

**Orientations and Lifeworlds of Carers of Older People  
in Tyne and Wear, UK**

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## **Abstract**

This thesis focuses on the subjectivities and everyday routines of people who provide home-based care to older people at a political juncture which is reorienting social care towards self-directed support. Promoting the uptake of personal cash budgets and encouraging more person-centred provision, personalisation agendas loosely knit with the recognition politics of the disability movement, and connect to the emerging 'Big Society' discourse by encouraging more support from family, friends and volunteers. Their discursive combination strengthen and legitimate choice and control agendas that are potentially progressive in many ways, but have less obvious benefit from a carer perspective.

This qualitative research draws upon semi-structured interviews and solicited diaries to explore the everyday practices, spaces and emotional investments of paid and unpaid home-based carers in Tyne and Wear, UK. Using feminist and poststructuralist understandings of diverse care economies, and phenomenological concepts of orientation and life-world, I argue that in negotiating the right thing to do, carer orientations in 'being for others' traverse competing social expectations, and disrupt and constitute caring spaces, practices and identities. Individualised notions of choice and control may fray and unravel when directed towards carers who de-limit possibilities in their everyday lives in a desire for coherence, predictability and legitimacy. Findings suggest that 'good enough' care imaginaries are often co-produced in a context of significant constraint. Yet, in augmenting imagined notions of home and family in everyday caring routines, carer respondents often insist on the necessity of practices which extend beyond utility, reflecting on the life-course to sustain meaningful stories and coherent identities for older people and for themselves.

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## CHAPTER 1: INTRODUCTION

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From a position of relative invisibility, there has been growing noise about old age and caring in the UK. The perspectives of older people are finding expression through autobiographical accounts of ageing and the life-course (Grant 1998; Athill 2009; Gilles 2009). The experience of caring for older people is shared by Andrea Gilles (2009) in her book *'Keeper'* which won the Orwell Prize for Literature in 2010. In it she portrays life caring for her mother-in-law who has Alzheimer's disease. Such developments in our cultural life set the tone for a new era which takes later life and caring issues more seriously. In this thesis, I hope to add to this noise by introducing the perspectives of carers from working-class neighbourhoods in Tyne and Wear, whose voices rarely carry beyond their own life-worlds.

### 1.1 Political Context, Changes and Challenges

The collective 'cradle to the grave' principle of the welfare state has waned as state resources have come under pressure. Successive governments have sought to promote more marketised and consumerised forms of welfare (Friedman and Friedman 1979; Clarke 1997; Le Grand 1999; Fine and Glendinning 2005), repositioning the state from a key provider of welfare to funding agency and market enabler within a mixed economy (Miliband 1995; Lister 2001; Mooney and Law 2007). The reconfigured mixed economy of care alters the roles and relationships of family carers, care-workers and volunteers.

#### 1.1.1 *Ageing Society and the 'Care Deficit'*

Prevalent discourses about the ageing population have meant caring is now receiving significant attention. Future projections for social care needs are regarded as unsupportable through existing arrangements. The oldest old (over 85s) are the fastest growing population in the UK (ONS 2005). Government projections estimate 1.7

million more people will need care in 20 years time than at present, and there will be a smaller workforce contributing to the taxes needed to support them (House of Commons 2010). Recent figures suggest that the UK employment rate is decreasing. In 2010, employment rate shown in DSO 3.7 for England was 75.2%, though this is regionally variable, with the most deprived areas having an average rate of 54.9% (DCLG 2010). In the North East region, it is expected that by 2030, the population of people over 85 will double to 4% of the population, slightly higher than the national average, however the number of carers is expected to increase by 5% compared to 15% nationally (Department of Health 2010). Such discourses often posit older people as an inactive population or ‘time bomb’ contributing to an expanding welfare bill. Prior to its election defeat, the Labour Government announced a £6 billion ‘funding gap’ in meeting expected social care needs by 2026 if the system did not respond to these pressures (HM Government 2009). Life expectancy in the UK has increased from 66 years at the time the welfare state was conceived, to 78 years today (ONS 2005). Amplified by a population bulge due to the ageing ‘baby boom generation’ it has been argued by successive governments this places a heavy ‘burden’ on taxpayers. These demographic trends are contributing to discourses about a ‘care deficit’ for older people. There are currently 400,000 people providing intense caring to older people, with the care-receiver/care provider ratio set to fall from 0.6 to 0.4 by 2041.

However, there is a significant ‘funnel of doubt’ about such predictions, being dependent on a number of complex variables which are largely speculative (House of Commons 2010).<sup>1</sup> This doubt is also expressed within academic debates which question an automatic correlation of older age, reduced mobility and ill health. This was taken into consideration in this thesis (described in the methodology chapter) in identifying inclusion criteria for carers of older people. No minimum age limitations were stipulated to define the term ‘old’ in this study in order to allow for definitions of respondents to be taken into account. This approach was adopted in light of debates which have taken place in academia and beyond about the relationship between

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<sup>1</sup> Section 60, House of Commons 2010. Estimates taken from Department of Health, *Shaping the Future of Care Together*, Cm 7673, July 2009:99.

chronological age and infirmity. All carers in this study came forward because they self-identified as caring for older people, with all care-receivers being over 50 years old, and most between 70-90 years old.

The lifestyle expectations of those retiring in contemporary Britain are increasing, with greater numbers of people expecting to live disability and illness free for many years. In an important intervention on this issue, Peter Laslett (1996) described in his work '*A Fresh Map of Life*' that later life should not be viewed as inevitable decline. Instead, retirement might bring greater enrichment, and an opportunity to participate in life-enriching activities denied during the constraints of working life. He described this period as the 'third age'. The first age describes youth, the second maturity, and a fourth, the period of decline before death (1996:3). This understanding allows room for description of specific practices and lifestyles in an otherwise ill-defined period of life following retirement. Gillearn and Higgs (2000, 2005) discuss this emergence of a 'third age' in a UK context.

The concept of a third age emerges from the lived experience of the post-war baby boom generation as they reached retirement. The fact that these 'third-agers' are much more active in later life than previous generations brought attention to the need for a more critical understanding of the relationship between old age and infirmity. Gillearn and Higgs suggest the life-course experiences which influence particular cohorts should be given greater consideration when discussing age and ageing. The emergence of 'third-agers' as a distinct sub-group of individuals with similar life-course experiences and aspirations towards later life has destabilised the relationship between chronological age and experiences of illness and infirmity. However, these do not represent universal changes across the entire cohort. Cultural shifts towards healthier lifestyles, such as reduced smoking and improved diet; advances in medicine and healthcare; reduction in the predominance of polluting industries and dangerous employment in heavy industry and manufacturing; and the baby boom following the end of the second world war, have each contributed to an increase in the number of older people, who are living in better health for longer. But it is important to emphasise that these improvements vary in extent and produce geographic patterns which reflect socio-economic contexts.

Rather than positioning a 'third age' as a new universal stage in the life-course (Laslett, 1996) Gilleard and Higgs suggest this may be seen a distinct sub-set of the current cohort of individuals, since it is well-off older people who are increasingly mobile and active in later life. Older adults who have had a history of manual labour in heavy industry or manufacturing for example, are more likely to experience infirmity at an earlier stage of the life-course than non-manual counter-parts. The existence of 'third-agers' can be further contextualised by such social and spatial differentiation. As is argued in academic accounts of ageing, wellbeing in old age is often contingent on lifestyle decisions, medical interventions, work histories and so on, which have accumulated effects felt in later life (Parr 2003; Andrews et al 2006; Andrews et al 2007; Bowlby et al 2010). Within the area of study, statistics gathered during 2007-9 in Sunderland for life expectancy and other health indicators demonstrate considerable geographical and social variation. A report produced jointly by City of Sunderland Council and Sunderland Primary Care Trust (2011) revealed that the life expectancy for men in Sunderland is 75.9 years, compared with 78.3 nationally. There is more variation at ward level, with a difference in life expectancy of fourteen years between the most affluent (80.3 years) and the most disadvantaged areas of the city (67.18 years). The report found that during the twelve year period up to 2009, the gap increased by 31% among men, and reduced by 8% among women. Furthermore, there is above national average experience of living with chronic health conditions at home.

Beyond the factors of material differentiation which can influence the relationship between ageing and infirmity, Hockey and James (1993, 2003) consider ageing as a cultural construction rather than an inevitable process of chronological progression or biological decline. They argue that discourses influence these constructions, and they are not simply attributes of material changes in the life-course such as those outlined by Laslett (1996) and Gilleard and Higgs (2000) above. Use of terms such as 'burden' in respect to older adults, or infantilising terms which construct old age as a second childhood, position older people with certain characteristics and attributes which affect the way carers and others engage with them (Hockey and James 1993, 2003) and can affect an older person's self esteem and material circumstances. The policy of Age UK, a voluntary body concerned with promoting the concerns of older adults continues to accept individuals over the age of fifty who wish to take advantage of their services.

The combination of factors which impinge on wellbeing and the prevalence of ageist discourses destabilise linear accounts of the ageing process, and consequently, on the range of services and care provisions and practices which emerge from them.

### **1.1.2 *Institutional Shifts towards Home-Based Care***

Government figures which attempt to make projections on the extent of the ‘care deficit’ or on the implications for public spending on social care based on chronological age are unlikely to reflect realities, and this is largely due to the existence of ‘third-agers’ on the one hand, and inequalities in health outcomes reflecting geographical and socio-economic position on the other. Within this concern for a care deficit, a question emerges about how such care is positioned in contemporary social structures and reward systems, given that women (the traditional carers) are now established members of the paid labour market. However, as Miriam Glucksmann (2008) suggests, the profile of those who engage in care-work is still predominantly of women from working-class and migrant backgrounds. This section considers the perceived care deficit alongside policy concerns to promote the home as the most appropriate site of care.

A shift in medical and public discourses to support older people to stay in their own homes for longer away from expensive or inappropriate institutional care options has dominated recent debates. The expansion of community services and domiciliary home-care which accompanied this shift poses a continuing challenge in light of increasing unit costs, less willingness to increase taxation for welfare spending, and inadequate private provision (as individuals have been reluctant to plan and save for social care costs in old age). As the role of domiciliary care agencies expand, documentary and media stories emerge about home-based care scandals (Panorama 2009) similar to those evident in residential care (for example, see Rose 2007; Panorama 2010). Chronic staff shortages (CSCI 2006) and high turnover of staff are regarded as detrimental to the quality of care. Categorisations of care as ‘unskilled’ and its association with ‘free’ labour at home may contribute to the devaluation. Paradoxically, the relatively high investment in training and accreditation can make other labour market options more attractive, resulting in significant churning in the industry.

Adult social care is distinguishable from nursing care because it does not require the medical knowledge of NHS staff, but is instead concerned with routine tasks of personal assistance. Home-based social care for older people is separated into two main types – personal care and domiciliary care.

Care workers provide a very wide range of services including washing, dressing, assisting with medication, dealing with incontinence and rehabilitative care classified as personal care; and providing help with personal finances, housework, laundry, shopping and pension collection classified as domestic care. (Wills 2003:3)

The organisational separation between health and social care (enacted in the Community Care Act 1990) which introduced managed competition led to complicated assessments, and institutional and budgetary hurdles in negotiating transitions from hospital care to home-based care. Some tasks and services have crossed the institutional divide between the NHS and Social Services, with responsibilities for funding moving with them (nominally and spatially). In 2006, forty council chief executives in England and Wales wrote a letter to the Guardian newspaper, drawing attention to the under-resourcing of adult social care, and the see-saw relationship with the NHS on this issue, with policies placing more financial, service delivery and safeguarding responsibility for the social care needs of older people onto local government.<sup>2</sup> Responding to this letter during a House of Lord's debate, Lord Hanningfield argued that adult social care was now 'the single largest challenge facing local government today' (Lords Hansard 2006:Col 1308).

### **1.1.3 *From One-Size-Fits-All to Self-Direction***

State spending limits and care deficit arguments have not resulted in lowered expectations for individual care. Instead, the desire to ensure more personally defined

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<sup>2</sup> See <http://www.communitycare.co.uk/Articles/2008/08/05/109032/safeguarding-should-councils-have-a-duty-of-care-to-vulnerable-adults.htm> for discussion on the 'No Secrets' (Department of Health and Home Office 2000) policy guidance to and evaluation of local authorities on protecting 'vulnerable adults'.

outcomes has emerged. The former Labour Government (1997-2010) introduced personalisation (intended to transform services to meet individual needs and desires) and self-directed support (in the form of Direct Payments and Individual Budgets) intending to improve choice and control for older people with social care needs (see Appendix A). Personalisation has been described as ‘the cornerstone of the modernisation of public services’ (Department of Health 2008:4, cited in Dickenson and Glasby 2010), part of the neoliberal drift towards more marketised and quasi-marketised consumer responsive welfare in Europe (see Eichler and Pfau-Effinger 2009). The discursive concatenation of the benefits of consumer choice with other social and political ambitions forms a key element of this wider neoliberal modernising agenda. This desire for continuous and radical reform in recent decades has often been referred to as ‘redisorganisations’ (Smith et al 2002) rather than modernisation (see also Newman et al 2008 for a critique of the term ‘modernisation’ in this context).

Enabling consumer choice through self-directed support is seen as the key mechanism to ensuring providers are more sensitive to individual desires rather than their own institutional or professional exigency. The disability movement was instrumental in critiquing and problematising medicalised welfare discourses (Hughes and Paterson 1997; Hughes et al 2005) which locate impairment and need with individuals, arguing instead for the way disability is constructed by social environment and socio-cultural responses. Part of this critique has involved challenging notions of care and welfare, the power of health and social care professionals, and critiquing the label ‘service user’. Following years of political campaigning from the Disabilities Rights and Independent Living Movements, with the motto ‘Nothing about Us, Without Us’ (Charlton 2004, cited in Leece and Leece 2006) personal choice has been incorporated into the discursive legitimisation of policies which promote co-production of services and market solutions to welfare.

Notions of reflexive or aspirational selves as ‘life projects’ have been presented as characteristic of modern society (Beck and Beck-Gernsheim 2001). One key feature of the New Labour approach between 1997 and 2010 was the promotion of the idea of ‘entrepreneurs of the self’ (Giddens 1991; du Gay and Salaman 1992; Beck and Beck-Gernsheim 2001), a shift from collective assumptions which underpinned the post-war



welfare state settlement. According to a study of economic beliefs and behaviour, Taylor-Gooby et al (1999) found that the value attached to state welfare is not necessarily diminishing, but there is a perceived inevitability to the current reform agenda among individuals, and therefore the personal consequences of increased self-reliance is an important factor redefining our relationship to risks of poor health (Taylor-Gooby 2000). This generalised acceptance that society is more individualised and self-reflexive has strengthened calls for consumer-based approaches to social care. As the Chairman of the Audit Commission remarked:

Ex-punk rockers and Rolling Stones fans are not going to be happy with a cup of tea and daytime TV. (Department of Health 2009:53)

The shift from ‘one-size-fits-all’ approaches to service delivery towards personalised services can be understood in the context of political shifts from redistributive politics to a concern for recognition (Fraser 1995, 2008; Fraser and Honneth 2003). Beneficiaries of a diversified consumer-based approach may therefore be identity grouping such as Black and Minority Ethnic (BME) communities, Lesbian, Gay, Bisexual and Transgender (LGBT) communities, faith-based communities and other individuals who fall outside of hegemonic constructions of a ‘typical’ welfare citizen. Enabling choice in diversified markets has the potential to disguise inequalities (particularly socio-economic) by assuming a level playing field in accessing the most appropriate and desirable services, as there is a marked contrast in the ability of more privileged groups to navigate through complex systems and obtain favourable access and better quality services (Le Grand 1999; Campbell et al 2000).

There are currently 31,000 older people using personal budgets in England (Brindle 2010). The ‘In Control’ organisation, established in 2003, was created to assist local authorities to move towards this as part of a wider reorganisation of welfare<sup>3</sup>. In 2007 when my PhD research was first conceived, self-directed support options through direct payments were regionally varied and had a relatively low take up (Glasby and

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<sup>3</sup> In Control is a partnership of NHS, local government, commercial organisations and citizens. It is now a social enterprise organisation.

Littlechild 2002; Riddell et al 2005). One reason given for this was resistance from some Labour-controlled local authorities, which regarded Direct Payments as a threat to public sector jobs due to the move towards competitive processes. Adoption was also uneven across ‘impairment groups’ (Riddell et al 2005:4), with older people less likely to take up the option than younger people. At the same time, the IBSEN project was underway which piloted Individual Budgets in 18 local authorities, reporting their findings in 2008 (Glendinning et al 2008). Though there were some cautious recommendations and significant concerns arising from the study, a national deadline of 2011 was announced for remaining local authorities to increase uptake of personal budgets to achieve a minimum 30% cost saving. The revised policy was intended to attract harder-to-reach populations and incorporate other funding streams. During the course of this research, the uptake of personal budgets has increased dramatically, as this graph of all user groups shows.

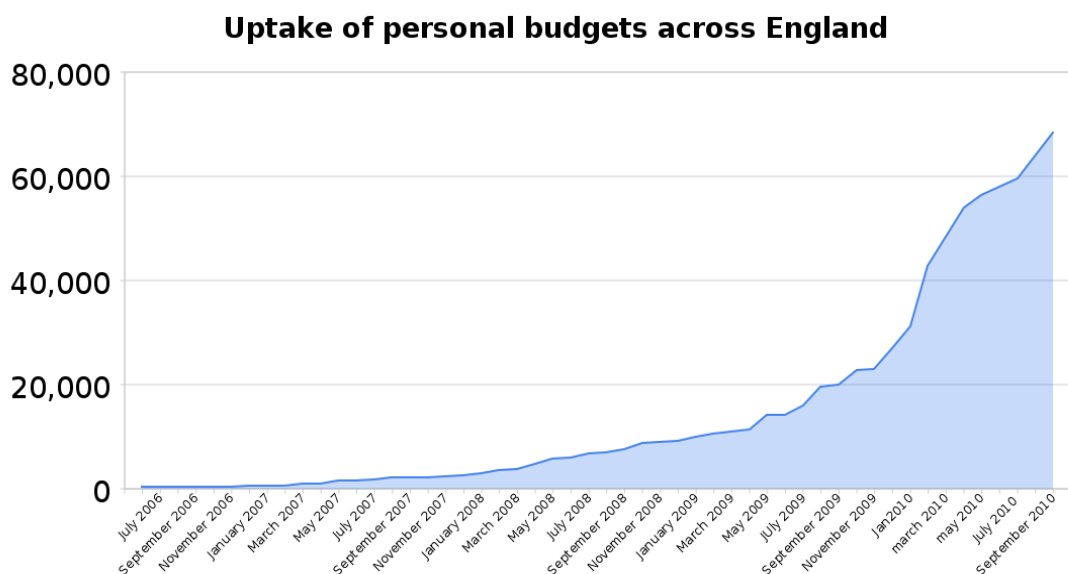


Figure 1: Uptake of Personal Budgets across England (In Control 2010)

At the start of 2008, the largest group using self-directed support was young people with learning disabilities, but by the end of the year it was older people (In Control 2010). The IBSEN Report had suggested that older people were anxious about the responsibilities of managing a budget (Glendinning et al 2008), and despite lack of evidence for cost efficiencies and beneficial outcomes for older people, this move towards self-direction remained a clear priority. Glendinning et al (2008) suggested

more work would need to be done to ensure personalisation is implemented appropriately as concerns were expressed about use of resources, audit and regulation, and consideration of the overall benefits compared to the high costs involved.

The Department of Health White Paper, *'Our Health, Our Care, Our Say: A New Direction for Community Services'* (Department of Health 2006) created a 'Personal Health and Social Care Plan'. This included a commitment to extending Direct Payment options and introducing Individual Budgets for long-term health and social care needs (integrating funding from a range of sources and expanding potential uses to more than traditional personal care), and opening up possibilities for diversifying support options outside conventional welfare systems. Some older people with personal budgets are using them to continue patterns of everyday activities, for example, by foregoing council-run bingo sessions in day centres to return to former leisure spaces (and friendship networks), using the budget to pay for travel into town (Brindle 2010). Early commentaries on the potential of self-directed social care emerged from Social Policy and Social Work disciplines (Leece 2000, 2006; Stainton 2002; Glasby and Littlechild 2002; Carmichael and Brown 2002; Spandler 2004). Questions were raised about reconciling individual and collective ideologies within different social care settings, and the continued need to secure adequate resources to ensure success of the policy (Stainton 2002; Spandler 2004; Riddell et al 2005; Leece and Leece 2006), suggesting that personal budgets on their own were no guarantee of effectively bringing choice, and were no panacea.

Early commentaries focused on the potential benefits to older people (Leece 2000; Carmichael and Brown 2002; Stainton 2002; Riddell et al 2005; Leece and Bornat 2006; Age Concern 2008). Policy disciplines considered: the continuing influence of 'street level bureaucracy' (Lipsky 1971, 1980) in determining eligibility (Ellis 2007); the effect this new payment mechanism would have on the social worker role (Spandler 2004; Lyon 2005); the introduction of brokers (CSCI 2006; Phillips 2006; Higham 2007; Leece and Leece 2010); the implications for care markets (Baxter et al 2008); and implications for the voluntary sector (Dickinson and Glasby 2010).

Direct Payments have been most notably researched by Janet Leece (Leece 2006; Leece and Bornat 2006; Leece and Leece 2006; Leece 2010; Leece and Leece 2010; Leece and Peace 2010). Her PhD study was one of the first UK mixed methods research studies on this topic, using questionnaires and semi-structured interviews. Leece found that one barrier to take-up was a lack of clear information, and a low awareness by social workers, despite being a statutory obligation upon Local Authorities to promote it as an option. Leece's study found that professional agents such as social workers made assumptions about clients' capabilities to manage finances independently, and some were reluctant to transfer power. For adopters, there was often inadequate support and too much paperwork and bureaucracy, making it more appealing to middle-class older people with managerial experience. This Leece suggested, gave the potential for a two-tier social care system to emerge based upon class position.

#### **1.1.4 *Informal Care, Active Citizenship and the 'Big Society'***

Care can occur within a number of structures and contexts. From a geographical perspective, solidarities and commitments can be viewed in relation to various scales (seen as either hierarchical or nested in place). The scales of care (and more broadly solidarity with others) can be understood in various ways. These can exist at global, national, local or familial scales. Most often viewed in relation to micro-social worlds, care at this scale is nevertheless affected by the forms of solidarity and connection occurring at meso and macro levels. This section considers the way responsibility and commitment are framed discursively and materially at the national scale, but which influence and are influenced by everyday practices, spaces and subjectivities. The social theorist Jürgen Habermas (1976) argues that society is separated into four spheres: family-consumer (private); market economy (private); the state (public); and citizen-participation (public). The relative predominance of each of these categories over time is a key facet of political and public discourse surrounding the future of welfare (Baines et al 2011), which includes arrangements and discourses surrounding the social care of older people.

Esping-Anderson (1990) in *Three Worlds of Welfare Capitalism* suggested the three categories of welfare capitalism in post-war Europe (social democratic; liberal/residual

and corporatist/conservative) led to greater or lesser de-commodification and creation of public social assistance as a set of rights conferred to citizens, and were based on a set of normative assumptions about family responsibility and household structure which had gender implications. The British welfare state was characterised by Esping-Anderson as a mixture of social democratic and liberal. The Beveridge Report (1942) contained clauses outlining how 'family services' such as home-helps, babysitters, nursery schools, laundry services and meals on wheels were being established as part of the social wage, in recognition of the difficulties inherent in women's everyday lives. Even at this time, the concern for an ageing population was evident (described in section 15 of the report). The provisions in this report mainly concerned the introduction of the state pension, but other measures were introduced which provided support to family carers of infirm older relatives (Beveridge 1942). These services were implemented in successive decades.

However, the Black Report (1980) which was based on the findings of a working party set up by the Secretary of State in 1977 to explore differences in health status between classes revealed the continued level of inequalities and privation in the area of health and social care. The report '*Inequalities in Health*' outlined a number of measures which aimed to 'reduce the risks of early death, to improve the quality of life whether in the community or in institutions, and as far as possible to reduce the need for the latter' (Black Report, 1980: 8.7(ii)). These largely amounted to encouragement for greater redistribution, and one of their recommendations (number 18) was to expand provision of home-helps, day centres and mini-bus transport. Their recommendations concluded that the role of government was vital in eradicating inequalities in health provision.

The post-war welfare state held a particular notion of citizenship entitlement based upon a set of assumptions about family life dependencies, constructed around a male breadwinner model with dependent wife who cared for dependent family members. Significant interventions from the 1960s by new social movements such as feminist, disabilities, gay, ethnic minority pressure groups, suggested these universalist assumptions had reinforced structural inequalities based around identities which differed from an assumed norm. The disability movement challenged the positioning of disabled people as dependents, seeking to deconstruct medicalised understandings of

disability in favour of social models which sought to alter instead the disabling aspects of everyday life, such as the built environment and everyday social relations. These challenges from the margins were grappled with by a new right discourse through the 1980s and 1990s which sought to promote individual freedom, and dismantle collective responsibilities in favour of individual consumerism. Part of this move towards individual freedom within neoliberal discourses involved negative constructions of dependency which creates moral distinctions between dependent and independent citizenship that denies inter-dependency in social relations (Dean and Taylor-Gooby 1992; Hockey and James 1993; Fraser and Gordon 1994; Kittay and Feder 2002; Fine and Glendinning 2005; Bowlby et al 2010).

This continued under New Labour from 1997 with measures designed to promote 'active citizenship' (Brindle 2008). The state was reimagined as an enabler rather than a provider of services within Third Way discourse and policy. Citizens were expected to adopt a more 'entrepreneurial' relationship to state services (Arksey and Glendinning 2007; Gilleard and Higgs 2000) which would have the effect of reducing the power and scope of the state. This could be viewed in light of Habermas' latter category of the public 'citizen-participation' sphere (Habermas 1976). Introducing conditional support redefined citizenship entitlement based on full-time paid employment, or at least encouraged trajectories toward this end, such as participating in welfare-to-work programmes. MacLeavy (2007) argues this has disproportionately affected women, and devalued informal care at home.

With the introduction of self-directed support as part of this broader ethos of active citizenship, two social policy agendas came together: measures which promoted more person-centred care; and active labour market policies aimed at reducing the 'care deficit', drawing family members, friends and neighbours into commodified care relations. Commodification is a term used to describe the transformation of social values into economic value where this was not previously the case. Care relationships which had been constructed, maintained and understood as based on love, mutual affection or kin obligation may engender a different but not necessarily contradictory set of new relations within commodified forms. The incoming Coalition government continued to support market-based options, but with more emphasis on unpaid provision

through the expansion of volunteering. In a press release, the new Health Secretary, Andrew Lansley announced their intentions to:

...extend the greater roll-out of personal budgets to both older and disabled people and carers to give more control and purchasing power; and increase direct payments to carers and better community-based provision to improve access to respite care. (Lansley 2010)

For informal carers acting as budget managers rather than commodified carers, self-directed support can bring additional challenges. A study conducted by Carers UK (2008) '*Choice or Chore?*' argued that whilst evidence was positive from a user perspective, carers administering the budget felt additional responsibilities and pressures, especially when no contingency plans were in place when things went wrong.

Local authorities must ensure that carers' needs are considered and that assumptions are not made about their willingness and ability to manage complex care packages on behalf of the person they care for. (Carers UK 2008:2)

They argued that self-directed systems should be accompanied by sufficient backup and support, with local authorities being prepared to step in during a crisis. The safeguarding role of local authorities is not abrogated within a self-directed support option, but created additional challenges to it (Glendinning et al 2008). As Local Government representatives suggested:

...the role of social workers is likely to be focused on advocacy and brokerage, rather than assessment and gate keeping. There will be a shift from a model of care where an individual receives the care determined by a professional to one with the individual firmly at the centre identifying their own needs and how these can best be met. (IDeA 2010)

Initially, a lot of emphasis was placed on the role of 'support brokers' to facilitate and co-ordinate community based provision to provide choice and control for budget holders. Support Brokers operate as a confederation of social enterprises or individual

brokers, largely in the South East of England, such as ‘Lives Through Friends.’<sup>4</sup> In East Sussex, the County Council has contracted its support for budget holders to a social enterprise, A4e<sup>5</sup>. However, in Tyne and Wear, the brokerage role has been largely incorporated into existing structures in the public and Third sectors.

## **1.2 Landscapes of Care in Tyne and Wear**

National social policies are concretised in local places, and there is often discretion afforded at the local institutional scale to take into account democratic preferences, local economic conditions, infrastructures and cultures (Hawkins 1992; Peck and Theodore 2001). The changing policy context towards self-direction was acknowledged or experienced first-hand by only a few carers involved in this study, though others recognised it as an emerging possibility. As part of this research, several key informants were interviewed across a range of organisations in Tyne and Wear during 2008-9, including public sector social care change managers, and a regional innovation organisation, private agency managers, large and small voluntary organisations. During this dynamic period of policy implementation, a picture emerged about local responses to the personalisation agenda when benefits and challenges were still being considered and worked through. The main issues which emerged focused upon: the progress of the five local authorities towards personalisation implementation by 2011; the importance of harnessing social capital and community resources to add capacity; concern to engage ‘hard to reach’ groups and extend take-up of the option; and managing the perceived risks of market choice.

A regional quasi-government agency, the North East Improvement and Efficiency Partnership (NEIEP) was charged with advancing the agenda in the region. They hoped to co-ordinate and share good practice across the five local authorities to change institutional cultures towards personalised service delivery, and to extend take-up of

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<sup>4</sup>See website - <http://www.livesthroughfriends.org/>.

<sup>5</sup>See website [http://www.eastsussex.gov.uk/NR/rdonlyres/95338ADA-FC59-4DD8-9D25-AF906D37B70/0/FS10DirectPaymentsfactsheet4August\\_4\\_.pdf](http://www.eastsussex.gov.uk/NR/rdonlyres/95338ADA-FC59-4DD8-9D25-AF906D37B70/0/FS10DirectPaymentsfactsheet4August_4_.pdf)



personal budgets. They saw key challenges as addressing the high turnover of care staff, developing new markets for care, and enabling improved consumer interfaces with providers of home-based care. One of the major barriers was managing and directing change within the private sector, as previous contact was limited compared to their strong connections with public and voluntary sectors. They hoped to better understand some of the blockages arising from local government commissioning behaviour and how personalisation might change this. The NEIEP key informant suggested some councils were taking a 'wait and see' attitude in order to benefit from the mistakes and innovations of others, while one or two took a 'siege mentality', becoming exasperated with the constantly shifting political agenda.

