. C. (2013). *Caring Democracy: Markets, Equality, and Justice*. New York: New York University Press.

Tronto, J.C. (1994) *Moral Boundaries*. London: Routledge.

Tronto, J.C. (1987) 'Beyond Gender Difference to a Theory of Care', *Signs, Within and Without: Women, Gender and Theory*, (Summer 1987), 12(4), pp. 644-663.

Tsur, N. (2022) 'Chronic Pain Personification Following Child Abuse: The Imprinted Experience of Child Abuse in Later Chronic Pain', *Journal of Interpersonal Violence,* 37(5–6), pp. NP2516–NP2537. DOI: 10.1177/0886260520944529.

Turner, L. (2013) 'The evocative autoethnographic 'I': The relational ethics of writing about oneself', in Short, N. (ed.), *Contemporary British Autoethnography*. Rotterdam: Sense, pp. 213–229.

Twigg, J. (2000) Carework as a form of bodywork. *Ageing and Society* **20**, pp. 389–412.

Urquhart, C. (2013) 'Getting started with coding', in *Grounded Theory for Qualitative Research*. SAGE Publications, Ltd, pp. 35-54. [Online]. Available at: https://dx.doi.org/10.4135/9781526402196 (Accessed: 3 May 2022).

Valentine, G. (2005) 'Tell Me About…Using Interviews as a Research Methodology', in Flowerdew, R. and Martin, D. (ed.) *Methods in Human Geography,* (2nd edn.), Harlow: Pearson Education Ltd, pp. 110-126.

van der Sanden, R. L. M., Bos, A. E. R., Stutterheim, S. E., Pryor, J. B. and Kok, G. (2015) 'Stigma by Association Among Family Members of People with a Mental Illness: A Qualitative Analysis', *J. Community Appl. Soc. Psychol.*, 25, pp. 400– 417. [Online]. Available at: DOI: 10.1002/casp.2221. (Accessed: 22 August 2022).

Vann Jones, S. and O'Brien, J. (2014) 'The prevalence and incidence of dementia with Lewy bodies: A systematic review of population and clinical studies', *Psychological Medicine,* 44(4), pp. 673-683. [Online]. Available at: DOI:10.1017/S0033291713000494.

Venkatapuram, S. (2012) ‘Health Inequalities, Capabilities and Global Justice’, in Lenard, P. T. and Straehle, C. (ed.), *Health Inequalities and Global Justice*. Edinburgh University Press: Edinburgh, pp. 65–82.

Venkatapuram, S. (2011) *Health Justice.* Cambridge: Polity Press.

Walker, M. U. (1998) *Moral Understandings: A Feminist Study in Ethics.* New York: Routledge.

Walker, M.P., Ayre, G.A., Perry, E.K., Wesnes, K., McKeith, I.G., Tovee M., Edwardson, J.A. and Ballard, C.G. (2000) ‘Quantification and Characterisation of Fluctuating Cognition in Dementia with Lewy Bodies and Alzheimer's Disease’, *Dementia and Geriatric Cognitive Disorders*, 11(6), pp. 327-35. [Online]. Available at: https://doi.org/10.1159/000017262 (Accessed: 10 June 2022).

Walsh, K, Scharf, T. and Keating, N. (2017) Social Exclusion of Older Persons: A Scoping Review and Conceptual Framework’, *European Journal of Ageing*, 14(1), pp. 81–98.

Wang, S, Molassiotis, A, Guo, C, Leung, I.S.H., and Leung, A.Y.M. (2022) ‘Association between social integration and risk of dementia: A systematic review and meta-analysis of longitudinal studies’. *Journal of American Geriatric Society*. pp. 1- 14. doi:10.1111/jgs.18094 (Accessed: 13 December 2022).

Warburton, N. (2013) *Philosophy: The Basics*. Abingdon, Oxon: Routledge.

Warner, J., McCarney, R., Griffin, M., Hill, K. and Fisher, P. (2008) ‘Participation in Dementia Research: Rates and Correlates of Capacity to Give Informed Consent’, *Journal of Medical Ethics*, 34(3), pp. 167–170. [Online]. Available at: https://doi.org/10.1136/jme.2006.019786 (Accessed: 10 June 2022).

Warren, D.J., Rohrer, J.D. and Rosser, M.N. (2013) ‘Frontotemporal Dementia’, *BMJ*, pp. 1-9, [Online]. Available at: doi:10.1136/bmj.f4827 (Accessed: 10 June 2022).

Watene, K. and Drydyk, J. (ed.) (2016) *Theorising Justice*. London: Rowman & Littlefield.

Weicht, B. (2015) *The Meaning of Care: The Social Construction of Care for Elderly People*. Basingstoke: Palgrave Macmillan.