I also met with strategic heads of transformation in three of the five local authorities in Tyne and Wear. Change managers who responded were keen to inform me of the positive moves they had made. Gateshead for example, was a pilot study area for the IBSEN study (Glendinning et al 2008). Though they were initially well in advance of others, their progress was overtaken by neighbouring authorities, such as Hartlepool. However, they argued that their approach was more cautious and more consistent, aiming to embed personalisation and totalising the transformation of services rather than simply promoting direct payments. They argued this was more in line with the ethos underpinning personalisation to nurture genuine choice. A common discourse was evident in terms of accessing 'community resources' and building upon pre-existing social capitals to improve community engagement. Social capital is a potentially useful concept to understand ability to access formal and informal support (Coleman 1998, 1990; Bourdieu and Wacquant 1992; Putnam 2000; Murphy 2006), and can be used to measure exclusions from social participation, and the transfer of value across various socio-economic practices. But it can also attribute 'blame' to communities who are not succeeding compared to others (Sennett 2003; Amin 2005) as some individuals and communities are believed to 'lack' the necessary social bonds and values to make adequate informal provision or access appropriate services.

Co-producing services is easier to achieve when partnering with those already engaged, but this may not account for the lived experiences of harder to reach groups. This issue has been raised before by academics and policymakers<sup>6</sup>. Engagement activity was often with ‘usual suspects’ accessed via community groups. Some local authorities had formed partnerships with ethnic minority groups to identify specific issues, though no key informants raised diversity issues around experiences of older people within LGBT communities. Moving away from a ‘one-size-fits-all’ approach suggests this is a critically important aspect of the reorganisation of services, but one which is difficult to achieve in practice. Obtaining insight into choices and experiences in these and economically marginalised communities presented a similar challenge in this research.

Managing the perceived risks of market choice was expressed by local policy makers and service providers. Local Authority change managers were concerned about the potential for financial abuse by family carers, the issues around costly CRB checking and audit trails for spending budgets appropriately. The main concern raised by care agency managers centred on how consumer choices may breach equalities legislation. One care agency manager commented that under the current system of block contracts, some clients asked for particular carers, tending to prefer women over men, and white British over ethnic minority carers, which made it more difficult to give an equal distribution of hours to their employees. The findings of Baxter et al (2008) support this observation. As one care manager in their study put it ‘their bigotry will be allowed to creep in’ (Baxter et al 2008: 46). For personal assistants employed directly by budget holders, this may be even more prevalent, as proving discrimination on a one-to-one employment relationship within the home is difficult (Leece 2006).

Discussions with voluntary service providers highlighted the mixed opportunities and threats of personalisation. Large charities such as Age UK saw this as an opportunity, and were redesigning their services away from generic day care services as well as extending their services to take on a brokerage function through local authority

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<sup>6</sup> This issue was raised at a conference organized by Voice North and the Institute of Ageing and Health, held at Newcastle University in 2009. Policymakers and local service providers were concerned about finding more successful ways to seek the views and experiences of hard to reach groups.

referrals, offering budget holders advice in managing an employer role. However, smaller charities providing support to older people and respite to carers feared competition from larger corporations, whose glossy brochures and lower unit costs would attract individuals to their services, though with no guarantee of these being of better quality. They feared the loss of the council block contract, and questioned whether they would manage their financial planning in such a competitive and uncertain climate, since they did not have the capital reserves of larger organisations to reorient themselves to these new market conditions. Smaller voluntary organisations, such as church groups, might benefit from entering contractual relations on an individual basis, given that they could not currently successfully bid for local authority contracts, due to the economies of scale of existing arrangements.

### **1.3 Aims and Direction**

The move towards home-based care and self-directed support makes understanding the micro-geographies of everyday life for carers, and issues of choice and control important. In considering the position of carers in working-class communities, which are more at risk of experiencing health inequalities and where the uptake of Direct Payments has been slower (Glasby and Littlechild 2002; Riddell et al 2005; Leece 2006; Glendinning et al 2008), I was interested to explore current material contexts influencing choice and control for carers, and how this might alter as personal budgets become a mainstream option and expectation. I have approached this by considering the boundaries and distinctions between multiple care economies (paid/unpaid, love/money, formal/informal, public/private) and how these are challenged and accommodated in everyday life by a range of carers; the role of social expectations in constructing care subjectivities and identities, and how these expectations influence decisions when adopting caring roles; how these are negotiated in practice as precarious settlements, and the effects these have upon everyday experiences and routines of care.

The research questions were developed through initial engagement with literature on the personalisation of adult social care, and conceptual literature on the landscapes of care. Part of the concern to understand the landscapes of care in Tyne and Wear was to

understand the lived experiences of carers from a variety of backgrounds, who live and work in working-class areas, or who identify as working class:

- circumstances leading to the adoption of caring roles
- past orientations, current understandings and future trajectories
- process of negotiating caring relationships
- spaces and places in which caring practices occur
- meanings and ambivalences attached to spaces of home, work and community
- spatial and emotional proximity in carer relations
- performance and disruption of carer identities across time and space
- lived experiences and embodied life-worlds
- time and the establishment and disruption of routine
- pace and timeliness in enacting and procuring caring practices
- the potential impact of these to reframing policy discourses about care

The research questions were:

- 1 In what ways are stakeholder organisations being affected by and responding to personalisation and marketisation of care for older people?
- 2 How are carers' subjective meanings and identities constructed, negotiated and experienced in relation to others?
- 3 How are spatialities of care constructed, negotiated and experienced by carers of older people?

The first question was approached by interviewing fourteen key informants who were involved in implementing personalisation within Tyne and Wear, or who had some stake in the implications of this from an organisational perspective. The data from these interviews are not included in the data chapters, which are restricted to carer accounts. My decision not to recruit via personal budget holders (see chapter three) meant there would be a disconnection in focus compared to those of carer respondents. Therefore, key informant observations and concerns are instead reflected upon in chapter eight, which seeks to respond to the first question and how these relate to subsequent questions. The second and third questions were approached using semi-structured interviews with carers and solicited diaries to understand routines and spatialities of

care. It is hoped that the significance of commodified informal care, individualised market choice, and expanded voluntary care may be better understood.

#### **1.4 Structure of Thesis**

Chapter one has provided an overview of imperatives behind the changing national and regional political context of social care towards self-directed support, drawing on policy literature and discussions with key informants at the local and regional level. The chapter now concludes by outlining the aims and direction of the research and reiteration of the thesis structure. Chapter two situates the research within existing academic literature to understand diverse caring practices, care relations and everyday geographies. Chapter three discusses the execution of the research from research design, sampling, recruitment, data collection and analysis.

The empirical data is presented in chapters four, five and six and is organised around three aspects of the care experience, with carer types separated into sub-sections for identification. Due to the sample size and three-way split in the sample, and for reasons of clarity, it was decided that this systematic approach would be taken throughout each of the chapters, seeking to establish points of connection and disconnection between family, care-worker and voluntary carers along various axes of care experience. Chapter four discusses orientations of care in order to understand why carers do what they do; chapter five considers the negotiation of roles and relationships between carers and others, particularly the older person, in establishing everyday routines and choices; and chapter six looks at the life-worlds of care, focusing on how routines and experiences of caring spaces are constructed and the impact this has on carer subjectivities and identities. Together, they demonstrate the processes of adopting, practicing and experiencing care across diverse economies.

Chapters seven and eight look across the three data chapters, drawing together emergent themes, focusing on responses to the necessity of care, the management of routine, the ambiguous spaces of home, the invocation of family and friendship in carer imaginations, and in the relational agency of care. The discussion chapter suggests that these themes present challenges to policy initiatives which regard diverse care

economies as distinct categories of practice and experience. Instead, the chapter proposes that similarities of experience exist within social support networks which cut across formal and informal care economies, and is negotiated, resisted, practiced, situated, embodied, and routinised in connected but limited ways. The concluding chapter presents the key contributions of the thesis in relation to choice and control for carers by presenting issues relating to the commodification of family care, the individualisation of care markets, and the expansion of voluntary care. The chapter concludes by presenting some limitations, policy implications and suggestions for further research.

## CHAPTER 2: UNDERSTANDING HOME-BASED CARE OF OLDER PEOPLE

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### Introduction

This literature review chapter introduces some of the ways home-based care for older people has been conceptualised, and suggests how the choice and control agendas of personalisation might be problematised when such understandings are taken into account. This literature review begins by exploring the definitions and boundaries of care, seeking to examine how these reflect lived experiences across paid/unpaid, formal/informal and public/private divides. Part of this consideration involves an exploration of the ‘pathways of feeling’ which influence the development of care subjectivities and responsibilities across the life-course. These include classed and gendered moral rationalities of establishing the right thing to do. The chapter goes on to present an account of the changing nature of social relations, including changing positions of family, friends and others within the social support networks of older people. The final section draws upon literature from social geography to explore the relevance of space and time to care at home, and the implication of these for policy and practice. As Anderson and Smith (2001:7) contend, ‘relevant policies may have to be small in scale, humanising in intent, embedded in context, enacted through bodies’.

### 2.1 Defining the Practices and Economies of Care

#### 2.1.1 *Care and Inter-Dependency across the Life-Course*

Care can be considered as a set of relationships, and as a set of practices which influence the subjective experience of the other. The word ‘care’ is derived from old English, defined by the Oxford English Dictionary as:

Noun: 1 - the provision of what is necessary for the welfare and protection of someone or something; 2 – protective custody or

guardianship provided for children by a local authority; 3 – serious attention or consideration applied to avoid damage, risk, or error; handle with care; 4 – a feeling or occasion for anxiety. Verb: 1 – feel concern or interest; 2 – feel affection for or liking; 3 – like to have or be willing to do; 4 – look after and provide for the needs of.

Care has been described as both material caring for, and emotional caring about (Milligan and Wiles 2010). Though there are distinguishing features between caring for and caring about, in practice they are often mutually reinforcing (Twigg 2000; Milligan 2003, 2005; Grant et al 2004). Common use of the term care implies an all-embracing willingness to do what is necessary to avoid harm or to provide assistance, especially for others. Care is discursively associated with ambiguous and highly loaded positively construed terms such as love, understanding, kindness and duty, to less positive discursive associations with responsibility, paternalism and caution, and is even descriptive of institutions i.e. 'being in care'. A legal definition positions care as the absence of negligence, especially where a duty is implied (Witting 2005). This demonstrates the ambiguous moral relationship 'care' can have - as an active stance or practice towards some good end goal, or the passive stance or practice to avoid some bad end goal. Connidis and McMullin (2002) describe how ambivalence exists within everyday interactions and within commonly structured social relations, and suggest this ambivalence can be used as a bridging concept between social structure and individual action. This thesis argues the ambivalence and asymmetry of caring practice and obligation is important to understanding the directive agency, commitment and embodied knowledges of carers.

There has been significant debate around notions of dependence and independence within care relations in the way these construct a sense of self for givers and receivers of care, and for assigning social categorisation to individuals and groups. Older people with declining health are often positioned as belonging to an unproductive/dependent stage of the life-course, which can involve increased demand for (or dependency on) a range of support and care services (Andrews et al 2007:152). However, as Bowlby et al (2010) have argued, the life-course is permeated by a series of inter-dependencies which are differentiated across time and space. Caring practices and subjectivities emerge, settle and become unsettled throughout the life-course in a variety of ways, and with



varying degrees of social expectation (Hockey and James 1993; Katz and Monk 1993; Gilleard and Higgs 2000; McKie et al 2004; Hughes et al 2005; Bowlby et al 2010). This can involve considerable commitment of time and resources, as human dependency fluctuates across the life-course. Deferred gratifications, responsibilities and dependencies contribute to the mechanisms for support between family members and friends (Bowlby et al 2010; Milligan and Wiles 2010), with some practices enacted with enthusiasm, some with indifference, and some performed reluctantly. When these practices are habitual, they can settle to form part of an invisible and accepted landscape, whilst others are continually produced, negotiated or resisted.

Biographical moments are important to understanding negotiations with others, and the way these generate complex and uneven relations of care (Tronto 1993; Sevenhuisjen 2003). Assuming the role of carer to older people is often presented as a result of biographical disruption caused by the onset of illness (Bury 1982), with the progression of the caring role viewed as an alternative trajectory to pre-conceived pathways. In this sense, care can be taken up with a degree of ambivalence arising out of immediate necessity, or can reflect the fulfillment of expectation. Understanding the perpetuation, disruption and renegotiation of care obligations and responsibilities is particularly important in the context of increased prevalence of women in paid employment, which may create tensions between 'work' and 'care' and which is purported to establish a 'care deficit'.

The inter-dependencies, reciprocities and solidarities which exist between family, friends, community and wider society (in the relations between individuals and households with the state or other public body as citizens) are inevitably asymmetrical across the life-course rather than framed as a balance sheet of giving and receiving benefit. Himmelweit (1995) argues that there is inseparability between notions of care and the person providing it. As Polanyi has argued 'reciprocity demands adequacy of response, not mathematical equality' (Polanyi 1957:73, cited in Ledeneva 1998:3). Theories of social exchange suggest reciprocity is considered over time, not in the immediate context, though it has been suggested that 'voluntaristic' relations are less tolerant of inequity and lack of reciprocity than kin relations, which can carry

obligations across several generations (Abel 1986; Finch 1989; Aronson 1992; Finch and Mason 1993; Twigg and Grand 1998).

The construction of rights-based approaches within the UK welfare state has prescribed to a large extent the definition of need, entitlement and responsibility. Narrow definitions of both need and its redress through care can restrict access to state or other support and benefits; whilst broader definitions may encompass diverse individuals, practices and spaces at home and in the community that are not usually considered. As argued by Egdell (2009), medical diagnoses and needs assessment by welfare professionals can act as a 'passport' to benefits and other sources of support in adult social care (see also Lipsky 1971; Ellis 2007). Rights-based approaches to meeting basic human needs (as defined in the Beveridge Report discussed in chapter 1) have been criticised as running the risk of uniformity which may disempower individuals (Doyal and Gough 1991). State-based health and social care professionals have been criticised for distorting conceptions of human need to privilege their own position (Illich 1978:306; Doyal and Gough 1991; Le Grand 1997).

Need is often posed as a combination of embodied deficiency or emotional privation that can be resolved or ameliorated by care. Defining social care 'need' in later life is therefore a crucial parallel element in defining the practices and boundaries of care. It is also politically relevant as these definitions and understandings have implications for the level of resources which are made available to mitigate declining health in old age, and how much of this is perceived to be accepted as inevitable decline. Advances in medicine and the development of assistive technologies (Gilleard and Higgs 2000, 2005) continually reshape the way physiological decline is responded to and resisted. However, access to such medical and technological interventions may be affected by personal financial means; ability to navigate complex information and service options; and previous experiences such as disappointments, knock-backs and sometimes condescension from state professionals (Skeggs 1997; Charlesworth 2000).

Self-directed and person-centred practices of care are intended to shift emphasis to enable greater possibility for stipulating personal outcomes, and enabling greater choice of services. The focus of transformation in social care shifts from meeting basic

physical needs to actions which support individually-defined wellbeing. Whether choice-based systems reduce inequalities of access or outcomes is not yet known. In moving away from universality to choice-based welfare, Julian Le Grand (1991) identified a number of moral problems in relation to notions of equality and regimes of choice in welfare. He argues moral discourses emerge when the factors which produce inequality are within the control of the individuals.

Distributions that are the outcome of factors beyond individual control are generally considered inequitable; distributions that are the outcome of individual choices are not (Le Grand, 1991:87).

Le Grand argues that the solution to incorporating particularities of choice into welfare systems that account for socio-economic inequality is to identify constraints which limited possibilities and choices. He argues that equality of opportunity may mask class-based lack of confidence in pursuing actions and may also be affected by material constraints once choices have been made which at first glance appear equitable. These possibilities and constraints will be considered later in this thesis in relation to carer choice and control. This discursive and policy shift towards personally-defined outcomes in a self-directed social care system has implications for the way care is defined and practiced within it. The way carers perform their daily routines with older people and the way they interact emotionally is a crucial indicator of 'quality' of care, which is difficult to assess or quantify, except through subjective measures of satisfaction which are difficult to compare to ensure equity. This presents a challenge for evaluating personalised support. There are a number of relevant factors which may influence perceptions of care quality: the mode of care (i.e. family or paid care agency); the site of care (day centre or home); and the nature of the practice (e.g. intimate personal care). There are also a myriad of personal (kin and non-kin) and contractual relationships which affect how these practices are perceived (Twigg and Atkin 1994).

The disability rights movement challenged policymakers and service providers to move away from a focus on 'need' towards generating positive and personally defined outcomes and aspirations. Critical discourses suggest the concept and practice of 'care' itself can be potentially oppressive and disempowering (Hughes and Paterson 1997; Hughes et al 2005). These discourses question whether care should be regarded as a

practice, an intention or an outcome or achievement. Hills proposes that care is successful if the intention is appropriate (Hills 2007:397). However, by privileging the intention of the carer, this may disempower care-receivers (Hughes and Paterson 1997; Stainton 2002; Charlton 2004; Duffy 2004; Hughes et al 2005; Chouinard et al 2010). These debates have informed the concerns of Eva Kittay (2011), who critiques suggestions that intention alone is sufficient to infer care, favouring instead consideration of the achievement of care – identified in a concrete sense by the gracious acceptance of the care-receiver. However, I argue this approach acknowledges the agency of care-receivers, but attaches less concern for the agency of care-givers. Neither intention nor acceptance is adequate to categorically state the achievement of care. The data chapters which follow present data suggesting this aim should be bracketed in favour of focusing on the inter-dependency of care as a social relation - as a process which involves negotiating intention and outcome, but which can never be categorically established due to its inherent relationality.

### **2.1.2 *Binaries and Boundaries in the Mixed Economies of Care***

Care can be considered a form of socio-economic practice, being both an exchange of economic value and meaningful social interaction. There are a variety of economies within various care spaces, particularly within home-based care. These can be delineated in various ways: by whether they are formal or informal, paid or unpaid, public or private; each influencing the way care is exchanged and understood. These binaries are not always equivalent, but there is often a perceived association, such as an association with unpaid, informal care and motivations of love. However, cash exchanges can be used by kin and friends as a way of avoiding reciprocal obligation, or to prevent these going sour if reciprocity would be difficult (Samers 2005). Consequently, informal care relations are not always performed solely for love. Similarly, commodified care by formal agency workers can go beyond their contractual obligations, and sometimes care-workers build intimate bonds with their clients.

One important distinction between carer types is their relationship to home as a site of work. Home has traditionally been positioned as a physically separate space to that of work (see broader discussion on the spatialities of care in section 2.3.1). This is evident

in an early account of the processes involved in capitalist separation of production and reproduction. Max Weber argued in *'The Protestant Ethic and the Spirit of Capitalism'*, written in 1904 that separation of business from the household was central to capitalist modernity, as rational methods of business contrasted with home and family life (Weber 1992:22). Connected to the Protestant work ethic was a concern for the inner isolation of the individual, a distaste of 'all the sensuous and emotional elements' and the 'corruption of everything pertaining to the flesh' (Weber 1992:105). This set the cultural tone towards a disembodied rationalism. This conception of the 'work ethic'<sup>7</sup> and the pursuit of vocation disconnected the 'economy' from the messy, fleshy concerns of social reproduction. However, Weber (1949:90) acknowledged how a 'conceptual utopia of abstraction' is evident in theorising economies, suggesting that ideal types are never realisable in practice but instead always enmeshed with other social economic relations.

This public/private separation of work and home has been discussed at length by feminists who argue that domestic and social reproductive practices also constitute work, and is a public rather than a private concern. The omission of social reproductive work at home (including unpaid care) from measurements of 'the economy' has been critiqued by several feminists (see Cameron and Gibson-Graham 2003). Various metaphors have emerged to describe the gendered binaries of socio-economic practice, including: hand/heart; exchange and gift; icing and layer cake – each seeking to include and make visible the contribution of care and social reproduction to the whole economy. Cameron and Gibson-Graham (2003) suggest that work which is historically and predominantly performed by women at home should be added on and counted in to get a better sense of what is being done, by whom, and for what benefit.

In seeking to understand the consequences for the whole economy, Iris Marion Young (1997:34) suggests we need to ask how performing gender-differentiated activities impacts on the distribution of resources. Chantal Mouffe (1993) suggests there is no reason why sex or gender difference should be pertinent in all social relations, or the

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<sup>7</sup> The accumulation of wealth through industry was regarded as virtuous practice, indicating self-restraint through resisting individual over-consumption.

most dominant. An individual, bearing an ensemble of identities, can be in a position of domination in one, and subordination in another, constructed by a diversity of discourses. Therefore, these identities are always:

...contingent and precarious, temporarily fixed at the intersection of those subject positions...it is therefore impossible to speak of the social agent as if we were dealing with a unified, homogeneous identity. (Mouffe 1993:77)

She proposes we should conceptualise every situation as an encounter between private and public, which is represented by Gibson-Graham (2006) in Figure 2 below as the visible and invisible practices of socio-economic life. The work of Roger Lee (2006) and Gibson-Graham (2006) has been influential within social and economic geography to considerations of formal and informal economies. They argue that everyday practices are always already both economic and social. They use the term 'socio-economic practice' to include a range of activities which cut across categories of work and non-work, public and private, and paid and unpaid exchanges of social and economic value. Gibson-Graham argue the complexity of these socio-economic practices, which make up everyday life within communities have implications for thinking about how class position should be considered. Both in terms of material position and social identification, the class position of women is complicated by attention to diverse everyday socio-economic practice at an individual and household level. Rather than view class as based on one's relations to the means of capitalist production, Gibson and Graham (1992:116) conceive 'a decentred, fragmented and complexly structured totality in which class and other processes are unevenly developed and diverse'.

The typology in Figure 2 illustrates the range of practices and economies entwined in everyday life. This loosens binaries of paid/unpaid, formal/informal, production/reproduction and love/money to present a more pluralistic picture which includes alternative exchange practices, family provisioning and other economies of regard (Offer 1997). Considering these multiple and diverse practices, self-directed support policies may create further ambiguities and blurred boundaries by enabling the commodification of informal care practices between family, friends and community members.



Figure 2: Diverse and Alternative Economies, Gibson-Graham's (2006) (drawing by Ken Byrne)

This concern for the mutability of practices across structures of care has been demonstrated by Twigg and Atkin (1994) who describe how informal care can be influenced by professional practices. Similarly, professional practices can be influenced by experiences and observations of informal care. The 'becoming' aspect of carers' roles as they develop across the life-course and are influenced by one's position within wider support network is an important challenge to understanding carers as pre-existing actors with intentions, knowledges and tacit skills to perform given roles. As has been argued, carers' moral and material positioning, practices and knowledges can reflect lifelong learning, or may have been negotiated in response to a recent crisis. The principle structural positioning of carers may influence, but not necessarily determine, the way practices and relations of care are produced. As Dipesh Chakrabarty (2000:672) has suggested, we reflect and relate as human beings in ways which are not necessarily aligned with the logic of capital.

This has relevance for the concerns of this thesis, and is evident in discourses presented by carers in this research who enter into negotiations with each other in home-based care contexts. Givers and receivers negotiate understandings of 'good' and 'good

enough' care within this complicated landscape. The data chapters demonstrate how formal care-workers are influenced by the expectations of their clients, by expectations and practices of family carers, and by their own moral rationalities in establishing appropriate care standards. Carers from formal and informal contexts regularly define good care as that which exceeds basic (embodied) needs, performed in adequate time to allow inter-personal engagement. The next section focuses on the relationship between the values of care and its associated value in terms of financial remuneration.

### **2.1.3 *Negotiating the Values and Value of Care: Love/Money Distinctions***

There is often a distinction made in social discourse between care undertaken for love, and care undertaken for money. These distinctions can have consequences for extent of choice and control complementary carers possess. Caring practice has traditionally been situated within naturalising and essentialising discourses which position women as natural carers, and family as the most morally appropriate care institution (discussed in more detail in section 2.2.1). Certain moral boundaries around caring practice have gendered characteristics, with women viewed as more appropriate carers to men than vice versa. Twigg and Atkin (1994) note how conventional expectations of cross-gender caring are asymmetrical with gender rules about bodily contact, and are more highly constrained for men. They found in their study of informal carers that men found cross-gender caring more difficult, and were more likely to define specific boundaries (around bathing for example). According to Fine and Glendinning (2005), this has positioned care within cultural discourse as a gendered moral activity.

Carol Gilligan's (1982) work *'In a Different Voice'* suggests that the different structural and relational positions of men and women have produced two distinct ethical systems. Gilligan argues that because of the historical predominance of women in caring contexts, women have formed a different moral voice which responds to contextual judgement rather than abstract principle. Gilligan suggests this has produced a distinctly feminine 'ethics of care' through which women negotiate the tensions, ambiguities and contradictory experiences of everyday life, leading them to navigate moral choices not considered by men, who instead operate within an 'ethic of justice' which abstracts universal notions of morality. Such 'feminine' modes of interaction are seen to challenge capital-centric



rationales and values (Gilligan 1982; Tronto 1993, 1995; Irigaray 2000; Sevenhuisjen 2003). In contrast to Kantian ethics (see O'Neill 2007), an ethics of care situates moral rightness or wrongness within established codes, structures, histories and expectations. Taking an ethics of care approach involves attentiveness to situated circumstances rather than taking guidance from universal moral precepts (Young 1989). As Arendt suggests, generalised solidarity and responsibility (such as by nation states and communities towards individuals in need) is ethically problematic, arguing that if all are responsible, then none are responsible (Arendt 2003). Given that tasks and responsibilities associated with particular social roles change over the life-course, these contextual judgements and commitments are not entirely fixed (Granovetter 1985; Hockey and James 1993; Gilleard and Higgs 2000; Bowlby et al 2010).

These moral distinctions and social hierarchies around care have implications for the value of care as a form of socio-economic practice, and its value in monetary terms within the wider economy. Lee (2006) argues there is a relationship between monetary value, the value systems which underpin hierarchies of distinction of merit or worth, and the mechanics through which socio-economic transactions are understood. Remuneration, if given at all, is conceived differently to productive work processes which are calculated by time and outputs. The 'surplus value' derived from the appropriation of labour is a concept developed by Marx (1847, 1865) to describe the conversion and accumulation of capital produced over and above the creation of use-value out of raw materials and labour. The difference in value between labour and wages is often referred to as exploitation (Wright 2002). However, Marx was principally describing the sphere of production, in which surplus value can be measured by the additional hours of unpaid labour extracted from a worker (in terms of value of products compared to wages and other costs). Labour appropriation in service industries and in the reproductive sphere relies as much on intensity and perceived quality than the duration of labour. Within commodified caring, 'surplus labour'<sup>8</sup> or value (Marx 1847,

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<sup>8</sup> Surplus labour is a concept developed by Karl Marx, and is related to the concept of 'surplus value' in which an element of unpaid labour contributes to the profit of capitalist enterprise. This is discussed in Marx's 1847 'Wage Labour and Capital' (in relation to the determination of prices of goods) and in his 1865 pamphlet 'Wages, Price and Profit'. This relates to the capacity of human labour power to create value through labour beyond the cost of its own physical reproduction.

1865) can reflect emotion work performed by service workers (Hochschild 2003a). In the context of care, Christine Delphy (1980:93) responds to a critical question: ‘Are we to see children and the old and disabled as exploiters?’ She suggests the appropriation of social reproductive labour should be understood in the context of psychological dispositions which have been constructed in structures of inequality, exploitation and domination.

Since labour given freely is perceived to indicate care given authentically (Folbre 2001), payment for care can contribute to its devaluation (Himmelweit 1999; Folbre 2001; Glucksmann 2008). The correlation of free caring labour with good quality care may contribute to the low paid status of the care industry. Care-workers seeking to conform to these social expectations may be disinclined to demand pay increases compared to other service work. Performing an ‘authentic’ caring demeanour as an indicator of quality service is explored in *The Managed Heart* (2003b) by Arlie Russell Hochschild. She recounts her experiences of domestic work, and argues that emotions are controlled and used for the purposes of the market in paid work, and considers the psychological impact this has on service workers. She defines emotional labour as requiring:

one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others.  
(Hochschild 2003b:7)

One consequence can be an estrangement between emotions expressed authentically and emotions which are in some sense manufactured. Jaggar (1997:385-411) argues that emotions are the experiential basis for the expression of our values. Without experiencing shame, joy, sadness, frustration, jealousy etc., we would have no basis upon which to make judgements about the behaviour of ourselves or others. We rarely acknowledge how far we are able to control our emotions, as this would be to deny their authenticity. Seeking to inculcate particular emotional responses within a service economy raises expectations of authenticity, but at the same time brings this into question (McDowell 1991; Crang 1994; Taylor and Tyler 2000).

The complexities involved in the emotional experience of caring labour in particular is arguably much more demanding than other service work, it being more likely to endure over time and more intimate in its practice. As Susan Eaton argues, there are things

companies cannot bill for ‘but that make all the difference,’ such as ‘time to listen to somebody’s story, time to hold their hand, time to comfort someone who is feeling troubled’ (Eaton, cited in Folbre 2001:62). In this sense, good care is presumed to require inter-personal connection and person-specific knowledge. Himmelweit (1999) argues that we need to consider the duration of paid relationships as affectionate relationships that can develop over time, making paid labour not so different to pre-existing caring relationships. However, as England et al (2007) suggest, neoliberal home-caring operates according to strict time pressures which involve moving from job to job and home to home, which may undermine the possibilities of the formation of close working relationships, even over time. Expectations for emotional engagement as evidence of authentic or good quality care can make carers vulnerable to impositions by the client and family members to work beyond their role (see Karjanen 2008). Limited resources are likely to impede the ability of carers to provide good quality care where there is a cost associated with carer time. Self-directed and personalised support systems may therefore be adversely influenced by diminishing care budgets in a time of welfare austerity.

In summary, this section has argued that diverse socio-economic practices operate within care settings which can operate in complementary or contradictory ways in the everyday lives of individuals and households. This understanding will be developed in section 2.3. The next section considers the changing relations of care, and how these operate across diverse economies in the range of formal and informal, paid and unpaid care relationships that may be involved in supporting older people to stay at home.

#### **2.1.4 *Care Orientations: Bounded Rationalities and Pathways of Feeling***

Given the complexity of everyday relations and the competing demands of paid work and care described in previous sections, this section considers how social expectations are renegotiated or challenged over the life-course. It considers how far individuals make moral choices that reflect individual rational choice, or establish the right thing to do as part of an inter-personal dialogue which denotes relational agency. Drawing on the concept of ‘pathways of feeling’ (Hochschild 2003a) this section proposes individuals become oriented towards particular care obligations over time, which can

correspond or conflict with social expectations or material circumstances. This concept is drawn upon to situate the complex moral rationalities involved in taking up caring roles in particular circumstances, which can then inform how marketised care is utilised and understood from a consumer perspective.

Mitchell et al (2004) suggest that neoliberal restructuring introduces economic choices into every aspect of our lives, making us rationally calculate the benefits and costs of everything we do. Rational choice theories derive from a neo-classical economic position which states that individual economic actors make choices to achieve optimum personal gain for the least effort or cost. This relies upon means-end calculations in which opportunity costs, potential benefits etc. are determined from available information, including predictions of likely outcomes. Sen (2004:4) describes such rationality as ‘the need to subject one’s choices to the demands of reason’. The individual focus of rational choice theory has been extended by Becker (1996) to describe the way household decision-making involves economically rational trading between partners to create an ‘optimal family division of labour’ (Becker 1996, cited Duncan & Irwin, 2004:391).

However, notions of rational choice fail to account for social ties, moral responsibilities, and limited knowledges that are grounded in constraints of space and time. Individuals are often concerned to maintain a reputation of being trustworthy, which may outweigh short term gains (Granovetter 1985:490; Caldwell 2004; Murphy 2006). Consequently, markers of morality and social acceptability become ingrained in decision-making processes. Establishing the right thing to do is therefore mediated by social expectations surrounding families, communities and societies (Deacon and Williams 2004).

However, as Granovetter has noted:

Actors do not behave or decide as atoms outside a social context, nor do they adhere slavishly to a script written for them by the particular intersection of social categories that they happen to occupy (Granovetter 1985:487).

This section considers how far individuals and groups make choices to optimise the most advantageous circumstances for themselves, or whether satisficing rationales are used to produce ‘good enough’ care imaginaries. This is important for understanding

disjuncture between individualising consumer discourses inherent in personalisation policy, and the inter-dependent, situated rationalities of givers and receivers of care. The work of Herbert Simon (1957) has been influential in proposing an alternative perspective to rational choice. Simon argues instead that habitual choices, partial knowledge, and evaluations based on pre-determined criteria are important influences on actual outcomes. He suggests this leads to 'satisficing behaviour' in which compromises are accepted, and argues such behaviour reflects 'bounded rationality' in which people attempt to 'make do' with what is immediately at hand, most convenient or familiar. This approach complements de Certeau's (1984) phenomenological concern with the strategies and tactics involved in 'making do' in everyday life, and is favoured in this thesis over rational choice theories. Some social practices and roles are adopted in varying degrees of willingness: to do what is the most convenient, pleasing to others or which creates least disruption.

Bounded moral rationalities may reflect differences according to gender, class or other intersecting category, which may influence the range of questions, actions and intentions that are considered relevant or possible within an individual's frame of reference. The moral acceptability of choices within these bounded choices influence the decisions made. If tensions emerge in an individual's life, such as might occur when juggling competing priorities (such as work and care responsibilities), our expectations, value systems and practical abilities to resolve these can induce a psychological state known as 'cognitive dissonance' (Festinger 1957). This can generate such feelings as guilt, anxiety or ambivalence when seeking to reconcile competing demands and intentions. Anxiety can result when adherence to expectations becomes difficult in certain contexts, or when one's goals become misaligned with social expectations (Festinger 1957; Rose 1999; Giddens 1991; Sayer 1992; Hochschild 2003a,b; Ahmed 2006).

Drawing on Simon's (1957) assertion that individuals display 'bounded rationality' in everyday decision-making, Duncan and Edwards (1997) argue that only once (gendered) moral boundaries have been established will an individual seek to make economic calculations of the type described by rational choice theory. Particularly within household decision-making, decisions are not often made for purely individual

ends but are negotiated to meet conflicting and changing needs of multiple others (Duncan and Edwards 1997; Duncan and Irwin 2004; Duncan 2005). In an empirical study of New Labour's expansion of childcare from 1997, Duncan and Irwin (2004) found that working-class women valued trust and the peace of mind afforded by personal attention by a relative; whereas middle-class women preferred the education and socialisation benefits of formal nurseries. Practical issues of cost, timetabling and accessibility were secondary to these. In a different study about childcare choices, McDowell et al (2006) found that gendered and classed moral rationalities are positively and negatively affected by the choices of other parents facing similar decisions.

These studies suggest choices are not only reflective of classed rationalities and aspirations, but that class can be articulated through these choices to shape future opportunities. When considering parental choice of schools, Lucey (2004) suggests middle-class parents project anxieties about selecting the right school for their children, because going to the right school is about 'the person we are and the person we want to become' (Lucey 2004:93). In contrast, working-class parents and children express anxieties and fears of failure and rejection, which are minimised by opting for lower performing schools. Lucey concludes that psychic defences to avoid stigma and condescension (Goffman 1963; Skeggs 1997; Lucey 2004; Lawler 2005) can be as important to some parents as academic performance or status considerations.

Acknowledging the external world's awareness of us (Sartre 2003) can bring feelings of shame, pride or indifference, depending on whether we feel aligned or misaligned with the goals of others or our take on the world. We therefore manage impressions of ourselves (Goffman 1959, 1963) and induce desired emotional responses in others. Judith Butler argues that since we are opaque to ourselves, we require validation and recognition, and this positions us psychologically as 'beings of dependency' (Butler 2005). This thesis draws on Arlie Russell Hochschild's (2003a) use of psychoanalyst Judith Katz's work to consider how we express feelings and focus on aspects of everyday life through particular lenses. Katz suggests repeated feelings about certain activities or individuals develop into 'pathways of feeling' (Hochschild 2003a). They are familiar modes of thought which are habitually reproduced, but which can become disrupted in response to new challenges and possibilities. Similarly, Margaret Archer

(2000) proposes that we seek to reconcile our 'internal conversations' and dilemmas with circumstances in the external world. She describes these internal conversations as commentaries on human concerns, which help to forge personal identities recognisable to others. This thesis suggests pathways of feelings develop over the life-course, directing individuals towards particular attachments, moral commitments and responsibilities as 'embedded individuals' (Granovetter 1985; Deacon and Williams 1995, 2004). These are described throughout the thesis as 'orientations' which can reflect past, present and future alignments. Former orientations, motivations and contexts are not entirely lost to us as we move through time and space, since we seek to construct coherent narratives and direct our future paths in fulfillment of these (Arendt 1958; Sayer 2005 a,b).

Within the range of caring practices and relations which are established throughout the life-course, comparisons can be made between those relating to childcare and those relating to supporting older people. There are different considerations to be made which affect how these practices are understood. There is an assumption with childcare choices that a parent and child share aspirations and values, or that parents have the authority to make the final decision in the best interests of their children. Older people as adult citizens may negotiate their own choices, aspirations and anxieties with family carers, though for older adults with diminishing cognition, carers can have a strong influence. Although there are no distinct social practices or cultural ceremonies which celebrate the attachment and commitment of the caring decision towards older people, as exists with parenthood, this does not mean there is no moral censure attached to the role. Being able to distinguish and select what is most appropriate for the situation can involve considerable rumination prior to action. Often, the 'good enough' fit does not present itself immediately and the outcome can be inaction, maintaining less than ideal circumstances for one or both subjects. The consequences of taking the wrong option may be potentially damaging to relationships, for example, selecting inappropriate levels and modes of care.

Self-directed support introduces greater consumer choice and control, but potentially adds to the responsibility for older people in need of care, and those who coordinate their care. In a study of the way early personal budget holders navigated market choice,

Baxter et al (2008) found clients tended to stay with familiar care agencies due to an unwillingness to take risks, even when measures of 'quality' positioned their choices as inferior. Careful consideration is therefore taken in choosing means of formal support, and can often be characterised as resolving moral conflicts with practical considerations to produce a 'good enough' fit rather than adopting maximising strategies. These may reflect a 'tyranny of small decisions' (Jarvis 2005:212), which are constrained by the need for adaptability, and so may appear 'sub-optimal or perverse to the outside observer' (2005:213).

This thesis argues that care choices may reflect more than rational calculations which aim to maximise economic or social benefit. They also reflect enduring moral rationalities which aim to demonstrate personal integrity and positive evaluations from others. Established relations are always being undone by changes in the respective life-course events of individuals within it. Aneshensel et al (1995:349) describe how caring involves 'not so much an array of responsibilities, as a recurrent redirection and reorganisation of one's life'. Commitments and moral obligations involved in care practices are often reconfigured as care needs arise, requiring renegotiation so that individuals can reconcile pathways of feeling with emerging realities. This is particularly pertinent when considering care of older people. Hannah Arendt (1958) suggests we seek to maintain a sense of purpose and meaning to life which would otherwise be characterised by uncertainty and the happenstance of unintended consequences. She suggests settlement through forgiveness and binding to promises re-establishes our personal narrative in relation to others:

Without being bound to the fulfillment of promises, we would never be able to keep our identities; we would be condemned to wander helplessly and without direction in the darkness of each man's lonely heart, caught in its contradictions and equivocalities (Arendt 1958: 238).

As has been argued earlier, obligations and inter-dependencies across the life-course are not stable. This section has argued that achieving good enough responses in meeting the needs and desires of others draw upon bounded rationalities which may reflect gendered and classed expectations of the 'right thing to do' in particular circumstances, and informed by pathways of feeling which develop across the life-course, which orient care



practices towards particular individuals, objects and spaces. The next section reviews and discusses suggestions that society is witnessing a reconfiguration of obligations and commitments away from family and towards more diverse and plural solidarities with others.

## **2.2 Changing Relations of Care**

There are a number of anthropological terms which describe different forms of interpersonal relation: consanguinal (blood ties), affinal (related by marriage), and fictive (taking non-kin as kin) as outlined by Ibsen and Klobus (1972). The family has traditionally been understood as based on ties of kinship – with bonds established through blood, marriage and adoption. More recent accounts focus on the pluralisation of family forms, and discuss the diversity of practices which constitute family life. As a consequence, the notion that family is a fixed social institution is challenged in favour of a perspective that argues individuals are not ‘in’ but rather ‘do’ families (Morgan 1996, 1999). This approach focuses on meanings and individual agency in the lived experience of family life, in contrast to structural accounts which present the family as containing a set of functions which reflect the social and economic order.

This section begins by describing structural understandings of family as kin within a shared household, and how these have been important for framing understandings of obligations and responsibilities around family care. The section concludes by questioning such structural accounts of family as kin/household by considering the pluralisation and diversification of family forms, drawing on Morgan’s (1996, 1999) notion of ‘doing’ rather than ‘being’ family. The section also reviews arguments which suggest friendship is becoming increasingly important within contemporary personal communities and social support networks. Using Pahl’s (2000) use of the notion of suffusion, this section considers the permeability of boundaries between family and friends. Acknowledging a discourse which suggests friends are becoming more important within our personal communities, the section goes on to reinstate the continuing relevance of family. Drawing on Weeks et al’s (2001) notion of ‘families of choice’, I consider academic debates about individualisation and reflexive agency (Beck

and Beck-Gernsheim 2001) which is purportedly characteristic of contemporary solidarities and personal intimacies.

These debates on the relative importance of family and friendship are then situated in the remainder of the section with reference to social support networks as a whole, and how these inform interactions, practices and caring roles. Arguing that individuals are embedded in a range of relationships in place, I draw on the work of Wenger (1991, 1996) to describe the various typologies of care networks which are more or less successful at supporting older people with social care needs. This section concludes by arguing that it is important to look beyond care dyads to consider the negotiation of roles and mutual support between complementary carers within a network.

### **2.2.1 *Structuring the Landscapes of Care around Family***

This section considers the role of kin to negotiating the care of older people with social care needs. Individuals and households notionally agree to support each other for a considerable portion of the life-course, deferring immediate personal advantage to adopt responsibilities and manage dependencies, often in a context of uneven mutuality. These practices construct inter-dependencies which can contribute to future relational obligations and responsibilities between family members, friends and others in the context of care of older people (Aronson 1992; Finch and Mason 1993; Milligan 2000; Fyfe and Milligan 2003; Milligan 2003; Wiles 2003a, b; Milligan et al 2004). Understanding the family as a social structure is central to recognising the way care is organised within it and around it, even though these understandings have been disrupted by accounts which suggest that the family is in decline.

Functionalist accounts position the family as an institution, which is part of a coherent social order whose functions involve socialisation, material and emotional security and is a key site for the regulation of identity (see Parsons and Bales 1955). From this perspective, the family has been viewed as self-evident and natural (based on kin/blood relations), and from which a set of obligations are implied. The primary role of the family as an entity for delivering care has influenced the historical construction of state welfare institutions as a supplementary and complementary system.

Marxist accounts situate the emergence of the nuclear family within a historical framework. However, though the family as an institution is viewed as complementary to the economic and cultural basis of social order, in contrast to functionalist accounts, Marxists view these structures as inherently unequal and exploitative (Engels 1972; Offe 1987). Structuralist accounts of the family were prevalent in discourse in the 1960s and 1970s, and formed the backdrop for feminist critiques. The subordination of women was understood as a consequence of marginalisation in the 'private' spaces of the home, and economic dependency, which is reinforced by male power. Feminist accounts have been important for challenging the assumption that family life is a private concern, instead positioning it as a key site of political struggle.

The modern nuclear family which emerged from industrial capitalism has been regarded as the foremost care institution, usually constructed in highly gendered terms (Willmott and Young 1957; Engels 1972; Young and Willmott 1973; Esping-Anderson 1990, 1996; Pateman 2000; Cochrane et al 2001; Folbre 2001, Lewis 2001; Pfau-Effinger 2005; Eichler and Pfau-Effinger 2009). Supplementary support systems of the modern welfare state developed around assumptions that family care is provided for 'free'. Folbre described the family as a 'little welfare state' (Folbre 2001:202). The value of social reproduction within families in terms of monetary exchange value, quality or extent does not usually form part of official calculations (Bakker 1998), though this labour heavily underpins the effective functioning of complementary economies.

Second-wave feminism has been an important influence in drawing attention to the undervalued position of social reproductive labour within families. Dalla-Costa and James (1975) argued that women were an 'indispensable workforce' ensuring the reproduction of the capitalist labour force, and therefore part of the 'productive' process. The concept of the 'family wage' assumes women's unpaid labour in the home (Barrett and McIntosh 1982), and Dalla Costa and James (1975:1) argued that if wagelessness was the source of women's powerlessness in the home, then demand for wages 'must be our lever of power'. This 'Wages for Housework' proposition led to debates within the feminist movement: on the one hand that women's skills and capacities as producers and reproducers of labour should be valued through wages like

other forms of paid labour; and, on the other, that the sexual division of labour is an undesirable and unnecessary way of organising family and social reproductive work which would be entrenched by payment (Young 1995).

Arguments about whether men or capitalist institutions benefit most from these arrangements have been the subject of much political and academic debate. Delphy (1980) contended that patriarchy pre-dates capitalist modes of production. Heidi Hartmann (1981) developed a 'dual-systems theory' (see also Fraser 1995) to account for the way capitalism and patriarchy were distinct systems which worked alongside each other in the way they positioned and affected women. This sought to address the disconnection between socialist and feminist debates during this period, suggesting their differences were real, but did not imply they were incompatible world views for one individual to hold. Hartmann argued in *'The Unhappy Marriage of Marxism and Feminism: Towards a More Progressive Union'* that men are privileged in the patriarchal ordering of society, and therefore sexism must be challenged as a separate issue to Marxist politics concerned with exploitation of labour. Walby (1986) also insisted that capitalism and patriarchy could exist without the other, arguing that capitalism is contingently gendered, sometimes compatible and sometimes existing in tension. This was also proposed by Sayer (2000), who suggests that exploitation for profit is intrinsic to capitalism. For a significant portion of its history, this has involved the exploitation of women's social reproductive labour. He argued the intention was not the oppression of women per se, rather capitalist rationales sought to acquire the cheapest and most effective possible means of reproducing the current and future workforce. Women have been represented by Marxists as a 'reserve army of labour' (Beechey 1977). This is explored by Jane Lewis (2001) who argues that following the Second World War in Britain, the state encouraged women to leave industry and manufacturing jobs and return to roles as housewives by reasserting the value of housework and care, and by making conditions more favourable.

Marxist-feminists have highlighted presuppositions that women carry out caring labour as a natural consequence of their embodied capacity (Mitchell 1966; Dalla Costa and James 1975; Delphy 1980; Walby 1986, 1990), though childbearing capability does not in itself imply responsibility for primary care thereafter, for children or other

‘dependents’. Folbre (1993) describes the adverse positioning of women in family relations as ‘gendered structures of constraint’. As a consequence, Bowlby et al (2010) suggest that inter-dependencies and responsibilities emerging during the life-course reflect social norms which are framed by the social and familial institutions which facilitate them. These are not necessarily imposed through force, but involve what Bruno Latour refers to as a process of ‘enrolment’ (Callon and Law 2010), and Althusser refers to as ‘hailing’ (Althusser 1971:163 in Ahmed 2006). Seeking recognition as a certain type of subject, and seeking recognition for moral worth in relation to others, which takes account of particular social expectations, makes us amenable to influence (Rose 1989, cited in Robinson 2000:71). These notions are used within the data chapters to describe the routes through to caring roles for respondents in this study.

Across the paid and unpaid divide, care continues to be undervalued as ‘women’s labour’ (Himmelweit 1995; Kittay and Feder 2002; McDowell 2004b) due to its association with family practices performed for love rather than money. Paid care work is still influenced by its unpaid form, since commodified care remains at the bottom of labour market hierarchies (Himmelweit 1995; Folbre 2001; England 2005). Social policy measures to promote equal pay, the expansion of higher education and anti-discrimination legislation during the 1970s have improved the circumstances of women in the paid labour market, and encouraged greater participation. Young and Willmott (1973) suggested that families were in a process of becoming more equal as more men take on responsibilities within the home and partners share decision making. Ruth Lister (1997) identified a universal worker/universal carer as the basis of new citizenship imaginaries, but this imaginary did not reflect experiences of many women who faced a disproportionate dual imperative to work and care (Macleavy 2007). The combination of moral imperatives to work and care has created a ‘second shift’ for women seeking to reconcile these positions (Hochschild 2003c).

Despite the relevance of these debates to the construction of care roles within families, and their monetary and moral evaluation in wider social processes, the care of older people does not fit neatly into feminist critiques of capitalist-patriarchal relations of exploitation. Ehrenreich describes the gender oppression which results when ‘the person

being cleaned up after is consistently male, and the person cleaning up is consistently female' (Ehrenreich 2000:61). When the person being cleaned up after is consistently older, does this dependence amount to patriarchal domination in the same way? As Aronson suggests 'someone's got to do it' (Aronson 1992:494). Within families, care is an example of generational reciprocity – a response to necessity partly built upon culturally inflected meanings, such as a sense of giving back for care received, and partly as a response to presumptions by the state that care will be forthcoming from within a family's resources.

In contrast to childcare, caring for older people does not imply a duty upon particular family members so clearly as to a parent or grandparent vis-à-vis their children and grandchildren (Finch and Mason 1993; Wheelock and Jones 2002). Caring for older family members is not necessarily planned into the life-course, but may arise following illness of a relative in unpredictable ways. There is no clear end point to the caring, as older people may live with social care needs for many years. Compared to childcare, which is invested with projected hopes for the future and aims to realise independence for the child, the horizons of caring for older people are arguably different, as successful care may be perceived as slowing the pace of inevitable decline and eventual loss.

As Twigg (1989) has argued, state support and voluntary support with caring has usually been provided only when family support is considered wanting in some way. Fewer siblings in modern families mean that there is less available kin support than in the past (Abel 1986:481), which suggests a focus beyond gender to other relevant identity intersections to better understand who carers are, why they do what they do, and how their other social roles affect the relations they negotiate with those they care for. Current data suggest that men care for their spouses in later life in significant numbers, but this is variable according to a number of factors, such as age group and number of care hours provided (Department of Health 2010). Adult children provide care, but this may be regarded as returning care already received. This may also reflect gender in the way this care is shared between siblings (Joseph and Hallman 1999). The historical unsettling of the rights and responsibilities of national citizens, communities and family members make identifying the relations of care more difficult to describe without contextualising in time and space.

### **2.2.2 *Personal Communities: the Changing Role of Family and Friends***

This section explores the extent to which friends are positioned in relation to family within contemporary understandings of intimacy, inter-personal connection and responsibility. The geographer Ferdinand Tönnies (1855-1936) envisioned community (*Gemeinschaft*) as made up of one's family and was concerned with one's intimate relations. In contrast, he viewed society (*Gesellschaft*) as an 'imaginary and mechanical structure' (Tönnies 1955:37, cited in Johnson et al 2000). Tönnies argued that industrialisation and urbanisation at the turn of the 20<sup>th</sup> century diminished family and community life, which he understood as rural in origin and essence. This understanding demonstrates the paradoxical position of the emerging family forms which arose during early industrial capitalism, viewed as being both threatened by these socio-economic and spatial processes, and reflective of them in Marxist accounts. In a post-industrial era, commentators now propose that family life which was strengthened by the imperatives of industrial capitalism is becoming derailed in the flexible or 'liquid' post-industrial era (Bauman 2003). These accounts of demise suggest family and community are idealised motifs which are constantly imagined to be under threat from contemporary social forces. Coontz (1992) disputes the notion that the perceived decline of the family in recent decades is a new phenomenon. She argues:

families have always been in flux and often in crisis; they have never lived up to nostalgic notions about 'the way things used to be' (Coontz 1992:2).

The difference between earlier accounts of the demise of the family and contemporary debates is perhaps the infusion of more optimistic observations around pluralistic forms of solidarity and intimacy. Within contemporary debates, there is therefore a mixture of optimism and pessimism. The apparent decline of the family is seen alongside the growing importance of friendship, though with different implications. Several commentators in recent decades have debated how far the role of the conventional nuclear family is diminishing or becoming under strain in contemporary society (Gittins 1985; Dizard and Gadlin 1990; Beck and Beck-Gernsheim 2001; Levine 2004). The increase in divorce, increased cohabitation, increased solo living, living together apart, and the prevalence of reconstituted families are cited as evidence for this growing

demise (Smart and Neale 1999; Portrie and Hill 2005; Jamieson et al 2009). There has been a perceived shift away from the male breadwinner model to universal citizen models within contemporary family forms (Janssens 1997; Lewis 2001) which reflect changing gender and class relations vis-a-vis paid work and unpaid care. However, the continuing importance of the notion of family has been evident in the way households continue to define themselves as families. Diana Gittins (1985:2) proposes the concept of 'the' family in favour of a pluralised notion of families.

Pessimistic understanding of this social transformation towards more plural forms of intimacy is concerned with the way solid family responsibilities are waning. They suggest that commitment and care are being diminished in favour of individualised and self-maximising concerns (Beck and Beck-Gernsheim 2000; Bauman 2003). Beck and Beck-Gernsheim (2001) conclude that the individualised reflexivity of the modern age represents the decline of social commitment, opening up choices but bringing greater individual risk since more democratic forms of intimacy are potentially more fragile.

Optimistic accounts applaud the loss of restrictive and gender oppressive practices which are believed to reflect nuclear family forms. They point to the way plural notions of family are replacing the asymmetrical relationships contained within a conventional nuclear family – family forms which have been extensively critiqued by feminists as marginalising and oppressing to women. The decline of the conventional nuclear family is therefore viewed as a positive shift towards more egalitarian relationships. These optimistic accounts began with Young and Willmott (1973), who described equalising transformations in family life.

The shift from singular to plural conceptions of family has been influenced by literature which explores intimacies within same-sex personal relationships. Several accounts have emerged in recent decades which critiqued discourses which positioned a 'gay lifestyle' as antithetical to notion of family (Giddens 1991; Weston 1991; Nardi 1999; Weeks et al 2001; Roseneil 2004; Perlesz et al 2006). Findings from empirical studies suggested that the notion of family is employed and attributed within same-sex relationships, and that this draws attention to the way family can be chosen as well as given (Weeks et al 2001). Nardi (1999) suggests that since the concept of family has



been given such a privileged place within western culture, using familial terms is a way of emphasising the importance of some friends as ‘like family’. In an ethnographic study of the way children and grandparents of lesbian parents perform and display family practices, Perlesz et al’s (2006) highlight the way everyday practices can navigate ‘mainstream’ and ‘marginal’ spaces of contemporary family life. Furthermore, Giddens (1991) proposes that these diverse understandings of family are better able to express ‘pure intimacy’ since these encourage more equal, friend-like characteristics (a suggestion which has been debated and critiqued – see Jamieson 2005). Regardless of attributions of family to these relationships, Roseneil (2004:411) suggests that lesbians and gay men rely more strongly on friendship for vital support in later life:

Networks of friends, which often include ex-lovers, form the context within which lesbians and gay men tend to build their personal lives, offering emotional continuity, companionship, pleasure and practical assistance (Roseneil 2004:411).

These insights can be used to reconsider the position of older people whose personal networks mirror those of diverse (minority) households - as partners may be absent, deceased, separated through divorce; or they may never have had a permanent or monogamous relationship. Beyond the literature in sexuality studies, friendship has become a more prominent topic for discussion in light of suggestions that society is increasingly characterised by individual reflexivity and risk. One of the leading academic commentators, Ray Pahl (2000), suggests we increasingly turn to our friends as a touchstone: to confirm the coherence of our actions and values within a recognisable, consistent self identity. Therefore, if friendship is increasingly defining our sense of self, and friends are more likely to be geographically proximate than our biological relations in later life, maintaining these connections (or social convoy as Pahl describes it), may be increasingly important.

The concern for plural notions of family and more friend-like kin relations is one element to understanding contemporary solidarities. A number of academic accounts have emerged that seek to explore the role of friendship to contemporary intimacy and responsibility to others (Derrida 1997; Pahl 2000; Fischer and Oliker 2001; Bridge 2002; Coakley 2002; Andrews et al 2003; Deacon and Williams 2004; Miewald and McCann 2004; Spencer and Pahl 2006). Some focus on the number of friends, noting

how size of friendship networks may be the result of different structural and dispositional positions of men and women over the life-course (for example see Fischer and Olicker 2001). This concern can be linked to notions of social capital which is broadly defined as possessing the disposition or capability to adhere to certain norms in order to build networks of trust, reciprocity and establish community (Coleman 1988, 1990; Bourdieu and Wacquant 1992; Putnam 2000). However, as Spencer and Pahl (2006) argue, inequalities between 'friend rich' and the 'friend poor' (in terms of quality of support network) is not merely based on numbers or frequency of contact, but involve degrees of meaning which can take on greater significance in later life.

For those older people who find themselves without a regular and reliable network of family and friends, incorporating formal voluntary support becomes an option, but one which is fraught with tensions in establishing the basis of these relationships. Andrews et al (2003) discuss local authority befriending schemes where paid workers or volunteers act as surrogate friends in situations where older people would not otherwise receive visitors. Despite the stigma often attached to befriending schemes, they argue that the voluntary nature of the befriending service was important to older people, suggesting money disrupts notions of authenticity and dignity in care relations (Andrews et al 2003:355-6). However, they also suggest that relationship boundaries needed to be carefully negotiated in order not to appear artificial on the one hand, or place too much emotional or time-burdens on the visitor on the other.

The relationship between care and friendship can be understood to pivot around conceptions of obligation, dependency and freedom of choice. Friendship is defined in the Oxford English Dictionary as 'a bond of mutual affection, typically one exclusive of sexual or family relations' and as 'a familiar and helpful thing'. The word's origin is related to the word 'free' in Old English. In *The Politics of Friendship*, Derrida (1997) argues it is the rareness and indeterminacy of friendship which gives it value. Consequently, the fragility and autonomy of friend-based relations is a challenge for establishing appropriate frameworks for care support in later life, compared perhaps to family relations that are based on social expectations, or paid care which has a formal contractual obligation attached. Derrida argues that friendship is always 'a thing of

distance, a thing of the future' (Derrida 1997:285) rather than a given obligation or expectation between people.

There is no friendship without confidence, and no confidence which does not measure up to some chronology, to the trial of a sensible duration of time [...] friendship does not – and above all must not – have the reliability of a natural thing or a machine; since its stability is not given by nature but is won, like constancy and 'fidence', through the endurance of a virtue (Derrida 1997:14-23).

Friends can care for each other (practically and emotionally), and may or may not draw on these circumstances to inscribe notions of care or to invoke fictive kin relations into these friendships. Allen (1986) argues that friends may offer support in a crisis, but to do so indefinitely would undermine the basis of the relationship itself. He questions whether friendship is a suitable basis for care-giving, arguing that 'normal exchange rules' are undermined by the long-term care needs of older people. Friendship is likely to be important to older people as kinship ties loosen in later life, as older family members pass away, and younger family members move away to seek employment. Friendship in later life can be significant for framing understandings of personal care needs and future aspirations. The ageing process - the experience of mental and physical decline (McDowell and Sharpe 1997; Twigg 2000) can arguably be best supported by friends who might be sharing this experience (Pahl 2000; Dawson 2002; Misztal 2003; Spencer and Pahl 2006).

Being 'at hand' and sharing in the display of valued friend relationships therefore has considerable value. Friends can influence what is considered 'good ageing' and redefine perceptions of need. Display and performance within a peer group is therefore an important element of the ageing process, which is not simply an essentialised process of biological decline. There may be varying expectations and practices which influence the way ageing and caring is imagined which reflect class identities and work histories. For instance, Dawson's (2002:24) study of clubs in working-class mining communities found that 'being considered a totem of good ageing is a source of cultural capital'. The boundary between care and friendship is therefore understood as a porous one, but whose boundaries are nevertheless important to maintain. Friendships which move towards an asymmetrical care relationship (more associated with kin obligation) may

provoke a desire to reinstate more democratic and reciprocal relations associated with friendship *despite* the practice of ‘care’, which may be minimised or underplayed.

### **2.2.3 *Doing and Re/Doing Family: Practicing and Displaying Care***

This section builds on the previous two sections to consider in more detail practice-based understandings of families and friendship to explore how contemporary solidarities influence understandings of care across the life-course. Beck and Beck-Gernsheim (2001) remark that as women’s ‘adhesive role’ declines in the post-Fordist era, there is no obvious successor to assume family and community responsibility as individuals reflexively focus on themselves as ‘life projects’. Their arguments imply that the condition of post-modernity adds to the care ‘deficit’. However, Deacon and Williams (2004) argue that the notion of an embedded individual challenges the claim that reflexive individualism is associated with the degeneration of family and community. In a report on a five-year programme on the future of parenting and partnering, Deacon and Williams (2004:387) found that:

...people attempted to balance their own sense of self with the needs of others. What it means to be a good mother, father, grandparent, partner, ex-partner, lover, son, daughter or friend is crucial to the way people negotiate the proper thing to do

They argue, in contrast to Beck and Beck-Gernsheim (2001), that our connections and solidarities with others remain an important aspect of creating a sense of self-identity and ethical position.

The work of Ray Pahl and Liz Spencer (Pahl 2000; Pahl and Spencer 2004; Spencer and Pahl 2006) has been a significant influence on debates surrounding contemporary obligations and personal networks. They use the notion of personal communities to explore the association of responsibilities and affections towards kin and friendship networks. They identify five constituent elements of personal community from their empirical research: friend-based; family-based; neighbour-based; partner-based; and professional-based (Spencer and Pahl 2006:130). They argue that each of these have distinctive combinations of family-like or friend-like, given or chosen ties, each producing different roles within the personal community of an individual. These include

expectations of love; whether these relations are expected to last; and whether these are primarily intended to be supportive, companionate or one of sharing confidences. Evidence from their research found that partners exemplified a combination of being both family and friend. Pahl and Spencer (2004:123) suggest there is a continuum of degree to which individual relationships are suffused (having overlapping roles) or specialised (having separate roles). They found that some family members were viewed as if chosen as friends, whilst some friends were viewed as if given like family.