Weicht, B. (2011) ‘Embracing Dependency: Rethinking (In)dependence in the Discourse of Care’, *The Sociological Review*, 58(2), pp. 205-24.

Wendell, S. (1996) *The Rejected Body: Feminist Philosophical Reflections on Disability*. London: Routledge.

West, H.R. (2004) *An Introduction to Mill's Utilitarian Ethics.* Cambridge: Cambridge University Press.

Westlund, A.C. (2003) 'Selflessness and Responsibility for Self: Is Deference Compatible with Autonomy?', *The Philosophical review*. 112(4), pp. 483–523.

Whipple, T. (2018) *Pfizer Gives up on Dementia Research.* The Times, Available at: https://www.thetimes.co.uk/article/6ceaa8dc-f4b3-11e7-9cfd-f28094b4d5ce (Accessed: 25 April 2022).

WHO (2022) *Dementia.* Available at: https://www.who.int/news-room/fact-sheets/detail/dementia (Accessed: 20 April 2022).

WHO, (2015) *Epidemiology and Impact of Dementia,* Available at: http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf (Accessed: 19 August 2017).

Wiles, J., Leibling, A., Guberman, N., Reeve, J. and Allen, R.E.S. (2011) 'The Meaning of Ageing in Place to Older People', *The Gerontologist,* 52(3), pp.357-366.

Williams, A. (2007) *Therapeutic Landscapes*. Aldershot: Ashgate Publishing Ltd.

Williams, A. (2002) 'Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space', *Social Science & Medicine,* 55(1), pp. 141-154. [Online]. Available at: DOI: http://dx.doi.org/10.1016/S0277-9536(01)00209-X. (Accessed: 10 September 2022).

Willyard, J., Miller, K., Shoemaker, M. and Addison, P. (2008) 'Making Sense of Sibling Responsibility for Family Caregiving', *Qualitative Health Research,* 18(12), pp.1673-1686.

Wittenberg, R., Hu, B., Jagger, C., Kingston, A., Knapp, M., Comas-Herrera, A., King, D., Rehill, A. and Banerjee, S. (2020) 'Projections of care for older people with dementia in England: 2015 to 2040', *Age and Ageing*, 49(2, March 2020), pp. 264–269, [Online]. Available at: https://doi.org/10.1093/ageing/afz154 (Accessed: 14 April 2022).

Wittenberg, R., Knapp M., Hu, B., Comas-Herrera, A.,, King D., Rehill, A., Shi, C., Banerjee, S., Patel, A., Jagger, C. and Kingston, A. (2019) 'The Costs of Dementia in England', *International Journal of Geriatric Psychiatry,* 34(7), pp.1095-1103. [Online]. Available at: https://onlinelibrary.wiley.com/doi/full/10.1002/gps.5113 (Accessed: 2 May 2022).

Wolff, J. and De-Shalit, A. (2007) 'De-clustering Disadvantage', in Wolff, J. and De-Shalit, A. (ed) *Disadvantage*, pp.1-25. [Online]. Available at: https://oxford.universitypressscholarship.com/view/10.1093/acprof:oso/9780199278268.001.0001/acprof-9780199278268-chapter-9?print=pdf (Accessed: 10 June 2022).

Wolkowski, A. and Carr, S.M. (2017) 'Does respite care address the needs of palliative care service users and carers? Their perspectives and experiences.', *International Journal of Palliative Nursing*. 23(4) pp. 174–85.

Wood, A. W. (2007) *Kantian Ethics*. Cambridge: Cambridge University Press. [Online]. Available at: DOI: 10.1017/CBO9780511809651. (Accessed: 29 June 2022).

World Happiness Report (2022) Available at: https://worldhappiness.report/ed/2022/ (Accessed: 10 June 2022).

Yeung, H. W. (1997) 'Critical realism and realist research in human geography: a method or a philosophy in search of a method?', *Progress in Human Geography*, 21(1), pp. 51–74. [Online]. Available at: DOI: 10.1191/030913297668207944. (Accessed: 16 September 2022).

Young, I.M. (2002) 'Autonomy, Welfare Reform and Meaningful Work', in Kittay, E. F. and Feder, E. K.(ed.) *The Subject of Care: Feminist Perspectives of Dependency*, Oxford: Rowman and Littlefield Publishers, pp. 40-60.

Young, I. M. (1990) *Justice and the politics of difference*. Princeton, New Jersey: Princeton University Press.

Zeitlow, A. (2014) 'The Club Sandwich Generation', *Institute for Family Studies,* [Online]. Available at: https://ifstudies.org/blog/the-club-sandwich-generation/, (Accessed 24 January 2022).