...where people acknowledge a process of suffusion, it is not the case that they believe that family members have actually become friends, or friends have become family, but that there has been some blurring of boundaries. The evidence from our study suggests that, contrary to gloomy forecasts predicting the erosion of personal responsibility, the process of suffusion – with given-as-chosen and chosen-as-given ties – may involve a high degree of commitment and does not necessarily imply a loosening of social bonds.’ (Pahl and Spencer 2004:125).

The notion of suffusion suggests intimate relationships are not simply based on either fate or choice but are a complex set of differently functioning relationships with negotiated tasks and responsibilities, allowing a blurring of boundaries between friend and family relations. Allen (2008) has critiqued the idea that suffusion has led to a reprioritising of friends as more important than family, arguing there still exists a clear boundary distinguishing friend relations from family ties within cultural practice.

The shift away from structural accounts towards practice-based accounts proposes that individuals are ‘doing’ family in different contexts. Morgan (1996, 1999) suggests that it is in everyday practices and performances that the notion of family is established and reproduced. Performing and practicing family outside of kin relations does not imply that commitment to others has waned in an individualised world, as suggested by Beck and Beck-Gernsheim (2001). This reflects the agency and intentions of individuals to recognise the importance of certain individuals, who may draw on analogies of family to describe the intimacy and responsibilities between them. Given the relevance of more diverse social networks of support, which commentators such as Pahl (2000) suggest are increasingly characteristic of contemporary social solidarities, the notion of ‘doing family’ can be used to extend beyond kin to other social relations, as part of a related process of ‘choosing family’ (Weeks et al 2001).

Distinction and clarity of roles may be done and undone variously across time and space and within the social support networks of older people. The concept of ‘doing family’ (Morgan 1996, 1999) may be usefully drawn upon to understand the construction of responsibilities and identities across a social support network. Jamieson (2005) and Finch (2007) suggest that displaying intimacy is an important aspect of family practice – evident in the way family members share meals (see also James and Curtis 2010), show commitment and offer gifts to demonstrate their involvement in ‘family’ events and processes.

the need for display is greater as relationships move further away from those which are readily recognisable as constituting family relationships (Finch 2007:71).

This may be especially necessary within non-conventional families as a means of inscribing family where relationships might be misrecognised as some other form. The next section considers the implications of the existence of other carers within an older person’s social support network for the performance of caring identities and acceptance of caring obligations.

#### **2.2.4 *Care-Giving and Care-Receiving Across Social Support Networks***

Practice-based accounts of ‘doing’ and ‘displaying’ family (Morgan 1991, 1997; Finch 2007) have proposed that structural understandings of the boundaries of family, friendship and other solidarities and intimacies do not adequately account for the blurring of these in practice in everyday life. Together with Pahl and Spencer’s (2004) use of the notion of suffusion which describes the range of ways relationships and obligations can be configured, these more contingent and diverse conceptualisations can be drawn upon to better understand the construction and maintenance of caring roles. Moving beyond attempts to define and explore the construction of obligations and care as outlined in section 2.1, this next section proposes care should be understood as a negotiated process which can go beyond carer to cared-for dyads to include wider negotiations between complementary carers in a network (Wenger 1991, 1997; Keating et al 2003). As Keating et al (2003:124) suggest:

The social network and social support literatures provide an excellent foundation from which to develop our knowledge of the caring capacity of the informal sector. The accumulated research also provides a template for moving care-giving research from its focus on individual care-givers to networks of care.

In a socio-economic sense, being successfully embedded within social networks has been described as a form of social capital that allows individuals to capitalise on (embodied) knowledges and other pertinent circumstances in a field of social relations (Coleman 1988, 1990; Putman 2000; Bourdieu 2004; Deacon and Williams 2004). The social networks of older people offer significant capacity for care support, as demonstrated by Keating et al (2003). They argue that instead of considering care dyads between older people and an individual carer, attention should focus on the way care support is given and received within a network. They argue that the care network should be the basic unit of analysis for understanding the care of older people. In doing so, they argue that distinctions should be made between ‘social’, ‘support’ and ‘care-giving’ networks (Keating et al 2003:117). They argue networks can be delineated in the following way:

Network characteristics including size, composition, density, continuity, normative expectations, proximity and recipient characteristics, tend to make care-giving networks smaller and more focused in comparison to the support and social networks from which they emerge (Keating et al 2003:123).

They argue that the support potential of social networks should be thought of as ‘network social capital’ (Vogt et al 1992, cited Keating et al 2003:117). Their analysis of literature on care suggests that the size of social networks is not a good predictor of support, and the transition from social to support is little understood and often conflated. They cite evidence from Wenger et al (1996) which demonstrates older people have an average of twelve to thirteen close ties. They argue support networks are qualitatively different to social networks, being more focused on long-standing ties, with high expectations for reciprocity and support. Reciprocity is seen as more important in friend-like relations than with kin support, which is more normatively based on obligation. Wenger (1991) identifies five categories of social networks that are composed of different groupings of individuals and different relationships and

proximities. These are: locally integrated (strong and geographically proximate support from family, friends and neighbours); wider community focused (made up of community ties and friendships, perhaps due to absence of family locally); local self-contained (smaller local networks focused on home); local family dependent (primary reliance on family, usually adult daughters, with little formal support); and private restricted (very limited or no support, characteristic of some older people who may be widowed, migrants or who have outlived their peers).

In a residential care context, Powers (1992) suggests the following typology of network types: institution-centred networks, where ties were simple and focus on small clusters within the care home; kin-centred networks, which focus on visits from family; and balanced networks with a range of contacts, including other residents, staff and families. She suggested the latter category was the most resilient and supportive to the older person. In a home-based context, the construction of care-workers as 'fictive kin' or 'like family' has been investigated (Rae 1992; Barker 2002; Andrews et al 2003) but less is known how far carers themselves (and their personal community) attribute clients and befriendeds as fictive kin. Pennington and Knight (2008) found in their phenomenological study of an Australian befriending scheme that both friendship and family attributes were assigned to these relationships by both sides of caring dyads. The focus of attention on support networks in care contexts is often on the older person as a central hub, but less attention has been given to the way support is transacted across the network, and the way roles and identities are negotiated within these different network types. Keating et al (2003) argue that the inter-relations of care networks warrant further attention:

Many important questions about care-giving networks have not been addressed, such as whether neighbours and friends are members only when close kin form the core, whether non-kin provide only a restricted set of tasks, and whether their contributions will become increasingly important with changing family dynamics (Keating et al 2003:123).

In conclusion, this section has described the changing social relations of care, and how family, friends and others relate to each other in wider networks of support for older people. Social commentators refer to the increasing complexity of social and cultural life which destabilise taken-for-granted assumptions and choices, and inform responses



to new challenges. Given the plurality of competing principles and concerns we face, the task is not simply applying practical judgement to a single principle of action, but satisfying a plurality of principles and foci for our attention. The data chapters discuss how family and friendship is practiced and displayed through the negotiation of roles between care-givers and a range of care-receivers. This does not occur only with a care dyad, but includes performance and display between care-givers within networks of support. The data chapters demonstrate how these are constructed to reflect their different carer positions in relation to the older person, and that these are contingent in time and space depending on the presence of others within the support network. These include non-family carers who describe family-like characteristics in some contexts, but may emphasise alternative forms in the presence of biological kin (particularly family carers) to minimise or alter perceptions of their role with complementary carers.

## **2.3 Geographies of Care**

When thinking about care as an activity or as an inter-personal interaction, the times and spaces of care are brought into focus. Over the life-course, there are normatively constructed stages when particular care and/or work obligations are instantiated and relinquished, particular spaces imagined in which such activities take place, and certain practices and identities invoked when framing these activities. This section seeks to explore the importance of geography and spatiality to the giving and receiving of care in its lived experience. The concept of ‘life-world’ (Husserl 1936) is used to describe the spatial and temporal experiences of caring practice, which settle to form familiar features of lived reality. Also considered in more detail is how time (particularly with reference to timeliness and pace) is a key experiential dimension of caring practice.

### **2.3.1 *Spatialities and Life-Worlds of Care***

Human and social geography has been described as a complex assemblage of different theoretical and methodological approaches, in which interactions are constructed through a variety of social, economic and political institutions and practices (Del Casino 2009:15-16). A central concept within human or social geography is ‘spatiality’. This is defined as the effect that space has on concepts and theories (Johnson et al 2000). Social

geographers have sought to explore in particular dimensions and experiences of space and time in our everyday lives. Space and place are outcomes of the accumulated constructions and reconstructions of particular inter-personal and organisational processes over time. The historical construction of places have been described using various terms, such as Doreen Massey's (1984, 1994) use of a geological metaphor and Katz's (2001) concept of 'topographies,' to describe both the accumulation of sedimented social relations and the 'perspective' of places in relation to other places. Similarly, McDowell et al suggest place is not

... a static, bounded container for social relations, but is instead the coincidence of a range of interconnected social processes operating at different scales over different time-periods (McDowell et al 2006:2163).

Chombart and Louwe were early social geographers interested in the construction of social space. They identified two distinct components of space - objective and subjective (Chombart and Louwe, 1952:190-1, cited in Buttimer and Seamon 1980:24). The objective component describes the spatial framework of living for particular groups, by identifying how these have been influenced by ecological factors. This reflects a behavioural approach to human geography, particularly the concern for time-space pathways and the ways these create characteristics of particular spaces and places. This is important since individuals and groups are variously positioned within social institutions and networks which may constrain or facilitate certain activities and knowledges. Soja (1980) suggests the production of space has political significance in defining practices, shaping experiences and constructing power relations.

Within this understanding of the relevance of 'objective' characteristics of space and place, social geographers have consistently explored the significance of spaces of care. Some contemporary social geographers continue to seek to objectively measure or map social processes. An example of this approach is found in medical geography, which attempts to map health provision and wellbeing in particular places. This provides a useful contextualisation of the patterns of social life, but is insufficient to explore in a nuanced way the emotional and symbolic significance of how health and social care is experienced in particular settings, such as community day centres or the home-space (Milligan 2000, 2005; Conradson 2003 a,b; Parr 2003; Parr and Philo 2003; Bowlby et

al 2010). Addressing this concern is explored in Chombart and Louwe's second component; the subjective experience of space. This takes into greater consideration the perspectives of particular groups, with critical geographers being concerned to express the experiences and perspectives of those who may be marginalised in policy and decision-making processes.

Findings from quantitative studies can advance new research areas for qualitative research and vice versa, each contributing to objective or subjective understandings of social space. Some social geographers use a mixed method approach (using quantitative and qualitative techniques) to explore the lived experience of space and place by paying attention to the infrastructures of daily living (in different spaces) and how these are experienced by different social groups (Buttimer 1976; Jackson, 1981; Duncan and Ley 1993; Gilroy and Booth 1999; Holloway and Hubbard 2001; Jarvis 2005, 2011).

As care is positioned across paid/unpaid and work/non-work binaries spatial and temporal conceptualisations can be complex (Folbre and Nelson 2000; Himmelweit 1995). In recent decades, some forms of social reproduction have been commoditised and marketised outside the home at the point of production or consumption. An expanded service sector which includes eating out, laundry and ironing services etc., have altered the spaces and economies within everyday life. Other activities, such as care of older people, are being redirected back into in the home (Dyck et al 2005). This objective refocus on the home-space affects subjective experiences of home for those who live and work within these spaces. Christine Milligan (2003:456) argues there should be more engagement in the explicitly spatial nature of care, which she suggests is under researched, as conceptualisations to date have focused on care as a gendered activity, and on definitions and boundaries of caring practice. This historically positions care as private, becoming public only when informal caring breaks down (Twig 1989).

Across the continuum of care (from informal care at home to institutional care) Milligan argues that macro-policies can influence the availability of financial support, and the rights and responsibilities attached to care (Milligan 2003:467), which can directly influence everyday experience. Some have gendered origins and consequences that have received significant feminist critique, since women have historically been most

associated with competing demands of care and work, which create competing emotions, energy and capacity (Folbre 2001; Fine and Glendinning 2005). As Milligan and Wiles (2010) have suggested, spatial or emotional proximity can introduce responsibilities and commitments to care. Spatial and temporal dynamics exist in more or less sustainable ways, producing rhythms which open up or foreclose possibilities for social connection (Massey 1994; Gilroy and Booth 1999; Jarvis, 1999, 2005). Material conditions and temporal rhythms have experiential effects, structuring routines within particular households and communities.

Landscapes of care, care-scapes or caringscapes (Milligan 2000, 2005; Conradson 2003 a,b; Bowlby et al 2010; Milligan and Wiles 2010) are terms which have been used to describe the mixture of material, organisational and cultural influences which constrain and enable certain care practices. From the global scale to the intimate spaces of domestic caring at home (Twigg 2000), a range of individuals, institutions and spaces construct caring landscapes (Milligan 2000, 2001, 2003). Care landscapes can include a nested geography of various formal and informal practices within place, which are constantly reconfiguring, and can be precarious combinations rather than seamless, coordinated sets of practices. As top-down state welfare provision shrinks, this refocuses attention to the family and community.

Home-based care of older people crosses physical boundaries of the home, demarcating these spaces as both 'private' and 'public'. These boundaries and meanings are carefully negotiated by paid and unpaid carers. Blunt and Dowling (2006) describe how home spaces and the material objects which fill them are important for constructing a sense of self. Individuals learn to experience significant or meaningful objects and others around them in accordance with pre-conceived desires and aversions (Sartre 2003). Sayer (1992:51) describes these as 'conceptually saturated'. Gillian Rose (2003:4) describes how the materiality of home gives indicators of identity and meanings through the display of cherished objects, such as family photos, mementos from holidays, or the display of wealth, taste or interests, which transform a house into a home.

This may be aspirational and performative as well as historical and reflective. Reading indicators of personhood through the home requires co-presence which is not

preoccupied with physical tasks at hand. In addition, ordinary household maintenance tasks may attract considerable concern that standard be maintained, and that domiciliary carers show appropriate thoughtfulness when handling cherished objects. Bowlby et al (1997) explore the performative and practice-based notions home, but this approach can apply to voluntary and organisational spaces of care (Bowlby et al 1997; Milligan 2001; Conradson 2003 a,b; Fyfe and Milligan 2003).

Contrasting home to institutional ‘non-places’, Milligan (2003) draws upon Twigg (2000:77) to note ‘the intrusion into the private world of values, rationalities, and temporal structures that belong to the formal world of service provision’. The physical boundaries and spaces of care can influence the viability of different care practices (Twigg and Atkin 1994:140), since professional agents operate within particular spatial settings and therefore their encounters with other caring professionals and informal carers are influenced by the way the context of interaction enabled between them. For example, as Twigg and Atkin describe, GPs and day centre staff perceive informal carers in their formal organisational setting, and consequently have limited knowledge about the lived reality for informal carers. Home-based carers are most likely to have awareness of the particularities of circumstances for informal carers, yet are not given the same power to contribute to decisions which takes this knowledge into account.

Home can be a contested and ambiguous space (Barrett and McIntosh 1982; Bowlby et al 1997; Young 1997; Blunt 2004). As Bowlby et al (1997:345) argue, the home can become ‘a site for the creation, reproduction and maintenance of patriarchal relations’, or as Blunt (2004:3) proposes, a ‘space of belonging and alienation, intimacy and violence, desire and fear’ and one ‘invested in meanings, emotions, experiences and relationships that lie at the heart of human life’. Similarly, Young (1997) argues that home also carries a core positive meaning, creating an anchor for agency and shifting identity, and Williams (2002) suggests this makes the home a complex site for study and medical intervention as a potentially ‘therapeutic landscape’.

Despite the contested and ambiguous nature of the home, it is still often valued as the most appropriate and morally valid place for caring, but caring practice by family members can turn home into a site of work, confinement or isolation. This has

consequences for paid workers where privacy needs to be negotiated in the homes of others and for befrienders as the older person's home becomes an opportunity for association. Home is often contrasted with the care home, which is often viewed as alienating and de-personalised. Peace and Holland (2001) argue that attempting to make care-homes more 'home-like' should be abandoned since these spaces can never replicate the feelings of home, and the personal autonomy that goes with it. Instead, they argue that care homes should be viewed as village-like communities.

The focus on the micro-scale of the home has been accompanied by a growing focus upon the scale of the body within geography (Nast and Pile 1998; Valentine 1999; Holt 2008), with geographies of the body being described as 'geography closest in' (Nast and Pile 1998). Attention to various embodied necessities of caring for older people (however contested and culturally inflected these may be) can reveal how particular time-space constraints affect individuals differently, whether these are family members, care-workers or voluntary carers, whose tasks and relationships may be more or less bound to the bodily needs of older people (see Joseph and Hallman 1998; Angus et al 2005). For example, Joseph and Hallman (1998) describe the negotiations of adult siblings when caring for their parents. They question the extent to which geography 'selects' care-givers (in absolute terms and in relation to specific care practices). They suggest a 'distance decay' emerges for some siblings, with a gender asymmetry to this. Activities which do not require face-to-face contact and can be done at a distance (such as managing finances) is compared to shopping, cleaning and personal care, which requires proximity. They conclude that spatial proximity is related to the imposition of gendered expectation, with working women squeezing 'more into already tight time budgets'. As Milligan and Wiles (2010) argue, closeness is not merely reflective of geographical proximity, but the latter can hail more caring obligations. The 'being there' of care is a fundamentally geographical concern.

In considering the objective spatialities of care routines and the way these construct care roles and influence care experiences, this thesis draws upon the term 'life-world' to describe the experiential basis of everyday care settings. This is a phenomenological term derived from Husserl's (1936) work '*Crisis in European Societies*'. The term life-world describes the accumulated settlement of practices, subjectivities, material spaces

and taken-for-granted assumptions within one's purview from which meaning is derived (Buttimer 1976; De Certeau 1988; Sartre 2003; Ahmed 2006; Merleau-Ponty 2007). The term is used by a number of phenomenological writers to describe the embodied material circumstance of individuals as '*Dasein*' or 'being-in-the-world' (Heidegger 1962). The contention of phenomenology is that existence is mediated through the body in the form of everyday practice (de Certeau 1988; Merleau-Ponty 2007). This, it is argued, reveals the embodied limits to individual agency as 'consciousness in being-towards-the-thing through the intermediary of the body' is influenced by pain, hunger, and other sensations (Merleau-Ponty, 2007:159-60). He argued that we incorporate our world and our actions into the materiality of our body, and this 'knowledge in the hands' cannot be detached from its embodied action.

To understand is to experience the harmony between what we aim and what is given, between the intention and the performance – and the body is our anchorage in a world (Merleau-Ponty 2007:167).

From a phenomenological perspective, the material and embodied proximity of 'being there' is important to the construction of duties and obligations. Folbre (2001:38) argues that people may learn to avoid situations in which they are called upon to care, as availability and willingness can lead to a 'cascading level of commitment'. Though as Milligan and Wiles (2010) suggest, emotional closeness can enrol carers as much as physical proximity. Nevertheless, the concept of 'life-world' elevates the significance of emotional and embodied geographies in understanding carers' orientations and experiences, and as Hochschild (2003a) has proposed, individuals develop 'pathways of feeling' based on regular emotional and embodied experiences which produce predictable responses to certain events.

Within geography, phenomenological accounts which incorporate understandings of life-worlds (Buttimer 1976) are useful to describe the accumulated settlement of habitual practices, meanings, subjectivities, and taken-for-granted assumptions which reflect our existence in care environments (Buttimer 1976; De Certeau 1988; Heidegger 1962; Sartre 2003; Merleau-Ponty 2007), and from which we can better understand the construction and experiences of care practices and spaces.

### **2.3.2 *Temporal Horizons, Timeliness and Pace***

There is a broad tradition within geography concerned with how we segment and coordinate activities into units of time, shaping our life-worlds (see Pred 1977; Hägerstrand et al 1981). Time is not separate from space, but rather an important dimension of experiencing it (Massey 1994:251). Fordist working patterns typical in heavy industry and manufacturing were constructed around the political gains of the trade union movement to separate work, sleep and leisure into eight hour parcels of time, agreed as necessary for the satisfaction of human needs and dignity. These temporal packages were implicated in the construction of space and social relations within families through a gender division of labour. Women's participation in the paid labour force poses a challenge to gendered divisions of labour and care's temporal and spatial structures. Twigg (1989) observes that when care at home is delivered by formal services, this ushers in other rationalities and temporalities within the spaces of the home, carrying experiential and emotional consequences.

Formal service provisions operate by strict scheduling and management of human resources. In comparison, informal domestic time is regarded as more open-ended and diverse, often marked by competing demands for time and attention, including paid work outside the home. However, within care settings, routines are understood to be both a coping strategy and a constraint imposed by the complexity and volume of the multiple tasks and responsibilities involved (Wiles 2003a). This section considers the way care is performed in relation to time, and how this constructs spaces and experiences of care. It concludes by suggesting how personalised systems might have implications for the temporalities of care in family, care-work and voluntary contexts.

The physical, material and social world are interconnected by focusing on routine and mobility— and the spatial impact this has to everyday life. A key figure in the theorisation of time in human geography is Torsten Hägerstrand (Pred 1977; Hägerstrand et al 1981). Hägerstrand's conceptualisations led to a concern to study the



paths which arise from successive repeated practices of everyday life, and to the projects, goals and strategies which generate these time-space patterns. He suggests movement across space and time is constrained in three ways: capability constraints, (e.g. bodily restrictions or lack of transport); coupling constraints (requirements for certain individuals to be co-present); and authority constraints (preclusion of individuals from certain spaces or during certain times). Pred (1977:218) describes the way we shape and sustain everyday practice as ‘the choreography of individual and collective existence’. One of the challenges of Hägerstrand’s time-space studies is how meanings and experiences can be captured, to understand why paths form as they do. Space and time are unlikely to be experienced uniformly, as our practices and intentions conform or collide with the practices and intentions of others in particular time-space configurations, as precarious settlements and achievements, rather than as seamless, embedded systems.

The temporalities of care differ within the context in which they occur. Distinctions between forms of socio-economic practice were outlined in Arendt’s (1958) work ‘*The Human Condition*’. In this work she provides a description of the similarities and differences between labour (focused on satisfying embodied need); work (production of useful physical artefacts) and action (political engagement with others). Arendt considers how the temporalities of these human practices can have consequences for their moral ordering in social hierarchies. She proposes that reproductive labour follows the cyclical flow of the body, in contrast to the linear trajectory of ‘productive work’. As has been described in sections 2.1.3 and 2.2.1, caring labour and productive work has been historically constructed along gender lines, often framing paid employment in ‘productive’ industries according to the clockwork of men’s lives (Abel 1986:484).

Caring labour implies attention to the micro-scales of the body and the household, and the accessible spaces that are constructed through limitations of movement imposed when engaging in caring practices. Co-resident carers conform more easily to bodily rhythms than care-workers who attend to clients in brief episodes, with the same tasks usually performed upon multiple clients over the course of a working day. Care-workers operating on specific task driven, time critical schedules may therefore be involved in the care of more than one individual. According to Arendt (1958), embodied care is

culturally positioned as the lowest of human endeavours, and yet it contains the most basic essence of human happiness – the satisfaction of being alive. The enjoyment, through exhaustion and toil through everyday social reproductive consumption - its regularity and circular temporality gives it a predictability which is important to maintaining a coherent sense of self. In contrast, the temporal dynamics of embodied care for paid care-workers are different, impacting on the ability to form relationships with the people they care for (McKie et al 2002; Wiles 2003a). It is this concern about dignity and wellbeing for older people (Woolhead et al 2004) who are not receiving adequate recognition, which has prompted a desire for reducing the power of organisations to elevate personal consumer choice.

Timeliness is a specific cultural choice shaping the appropriate sequencing of activities during the course of the day, or through the course of a month or year. Timeliness is a concern which relates to the embodied characteristics of social care, and to cultural expectation. Institutional processes which are concerned with rationality and efficiency do not fit easily into the everyday realities and contingencies of care at home. Contrary to popular rhetoric around personalisation which suggests there will be greater demand for diverse provision in social care, this thesis argues standardisation may follow as care agencies seek to meet consumer demand which reflect cultural conventions about what the appropriate time-slots are for getting out of bed, eating and bathing, and ensuring that these occur in the appropriate sequence over the course of the day.

Pace in this context refers to a concern for slowness: to pause to allow reflection; to consider the unique personhood of the care-receiver; and to allow the uniqueness of the care-giver to be recognised. Production-line rationalities of Fordism/Taylorism allocate tasks into discrete units of time to improve efficiency. Blauner (1970) argues this reduces choice and control for human beings in a process of alienation - a condition effectively represented in Chaplin's 1936 work '*Modern Times*'. In care contexts, the fast-paced imperatives of commodified care may produce alienation for both care-givers and care-receivers. Hochschild (1997, 2003a) and Twigg (1989) suggest the reproductive sphere has been influenced by Fordist rationalities and concerns for efficiency and cost-reduction. Finding an appropriate pace for care tasks and relationships is a concern which reflects recognition, often viewed as being at the heart

of personalisation discourses, but which is discursively associated with promoting marketisation in care. One aspect of pace is not just the discrete present-moment and its duration through the completion of tasks, which is a resource issue for increasing hours of service for individual clients, but also an issue of longevity of care relationships. Relationships of trust and embodied competence may develop slowly, and getting this right may involve ensuring consistency and sustainability of care relationships in an industry with a high degree of churn. In addition, allocating more time, not just the right time, is important for building personable caring relationships.

## **Conclusion**

This literature review has presented an account of the ways in which care has been defined, and the number of binaries and boundaries which accompany such definitions in a mixed economy of care. These reflect how inter-personal relations are established and maintained between care-givers and care-receivers within particular organisational and relational contexts. A diverse economies framework enables complex interplay and blurring to exist as individuals navigate various roles, practices and subjectivities of care associated with age, family position and work, which shift across time and space. To understand how individuals maintain coherence across these various domains in everyday life, Hochschild's (2003a) use of the concept of 'pathways of feeling' is drawn upon. Pathways of feeling emerge through the life-course creating moral positions and emotional responses to situations which represent 'who we are and who we want to become' (Lucey 2004). These pathways of feeling are not always aligned with self-maximising strategies, but are instead the result of complex bounded rationalities in establishing the 'right thing to do' in our various relationships with others as 'embedded individuals' (Deacon and Williams 2004). These understandings may have implications for self-directed support systems which align carers towards marketised and contractual care arrangements.

Whilst arguments have been made about the decline of the family as a natural route for social connection and solidarity, I have argued that diverse forms of social interaction and community solidarity can re-inscribe notions of family (Weeks et al 2001). The concept of 'doing family' drawn from Morgan (1996, 1999) suggests that a practice-

based understanding of social connection loosens structural associations of family as a given entity, and instead points to historical variability and multiplicity of family practice over time and space. As Finch (2007) suggests, this involves an element of display. Non-kin can be regarded as authentic family and/or friend like in practice. Rather than conclude that friendship is overwriting family in contemporary family relations, this thesis suggests that notions of family can permeate friend-like relations (and vice-versa) in a process of suffusion (Pahl and Spencer 2004) in which role boundaries are permeable and negotiated in everyday caring practice.

Furthermore, Wenger's notion of networked social capital enables a consideration of how social support networks are constructed and maintained over time (Wenger 1991, 1997; Wenger et al 1996; Keating et al 2003). These are not simply focused on a central figure (an older person) from which a number of atomised individuals are connected. Rather, the concept of the network allows us to think of the inter-connecting relationships which can build capacity, flexibility and mutual support. Inter-personal exchanges of practical care-giving and emotional intimacy are explored in the following chapters by paying attention to how these are constructed in family-carer, care-worker and volunteer accounts. These involve consideration of the spatial and temporal experiences of giving and receiving care at home. In doing so, this thesis seeks to explore the extent to which various binaries of care can be blurred or overcome in everyday spaces and practices of home-based care.

## CHAPTER 3: METHODOLOGY

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### **Introduction**

The previous chapters outlined the changing political context in which home-based care is situated, exploring key themes and concepts which frame existing debates about care. This chapter builds on these foundations by explaining how these understandings influenced the way this research was carried out. The chapter is organised into discussions which: introduce the research design; explain the choice of method; outline the empirical focus of the study, including location and sample; and consider issues arising from data collection, coding and analysis. It is hoped this chapter may contribute to an enhanced understanding of data contained in the chapters which follow.

### **3.1 Research Design**

Medical understandings form part of the everyday discursive terrain for professionals and lay people across various care settings. However, academic disciplines concerned with the care of older people (including gerontology, health and social geography) are increasingly turning to a life-course approach as a critique of essentialist constructions of age, noting that wellbeing in old age is often contingent on decisions taken over the lifespan (Parr 2003; Andrews et al 2006, 2007; Bowlby et al 2010). Attention has also shifted to the meanings and relations experienced within home-based and community care environments (Kearns and Gesler 1998). Within social geography, concern for the spaces and temporalities of home-based care is well established (Katz and Monk 1993; Twigg and Atkin 1994; Bowlby et al 1997; Kearns and Gesler 1998; Jarvis 1999; Milligan 2001; Conradson 2003 a,b; Fyfe and Milligan 2003;; Parr and Philo 2003; Wiles 2003a,b, 2005; McDowell 2004 a,b; Dyck 2005; Dyck et al 2005; Andrews et al 2006, 2007). Though the focus is often on the experiences of older people receiving care, there is emerging research which takes an explicit carer perspective.

### **3.1.1 Terminology**

Following an understanding of ageing as a social and cultural construction rather than a chronological process of biological decline, this research follows the terminology suggested by Bond and Corner (2004) to de-couple understandings of ageing as following from chronological age. They use the term ‘older people’ in a (non-specified) chronological positioning of individuals to enable a contrast with younger people. The term older people is used to include third-agers and fourth-agers (see 1.1.1 for an explanation of these terms). They suggest use of the term ‘third-agers’ is appropriate to describe a cohort of individuals born in the post-war baby boom who share historical and socio-cultural experiences and expectations (a notion less associated with chronological age). They distinguish these from ‘fourth-agers’ who are physically and psychologically dependent due to diminished capacity (Bond and Corner 2004:15). They propose the term ‘fourth ager’ is appropriate to use when seeking to make distinctions between active and frail older people, but warn this term can have negative connotations similar to those evoked by terms such as elderly, frail or infirm, when used as a generic descriptor of individuals. Given this thesis is concerned with older adults with social care needs, active and healthy ‘third-agers’ did not reflect the composition of respondents’ family members and clients, so the terms ‘older people’ or ‘older adults’ are used to describe those in ‘fourth-age’ categories of experience, unless otherwise stated.

### **3.1.2 Introducing the Approach**

In order to ensure the research is relevant and well informed by existing literature, it is important to appreciate the field of study through conceptual and theoretical grounding prior to data collection, and to ensure that the research questions are not duplicating previous knowledge (Kvale 1996). A review of knowledge of existing empirical and theoretical studies on carers’ lives and on the personalisation of adult social care (Leece 2006; Leece and Peace 2010) was useful in framing the empirical direction of the research. Situated within this emerging policy context, it was my intention to uncover meaning and sense-making by respondents about caring practices and choices - as they were conveyed to me at the time, rather than to identify ‘truth’ in any absolute sense.

In social geography, a diverse range of qualitative methods and techniques are drawn upon to capture the spatial, temporal and emotional worlds of research subjects. Understanding the way carers describe their experiences, motivations and practices led to an epistemological preference for a qualitative rather than quantitative research design to explore the complexity of social experiences of care. The process of research is inter-subjective, and also situated in the social experience of the researcher. Denzin and Lincoln (1998) propose that qualitative researchers bring their own lenses which enable them to observe and describe events, ensuring they are not confronted with chaotic and fragmented phenomena.

The theoretical perspective taken in this research is based on phenomenological accounts which seek to retain the materiality of everyday caring practice as well as understand the social interactions which produce the spaces and temporalities of care. The discipline of geography moved away from positivist scientific approaches seeking to provide objective accounts of social reality, and political economy approaches prevalent during the 1960s and 1970s seeking to demonstrate systemic processes of economic differentiation, in favour of cultural interpretive accounts of meanings and experiences of place. Chombart and Louwe (1952:190-1, cited in Buttimer and Seamon 1980:24) identified two distinct components of social space – objective and subjective. The objective component describes the spatial framework of living for groups whose social structure and organisation have been conditioned by ecological and cultural factors. This aspect reflects behavioural approaches to human geography, particularly the concern for time-space pathways and their influence in particular spaces and places. Literatures emerging from the concern to map time-space configurations of care have been described in section 2.3 of the literature review. However, it was not my intention to map the everyday practices of carers in this way, and instead my concern was to understand how this movement across time and space influenced experiences of care.

This thesis focuses on the ordinary and routinised contexts of care, and the way this shapes and is shaped by hopes, fears and motivations of carers as they reflect on their own life-course trajectories and those they care for. This thesis draws on literature which helps to describe lived experiences of a particular phenomenon, drawing on the concept of orientation and ‘life-world’ (Husserl 1936) to understand care contexts and

lived experiences. A phenomenological approach has been used in social geography as a means to explore lived experience, and to understand how everyday practices influence the construction of space and place (Buttimer 1976; Jackson 1981; Duncan and Ley 1993). Such practice-based accounts move away from structuralist theories which can deny agency to individuals. Jackson (2001) following Delphy (1980) argues the ‘micro-sociologies’ prevalent in the 1960s which drew upon phenomenology and ethnomethodology traditions can be used to move beyond structuralist debates (of class and gender) to understand complex subjectivities and practices. Similarly, this approach within social geography is intended to maintain a materialist perspective to the lived realities of care of older people. This acknowledges individuals and structures are always ‘becoming’ and situated within a variety of discourses, social practices and material spaces that are value laden (Sayer 1992; Sartre 2003).

### **3.1.3 *Choosing the Method***

What counts as data is an important question, closely followed by how one acquires and seeks to understand the information gathered. In taking a social geography perspective, I was concerned to situate complex lived meanings and experiences of care, and to account for material and spatial infrastructures, services and information flows which may act as barriers and facilitators. Rather than viewing such materialities of the social world as ‘real’, appreciating particular vantage points suggest these are multiple and conditional. Everyday practices are negotiated, sanctioned, desired or contested within particular social contexts, and it is therefore important to gain understanding of these contexts as well as to understand the practices and experiences which emerge from them. Therefore, choosing the right method(s) is not only a matter of finding the right fit with the research questions, but also about complementing ontological understandings of the limits of self-knowledge. That we are not fully known to ourselves is an important methodological concern. For example, Judith Butler observes that:

I cannot tell the story in a straight line, and I lose my thread, and I start again, and I forgot something crucial, and it is too hard to think about how to weave it in. (Butler 2005:68)



This observation provides an important post-structuralist corrective to realist understandings which suggest self knowledge is obvious and always at hand. For this reason, more than one discursive account was employed in this research - face-to-face interviews and solicited diary writing. Semi-structured interviewing is a standard research tool for qualitative research in social sciences, and is discussed in more detail in section 3.2. The use of two methods was not so much intended to 'fill gaps' or bridge limitations of one or other method, but rather to reveal the fragmentary hidden/revealed, certain/uncertain and forgotten/remembered nature of everyday life. Both data collection methods were undertaken with concern to understand the circumstances of their iteration, such as who was being addressed, the social setting of the encounter, and the perceived use to which the information would be put. Capturing decisions and meanings across the life-course which have influenced the current state of affairs and mind-set were as important to understand, as the current day to day realities of care. Ruling out costly and time-intensive longitudinal analysis, interviewing seemed a valuable and appropriate means of exploring complex carer accounts of their life-course, yet provided a degree of direction to the encounter in acquiring relevant knowledge by asking pre-conceived questions based on my own assumptions about care.

In seeking to understand current practices and the meanings attached to them as inflected by life-course history and future trajectories, one common approach is through auto-biographical writing or narrative interviewing. Autobiography is often employed to understand the lives of prominent figures, and within the sociologies of work, this method has been used successfully to describe working practices and experiences of everyday life (Terkel 1975; Russo and Linkon 2005). A common approach to acquiring personal narratives is through solicited diary writing, which is seen to 'give voice' to the everyday concerns of ordinary people (Stanley 1992; Lee 1993; Stanley and Wise 1993; Meth 2003; Latham 2010). Solicited diaries are distinguished from self initiated diary writing as they are produced specifically for research purposes (Bell 1998:72) with varying degrees of direction from the researcher, and are increasingly valued in social geography or health research to understand fine grained time-space issues (McDowell 2004b; McDowell et al 2006) or in identifying priorities and strategies (Meth 2003; Milligan et al 2005). Directly questioning respondents from my own frame of reference

and assumptions may not elicit apparently minor but nevertheless significant details of routine and embodied practice as effectively as solicited diaries. The drawbacks of this approach is that instructions may be interpreted differently by respondents, who may apply different levels of effort or creativity in completing them; or be subject to differing levels of writing ability to make comparison or analysis effective (Meth 2003; Bijoux and Meyers 2006; Latham 2010).

In this study, respondents were provided with basic instructions about format and style (Appendix B), and given an opportunity to produce individual accounts which reflected their concerns and experiences but which provided some level of consistency in data collected. One middle-class carer included a poem to express how caring made her feel, which was incredibly powerful in conveying the complexity and collision of different emotions, but she drew upon a writing ability not shared (or perhaps divulged) by all respondents. A male carer in this study was able to articulate in a diary intimate details of his caring which he perhaps did not feel able to share face to face.

Accommodating these different expressive abilities and different levels of engagement was partially achieved using two methods in conjunction with ethnographic observation. However, the use of these two methods, either separately or in combination, was not intended to capture 'authentic' representations of actual events, routines, experiences or motivations, since disclosures by respondents are shaped by the research context, and are a complex articulation of past/present rationales viewed from the perspective of present concerns and future intentions. Given constraints of time and resources, these methods provided an appropriate means of understanding care subjectivities and everyday lives. Diaries also enabled prompts in interviews, to follow up on interesting avenues, or where significant differences emerged in describing the practices and meanings of everyday life.

#### **3.1.4 *Researching Different Carers 'Types'***

Given the discussion on the definition of older people outlined in sections 1.1.1 and 3.1.1, this thesis sought to research carers of 'older people' and used the term in recruitment literature. This literature did not specify a minimum age bracket, and those

individuals who came forward to take part in this study did so because they regarded themselves as people involved in the care of older adults. The minimum age requirement to receive Direct Payments or Individual Budgets in the UK is 16, and there is no upper age limit, so there is no missing middle in terms of age barriers separating provision for younger adults and older adults in personalisation policy.

It was felt that not specifying a minimum age for defining an older person (as over 65 in policy terms, for example) was appropriate, given I was keen to consider the lived realities of carers in Tyne and Wear, where it might be expected that social care needs may arise earlier in life due to work histories in heavy industry, manufacturing and other physically demanding jobs for both men and women. This was left open to appreciate the different constructions and experiences of ageing in place (and its relation to infirmity), rather than regard the term ‘older person’ as reflecting a specific age bracket. Ultimately, respondents defined themselves as carers of older people with social care needs, and therefore eligible to participate in this research. In fact, all respondents who came forward were caring for adults over the age of 50, which is the minimum criterion set by Age UK. The majority of respondents cared for adults aged 65-90, which falls within conventional understandings of ‘older’ in most policy and academic accounts. Appendix C provides a brief profile of carers in this study.

Twenty nine respondents took part in this study (see Table 1 below): ten family carers; eleven care-workers and eight volunteers. With two data collection methods, there were 42 respondent transcripts.<sup>9</sup> A further four respondents came forward, but subsequently withdrew.<sup>10</sup> Of the 29 respondents, 27 respondents took part in an interview,<sup>11</sup> and 17 submitted a solicited diary. There was one instance of technology failure, and in this case, researcher notes were drawn upon. I adopted the term ‘respondent’ to describe individuals who came forward to take part in this research. Other terms such as ‘participant’ are more commonly used in feminist literature to suggest more parity

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<sup>9</sup> This figure does not include key informant interviews.

<sup>10</sup> Some respondents did not complete diaries given to them, and did not respond to subsequent correspondence. One family carer withdrew whilst completing her diary because of a family emergency.

<sup>11</sup> For one respondent, changes in her mother’s health condition made her continued involvement impossible. For one care-worker, difficulties making interview arrangements due to excessive shift patterns were cited as reason for non-participation beyond the diary stage.

between researchers and researched (Stanley 1992; Stanley and Wise 1993; Maynard and Purvis 1995). However, involvement and power in this research was not equal as I designed, conducted, analysed and framed the research, though this was partly out of respect for the considerable time pressures facing carers. Other studies use the term 'subject' which I felt gives too little agency to those who took part, though they did not assist in the design or analysis, individuals actively responded to a request to take part in this research project, and did so for their own reasons. Furthermore, the interview and diary data reflect their intentions as co-producers of the knowledge contained in this thesis, as the semi-structured to unstructured methods afforded a significant role in defining the direction of the data collected. Consequently, I prefer to use 'respondent' as this avoids making claims about equal power relations whilst acknowledges the agency of those who took part.

Given the practice based understanding of care and its boundaries discussed in section 2.1.2 of the literature review, separating the multiple practices and roles of everyday life into three categories or care economies of family, agency care-work and voluntary care may be contested, since a structural approach does not do justice to the overlapping and nuanced way care is practiced and experienced by differently positioned carers in formal (regulated) and informal (unregulated) contexts. One initial dilemma was whether to position friends and family together as informal care in contrast to formal support from paid care and volunteers, and to what extent volunteers could also fit into the category of friend. As the research progressed, the various overlaps became apparent, and the settlement on these three care economies was made to triangulate issues which might reveal these similarities, differences and ambiguities rather than reinforce binary associations within care. The three categories of care adopted in this thesis – family care, market-based care and voluntary care should therefore be seen as temporary fixings for particular discursive purposes, rather than essential categories. Each of these categories contains practices and subjectivities which cut across formal and informal divides. Though many respondents had several caring roles that could place them into more than one carer category, each were assigned the category which best reflected the primary focus of their discussions and the stated reason for participation.

Aneshensel et al's (1995) typology of carers looks across the care career, proposing a staged process of accepting, actualising and relinquishing the carer role. The respondents in this study were mostly at stage two in their care career, but drew upon accounts of earlier caring, and described the process of relinquishing their roles, and the effect this had on subsequent ones. For the purposes of this thesis, which considers past, present and future care roles across the sample, this typology was not a useful way of categorising respondents. Twigg and Atkin's typology was more useful, drawing on relational dynamics within care dyads, positioning carers as either co-workers, a free resource, co-client, or someone to be 'superseded' (Twigg and Atkin 1994:12-15). Though used by them to describe informal carers, it could also apply to a certain extent to care-worker and volunteer respondents. However, these categories are not used to definitively categorise respondents, but are drawn upon where applicable in discussions about their caring relations. Individuals are often involved in multiple caring relationships, and adopt stances or perspectives to each of these – for example one individual can be a worker, daughter, friend and neighbour, and perform these roles differently according to relations they support. The various identities that make up an individual can also carry over into other relationships, as they seek to maintain a coherent sense of self in the construction of everyday routines and life-worlds.

In deciding on how to place respondents into categories for analysis, their stated purposes for taking part in the research, and the focus of their discussions on care were used, rather than measures of number of hours or intensity of the role. Some family carers spent more time as a paid care-worker, but the reason for taking part, and the focus of their discussion was on family caring responsibilities, with paid work only entering discussions as an explanatory or influencing factor. Furthermore, since respondents were not known to each other and do not refer to each other, it was important to understand the perspective each respondent had towards unknown supporters of their caring practice, such as other family members, care-workers and volunteers not participating in this study. So when a care worker spoke about family care as having an impact on their work role, it was important to keep this distinct from family carers' discussions of how paid care-workers impacted on their informal caring, because the relational context was different.

The number of family respondents with involvement in Direct Payments or Individual Budgets was low (one at the point of recruitment, two by the end) which was roughly representative of the regional take-up of the option. Most family carers had not heard of self-directed support, personalisation, individualisation or Direct Payments, and those who had, were wary of what it would mean for them. One family carer, Gayle, found writing the diary time consuming, and used this experience consider the difficulty she would have keeping up with the paperwork. Carol took part to discuss the care she formerly provided to her mother, for which she received Direct Payments. After her mother's death, she then took employment as a PA under Direct Payments to care for a distant relative. Following the research encounter, James, subsequently took up Direct Payments to employ paid care-workers which allowed him to return to work for two days a week. Some of the care-worker respondents had Direct Payment clients, but this was not seen to significantly affect their relationship as they were still employed via an agency, and not by the older person themselves.

Information about respondents were obtained in a proforma issued with and returned with the diary or completed prior to the interview. These adhered to conventions common in UK demographic information forms (such as those supplied for equalities monitoring). These included options of 'other' and 'rather not say' to enable self-definition beyond the options supplied, and to enable disclosure of sensitive information as deemed appropriate. For brevity, and given the relatively small sample, the categories presented in the tables below reflect categories selected by one or more respondents, rather than an inclusive list of options suggested.

Table 1: Respondent List<sup>12</sup>

Respondent	Designation	Caring Responsibility	Co-resident?	Gender	Age	Ethnicity	Relationship Status	Class	Parents' class	Highest qualification	Religion	Diary Completed
Amanda	Family	Father	Yes	Female	51	White British	Single	Working class	Working class	NVQ 4	Christian	Yes
Barbara	Family	Husband	Yes	Female	76	Undisclosed	Married	Don't know	Don't know	Other	Christian	Yes
Ben	Volunteer	Befriender	No	Male	36	White British	Single	Mixed	Middle class	NVQ 4	None	Yes
Carol	Family	Mother	Dual-residence	Female	48	White British	Married	Working class	Working class	Undisclosed	Christian	Yes
Coleen	Volunteer	Befriender	No	Female	45	White British	Married	Middle class	Undisclosed	NVQ 4	Undisclosed	No
Danielle	Volunteer	Befriender	No	Female	29	White British	Single	Middle class	Middle class	NVQ 4	Undisclosed	No
Dawn	Volunteer	Befriender	No	Female	63	White British	Widowed	Working class	Working class	None	Christian	Yes

<sup>12</sup> Source: All information (except designation and co-residence) is derived from a proforma completed by respondents prior to interview or information supplied during the interview. In the proforma, example categories were provided, with additional space for self-definition. Designation of carer type was according to criteria described earlier in this section. Co-residence refers to care location as own home; dual residence refers to respondent living equally between the care location and another home; variable residence refers to regular overnight stays and frequent daytime visits between the care-site and own home; non-residence refers to daytime visits only.

Respondent	Designation	Caring Responsibility	Co-resident?	Gender	Age	Ethnicity	Relationship Status	Class	Parents' class	Highest qualification	Religion	Diary Completed
Edward	Volunteer	Befriender	No	Male	43	White British	Undisclosed	Working class	Working class	NVQ 3	Undisclosed	No
Elaine	Volunteer	Friends & Neighbour	No	Female	71	White British	Widowed	Middle class	middle class	None	Christian	Yes
Elizabeth	Care-worker	Clients	Variable	Female	23	Black	Single	Undisclosed	Undisclosed	Undisclosed	Christian	No
Ewa	Care-worker	Clients	Dual-residence	Female	57	Polish	Divorced	working class	working class	NVQ 2	Christian	Yes
Frances	Family	Husband	Yes	Female	88	White British	Married	Undisclosed	Undisclosed	NVQ 3	None	Yes
Gayle	Family	Husband	Yes	Female	61	White British	Married	Working class	Working class	NVQ 3	Christian	Yes
Gemma	Care-worker	Clients	No	Female	35	White British	Single	working class	working class	NVQ 3	Undisclosed	Yes
Hilary	Family	Husband	Yes	Female	75	White British	Married	Working class	Working class	None	Christian	Yes
Isabel	Family	Mother	Dual-residence	Female	44	White British	Married	Working class	Working class	NVQ 3	Christian	Yes
James	Family	Mother	Yes	Male	59	White British	Single	Middle class	Middle class	NVQ 4	Christian	Yes
Joseph	Family	Grandmother	No	Male	21	White British	Single	Middle class	Middle class	NVQ 4	Christian	Yes



Respondent	Designation	Caring Responsibility	Co-resident?	Gender	Age	Ethnicity	Relationship Status	Class	Parents' class	Highest qualification	Religion	Diary Completed
June	Volunteer	Befriender	No	Female	35	Asian	Single	Undisclosed	Undisclosed	Undisclosed	Christian	No
Kelsey	Care-worker	Clients	Variable	Female	24	White British	Single	Working class	Working class	NVQ 2	Christian	Yes
Lorna	Care-worker	Clients	No	Female	56	White British	Married	Undisclosed	Undisclosed	Undisclosed	Undisclosed	No
Marta	Care-worker	Clients	Variable	Female	30	White British	Married	Undisclosed	Undisclosed	Undisclosed	Undisclosed	No
Megan	Care-worker	Clients	No	Female	51	White British	Married	Working class	Working class	NVQ 2	None	No
Neil	Care-worker	Clients	No	Male	40	White British	Single	Working class	Undisclosed	NVQ 2	Undisclosed	No
Oliver	Family	Father	No	Male	55	White British	Divorced	Working class	Undisclosed	Undisclosed	None	No
Phoebe	Volunteer	Multiple	No	Female	45	White British	Married	Undisclosed	Undisclosed	NVQ 4	Christian	No
Rachel	Family	Aunt	No	Female	52	White British	Single	Undisclosed	Undisclosed	Undisclosed	Undisclosed	No
Susan	Care-worker	Clients	Dual-residence	Female	75	White British	Married	Working class	Working class	NVQ 2	Christian	Yes
Wendy	Care-worker	Clients	No	Female	48	White British	Married	Working class	Working class	None	Christian	Yes

The information supplied by respondents can be summarised as follows:

Table 2: Gender

	Male	Female
Family	3	8
Care-worker	1	9
Volunteer	2	6

Table 3: Age

	18-24	25-44	45-64	65-74	75+	Undisclosed
Family	1	1	6		3	
Care-worker	2	3	3		1	1
Volunteer	0	4	3	1		

Table 4: Self-Identified Social Class Position

	Working Class	Middle Class	Other	Undisclosed
Family	6	2	1*	2
Care-worker	7			3
Volunteer	1	3	1**	3

\* Ex-teacher, you decide (respondent's description)

\*\* Middle-class, but working-class job (respondent's description)

Table 5: Parents' Social Class

	Working Class	Middle Class	Other	Undisclosed
Family	5	2	1*	3
Care-worker	6			4
Volunteer	2	2		4

\* can't decide (respondent's description)

Table 6: Highest Educational Attainment

	None	NVQ2	NVQ3	NVQ4/degree and above	Other	Undisclosed
Family	1	0	3	3	1*	3
Care-worker	1	5	1			3
Volunteer	2		1	4		1

\* teaching qualification (respondent's description)

Table 7: Ethnicity

	Black	White British	Asian	White European	Undisclosed
Family		10			1*
Care-worker	1	7		1	1
Volunteer		6	1		1

\* I find such questions divisive (respondent's description)

Table 8: Religion

	Christian	No Religion	Undisclosed
Family	8	2	1
Care-worker	5	1	4
Volunteer	4	1	3

Table 9: Relationship Status \*

	Single	Married	Divorced	Widowed	Undisclosed
Family	4	6	1		
Care-worker	4	5			1
Volunteer	3	2		2	1

\* N.B. all respondents identified as heterosexual

### 3.1.5 *Researching Care Experiences in Tyne and Wear*

This section considers the implications of researching within Tyne and Wear, and how this relates to the concerns of the research to understand the implications of self-directed support. Most literature on care of older people at home does not refer to how class relations or identities might influence the giving and receiving of care. As formal and informal provision is disrupted and transformed through self-direction, this may be a significant consideration. Therefore, the intention was to weight the research sample to include as much as possible the experience of individuals who identify as working class, given that Leece (2006) found that middle-class older people (and their primary carers acting as delegates) were the primary beneficiaries of expanded choice and control within self-directed support systems. The main concern was to consider the existing position of carers, and how they might relate to self-directed support options being promoted in policy.

Selecting Tyne and Wear as the empirical focus for the research was intended to enable consideration of how marginal places might reveal something about socio-economic and institutional processes often seen to emanate from elsewhere. Stenning (2005:11) argues that de-industrialised working-class communities (being positioned at the margins of the centre) may be a useful locus for considering the implications of neoliberalisation or marketisation (Katz 1995; Stenning 2005; Robinson 2003, 2006). I found it appropriate to select Tyne and Wear as a case study which was not particularly dynamic or exceptional in terms of policy implementation (Robinson 2003; Newman et al 2008).

There was also an element of pragmatism in selecting Tyne and Wear as it was easier to conduct the research and maintain a base at Newcastle University. As a local person, I had background knowledge of the physical, economic, organisational and cultural milieu of the area. Furthermore, the preponderance of former heavy industrial areas, pockets of deprivation in urban, suburban and rural locations made it an appropriate site to consider a range of socio-spatial factors which might impact on care at home. According to 2001 Census figures (Department of Health 2010) there are slightly more carers in the North East than nationally (11% and 10% respectively), though this figure includes all informal carers. Care hours in the North East are often in excess of the

national average, with the most common age for caring (across all informal care groups) being 25-49 and 50-64 for women, and 50-64 and 65-74 for men. The Census also found that people in the region who cared for over 20 hours per week (38%) were considerably more likely to live in social housing, live in a household with no working adults and suffer poor health (see figure 3). The projected number of older people living in the region by 2030 is growing faster than projections of the number of carers.<sup>13</sup>

As Figure 3 below indicates, there is a geographical distribution of carers in poor health across the region, impacting differently within the five local authorities of Tyne and Wear (Gateshead, North Tyneside, South Tyneside, Sunderland, and Newcastle). All metropolitan authorities within the scope of this research are adversely affected in terms of the health of carers compared to surrounding rural areas. However, this regional map does not show the significant ward-level variations which are likely to exist, given the ward-level variations evident in the Index of Multiple Deprivation (IMD 2004).

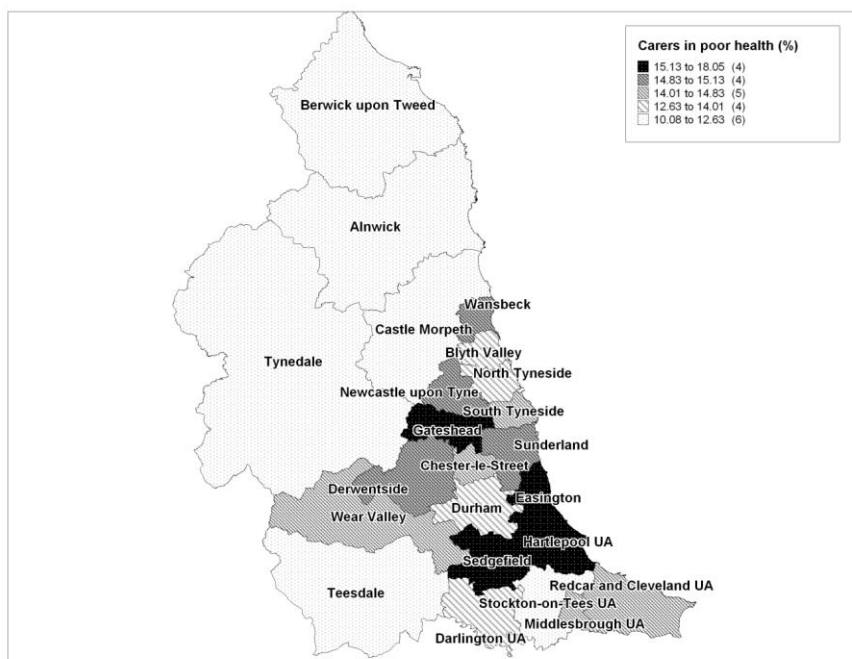


Figure 3: Carers in Poor Health, Source: 2001 Census Standard Tables, Crown Copyright 2003. Data provided through EDINA UKBORDERS with the support of the ESRC and JISC and uses boundary material which is Copyright of the Crown, taken from Department of Health (2010b)

<sup>13</sup> Source: ONS, 2006-based sub-national population projections, Crown Copyright; 2001 Census Standard Tables, Crown Copyright 2003, Department of Health (2010b)

The cultural legacy of a classed and gendered labour market in relation to heavy industry and its spatial divisions of labour (Dennis et al 1956; McDowell and Massey 1984, Strangleman 2005a,b, 2008) was also important when considering the selection of Tyne and Wear. The loss of heavy industrial jobs has led to a growth of women's service sector employment. This may also contribute to redefined moral rationalities in meeting expectations and obligations of work, home and community, as each cohort of older people is shaped by engagement with particular modes of work and welfare over the life-course (Strangleman 2008; Strangleman and Warren 2008). Some occupations in the NE region were physically demanding (shipbuilding, mining, manufacturing), and were likely to produce health problems, but may have had generous pension schemes attached to them. Particular industry norms shaped expectations of the duration of work and its 'end' point in retirement, and these are often classed and gendered. These modes of work were often accompanied by leisure, welfare and community spaces (Russo and Linkon 2005) which were financed by the employer or employee social funds, as can be seen in the former shipyard and mining communities of Tyne and Wear. The loss of direct benefits acquired through employment (such as pensions, retirement homes, respite holidays) that were once provided by large corporations and industries declined era, make it increasingly likely that the current cohort of workers need to provide for retirement through private rather than employee-contribution.

In seeking to explore the relevance of class as a social category within home-based care, there were a number of obstacles to identifying a class differentiated sample. The first obstacle was in considering the relationality of care. In such a study, the subject may be working-class older people; older people living in working-class areas (or those indicated in the IMD 2004 as deprived); or working-class carers. Given that my focus was on carers across the mixed economy, I was restricted by the terms of my ethical approval to recruit carers rather than older people with health conditions. As a result, there was a challenge in identifying carers of older people who identified as working class or lived in working-class communities. This was possible to approximate for resident family carers only, since paid care-workers, volunteers and non-resident family might operate in a variety of socio-spatial contexts. It was therefore unclear how relevant some identifiers of class position would be for all carers across the mixed economy of care. Given the ambiguous position of informal caring practice within class

hierarchies that are based on models of paid employment in the productive sphere, there was also an issue of seeking to reconcile current and former financial circumstances (as informal carers move into caring from a range of careers and pathways) with the class identity and affiliations of carers, based on self-identification or family background for example. The diverse economies perspective outlined by Gibson-Graham (1992, 2006) suggests practice-based approaches seeking to value the range of economies and social networks an individual may be engaged in can make positioning an individual within one coherent class structure more difficult.

Consequently, there are several ways in which the class positions and affiliations of respondents can be inferred. The criteria used include: current and former employment; the self-identified class position of carers; the educational attainment of carers; and self-definitions of parental class position. For co-resident family carers, residential location in a ward in the lowest 10% of the IMD (2004) was also used since residence in deprived neighbourhoods can be an indicator of poverty and reduced access to resources (Townsend 1987; Bridge 2002). This informed the spatial strategy for recruiting respondents who were more likely to identify as working class, since the intention was to capture issues faced by family carers who may have limited financial, infrastructural or information resources, and who may display moral rationalities in making choices that may differ from policy assumptions. However, due to socio-economic variation within these wards, this alone was no guarantee that potential respondents would come forward from the lowest 10% socio-economic group. Taking into account the difficulties experienced by McDowell et al (2005 a,b) when recruiting working-class women to discuss their childcare arrangements, I felt that attempting to recruit only those who identify as working class was likely to be challenging. Given the focus on the geographies of care at home, it was decided that middle-class carers who lived in wards in the lowest 10% of IMD (2004) would also be eligible to participate in this study.

Tables 4 and 5 above indicate how respondents position themselves in terms of their own social class and those of their parents. A further indicator was educational attainment (see table 6). Information was derived from a proforma given to potential respondents, which was either returned with solicited diaries or completed before the interview, or was otherwise elicited during the interview. Some indicators are less

applicable or obtainable for some carer types (particularly residential location of paid care-workers).

Most respondents identified as working class (many describing traditional industrial working-class family backgrounds), with some identifying as middle class. Most care-worker respondents did not disclose how they defined their class position; however given the position of the social care industry at the bottom end of the labour market, with a few exceptions, it can be inferred that most would be placed in Social Class IV or V (semi-skilled or unskilled manual) according to the Registrar General's classification of occupations. However, occupation alone may not be an accurate representation of power or material wealth. Many family carers, for example, those who identified as middle class had found themselves in adverse economic circumstances due to the emergence of caring obligations, and the reduced prospect of being able to remain in full-time paid employment. One self-defined middle-class carer, James, described having to reduce his hours to part time in order to care for his mother at home. He described how this meant outgoings were often in excess of income, and at the time of the interview, James was in the process of applying for a carers' allowance of approximately £50 per week. Other respondents could not be described as economically marginalised, yet they may nevertheless face issues of lack of resources or infrastructures by virtue of their residence in deprived wards. The eventual mix of class positions and affiliations in the research sample is weighted heavily but not exclusively as working class, and as such is perhaps fairly representative of the socio-economic profile of Tyne and Wear.

Furthermore, the variability in willingness of some carers to share personal information of this nature also affected how comprehensive the data gathered on class position could be. The tables in section 3.1.4 give an overview of the profile of respondent profiles. However, they do not demonstrate the complexity of the intersections of the categories occupied by individual carers, and they do not provide much insight into how these social categories influence everyday caring practice. This is particularly relevant to discussions of social class, and to discussions on the relative constraints involved in caring for older people for those with other responsibilities and commitments.



## **3.2 Data Collection**

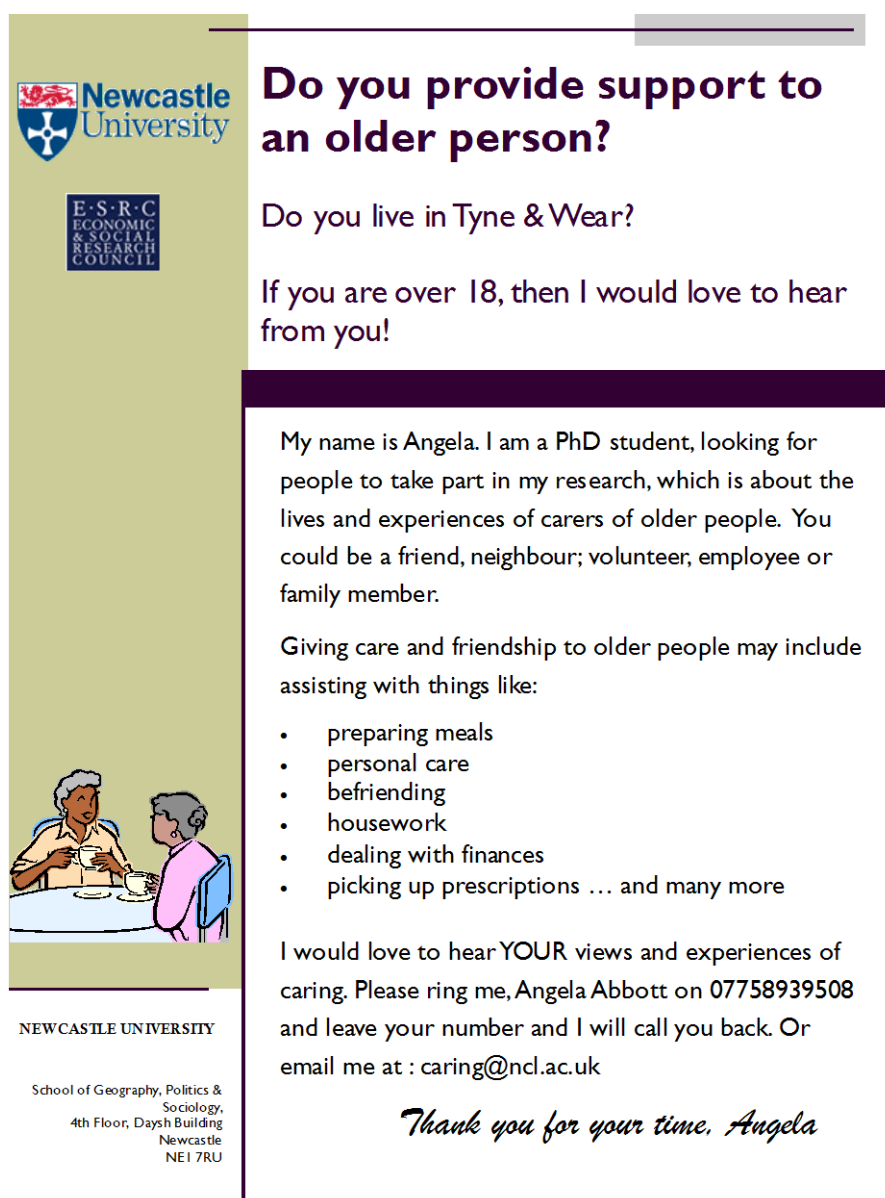
Data was collected between February 2009 and February 2010. The respondents were firstly asked to complete a two-week day diary of their everyday caring routines. This was then followed by a semi-structured qualitative interview to discuss aspects of the diary and to understand life-course experiences. Though most respondents experienced these methods sequentially, there were not distinct phases to the research according to method as there were continual overlaps due to the ongoing recruitment process.

### **3.2.1 *Recruitment Activity***

In recruitment material, I used the term ‘carer’ broadly, and included the term ‘friend’ to attract the attention of those who considered themselves as carers as well as those who did not define themselves in this way, but whose activities were intended to benefit the wellbeing of older people. In doing so, the emotional aspects of ‘care’ were emphasised as being as important as the physical tasks; as it was assumed that friends do not necessarily provide intimate care. The extent and the intensity of the caring role were not stipulated, as it was important to understand loose connections and obligations as well as intensive ones. More contextual understandings of the relationship between chronological age and wellbeing (as described in 1.1.1 and 3.1.1) have made automatic associations of age and infirmity problematic. For this reason, I did not stipulate a minimum age criterion for designating care-receivers as older people, and this was left to carers’ self-definition. From information supplied by carers during interviews, the age range of care-receivers in this research was 52 to 90, with most care-receivers in their late seventies and early eighties.

An email account was set up, [caring@ncl.ac.uk](mailto:caring@ncl.ac.uk), which was created so that the inbox address would appear as ‘Care and Friendship Project’. This was used to send emails to inform organisations of my research, to encourage participation from carers who may be friends, neighbours and volunteers. This email address was also used in correspondence with carer-respondents and key informants where this was preferred. The preliminary recruitment activity consisted of writing introductory letters to organisations to arrange

visits so that I could discuss my research and distribute leaflets to their clients (Appendix D). Following a response, I either talked to an individual at the organisation, or gave a bundle of leaflets for them to pass on or leave on the premises; or if appropriate, I addressed groups directly on the organisation's premises, explaining my research and providing leaflets with my contact details. I had two leaflets – one a 3-way folded leaflet with a cut-out coupon to express interest if this was preferred to telephone or email; and an A5 leaflet, as shown below in Figure 4.



The image shows a recruitment poster and an abbreviated leaflet. The poster is on yellow paper and features the Newcastle University logo and the Economic & Social Research Council logo. The main heading is "Do you provide support to an older person?" followed by "Do you live in Tyne & Wear?" and "If you are over 18, then I would love to hear from you!". Below this is a text box containing a personal introduction from Angela, a PhD student, and a list of activities that might include caring for older people: preparing meals, personal care, befriending, housework, dealing with finances, and picking up prescriptions. The text concludes with contact information for Angela Abbott, including a phone number (07758939508) and an email address (caring@ncl.ac.uk). The leaflet is a smaller version of the poster, containing the same text and graphics.

**Newcastle University**  
E·S·R·C  
ECONOMIC & SOCIAL RESEARCH COUNCIL

## Do you provide support to an older person?

Do you live in Tyne & Wear?

If you are over 18, then I would love to hear from you!

My name is Angela. I am a PhD student, looking for people to take part in my research, which is about the lives and experiences of carers of older people. You could be a friend, neighbour; volunteer, employee or family member.

Giving care and friendship to older people may include assisting with things like:

- preparing meals
- personal care
- befriending
- housework
- dealing with finances
- picking up prescriptions ... and many more

I would love to hear YOUR views and experiences of caring. Please ring me, Angela Abbott on 07758939508 and leave your number and I will call you back. Or email me at : caring@ncl.ac.uk

*Thank you for your time, Angela*

NEWCASTLE UNIVERSITY  
School of Geography, Politics & Sociology,  
4th Floor, Daysh Building  
Newcastle  
NE1 7RU

Figure 4: Recruitment poster and abbreviated leaflet. This was printed on yellow paper to assist readers with visual impairment.

Where permission was granted, I leafleted directly within public buildings such as libraries, churches, social services offices, job centres, community centres, and also in local shops that seemed appropriate. I also posted leaflets to carer organisations, the Women’s Institute and similar organisations. This has been described by other care researchers as a good means of recruiting the ‘usual suspects’. In this research, it worked fairly well in attracting carers who were involved in formal organisations, but was less successful in attracting people who drew upon informal care, and consequently in targeting carers from lower socio-economic groups.

A lack of community sites in some deprived areas made recruitment difficult, but I also felt there were other barriers, such as (mis)perceptions about university research which I felt had an impact on responses to my leaflets and posters. Additional purposive recruitment methods were therefore employed, such as leafleting leisure and retail spaces likely to be frequented by informal carers in marginalised areas. In making more explicit my cultural capital as local and working class, I began leafleting outside local shops in housing estates rather than town centres, and distributing leaflets at certain bus stops. I visited appropriate venues such as workingmen’s clubs, bingo halls, and sent leaflets to home hairdressers and mobile libraries. However, targeting working-class venues and drawing upon my working-class identity was not particularly effective in this research, and I doubt if this strategy generated any change to the socio-economic profile of respondents.

Table 10: Recruitment Methods

Leaflet	Carer Centre	Community Space (e.g. church; day centre; shop)	University	Care Agency	Online Forum	Voluntary/ Befriending Organisation	Women’s Organisation
Family	4	3	1		1		2
Care-worker	1	1		8			
Volunteer		2				5	1

In hindsight, recruiting in some of these places may have created a negative impression of my research. For example, recruiting at bus stops and bingo hall queues may have been inappropriate in that I may not have been taken seriously enough for the personal disclosure and trust demanded of potential respondents in the research. However, I do not dismiss the value and potential of such everyday sites of working-class life as a means to recruit, or in the possibility of establishing rapport through shared class identity. The time-frame was perhaps inadequate in this case to make a clear evaluation of its benefits. With better planning, more resources, and more time, these purposive recruitment strategies may have been more effectively and creatively employed.

### **3.2.2 *Conducting the Research***

This qualitative research was conducted using solicited diaries and interviews. In a continuum of structured, semi-structured to unstructured interviews, this research tended towards semi-structured to unstructured. Many became fluid, conversational encounters where key questions were explored in no particular order, but instead followed the ‘story’ of the respondent. In many cases, upon asking the first question about how the caring started, the narrative, possibly iterated several times before to medical professionals, social workers, friends and others, led to further questions, which were followed through as part of, often deviating from the schedule outline. I found allowing fluidity in this way enabled respondents’ concerns to be better articulated. Most interviews were between 60-90 mins in length, the range being 35-110 minutes, and were digitally recorded to assist with transcription and analysis. Interviews conducted in under an hour were adversely affected by several factors, often in combination: sited in public cafes or at home with children present making long conversations difficult; conducted with migrant care workers for whom English was not their first language; where there was no preliminary face-to face meeting due to time constraints of the carer; or when a diary had not been completed beforehand, making prompts at short responses more difficult. Interviews with family carers were consistently longer, and may reflect the increased reflexivity of this group in responding to my questions, who occasionally articulated feelings of isolation. The longest interviews were not necessarily the ones where the richest data was gathered, instead reflecting the prosaic conversation style of some respondents.

The nature of the research questions meant that some discussions and information obtained through diaries and interviews could be of a personal nature, such as revealing details of intimate personal care needs of the care-receiver. There was also the potential for criminal disclosures, such as physical or emotional abuse. Care was therefore needed in preparing respondents for this, by ensuring research was conducted in a setting which felt most comfortable to them. The respondents were given an opportunity to select their preferred interview venue at the diary stage in order to conduct the research in a sensitive and ethical manner. Interviewing respondents in their own homes is often favoured by feminist researchers (Finch 1993), but sometimes a more neutral community venue or the anonymity of a university setting was preferred, or was most convenient to respondents due to caring pressures at home or at work. No care-workers or volunteers were interviewed at the university, which may be the result of time pressures or perhaps lack of familiarity with university settings making this an unattractive option.

Table 11: Interview Location

	Home	University	Cafe	Workplace
Family	6	3	2	
Care worker	5		2	3
Volunteer	5		3	

Interviewing respondents at home had several advantages, as well as some disadvantages. The most significant advantage was enabling me to gain insight into the life-worlds of caring, such as seeing the bed in the dining room, the displacement of ornaments and usual domestic furniture in favour of medical equipment such as specially designed chairs, hoists, convenes, grab rails and bespoke telecommunications equipment. Beyond the physical accoutrements in the home, I also experienced the sense of time ticking slowly, the faint smell of urine, the family photos on the sideboard, the chatty presence of care-workers opening drawers to get what they need to perform today's given task. Sometimes I was introduced to the older person being cared for, which was invaluable, and being given so much trust was an unexpected privilege. Experiencing first-hand the 'emotional tonality of the room' (Conradson 2003b) during

data collection brought back the sights, smells, and sounds when reading the transcripts during analysis. From all of these sensory experiences, I understood a little better how older people and carers shared their lives together.

However, even though interviewing in respondents' own homes made respondents feel at ease and gave me an insight into the life-worlds of care, it also raised safety considerations as a lone researcher. This was particularly felt when meeting male carers. My safety was managed and the anonymity of respondents respected by sending a text message to a colleague before leaving for the meeting, with instructions that this was only to be opened if I did not get back in touch at a designated time. The first line of the text message began: DO NOT OPEN, followed by the location of the meeting, so that only the first line was visible to the recipient. On return, I was able to check that the text message had not been opened, and was deleted in my presence. One male carer requested the interview take place at the university out of hours, and measures were put in place to ensure a colleague was nearby.

Holding meetings and interviews in public places, such as cafeterias was often problematic, not in terms of safety, but in terms of privacy and problems using audio-equipment in noisy environments. These interviews were often shorter in duration and less engaged than those occurring within the home. A few of the interviews or meetings took place in the presence of the care-receiver. I never specifically requested their presence, nor did I request their absence, as I felt this was the personal choice of respondents, and was likely to be affected by practical constraints. Those respondents who were largely confined to the home, yet who did not want the care-receiver to be present, arranged the interview time to coincide with visits from care agency staff so we could be elsewhere in the house.

The topics to be discussed were explained before the interview commenced, and it was made clear to respondents that they were free to decline any questions they wished, without having to give a reason. When the cared-for older person was present, it altered the way the interview or meeting was conducted in both positive and negative ways. Their presence in the room during interviews on three occasions made my questioning more hesitant than usual, partly as I worried about causing upset to them by asking

questions that may present them as a ‘burden’, but also that they may hear explanations and experiences that they may not agree with. I was also concerned about the impact it would have in terms of collecting ‘authentic’ expressions of feeling, particularly negative feelings about care, as it may prevent carers sharing what might be hurtful to the older person’s feelings. However, contrary to my expectations, such articulations of frustration, disappointment etc. was as much present as in other interviews. In two of the three interviews held in this way, the care-receiver had a form of dementia, and the carer was more able than me to ascertain what they understood of the conversation. They were valuable experiences, as the day-to-day issues for the carer became more apparent as a result of their presence. Frances, a family carer in her 80s occasionally left the room to make cups of tea, whereupon her husband Fred, who had dementia, began chatting to me, though his words made little sense. Frances complained that she longed for time alone as her husband often followed her around the house constantly talking, and this encounter helped me to understand her feelings. On one occasion, the conversation was three-way, with Hilary and her husband Joe, who had suffered a stroke, causing memory loss and speech problems. The patience displayed by Hilary in teasing out the point of view Joe was seeking to convey, and the humorous approach they had developed for dealing with frustrating failures in communication, were often more enlightening than the content of the answers they gave.

### **3.2.3 *Relating Positionality to the Research Context***

One of the key elements of doing research informed by feminist principles is to position oneself as a research subject, open to as much analysis as everyone else who took part in the research. As Stanley and Wise (1993) suggest, the actions, demeanours and expectations of researchers towards respondents have an impact on the knowledge produced. Researching from a feminist perspective proposes it is desirable to be open and honest about one’s identity position. As Katz (1994) argues, presenting one’s gender, class, sexuality, ethnicity and age are contingent and variable, taking on greater or lesser significance at different times, and we exist in a state of in-betweenness navigating these identity positions as researchers.

The ethical judgement of how such performances were managed within this research was ultimately framed by the intention to conduct good research in a way which fully considered the feelings and material consequences for respondents, ahead of the desire to obtain useful data. Though similar information about me and the research was given to each respondent, I altered my approach slightly depending on commensurability. How I came to act in this way was partially unknowing and intuitive, but partially chosen in that I wanted to put the respondent at ease, to reassure them that I was not there to cast judgement on their caring ability, or on their homes, but that I was there to understand their circumstances better. Whilst I cannot speak for the way respondents altered their usual demeanour in my company, as our relationship was brief and circumscribed, there were some aspects of researcher-researched dynamics that are useful to explore in greater detail. In thinking about the impact this had, I would suggest that my ethical compass had to navigate several concerns: not to use respondents' assumptions about my positionality to underplay the level of editorial and representational power I have as researcher; not to contribute to assumptions which may undermine my 'credibility' as a researcher; and not to over-inflate the status and potential impact of the research by claiming too much knowledge and authority.

One of the key performances at work in this research within working-class communities was around class identity. Identifying as a working-class woman with a middle class education, when speaking to working-class men and women about their caring experiences, I often assumed a 'lay' identity which claimed little prior understanding, which I hoped would put people at ease. This approach to encouraging rapport was described and critiqued by England (1994) as the researcher acting as 'supplicant', critiqued because it disguises the representational power of the researcher. It has also been critiqued by Pile (2010) for generating uncomfortable affects and relations, implying and inducing distance between researcher and researched rather than encouraging familiarity and disclosure. However, sharing the reason for my personal interest in the research topic as a 'potential carer' often bridged this divide and made my lack of prior understanding less problematic.

In other contexts, however, I adopted a more 'professional' demeanour in order to encourage respondents and key informants to trust me enough to share their



experiences. Some respondents viewed my researcher role as akin to a social worker or other professional agent, and assumed I had medical or social welfare knowledge way beyond my possession. In middle-class homes, or when speaking to certain key informants, I emphasised a former work identity in local government, and down-played the working-class identity I had emphasised in other contexts. Perhaps this was not purely to put the respondent at ease, but also due to my own class inhibitions in the face of individuals I felt were in a more elevated social position or more knowledgeable than myself.

Some respondents viewed me as a student, needing to be accommodated with all the shortcomings and misguided questioning the label carries with it. As one respondent remarked when I thanked her for taking part, 'well you have to learn the ropes somehow', suggesting she understood me as perhaps a practitioner student of social work or nursing rather than as a social science researcher, despite the information I had provided. It was interesting that in almost every interview, my respondents made some reference to their education in relation to mine. Being a student clearly warranted a response by most people, either informing me they had never been interested or good at school, perhaps prefacing the discussion with a warning that I should not expect any theoretical knowledge on their part; or alternatively, that they too had a university education and knew the purpose and limits of social science research. In either case, a connection or rapport was established in some way before embarking on personal disclosure. Being able to move between multiple class positions proved to be beneficial.

As Oakley (1981:49) and other feminist writers suggest, the respondent can be made to feel 'at ease' with disclosures of personal details if the researcher shares her experience in return, though I would argue the ease of doing this depends upon respective identity alignments, cultural expectations and values. Establishing connection or commonality often referred to class, marital status, work history, whether or not I had children, and whether or not I cared for an older person myself. The fact that I have an ambiguous and shifting class, occupational and family background meant I was honest but never entirely open. I rarely articulated much of my personal background to any one individual. For example, I found it difficult to be open with my respondents about being in a same-sex relationship, though discussing respondents' personal relationships was a

crucial aspect of the research. My own assumptions about older people informed my decisions, as I felt sharing this aspect of my identity, rather than making disclosure easier, may disrupt the flow of the interview.

This alerted me to the probability that capturing the complexity of my respondents' relationships and motivations might not be straightforward if they adopted similar strategies of controlled disclosure, or had difficulties explaining complex life histories in a single response. Reflecting on researcher-researched dynamics brought into clearer focus the way identity positions of age, gender, class, sexuality and other factors intersect at particular moments and affect the way knowledge is produced. Much of the willingness to give over such information related to the rapport established between us and to understandings of the purpose of the study and the practical considerations of time and place in conducting the interviews. The semi-structured research design and use of open questions were intended to encourage disclosures of a complex nature, and I used probe questions and returned to issues where I felt this was appropriate. Comparing the interview responses with diary entries enabled further nuances and disruptions to emerge.

Being a researcher engaged in fieldwork meant an immersion into some aspects of the life-worlds of carers, though full appreciation is never possible. Not being a carer myself, this period was influential in understanding my own orientation to caring. Spending a year in these various spaces of care and speaking to my respondents not only developed my understanding of some of the issues, but made me feel more prepared and oriented to a future caring role. The fieldwork experience also helped me to appreciate how carers' orientations emerge in relation to presences and absences in the life-worlds of older people: that if one is not already oriented to the spaces, people and objects of caring for older people, then it is less likely that one will be drawn into these life-worlds through policy initiatives such as personalisation. It is likely to be familiar groups who continue to engage with caring for older people, existing family carers, paid workers and volunteers, thereby limiting diversification of support. The acceptance of the role of carer for older people is seldom deliberated upon until the point of 'necessity' during moments of particular crises or tipping points, but which nevertheless draw upon pre-conceived notions of responsibility.

### **3.3 Ethical Issues**

Discussing ethical issues situates this research in its context, reveals some of the concerns I had as a researcher, and highlights dilemmas and resolutions to various issues involved in doing this particular research. Together, they tell a story about how producing knowledge is not a linear or unproblematic process. Ethical considerations that are highlighted for discussion in this section include: obtaining formal approvals; interpreting the ‘vulnerability’ of respondents; and concluding the research encounter appropriately. Concern for obtaining formal approval was also negotiated by respondents. Many care-workers and volunteers were cautious about sharing details about the older people they cared for, and sought to protect their privacy, and clearly did not feel as free as family or friends to discuss certain aspects of their caring practice.

#### **3.3.1 *Obtaining Formal Approvals***

Delays in the publication of the Social Policy Research Unit personalisation pilot findings in 2008 caused a delay to finalising my empirical focus. Whilst I was not actively intending to recruit older people with social care needs, I nevertheless needed to ensure that my research complied with ethical approval requirements. If further approval is required from NRES<sup>14</sup> (if research involves potentially ‘vulnerable’ older people with health conditions), this can lengthen the process. After a significant delay of ten weeks, it was agreed by NRES that I would not be required to submit a formal application to them, with the proviso that I could not recruit from any NHS premises, through NHS staff or recruit by any other means anyone who was an NHS patient receiving treatment (or by virtue of them having had treatment in the past). Therefore I was not allowed to recruit in hospitals or doctors’ surgeries.

These delays impacted on my original recruitment plan to approach Social Services to obtain a list of personal budget holders, and from these to recruit carers. Since I was operating in five local authorities in Tyne and Wear, this could have involved a requirement to seek approval from five ethics boards. Therefore, I decided not to recruit

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<sup>14</sup> National Research Ethics Service

via Social Services. The first reason for this was that it might conflict with the instruction from NRES that I was not able to use health status as NHS clients as a basis for recruitment. Secondly, the time parameters of the PhD meant that I could not delay recruitment and data collection much further as starting recruitment late in the second semester of year two would not allow sufficient time for analysis and writing up of the research.

Therefore, the timing of formal ethical arrangements rather than issues arising from the research design led to a shift in the focus of the research from carers of older people using personal budgets in working-class areas, to a broader interest in the lives and subjectivities of a range of carers in working-class communities, regardless of their involvement in self-directed support options. Due to the low take-up rates across the region (about 500 at the time) it was clear that it would be difficult to recruit this population by general open recruitment, such as through flyers in libraries. However, though the original design was altered as a consequence of institutional ethical clearances, this had a positive effect on the research as a whole. It became apparent during the course of the interviews that very few respondents had heard of self-directed support or personalisation. The policy agenda and transformation rhetoric was not matched at that time by significant changes on the ground <sup>15</sup>(particularly for family carers with long-standing arrangements). Therefore, understanding how existing practices and subjectivities in working-class communities might align or conflict with choice and control agendas was perhaps more valuable than conducting an evaluation of the experiences of early adopters.

### **3.3.2 *Informed Consent to Participate***

It is a requirement of ESRC ethical guidelines to ensure that informed consent is received before involving individuals in the research (ESRC 2006). Appendix E presents the information supplied to potential participants, which was sent by post before meeting, discussed in a preliminary meeting before the handover of the diary, or

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<sup>15</sup> February 2009-February 2010, though uptake and awareness has increased since that time.

discussed prior to the interview.<sup>16</sup> At the early stages of the data collection process I ensured this form was signed before conducting an interview or accepting a completed diary. However, during the course of data collection I was convinced by arguments made by Leece (2006) in her PhD study of personal assistants that it may not equate to fully informed consent if respondents made such agreements prior to any questions being asked. Taking this into account, I gave respondents the choice of signing the consent form before the interview, or waiting until after the interview was concluded to ensure they were still happy for me to use the information supplied. In either case, it was always made clear that they were free to withdraw at any time without having to give a reason. Some carers who came forward often had very demanding caring responsibilities and time pressures which made participation difficult. I had to work within these constraints, accepting postponements and cancellations as inevitable. Because of the sensitivity of the research focus and the pressured lives of the sample, I felt it important not to recruit too determinedly with any one individual or organisation, or try to dissuade respondents who wanted to drop out of the process. Some respondents complained during the interview of the time taken to write the two-week diary. Since these were given to respondents before the planned interview, this may have explained why four respondents dropped out of the process. However, I had made clear in my research documentation what the likely time commitment would be, so there may also have been an issue of 'emotional' commitment that was underestimated by respondents who agreed to receive, but did not complete these diaries.

### **3.3.3 *Negotiating Respondents' 'Vulnerability' and Agency***

Raymond Lee (1993:4) has described sensitive research as 'research which potentially poses a substantial threat to those who are or have been involved in it.' A key concern in conducting ethical research is that at the very least, it should do no harm (ESRC 2006). Anonymity was a paramount concern, and was promised and maintained (with

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<sup>16</sup> The most common option for respondents was to receive the documentation in a preliminary meeting set up to discuss the terms of the research participation and to hand over the blank diary. Those who restricted their level of engagement to interview only, or who could not find a suitable time to meet, chose to have the information posted to them or explained prior to the interview.

confidentiality of data) within agreed limits, with the usual proviso concerning harm to self or others which would require disclosure to authorities. There were no major concerns, except one carer who spoke of having aggressive feelings towards her husband, which caused me some anxiety. Since no actual abuse was reported to me, and there was no intention, just an articulation of frustration, I reasoned this was exactly the borderland of emotion I expected to encounter in this research with carers, and there was no need for intervention by me.

There are a number of ways in which respondents could be classified as 'vulnerable'. There is no clear binary between carer-givers and care-receivers, as carers may be ageing or have other dependencies, and older people with social care needs can still possess mental, emotional or physical capacities to care for others. There were potential issues of class, age, ethnicity and occupational status which could create a position of vulnerability if my research breached its obligations: if information elicited was made known to their employer; or if in some other way, respondents came to harm as a result of participation in this research. Several respondents who care for older people were older themselves, and I had to anticipate this prior to recruitment. Documentation such as flyers, posters, consent forms and email correspondence were adjusted to a clear and large font size 14, clear accessible language was used, and all hard copies were produced on pale yellow paper, which is appropriate for respondents with visual impairment.

Asking people to describe their working lives in an interview is a valuable method if care is taken to ensure there is sufficient freedom for respondents to describe what is important to them (Terkel 1975). As Fiona Williams notes,

We all try to make sense of the world, but not everyone writes it down. (Williams cited in Shakespeare et al 1993:12).

Being able to adequately express oneself makes a big difference to data collected (Denzin and Lincoln 1998), and this should be acknowledged, even if this cannot be entirely resolved to enable all respondents to share their stories to the fullest extent. To assist respondents in sharing stories in a way they felt comfortable, clear, accessible language was adopted in interviews and written instructions, research documentation

and other correspondence. There may be barriers facing individuals being asked to write diaries. Respondent's educational attainment and first language was often unknown prior to such a request<sup>17</sup>, which may have presented difficulties for some. Ethnicity was relevant to this as some respondents were migrant workers for whom English was a second language, and my own lack of language skills meant I relied upon a translation service to transcribe a diary written by a Polish care-worker. For others, difficulty with writing diaries was caused by a lack of time to devote to writing. I explained in the instructions, written and verbally that the completion of the day diary was to be done in their own time at their own pace, and no expectation of word limit or expressive content was requested. It was also made clear that it was not a requirement that they participate in both methods of data collection. Other methods were considered to overcome these issues, such as using e-mail, text messaging, blogging, audio recordings, which have been used successfully in other qualitative research studies (Bampton and Cowton 2002; Hookway 2008). Given the age of some respondents, I felt these technology intensive methods may not be suitable, or would be difficult to use consistently across the range of carer types.

In considering the issue of informed consent, researching 'vulnerable groups' and ensuring the research is conducted appropriately and without harm, there are wider ethical issues to consider beyond ensuring formal codes of practice are followed. It is important to acknowledge that some respondents may be vulnerable, or experiencing isolation and loneliness, which may encourage their responsiveness to the research (Finch 1993; McRobbie 1982). Angela McRobbie (1982:57) suggests eagerness to participate in research may be the result of isolation, and exploitation of this by the researcher could be seen as 'yet another index of their powerlessness'. Whilst my interest in their stories and situation was often received positively, the research was not able to alter their circumstances to any significant degree. Due to the limited terms of engagement, my research does not claim to be action research aimed at transformation, so it was important that the extent of their participation was made clear in documentation supplied prior to agreement to take part, and that the research encounters

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<sup>17</sup> Educational attainment data was gathered in the form which accompanied the information pack, and returned with the diary, usually at the time of the interview.

ended appropriately. The offer of a copy of transcript was contained in a letter which thanked respondents for their participation, and suggested this would be followed up with a summary report of the findings once these were completed.

There is a danger that responding to ethical issues assumes a power and control as researcher, which fails to account for the agency of respondents, and may over-passify carers who have clear objectives of their own. There is agency and power on both sides, though these may be perceived differently. When respondents agree to take part in research projects such as this, there is often some sort of correlation between the purposes and intentions of the researcher in co-producing knowledge about a particular phenomenon, and the purposes and intentions of the respondent in sharing and constructing such knowledge, though these are not identical. For some, articulating their own care story can be an empowering experience, and for those whose caring had ended, it can provide an opportunity to reflect upon a time in their life, especially when there was perhaps little opportunity to do so at the time.

It has been 3 years since mam died, and writing this to you has once again shown me how much inner strength mam had. I so wish you could have met her. (Carol, D)

Carol understood that taking part in the research would bring this story to others as something worth recording. Carol's agenda therefore enabled me to consider how the source of carers' motivation and strength day to day comes from comparing their labour to the pain and courage of the older person. Though the purpose of the diary writing was, from my point of view, to demonstrate what carers were doing and how they felt about it, Carol rarely reflected on her own position, but on her mother's.

### **3.3.4 *Handling Data Appropriately***

Another potential harm that can be done through research relates to the loss of self-esteem (Bryman 2001) as a direct result of participation during or after the research encounter. One important concern in protecting the self-esteem of respondents related to the use of data, and the representation of their spoken words in textual form. Ethical concerns combined with epistemological reasoning, had an impact on decisions on this



issue. I decided to retain the verbatim nature of everyday speech and include some colloquial words as spoken by respondents rather than attempting to ‘clean data’ by making data appear as written text (see Cordon 2007 for a discussion on the inconsistent and diverse treatment of direct quotes in qualitative research). I felt it was important to maintain the integrity of the voices of respondents, however, there were consequences to this decision when presenting transcripts to some respondents.

One respondent described in a subsequent email her embarrassed at the way the transcript as speech made her seem rambling and incoherent. The inclusion of broken sentences, uhms and errs common in everyday speech for both parties involved in the interview made her feel uncomfortable. I reassured her and others who raised the issue that it was usual for transcripts to look this way, (with it being unusual to see speech written down) and that it did not give a negative impression of their ability to express themselves. I coded and analysed using the unabridged transcripts, however, where there are obvious repetitions and broken sentences which did not add to the sense of the quotes, these were removed upon inclusion in the thesis.<sup>18</sup>

Though this is often regarded as good feminist practice, furnishing respondents with a copy of the transcript raised an issue about the appropriate use of data. I was always quite hesitant in producing these documents and sending them to respondents, as I sometimes felt it was wrong to offer a tangible record of such personal disclosures. These transcripts potentially made respondents dwell on negative feelings and anxieties that they were able to return to because in print, whereas words spoken in conversation evaporate once spoken, and exist only partially through memory. This was especially important for me to consider when those feelings or experiences were painful or may be seen to attract moral judgement.

One respondent reported that receiving the transcript made her relive painful memories, and made her realise that what she said in the interview (and therefore what was asked) didn’t reflect what she wanted to convey. Her apparent frustration on receiving the

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<sup>18</sup> There are examples where pauses, hesitations and repetitions were influential to the overall meaning, and were therefore retained.

transcript is something I understood and was concerned about during the research. I was concerned that I may do harm to respondents by misrepresenting their experiences or feelings. Having been a research subject in my own MA research, I understood how difficult it was to convey my own meanings and experiences. What was interesting in this case was the interview itself ended positively, with the respondent commenting that she found the experience enjoyable and worthwhile, demonstrating how the 'ethics' of research encounters are complicated and uncertain. Receiving the transcript perhaps reinforced the knowledge that the conversation was not 'authentic', but was part of a research project, and the experiences described became an object.

In this sense, the power relations, sites and choices enacted through the interview encounter are shown to be negotiated and reinterpreted over time. I wondered whether such negative emotional outcomes may outweigh the positive purpose of soliciting further input to give space for reflection and further comment to the respondent. In light of some reactions to receiving the transcripts (though it was agreed at the time of the interview to send them), for future interviews it seemed more appropriate and sensitive to write an email or letter inviting those respondents to complete and return a slip if they wanted a copy of the transcript, which I found to be a much more appropriate way of dealing with this under-discussed element of the research process.

### **3.4 Data Analysis**

Data analysis was conducted with an eye to what Gibson-Graham (2006) describe as 'weak theory' and what Cindy Katz (1995) calls 'minor theory'. This suggests there a variety of scales of analysis, each adding in different ways to understanding social processes. Researchers are implicated in these messy and uneven processes when seeking to understand the social world, and therefore the intention in research analysis should not be to generalise too broadly but instead to make contingent claims based on the specific empirical findings of the research, and explain how these add to or critique existing knowledges. This is particularly pertinent given the relatively small sample sizes within qualitative research. The next section describes the research trajectory and approach to analysis, explaining the coding and interpretation process, and how different data collection methods were compared.

### 3.4.1 *Coding and Interpretation*

As the questions were designed to be as open as possible, respondents interpreted the questions differently, and answered other questions in the process. Some of these questions were responded to with ease and enthusiasm, indicating a resonance with the concerns of respondents. Others questions were met hesitantly, either because they did not connect in the same way, or that they touched on uncomfortable issues which neared the boundaries of what respondents wanted to reveal.

The initial analysis began when formulating the research questions, reading around the subject and generating the interview schedule, framing the research at the outset by limiting what the concerns might be. The inter-relatedness of caring practices also influenced how respondents answered particular questions. For this reason, the analysis was not conducted by comparing responses to each question, but by thematic coding of the entire interview, and relating emerging themes to the research questions. It was asking respondents to offer advice to other carers that best captured their reflections and experiences of caring for older people (Appendix F).

Most respondents were given details of the research at an initial meeting of approximately one hour, where a blank diary was issued. Instructions were pasted inside the diary to act as a general prompt on what may be included, but it was made clear that respondents could provide as much or as little information as they chose. Respondents completed a diary for two weeks to allow a comparison to be made between weeks to consider if life-worlds of care were routinised or variable. They returned the completed diary to me for transcription and analysis. The diaries were most likely to be written up at home, which is the usual site of caring for family carers, but not so for care-workers and volunteers. For the latter two groups, this may have affected the way these were written as there was an element of distance from the life-worlds of caring and the writing about it, although most family carers reported writing up their diary entries in private late into the evening when they had free time. Rudimentary instructions and material format restricted the potential ways in which these diaries could have been produced to make analysis easier, whilst allowing enough maneuverability for diarists to describe their everyday lives in a way which made most sense to them (Appendix B).

Most diarists followed a conventional format in date order that was task focused, while others focused on feelings, though most provided some combination of the two. It appeared that some apprehension was involved in the production of the diary, several mentioning they hoped it was what I wanted, others apologising for waffling, or even waiting for weeks which would be 'representative' before beginning their writing. The diaries were all handwritten, and one respondent, Dawn, explained in a telephone call that she was afraid to 'spoil' the diary and so wrote it first in her own notebook before copying it out on the notebook I had given her.

In terms of basic word length and structure, the diaries varied significantly in size from 48 to 627 lines of text. There was some variation in the way the diaries were introduced. Some provided a preamble, whilst others simply recorded the date and embarked on their account. This did not vary by carer type or by other variable. Dawn introduced her diary with a title 'Why I became a volunteer/befriender'. Barbara provided a title 'Introduction', giving a twenty-two line summary of biographical information which described the emergence of her husband's illness, then described her 'Pattern of a normal day' for a further twenty lines, itemising the activities involved in her caring routine. After this, she continued with the two-week diary. Carol (family carer) began with 'For Angela, to give a rough idea of the care and support involved'. She then listed enclosures; including details of her mother's illnesses, care plan and medication list, having typexed out her Mam's name throughout.

Each did as requested and organised the diary by date. Most respondents wrote a paragraph to half-an-A4 page for each day. It was apparent for many, particular care-workers, that there was little deviation from day to day. Some dealt with this regularity and monotony by stating the tasks and feelings day by day, whilst others abbreviated this to state 'same as usual' or similar statement. There were also occasions where the routine was offered apologetically, as if I was expecting something less mundane and more varied. Where I interviewed respondents following completion of their diaries, some commented on how the diary made them realise the lack of variety in the daily routine, or remarking on the tone of the diary as being more sombre than they intended to convey. For some, particularly the men, there was more engagement with the

emotional aspects of caring than was evident in the interview, and more discussion of intimate personal care tasks.

The way the diaries were concluded was also interesting. Elaine used a few lines to conclude the fortnight with her feelings on the process, and a summary of what it means to volunteer. Dawn, a volunteer, did something similar. Carol ended with a section, 'Extra notes for Angela' in which she discussed difficulties in going back to this paperwork and reliving those routines. Her thoughts on the time spent caring were included at length, and she discussed the help she had been given and the constraints emerging through tightening budgets at a national level. Recruiting Carol from a Carer website may influence her statement upon future policy, as she is a carer activist. Barbara concluded with a section titled 'Carers', in which she described the help she has received, praising the attitude of the paid carers involved in her husband's care. At the time the diary was written, a Panorama programme highlighted carer abuse in care homes, and in this section, Barbara commented on this from her own perspective.

It appeared from the diaries that perhaps due to the intensity of the caring practice, and the closeness of the relationship there was more inclination by family carers to give a fuller account in the diaries. Barbara, a retired teacher, organised the diary in more detail with clear sub-sections, summarising the routines at the start. This may be associated with class position or educational attainment, demonstrating greater confidence in writing. On the whole, family carer diaries were longer than those of non-family carers, suggesting more desire for lengthy description, with these often containing more personal information, and more description of their feelings than identifying tasks. In contrast to Barbara's account, perhaps due to the lapse of time or how this diary was originally kept as a Direct Payment record, the language in Carol's diary is less expressive and detailed, more in note form. A lot of what Carol described in the diary and in the subsequent interview concerned toileting, managing pain, and lifting, produced a more formal, medicalised tone.

Extra protective sheets on bed for any more accidents. Mam not passing much urine. Injections for pain have worked, mam more settled but very little mobility today. Needs lifting more and using the commode each time with assistance. (Carol, D)

The sheer quantity of possible codes can present a problem in analysis with a life-world approach. Indeed, it would be meaningless to simply count the numerical presence of key words, themes or concepts, and moreover, it is imperative not to lose sight of contextual understanding of the sequence of events, and the meanings and feelings attached to these for each participant, some of which may be between the lines of the text itself or indeed entirely missing from it. Revisiting transcripts, comparison with interview data, other participant data, and my own reflections helped to identify themes which may have been overlooked during initial stages. As the text under analysis was a two-week diary and face-to-face interview of multiple, everyday practices and thoughts about those practices, there were a large number of initial codes. The most frequently occurring codes are presented in this example from Barbara, a spouse:

Refusing or making difficult; toileting; coordination; humour;  
paid carers; TV; weather; transferring to other chair; calm;  
family; phone-calls; empathy with cared for; wrong chair;  
frustration; monitoring motor skills; mealtimes.

The generation of codes across transcripts led to group of parent nodes which generated broader categories. An iterative process of focusing on connections within and between the carer sample groups revealed processes and thematic connections. The process of selecting what to include as significant, and the process of grouping these into broader categories is unavoidably a subjective task, informed by the experiences and concerns I have as a researcher. The diaries and interviews were analysed together to understand the life-worlds of carers. There was considerable overlap in the codes which described the life-worlds of care between carer samples, with some notable differences. These suggested that structural contexts had an impact, even though they performed similar tasks, shared similar emotions, and occupied the same spaces.

These differences centred on their material positioning within particular economies, influencing the knowledges, motivations and skills. The negotiations were different because of the categorical differences in social roles they assumed as wives, sons, employees and befrienders. Similar stories, imaginative projections of family and home and affective experiences of care blurred the boundaries and altered emphases, but did not undo them entirely. Entering into and negotiating relationships emerged as the most important signifier of caring practice in this thesis. Some carers had enduring long-term

relationships with particular older people which altered how inter-subjective negotiations of care took place, and altered their positioning into the routines of the home. Apparently similar life-world constructions, overlapping motivations, concerns, practices and knowledges can be experienced and acted upon differently according to one's objective position in relation to others, producing different meanings.

### **3.4.2 *Relating Methods of Data Collection***

Different data emerged from diaries compared to interviews. In the main, the diaries were routinised often with little personal reflections in the description. They allowed for detailed explanations of the health conditions, sites and embodied routines involved in their caring, which were not articulated so much during the interviews – particularly personal issues such as toileting. This may have been due to the focus of questioning in the interviews, and the interpretation of instructions in the diary writing, though it could also have been due to a reluctance to discuss such 'private' issues face to face. This was more-so the case with paid workers, perhaps due to a sense of duty in maintaining dignity and confidentiality of their clients' conditions, or could have been due to a lack of rapport or trust upon meeting me for the first time, in some instances. Family carers produced larger diaries than non-family carers, with more description of their feelings. However, larger diaries did not always correspond with long interviews as some people had clearly provided as much information as they felt comfortable with, though family interviews were longer on the whole. Details in the diary enabled me to be more specific in my questioning, clarifying ambiguities and identifying issues and cues that I might not otherwise have done.

For the majority of the data collection period, interviews took place a couple of weeks following completion of the diary. This diary-interview approach allowed for an initial face-to-face meeting to build up confidence and trust, enabling better understanding of respondents' circumstances prior to the interview. A negative consequence of this was that occasionally diaries were taken away but not returned, with some dropping out of the process. On a few occasions towards the end of the data collection period I decided to ask respondents to take part in the interview first, and complete the diary afterwards. This was mainly due to difficulty 'pinning down' dates for meeting up with care-worker

respondents, and an awareness from past experience that getting diaries back could take two weeks, with some not returned at all. This approach was generally successful at securing the respondents participation in the interview, but perhaps at the expense of the quality of the engagement, as the interviews were less detailed due to lack of prior knowledge gained through a prior face-to-face meeting and analysis of their diary. In addition, many did not follow up the interview with the diary as planned. In all, 4 respondents dropped out during the diary-interview approach, and 4 failed to complete the diaries with the interview-diary approach. In hindsight, to maintain consistency and quality, it would have been better to have maintained the diary-interview approach, and accept that this may mean a higher dropout rate and consequently a reduced sample.

## **Conclusion**

The analysis of data collected was much more concerned with unspoken and hidden characteristics of caring practice than I had anticipated on embarking on this research. My positionality as a 'potential carer' allowed a certain openness when discussing difficult aspects of caring experience, since my knowledge of caring practice was not being compared directly. These revealed positive aspects such as the strength carers find in themselves and those they care for; and the warning signs to watch for as a means of self-protection. A different positionality may have produced a different set of responses.

To suggest that this research is emancipatory for participants would overstate the case. People who took part felt their voices were heard by somebody, believing that it may do some good to have their experiences made known to others. It also provided a space for respondents to reflect upon their care. I was careful not to be too optimistic about the amount of 'good' that might arise out of the research. The responsibility I took most seriously was not to do harm in the process, and I feel confident in achieving this more bounded aim. Thinking through the diverse literatures, practical obstacles, ethical dilemmas and power imbalances made this a valuable part of the research. The data chapters which follow present the knowledge which emerged from the research process. Hopefully this chapter has explained how and why data was produced in ways which expose some of the flaws, dilemmas and wrong-thinking that was necessarily part of that journey.



## CHAPTER 4: ORIENTATIONS OF CARE

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### **Introduction**

This chapter brings together the orientations and motivations of carers across different care economies. As has been argued in the literature review, classed and gendered moral rationalities influence the adoption and experience of caring roles. Sometimes these require negotiation to accommodate competing responsibilities and obligations, such as between paid work and informal care. The three carer respondent ‘types’ are discussed in sections as a convenient way of maintaining the connection between material circumstance of care and carer orientation. The everyday material circumstances involved in the way carer roles are taken up, practiced and experienced are separate to, but parallel with, processes of subjectification over the life-course, through which carers define their identities, practices and orientations in relation to others.

### **4.1 Why Family Carers Do What They Do**

This section outlines some of the issues which emerged for family respondents which influenced their orientations to care. These demonstrate varying degrees of complex agencies, barriers and constraints of particular circumstances in responding to the necessity of care. The main orientations can be organised around three themes: being there when needed; giving something back; and keeping true to the relationship. These are useful to understand the complexity of choice and control for family carers engaged in the care of older people.

#### **4.1.1 *Being There When Needed***

Being there when needed emerged as an important theme when respondents explained their motivations and orientations to caring roles. This was influenced by a number of

circumstances: family position and co-residence; gender and ‘hailing’ through a moral sense of establishing ‘the right thing to do’; proximity and the redefinition of family hierarchies; and finally co-option into caring roles by duress.

Co-residence often positions individuals as obvious carers, as spatial proximity is an important element to the appropriation of emotional and embodied labour, though not essential to it (Milligan 2005). In conventional family forms, it is assumed that a spouse is co-resident, and is the most appropriate carer when one partner becomes ill or frail in old age. There is also a common association of care responsibility for co-resident adult children, particularly those who have always lived with their parents (Abel 1986; Grundy and Harrop 1992). Single adult children are more likely to be co-resident with their ageing parents than adult children with families (Grundy and Harrop 1992). Of the ten family carers who took part in this study, four were co-resident spouses (Barbara, Frances, Gayle and Hilary); two were long term co-resident adult children (James and Amanda); and two (Carol and Isabel) were adult daughters with their own families, who regularly stayed overnight as their parent’s care needs progressed. The remaining two family respondents (Rachel and Joseph) were niece and grandson respectively, and as such were not co-resident, but were enrolled by virtue of their geographical proximity to their older relative.

For all co-resident spouses in this study, the reasons for adopting their caring role were barely reflected upon. Commitment to their partners for life was viewed as obvious, even naturalised, although expressions of weariness and anxiety about the future were often expressed, particularly when the respondents were themselves feeling the effects of growing older, some being in their late eighties. This limited reflection on marriage as commitment for life may alter with subsequent generations of spouse carers. Whilst rarely expressing their caring roles in terms of personal choice, seeing it as an expression of love and commitment (and often construed as the ‘ideal’ to which other types of caring is compared) these ‘self-evident’ assumptions could have detrimental consequences for one or both in the relationship.

Gayle’s story illustrates how her caring role developed over time as her husband Peter became affected by multiple and related health conditions including epilepsy. Her

‘illness narrative’ (Kleinman 1998) spoke of an insufficient awareness of entitlement or information about choices on her part, and assumptions made by health professionals which led to a catalogue of medical crises and compounded problems which were perhaps avoidable. For Gayle, ‘being there’ to provide support to her husband came at a significant personal cost, and was a factor in her husband’s declining health. For twenty years she provided sole caring at home without any additional support, other than visits to her GP for advice and medication. Decades into her caring, Peter fractured his skull during an epileptic episode. Their GP suggested Gayle contact the ‘epilepsy nurse’ about a protective helmet. Although her husband had suffered various head and body injuries over the years as a result of his epilepsy, until this point Gayle had never been told about the existence of a specialist who could have provided equipment and advice to prevent this. She expressed frustration and anger that her GP and other health professionals had failed to offer her adequate support or direct her to available services, assuming that she was coping (see Milligan 2005).

In a similar manner, it was not until Peter broke both wrists in a fall (which meant he could no longer share in the weight distribution when getting in and out of bed or going to the toilet) that the hospital arranged social care support through social services. Waiting for this to be put in place led to an extended stay in hospital, as alterations to the home were needed. Peter then contracted MRSA, which meant significant and irreversible complications to his existing health conditions. Later, when Gayle needed to receive hospital treatment herself for a back injury, Peter was placed in a care home, again resulting in a deterioration of his physical and mental health. But it was only because of these crisis events and subsequent interventions that a long term care package was arranged, and this regular and continued support from paid agency workers enabled a stabilisation of Peter’s condition. Gayle now takes a monitoring and supporting role to his paid care, ensuring equipment and consumables are in stock, and complementing the rushed shifts of the agency workers, acting as a stand in when needed. Gayle’s experience demonstrates how ‘being there’ is often an unreflected upon way of becoming a carer, but is not unproblematic in its consequences.

For co-resident adult children, the orientation to their caring role arose in part from their proximity, which had a temporal element to it in ‘being there’ over time. The intensity

of care required, or an expectation surrounding caring support is important to understanding how co-residence and care orientations are related. As with spouse carers, adult children responded in recognition of need, and to expectations assumed to be contained in the parent-child relationship. This is influenced by social expectations around age and gender roles, and inflected by classed moral rationalities within families (Pyke 1999). Fewer siblings in recent generations mean there is less available kin support than in the past (Abel 1986:481). As suggested by feminist literature on care, gender can be an important factor in the enrolment of carers. The daughters in this study commented on the relative absence of brothers or other male relatives in their everyday caring routines, even if they lived close at hand. However, this was never elaborated upon in any detail, the subject seen as too delicate or awkward, even when compared to discussions on intimate personal care. 'Let's not go there' summed up many responses on the subject.

There were four adult children in this research: James, Amanda, Isabel and Carol. Isabel and Carol were married with children and lived in their own family homes, but James and Amanda had always lived in their respective parents' homes. When asked directly what her motivation was for providing the care she did, Amanda looked puzzled and replied 'He's my Dad'. The self-evidential nature of such a response indicates how deeply held such a commitment is, though compared to spouse carers, there was more reflection as their roles needed some readjustment to enable 'children' to care for parents. It is argued that the transition in the life-course to the caring role for an adult child in caring for their parents has psychological implications, as they must 'relinquish the fantasy that their parents are omnipotent and can still offer protection' (Abel 1986:487).

As Amanda explained, her continued presence at the parental home meant the care she provided to her father was less onerous than it might otherwise be if she lived elsewhere, as many everyday household tasks would then be duplicated, such as cooking, cleaning and paying bills. She felt ensuring her father's needs were met did not require much additional effort, since he was housebound but otherwise able to 'potter' day to day within the house. She did acknowledge, however, that it added to her worry, as she felt responsible for his welfare. Amanda had recently cared for her mother at

home, which had involved intensive personal care for three years until her mother's death. This long term intensive caring had placed a lot of strain on her capacity to continue working, and eventually had an impact on her own sense of wellbeing. Despite the intensity of this caring, Amanda was nevertheless committed to providing the same level of care for her father in the future if it became necessary. Living in the family home positioned her as the available carer - a role she could not imagine relinquishing.

I don't know how people do it. I mean I, I suppose yeah if you're living opposite ends of the country you haven't got much choice. I lived with them, there's no way I could have not done it, you know (Amanda Interview)

Being a co-resident adult child, and being single without childcare responsibilities mitigated to some extent gendered expectations and orientations. Also in this position was James, who has been caring for his mother (now in her eighties), since the death of his father in 2002. This initially involved accepting responsibility for household affairs.

Basically just sort of tried to fill the gap that my Dad left I suppose, and part of that was sort of a caring function really, just generally being responsible I suppose (James, Interview)

In the same year, his Mum had a stroke. This caused her to lose some function in her left side, affecting mobility. As her health deteriorated, James' caring role developed, though he continued to work full time in the public sector. James has two married siblings (brother and sister) who are non-resident but who contribute to decision making and provide regular respite for James. He managed in this way with the assistance of Meals on Wheels and daily home care who assisted with washing and dressing and bringing his mother downstairs. Until 2008, his caring role consisted of arranging his mother's breakfast before going to work, making meals in the evening and putting her to bed. But he increasingly realised that his Mum didn't feel 'herself' in the mornings, though she usually improved as the day went on.

So I knew the mornings were the time, if I was going to help more, that would be the time that I needed at the time. So I was able to arrange through work to go part time (James, Interview)

This led James to reduce his employment hours from 37 to 18 ½ hours, starting work each day at one o'clock, which initially he felt worked very well. A few months into this

arrangement, his mother suffered a few falls in the mornings, making him feel increasingly uncertain about whether to leave to go to work in the afternoon. During the interview, he described how he would contact his work, 'I'm sorry I'm going to be late again today' expressing embarrassment and regret in his tone. Although his employers were considerate, he felt uncomfortable taking ad hoc leave so often and felt that remaining at work was becoming untenable. With support and advice from work, James eventually took the decision to take full time carers' leave. He remarked that he would not like to see this as his retirement, as it would be an unceremonious and abrupt ending to a long career. Since his interview, he informed me that he had been granted more support through Direct Payments which has enabled him to return to work for two days a week.<sup>19</sup>

Non-resident adult children are less likely to be enrolled into caring activity in comparison to co-resident siblings. But as imagined by Amanda, for those who do take on this role, the spatial and temporal dynamics can prove more difficult when caring and managing competing demands of home, work and care (Jarvis 1999, 2005). Not being co-resident, Carol and Isabel in this study were nevertheless there when needed. Carol did this alone, with support from her husband to pick up the childcare and housework responsibilities at her own home. Isabel, however, was able to draw upon the combined support of her sisters. Married with four children and young grandchildren, Isabel is in her late thirties and cares for her mother with dementia, her own household being a bus ride away from her mother's home. Her eldest three children live independently, but her youngest daughter (aged 12) lives at home, and often accompanied Isabel on sleep-overs at her mother's house. Isabel's mother is in her late sixties and has been suffering from Alzheimer's for almost thirteen years. When I visited Isabel, I was surprised at her mother's age, as she appeared to be much older than her years. Isabel's mother's condition had declined significantly over the past five years since the death of her husband, making her dependent upon her daughters for everything. The complexity of Isabel's shared caring responsibility was managed using her mobile phone, as there were limited opportunities for face to face interaction with

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<sup>19</sup> Following his interview, I was in email correspondence with James, who updated me on developments.

her sisters as they operated distinct shift patterns in their mother's home. The involvement of all the daughters as a team was perhaps the only way the sisters were able to maintain full time employment. Though their employment contributed to their ongoing fatigue, it was necessary to maintain their own homes and family units. Despite the extensive family and paid agency support, it was evident how difficult this caring was to sustain as a family. At least two of the three sisters were employed full time as carers - Isabel in a residential home for the elderly, and Claire who worked with Autistic adults (though it is not known whether these paid jobs were started before or after the family caring). One interesting outcome was the support provided by their own children, becoming a source of support rather than seen as (other) dependents. Isabel suggested her youngest daughter had developed a 'talent' for care, and seemed more adult than her years. Gayle also commented on the variability of her two daughters' 'talent' or 'sensitivity' towards care (and therefore as support to her), and can be seen as an example of socialisation into caring roles and resistances from it. This also raised in discussions by the paid care-workers in this research in relation to necessary aptitudes and demeanours.

Other relatives can sometimes be drawn into caring for older people due to proximity and other circumstances, but the expectations attached to this care can be markedly different to immediate family, though this is influenced by cultural factors in the strength of ties to extended family. Two family respondents (Rachel and Joseph) cared for an aunt and grandparents respectively. In this case, it is the physical proximity which becomes prominent in shaping the development of caring roles. Because a family member is 'at hand' there can be an assumption from outside agencies with a safeguarding responsibility that support will be forthcoming, regardless of how close family members actually are, geographically, emotionally or as kin relations (Twigg and Atkin 1994). Rachel discussed how formal agencies often positioned her as an automatic informal carer to her aunt (her father's sister) because she had previously acted as her aunt's advocate, raising concern about failures in service by her home care providers. She suggested that social services tended not to view family members as persons in their own right, or as having other responsibilities.

You're just a tool to keep somebody else safe... people who live with them have even less life, and you only get, if you're

working age, you only get the dole. And it's very difficult to actually get carers allowances, very difficult. (Rachel, Interview)

The strong tone of Rachel's account was borne of frustration when dealing with support agencies, which she saw as ineffective and always trying to pass the buck. Unable and unwilling to give up paid work in a finance setting, Rachel found it difficult to meet the requests of Social Services staff and health professionals to attend to the needs of her aunt who is blind and has learning disabilities. Her relative geographical proximity and the absence of other close relatives capable of such support meant she became more involved than she otherwise might. As she described, once she made her presence known, she was expected to take on a caring role, and described being reproached if she could not immediately get away from work to respond to an emergency. Her financial circumstances as a single woman with a mortgage of her own meant taking on a full time caring role was impossible to contemplate.<sup>20</sup>

#### **4.1.2 *Giving Something Back***

One common theme emerging prominently among family carers was the notion of 'giving something back' for the care they received in the past. This connects with accounts from the literature which characterises care as 'asymmetrical reciprocity' (Sevenhuisjen 2003) or the 'economy of regard' (Offer 1997). From this perspective, care is not calculated like a balance sheet of giving and taking, but rather operates as an imaginary across an entire life-course and beyond to other generations and involves (re)payment for care rendered past, present or future, to known and unknown others (Titmus 1970; Finch 1989; Offer 1997; Pahl 2000; Kittay and Feder 2002; Sevenhuisjen 2003; Deacon 2007; Bowlby et al 2010). Giving something back was most often articulated by adult children in this research. In caring for their parents, the trajectory is

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<sup>20</sup> To be eligible for the Carers Allowance would mean caring for 35 hours per week, with a benefit entitlement of just £53.10 This rate has been contested by Carer lobby groups such as CarerWatch (<http://carerwatch.wordpress.com/2010/10/15/can-we-afford-to-ignore-family-carers/>) as breaking minimum wage legislation, arguing it amounts to a payment for work with conditions, and should therefore be viewed as an employment contract.



usually viewed as repayment rather than as a store of future good will, and the way this is worked through is relational, and depends upon the distinct relationships that have built up over the life-course.

The relational dynamics between ageing parents and their adult children has been discussed by Pyke (1999). Pyke argues that 'individualist' or 'collectivist' attitudes to (inter)dependency between family members are influential in understanding levels of commitment, and how family members negotiate care. In 'individualist families', parental acquiescence is seen as necessary to ensure relations are free of tension. When parents did not adopt this stance, adult children express resentment and set firm limits on their caring. In 'collectivist families', ageing parents often defer to their children to avoid confrontation, and are highly accepting of their children's intervention. Collectivist parents were more likely to consider their children's wishes and interests when making decisions, and were viewed as 'easy going' by their children. Their acquiescence was also seen to show esteem and trust in their adult children, enabling them to feel good about their caregiving. As Pyke explains:

Parental deference appears to be an important way for elders to pay back their children for their services. Its absence represents a failure or reluctance to acknowledge the sacrifices adult children make when they provide assistance. (Pyke 1999:669).

Eva Feder Kittay (2011) has questioned the definitions and inter-personal dynamics of care relationships, arguing for a relational perspective, in which care is not care if it is not acknowledged or 'taken up with grace' by the recipient, which demonstrates care about the feelings of the care-giver. The adult children and grandchild in this research articulated a desire to repay love and support provided by those who now needed support from them. Joseph commented that he remembered the positive memories of childhood with his grandparents, and felt it was important to repay their generosity. In Joseph's case, 'giving something back' by caring for his Gran elevated his status within the family hierarchy. He felt he was 'giving back' as much to his parents as to his grandparents. Joseph's geographical proximity to his grandparents (as a student at a local university) gave him greater responsibility than he might otherwise have had, according to his kin status at the time his paternal grandmother suffered a stroke. This made him temporarily the second nearest relative, after his aunt. Though his aunt

provided the bulk of personal care, Joseph was often called upon to assist with shopping and leisure trips. He also provides support to his maternal grandparents to enable them to be more active and mobile, though this was less intense than the care he gave to his paternal grandmother. He described how he had become a proxy for his father's 'side' of the family, who had moved some distance from their parental home. Joseph felt he was assuming the responsibilities his father would have taken on had he lived closer by. Called upon in a time of need if his aunt was unavailable, Joseph felt he was helping his father as well as his grandparents in assuming this role. However, unlike Rachel who felt her caring role was taken for granted by formal institutions, Joseph felt his family position as grandson, not usually associated with a carer role, meant his duties were undervalued or invisible to others outside the immediate family.

I feel that the family support I provide is an undervalued and often ignored form of care. My presence can significantly increase the mobility of my elderly relatives, particularly my Gran. (Joseph, Diary)

The awareness Joseph expresses in defining these practices as care is notable. Part of the difficulty in recruiting individuals who provide such low level but nevertheless important support to older people was that this may not be understood as care. There is a perceived gendering to this, with ubiquitous everyday caring practices for older people often unseen by those who practice them, especially by older women. In this quote, Joseph is very aware of his carer status (perhaps because his gender and age make this more noticeable to him), yet he also felt his age in particular meant his caring role was often unrecognised by others. Joseph found this had consequences for managing commitments as a full-time student. For example, expenses incurred by keeping his car on the road, which enabled his Gran to get out and do her own shopping, were regarded as unnecessary expenditure by authorities when seeking financial support from a hardship fund. Overall he believed his age meant that his caring role wasn't taken seriously enough.<sup>21</sup> Care practices are often invisible when undertaken by someone with recognisable 'caring' attributes, but can be misrecognised entirely when

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<sup>21</sup> The Equalities Act 2010 now protects carers from discrimination at work and beyond, for instance, in not taking seriously caring obligations or making assumptions about capacity arising from these responsibilities. Disability and age discrimination also carries over to associated carers.

undertaken by those we do not expect to be carers. Consequently, the invisibility of care displays an interesting skewing along intersecting identities. For women, this may involve a lack of self-recognition, but for men and younger people, this may involve greater self recognition, which may not be recognised by others. This may contribute to adherence to social expectations (of age, class and gender for example) or reveal a defiance of them.

#### **4.1.3 *Keeping True to the Relationship***

Related to the theme of giving something back was an emerging theme to keep true to the relationship. The distinction is sometimes a subtle one, but is more apparent in the accounts of spouse carers. The concern to maintain the relationships that had developed over time or to keep faithful to idealised expectations of reciprocal family responsibility was a strong element in these accounts. Relating to past understandings of the relationship provided motivation and inclination to show commitment in the 'here and now'. For female spouses in this research, there were clear articulations of how this caring should be done, where this should be done, and who should be involved. There was a concern to maintain the sense of their husband as the person they had married, had children with, and shared their lives with.

One of the key concerns was keeping things as they had been for as long as possible, to resist the changes being imposed by the health condition, and to minimise the disruption made by organisations involved in the management of the condition. A key intention was to hold onto their spouse for longer. Keeping true to the existing relationship meant honouring dignity and boundaries as much as possible, for example, in providing intimate care such as dressing, showering or toileting. When this was necessary, the smallest steps taken to uphold the dignity and privacy of the older person took on great importance (Abel 1986; Twigg 1999). It is when this became difficult or impossible that family carers reflected on their role. Barbara often expressed frustration and anxiety about being called upon to assist with toileting as her husband resisted attempts by paid care-workers to assist him, though he was often no more responsive to her. Barbara commented often in her diary that she felt her husband resisted as much as he did to maintain control and dignity in spite of his failure to manage in practice.

During my interview with Barbara, a paid carer (not a respondent) entered the room, and on being told the reason for my presence laughed and said ‘I’m doing it for the money, honey.’ Barbara did not appear offended by this, which may suggest these two carers had found a common understanding over their respective roles, marking Barbara as the ‘genuine’ carer in a relational way. In contrast, Amanda contemplated taking up home-care support in the future, and described her concerns about being judged as a housekeeper and as a carer, and though paid home care was seen as largely undesirable, it was a better alternative to her father losing his independence by being placed into a care home. Keeping true to their everyday pattern of life was more important.

I think it’s the right thing to do. I’m reticent about bringing people into the home, but I think it’s a better solution, because I think it’s better for people to be in their own home, and that’s to do with choice. Once you go into care, your choices are taken away. You’ve got to get up when they want you to get up, you’ve got to eat what they want you to eat, you’ve got to watch telly, whatever’s on in the day room (Amanda, I)

Not only is being in one’s own home regarded by Amanda as key to ensuring dignity and choice, loss of control is seen to go with loss of the private space of the home that is such a taken for granted part of family life. Small indicators such as being able to ‘flick channels’ and get out of bed at a time of her father’s choice was seen as very important. Though Amanda used meals on wheels (which also restrict the choices and timing of meals) this was viewed as a price worth paying for the added peace of mind that their visit to the home brings during the day while Amanda was at work. That a care home enables, in theory, more surveillance and therefore more peace of mind was not articulated, showing that such moral decisions are not absolutes. Instead, they are contingent upon justifications for current realities, anguished over as not ideal, but which are regarded as the ‘best fit’ for what is available or desired on the whole at that time. It is possible that the pros and cons may be interchangeably drawn upon to argue for an alternative decision at a later date, for instance in justifying arranging residential care. It is the complexity, in material circumstance, coordination issues, and inter-subjective emotional consequences that such decisions to introduce other carers are made.

Maintaining personal privacy and family/home boundaries was articulated as important by many family carers as an ideal, and relevant to ensuring dignity of care. Hiding or revealing aspects of oneself and one's body is consequential for enacting individual agency and maintaining privacy. This can be understood as mediated by appropriate cultural value and social expectation i.e. what is expected to be shared, and what is expected to be kept private. Certain individuals gain privileges of access and knowledge, such as other family or health professionals, but this is not conceded at all times and in all places. In recognising this, the existential concerns of carers become more important to evaluating quality and consequences of caring practice. The way care is done, where it is done, and when it is done can be influential in determining the suitability and quality of care for particular individuals.

## **4.2 Why Care-Workers Do What They Do**

The relationships care-workers build with their clients are institutionally regulated more than is the case for family carers. Whether the employer is an older person using Direct Payments, a private company, or a state-based provider, this is likely to influence the relationship. Though there is a strong connection between organisational constraints and the orientations of care work, they do not entirely define them. It is therefore important to consider issues of motivation deriving from care-worker respondents' own life experiences, which hailed them as carers and informed the way they perform their work, and affected the relations they negotiate with the particular older person being cared for. In an individualised future for care-work, this becomes increasingly important to explore. Subjective and material factors are connected in constructing care worker orientations. These include: previous experiences of care across the life-course; empathy for the ontological position of older people (and imagined future for themselves and others); current circumstances of one's own family members in terms of emotional motivation; material and temporal barriers and facilitators to employment; labour market context; and attributions of skills and knowledges. This section outlines some of the connections and disconnections in understanding these factors in constituting the situated orientations of care-workers.

#### 4.2.1 *Convenience and Labour Market Conditions*

An individual's positioning within the local labour market influences decisions to become a care worker, despite the industry's relatively low pay and poor conditions. There is very little opportunity to move beyond hourly pay in the care industry (Balloch et al 2004; SCIE 2007; Glucksmann 2008; Lewchuk et al 2008), with it being a relatively flat hierarchical structure with few promotion prospects or other incentives. The Social Care Institute for Excellence (SCIE) commented that this has led to churning in the industry, as carers have little incentive to invest heavily in training, favouring instead easier work in the retail sector with comparative pay levels. This industry norm is reflected in the terms and conditions of agency staff in this research, with agency managers commenting that pay was just above the national minimum wage. Different rates for different shifts were common, but overtime was rarely paid. Reimbursement for travel was patchy, most requiring their own transport to do the job, with those using public transport managing multiple trips between clients. Being positioned in an unfavourable industry with poor terms and conditions, motivations of working for money were noticeably absent in respondent accounts. As was raised in the family carer section, even though Barbara's paid care worker spoke of money being the motivation, this was set within the context of the presence of the family carer (Wenger 1991, 1997; Keating et al 2003), and served to reinforce a love/money distinction between them. However, none of the respondents in this study spoke of financial reward unless prompted to do so, perhaps unsurprisingly, as caring for money may be perceived to delegitimize and devalue the quality of their caring practice. When responding to questions about pay and conditions, many smiled or gave a shrug to indicate unease, though some did articulate being contented.

Kelsey's motivation to enter care work was not a positive evaluation of the benefits of a career in caring, but rather was a result of limited options available when leaving school. Now aged 24, Kelsey had always worked in a care environment, but explained her limited options when selecting a Youth Training Scheme as a school leaver.

I just thought I would enjoy doing it 'cause there was nothing...like people, like hairdressing or stuff like that I didn't fancy, so I thought I'll try that (Kelsey, Interview)

Kelsey had previously done work experience at school, working in a residential care home.<sup>22</sup> Starting as a youth trainee for £40 a week over two years, she became pregnant and took maternity leave during this time. On returning to work, she worked in the kitchens as she was too young to work as a carer. At eighteen years old, she was able to move into caring, where she stayed until she was twenty three before moving into her current full time position at a home-based domiciliary care agency. The limited horizons on leaving school were perhaps reflective of the local labour market, and Kelsey did not envisage a change of career in the near future, at least while her child was still at school.

Two respondents were migrants, and one a refugee. The remaining respondents were mostly white British, long term residents in the places in which they cared. Some had previous experience in a residential or home-based care environment, but many brought informal caring experiences with them. Ewa, a Polish woman in her fifties, did not seem too concerned about the pay, explaining that it was sufficient and that there were regular increments.

I wouldn't bother looking for money. I quite happy. I don't need complain. So quite happy. Every year we have something more in April, it's nice. (Ewa, Interview)

When I asked about promotion prospects she answered she was not aware of any. Gendered skills were presented as explanation of her orientation to care. She explained that she thought it a good job for women, due to the life experiences acquired by older women.

I think it's a good job for a woman, especially my age. Because we understand more when we live more, and it's really good when you can help somebody and even get money for this, it's not very very responsibility like business, bank or something like that. So, it's okay. I think some more woman should be working in that [laugh] and in England there are many. (Ewa, Interview)

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<sup>22</sup> For a discussion on the class dynamics of school work experience and future career trajectories, see Heather McGregor, 'This will never be a fair country as long as middle class children get all the perks', *The Observer*, 27.02.2011.

The lower level of responsibility she associated with the job compared to others was interesting. A number of carers described care as a huge responsibility, one which was struggled over. Ewa felt more women should be working in the care industry, especially in England. Marta also expressed that it was very rare to have carers in Poland, as family usually performed this role. This evaluation of their work being a response to the perceived lack of family carers in the UK could be seen as a psychic defence (Klein 1952, in Lucey 2004:103), responding to familiar discourses about migrant workers and jobs, circulating within and beyond the deprived communities in which they were working. For Marta who had a young family, there were more practical issues of convenience oriented her to home-based caring:

I think the main motivation was the convenience, that me and the husband can both work because the work is quite flexible, so we could you know manage together. So that was the main, main motivation why I came to that kind of job. But again, you know, doing it, you can see so many rewards, you get to be with the people. And before I was a teacher, so I think that I always like to be with people, and more for and with people. So, that's it. (Marta, Interview)

Being a teacher in Poland, Marta was unsure about her future in the UK, sometimes feeling a desire to go home, and at other times, expressing a wish to train to become a teacher in the UK. The uncertainty of her current situation was influenced by the benefit to her children in learning English, but she was also concerned about them losing their Polish language and identity. In this sense, despite Marta's caring role giving her a degree of satisfaction by forging relationships in her community (compared to working in a factory or a residential care setting which she had done previously in the UK), this was tinged with ambivalence as it was not a life trajectory she saw continuing indefinitely.

Historical economic circumstances in the North East drew in carers who might not otherwise have taken up this work. After being made redundant from heavy industry in the 1980s, Oliver had been unemployed for five years. He suggested his trade union organising had hampered his attempts to find new work, so being given a second chance to take up any form of employment was welcomed. After doing some voluntary work, Oliver was offered a job at the local council as a residential support worker.



When I had the interview the first thing they said is we know your background, and it stays at the door, you don't bring it in with you. So I kind of, although I didn't drop everything, I dropped most stuff because I worked shifts anyway. So I started off in residential as a community support worker. (Oliver, Interview)

In the context of unemployment in the region at that time, care-work was perhaps one of the few options available, and would perhaps have been difficult for an industrial worker to adjust to, given the assumptions about tacit emotional and embodied skills of care, largely regarded as 'feminised' (Phillips and Taylor 1980). When I asked him about this adjustment to such employment, he replied that it was the hours that he found most difficult, such as 24-hour shifts which involved 'sleep-ins', rather than coming to terms with occupational status (or the difference in pay and conditions compared to heavy industry that one would expect to be a barrier (Folbre 2001:17). However, since he accepted rather than rejected this form of work, it might be expected that this was not present in his account, whether or not he struggled with it at the time. The hours within a residential setting where Oliver began his caring career was made difficult by declining health, so he moved across to day care services which supports both older people and people with learning disabilities. He described this as 'daunting' at first as he was just 'thrown in' but that experience of family members with learning disabilities eased the transition. Other paid carers interviewed also described their clients as a mixture of older people and people with learning or physical disabilities. The range of skills and knowledges brought to bear when caring for two different client bases may contribute to the complexity and versatility of the role.

For Oliver, this role as a carer within a day care setting brought him skills and knowledges of caring for older people which proved useful in his personal situation when his father's health declined. He argued that he often found it frustrating that other family members presumed he would know what to do, how to access the right sort of support, and often left him to it because of his work background. However, Oliver argued that this assumed existing knowledge, which in fact was learned along the way. This involved 'fighting the system' to determine what his father's entitlements exactly were due to the complexity of the benefits, social care and health care systems and the

delays and information blockages when trying to navigate and negotiate between them. This articulation of transferable skills and knowledges is discussed in the next section.

#### **4.2.2 *Having the Necessary Skills and Demeanour***

The evaluation of skills attached to particular jobs is socially constructed. Women's skills in care are often seen as natural feminine qualities, so jobs requiring these skills are deemed to be 'women's work' (Phillips and Taylor 1980). The historical association of women's work as pin money influences its continued low paid status. Lack of traditional union organising in these sectors also contribute to this effect (Wills and Simms 2003) as does part time nature of this work, and the implied ubiquity of the skill itself. Evaluations of certain roles and skills can be redefined over time to reflect new economic circumstances. Skills attached to traditional male jobs become less desirable in an increasingly 'feminised' service sector which dominates the UK labour market. Consequently, traditional masculine demeanours may also become undesirable, such as aggression (McDowell 2001, 2004a). One of the supposedly feminine demeanours which is valued is resilience; the ability to 'get on' with (repetitive) tasks that some may find unappealing. However, the association of caring as a 'natural trait' of women rather than an acquired skill influences the lack of reward for its possessor. Gemma articulates what appears to be an essentialist discourse surrounding the necessary demeanour for caring:

I don't know, I think you've either got a stomach for it or you haven't. I mean some people can be carers and some people can't. With all the goodwill, you know, they may be lovely people but it's just not for them, which is totally understandable. But I think over the years you just get used to. I know I've certainly changed 'cause when I was at college and they sent me on a placement, it was a special needs school. And I had to, the children were sort of slaving on their dinners and grinding their teeth, and I couldn't eat. I was physically, and that was when I was about sort of nineteen. But I mean now it's just [laughs] so you do change over the years, I have. You just deal with, you know you've got to. They're in your hands really, aren't they? So I mean there are certain parts of the job that I don't like doing, you know. But you've got to. And I certainly wouldn't not do them. Just put a smile on your face and get on with what you need to do, don't you? (Gemma, Interview)

Gemma describes feelings of disgust in her early experiences of caring for disabled adults. She suggests the right attitude comes with the job, developing through its practice and improved with more experience of life. The statement ‘you’ve either got a stomach for it or you haven’t’ is less about gender essentialised attributes or knowledges than about embodied experience and emotional resilience established as a consequence of gender roles. As a supervisor of new care staff, she values the skills and experience of older women who were easier to train into the job than college recruits. Over the years, she may have discovered those who had engaged in embodied work, either formally or informally, which may have unpleasant connotations, were more likely to succeed than those who had not. As older women are more likely to be placed in these caring roles, or are more likely to be socialised into these, essentialised gendered dispositions appear to inform the selection criteria, whereas the value is attached to embodied experience.

Gemma described herself as a tearaway when she was younger, which gave her the demeanour to respond to children with behavioural problems. Gemma now works with older people as well as children, as she wanted to alter her shift patterns because of family caring commitments. She has been working with two older women with MS for a year and a half.

I honestly, I was a bit of a tearaway when I was younger, so I always knew I could relate to sort of the naughtier children, and their behaviour problems. And the scenarios that some people have when they’re growing up. So I just sort of fit in and started off from there. I didn’t really do any basic care work. I went for like the mental health and the teenagers with behaviour problems were my thing. And then I got sick of doing shifts  
(Gemma, Interview)

As Liz Stanley (1992) argues, apparently natural personality traits for women (such as tolerance, patience, and contentment) emerge from the work that needs to be done and consequently, carer identities are a reasonable adaptation to conditions and expectations accrued across the life-course. Therefore identities emerge from an individual’s relationship to ‘necessity’ and the ‘at hand’ of everyday caring relations. This is not to essentialise intrinsic demeanours as gendered, but to explain the continued association

of care work as a gendered skill. One of the effects of this discourse is to elevate caring practice from the low regard in which it is held in formal reward structures to promote a sense of pride and achievement for those who engage in such work. Since academic knowledge is given credibility through qualifications and rewarded in status and privilege in social hierarchies, it is important to counter this within the organisation with discourses which value embodied and practical knowledge over academic achievement (Willis 1977; Holt 2008). This has become manifest at practice level, as evidenced in a survey of 1400 employers conducted by CIPD/KPMG in 2006 which found that employers most valued ‘communication skills, work ethic and personality’ when recruiting - above literacy, numeracy or qualifications.<sup>23</sup> The work readiness of potential employees involves an evaluation of appropriate motivation and emotional subjectivities. Expressions of distinction between those who can and those who cannot may raise the social esteem for those who succeed and who are acknowledged as good carers within the organisation, and improve job satisfaction. College students who applied to the agency for work and who Gemma was asked to train were largely perceived as lacking in common sense, with no practical skill compared to the valuable embodied knowledge of women with caring experience. Achieving vocational qualifications was not viewed as sufficient in themselves to producing quick learners or good carers.<sup>24</sup>

#### **4.2.3 *‘It’s A Nice Thing, I Like It’***

The previous section considered the relationship between skills and knowledges on the one hand, and the value and values attached to them on the other. Having certain skills often meant valuing those skills by gaining satisfaction from performing them. Previous experiences of care, both paid and unpaid, differed significantly between care workers and therefore did not appear to be a defining factor, but did contribute to motivations and sense of capability to care, and interacted in specific ways in the negotiation of

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<sup>23</sup> <http://www.hrnguide.co.uk/recruitment/school-leavers.htm>, accessed 01.04.07

<sup>24</sup> My apparently higher social status as a postgraduate researcher altered within this organisational space, and the interview relations were reversed in terms of perceived power and knowledge.

roles. Elizabeth described how her mother's caring roles in Zimbabwe have helped shaped her own orientation towards care.

It's because at home, my Mam is. She does care work as well... So I just thought it was really nice 'cause she looks after orphans and stuff so, I thought yeah, I will just go and do the same thing. (Elizabeth, Interview)

Her mother's experience of caring for children is associated with her own motivation for caring practice with older people, and can be viewed as more about the notion of care than with older people in particular. However, she goes on to describe her past experience and understanding of older people. As with the Polish carers, Elizabeth explained that paid caring for older people is not a common occurrence in Zimbabwe, as family members usually take on this responsibility. She described how she learned from being a child to care for older people within her wider family as there are no care homes, so families look after their elders until they die. This gave her an awareness and practical experience of caring while growing up. Recognising a limited supply of carers in the UK gave Elizabeth the motivation to carry on. As Elizabeth saw care as a positive and good thing to do, echoing her mother's work, this brought her satisfaction.

I think it's a good thing that I'm doing. And that some people really need my help. So I think if I stop now, who's going to help those people? Its okay, I'm giving a hand as well. Also, when I talk to my Mam 'cause sometimes she tells me 'oh this is happening, this is a good thing' and I say, let me just continue with this. It's a nice thing. I like it. 'Cause like, even like with my kids, you know, I just like looking after them. (Elizabeth, Interview)

Her looking to her mother as validation for her role as carer suggests how the reproduction of caring roles are a process of negotiating esteem and value. This was also evident in Joseph's account. Whilst not directly relating gender to care in the same way, he was acting as 'stand in' for his father's 'side,' which he felt would circulate goodwill and shift the understandings of dependency between parent and child. This process allowed both Elizabeth and Joseph to be seen to be more responsible in their parents' eyes, so becoming a carer facilitated their transition to adulthood. Rather than seeking stronger connections to family members through caring roles, Gemma saw the

benefit of her care work as being able to get out of the house and keep her mind active through paid employment.

I mean I love to work, I've always worked. I went back to work when my youngest, who was eleven on Tuesday, he was just over a week old when I went back to work. And a couple of nightshifts a week, just to. There's more to life than being stuck in the house, and housework and kids and. I like to keep going mentally as well as. I mean I think oh, I want a week off, but then I get to two days and I think, oh I'm bored. What am I doing? Then I end up working more in the house and stuff so [laughs] (Gemma, Interview)

Her family situation implies some resistance to being 'confined' at home. Her desire to find an external outlet can perhaps be explained by a comment she made at a different stage of the interview.

My eldest son's got ADHD, my Dad's just getting over cancer. We've got the whole [laughs] so it's like work at work. All just goes into one (Gemma, Interview)

Being involved in nursing care from an early age, Gemma's paid work in a care environment suggests the articulation of practices and subjectivities across care economies, as her home life and work life merge into one, creating acute pressures on her ability to respond to both. Similar to Oliver's account, her role as mother and daughter were perhaps generating a more intense pull to informal caring at home as a result of her skills developed through her paid work in care. Coping with multiple caring responsibilities, the resilience she appreciated when recruiting staff is evident in the humorous way she described this intense caring circumstance in her own life. In recent years Gemma took on administrative as well as a practitioner role upon being promoted to supervisor. Becoming accustomed to personal care, she described how she could go into work and perform effortlessly, which became monotonous. Being a supervisor brought new challenges, which she enjoyed, particularly as the role provided some different challenges to the ones she experienced at home and when on care duty.

Orientations to care for some care-workers came about in an oblique way, rather than drawing on conventional discourses about care, love, duty, family history or as an outlet from domestic responsibilities. For some, it facilitated a passion or hobby. Neil, who

worked as a paid worker in a carer charity, engaged in respite support for carers of people with dementia. This usually involved taking the older person away from their home for a drive around the local area, which he described as stimulative support. The purpose of the trips was primarily to provide a few hours break for family carers, though often they triggered some memories with the client, so that their mood was lifted on their return. Neil hoped these might form the basis of ongoing discussion with the family, retaining for all concerned a sense of personhood and life history (which was not about perpetual decline, but recoverable, even if momentarily).

Neil also gained from these personal memory triggers. He was passionate about local history, and his caring role enabled him to build up a richer picture of the past histories and geographies of Newcastle and surrounding areas. Though many of his clients had significant cognitive impairment as a result of dementia, he described how they were able to recognise significant places, and remember elements of their past through these journeys around the city. From his own knowledge of landmarks past and present, Neil pointed out former cinemas, dance halls and factories, drawing on information gathered from the older person's family about their work history and relationship to the local area. This became an important source of new information and illumination for Neil, before and during the trips themselves. He was then able to transfer this history and knowledge in other encounters with older people of similar age, using landmarks as prompts to uncovering forgotten memories.

They could remember going in there, seeing his family, going through the front door. Nothing had changed. From this building. And if you can find the place in Newcastle from say the 60's which is very hard. And bring it to modern days, it can bring. And then all of a sudden, they'll start opening up. And start talking about where they were, and to them they might be back in the 60's, so it's bringing it all back to them. And the nice thing is, it's when you take the client back to the carer at the end of the three and a half hours, and they've said they've had a fantastic afternoon (Neil, Interview)

He described one occasion when he drove an older client with dementia through the streets. Though he didn't often speak much at home, he was stimulated into conversation by what he saw.

I used to have one client who had dementia, who used to work for the gas board. Now I used to go out in the car, and he used to direct us round his old gas routes. And he, where he'd done the gas pipes and everything. And he could even, I allowed him to take the lead. And he would say turn left here. I remember where I am now. And just taking them right back to when he worked within there is a big thing. To me, bonus. The job when you know you're making, trying to make a difference to someone's life. Honestly. (Neil, Interview)

Neil found this a fascinating insight into a city he thought he knew very well, but which when viewed through his client's 'eyes' as an engineer, opened up a whole new world to him. Neil was very appreciative of the knowledge he gained as a result of his caring, and aware of the positive results this achieved for his clients.

#### **4.2.4 *Putting Things Right***

Some paid care-workers revealed how commitments to their work roles arose from their own family experiences. Lorna's experiences of care began while caring informally for her mother. At the time she worked full time in banking. Her experiences eventually led to paid employment in a domiciliary care agency. Lorna described the feelings she had when being asked to relinquish care of her mother.

I fought and I cried. I said I'll give up work, and they said 'No, you're never going to have a life, and you know, we think you've done enough'. And I just had to accept it. And then when I seen what happened in care homes and the lack of care that they get. People don't give a toss. Money going missing. Clothes missing. People smoking their cigarettes. And then I thought that's enough. And then she went into hospital, and I was told she was going to die, and I fought all ways. I says I want. They says you can't. I says I can do what I want, it's my mother. I'll take her home, I've done it before. (Lorna, Interview)

Dissatisfaction with care homes led Lorna to care for her mother at home. She found the lack of care she had witnessed difficult to come to terms with, and made her feel guilty about her mother's treatment, believing she ought to have cared for her mother at home from the outset. The quality of care homes in certain neighbourhoods, or those seen as affordable to those with low income, may have contributed in a structural and material



way to her sense of family duty to put things right. Lorna's mother died a week after leaving the care home. The negotiation with authorities was won too late for Lorna, perhaps prompting her decision to continue to perform a caring role for other older people in their own homes. Before this event, Lorna had never felt any desire to become a carer.

My daughter's a carer, and has been since she was eighteen. My mother was a nurse, but it never ever appealed to me. It was the farthest thing from my mind. It was just...lack of money, what you got paid for the job. I just couldn't understand why people wanted to work in it. As I say the death of my mother, I sort of just snapped. (Lorna, Interview)

Lorna's remarks suggest she views care as a somewhat 'irrational' career choice, the result of 'snapping' because of disturbance to her usual demeanour caused by bereavement. Standing as insider/outsider, she perceived the discourse of care as unvalued and unappealing, despite it being her daughter's chosen career. I felt Lorna was trying to make clear the depth of the change in her brought about by her mother's death which had prompted her new job role, it being a significant sacrifice to a formerly well established and well paid career in banking. Lorna's story prompts a consideration of Arendt's assertion that the ultimate aim of the life-course is to establish an enduring self identity from which to construct a coherent family (Arendt 1958; Morgan 1996 Finch 2007; Morgan 1999). The unpredictability of our relations in everyday life is founded upon a lack of perfect knowledge; of intentions, actions and outcomes within the complex web of relationships in which we are all engaged. For Arendt, central to this quest for coherence within such apparent chaos is the notion of forgiveness and promise; as the correctives to the irreversibility of past actions, and the uncertainty of our futures. Lorna herself did not speak of gendered expectations and characteristics of the caring role she had adopted as an explanation for why she did what she did, and instead emphasised how out of character this role was for her. Nevertheless the anxiety she experienced when confronted with her mother's poor care, brought into being a carer identity as a form of reparation for the poor care her mother received (Aboderin 2004).

### **4.3 Why Volunteers Do What They Do**

Academic and policy discussions on care tend to focus upon the traditional nuclear family as the axis around which caring labour is enacted and constituted. However, the considerable significance of friendship to caring should not be overlooked (Pahl 2000; Coakley 2002; Andrews et al 2003; Miewald and McCann 2004; Spencer and Pahl 2006). Eight volunteer carers took part in this research. Some had more than one volunteering role. Many respondents had found formal volunteering opportunities through VODA (Voluntary Organisations Development Agency) or through local church organisations. As will be demonstrated in the following accounts, motivations are often multiple, and orientations to care are influenced by material circumstances and existential concerns. Rather than viewing volunteering activity through the lens of the increasing importance of friendship, the following accounts suggest how ‘doing family’ can be enacted beyond kin to individuals within the community.

#### **4.3.1 *Doing Something and Making a Difference***

The motivations in voluntary care correspond less to specific relationships with older people than to older people in general. Such ‘intrinsic’ motivations of volunteering include wanting to ‘make a difference’ with volunteers often describing the desire to ‘do something’ (Fyfe and Milligan 2003; Jones and Cullis 2003; Baines and Hardhill 2008; Milligan and Wiles 2010). The volunteers in this research expressed similar sentiments, and most were engaged in multiple volunteering activities or had significant experience in the past, some of which involved older people. Seeing volunteering as a good thing to do generally, many spoke of their motivation to support older people in particular because they felt their needs were not being met.

Danielle is 29 years old, lives with her partner, does not have children, and works full time in a professional role in the Third sector. Her paid work in a charity gave her an appreciation of the need to find volunteers. The combination of her work and family circumstance positioned her with an orientation to volunteer, perhaps less in terms of her time, but in terms of her capacity to focus beyond family.

‘Cause I’m not caring for anyone else, I don’t have any kids either so I think I wanted to do something for somebody else.  
(Danielle, Interview)

But time was influential in establishing the care decision as appropriate for Danielle. Due to her busy work schedule, she had been reluctant to take up any formal volunteering previously, fearing she may take on too much. Avoiding feeling guilty about lack of substantial commitment and engagement, she sought a role which allowed her to volunteer within limited parameters. She noticed a postcard in a coffee shop:

There’s a little advert, something to do with a cup of coffee I think, and it said, that’s all it said. Have you got a spare hour? It was a really really straightforward message, and I just thought because I’m, I have a really busy job anyway, I wanted something that I could do without feeling guilty, like if I couldn’t make anything. So the fact that it was just one hour per week, I knew exactly where I stood, I was like well that’s perfect for me. (Danielle, Interview)

Phoebe described how in a very basic sense, her volunteering as an advocate would give older people choices that they might not otherwise have. She developed polio in her late thirties, and not wishing to give up work entirely, felt that a voluntary role to start with would be beneficial. She took a course in advocacy, specialising in advocacy with older people rather than people with learning disabilities, and explained that although during her years as a nurse she had disliked nursing older people, she felt it was the right direction. When I asked why she disliked nursing older people she explained it was the medical model of healthcare which pigeon-holed older people according to their ailments that meant their choices were being limited and there was no forward thinking, with most medical practitioners viewing residential care as an easy option:

Well you know, he’s got dementia. She’s got Parkinson’s, you know – they’ve got this, they’ve got that. They’ve got the other. When really, we should be thinking in terms of giving people the care they need rather than pigeon-holing them into a condition. And it was at that point that I started to think well, how much choice do they have? (Phoebe, Interview)

She felt that going into an advocacy role for older people would help people articulate their choices, so that they were not automatically assumed to be in a residential setting for the rest of their lives. Phoebe has been an advocate for over 10 years. She initially

worked with clients in local authority day services, and described how the subsequent loss of day care services in her locality (through privatisation) had a negative impact on the older people who used them following transfer from hospital care. For the short term, respite, day care and long term care plans for people with dementia, Phoebe spoke of the importance of people knowing who they were, rather than being judged on their apparent behaviour. She noted a difference between short term and long term care, in which short term care clients were continually assessed, which meant people got to know them. She found that getting to know the routines, the staff, the food and other residents was important for older people to manage transitions to permanent residential care, or to manage transitions to home-based care. She found that once some older people display negative behaviour, their choices are removed. Her advocacy is a means of addressing this.

You know, the family would say you know, he gets bad to deal with. And then the next thing you know, he's tagged as being difficult. I go in and I have a chat, and I find that he's neither. He's just really upset that the pace of his life has gone to full speed, in terms of change, and he just can't come to terms.  
(Phoebe, Interview)

In contrast to those respondents who felt they were aiming to 'make a difference', others felt that their support to older people was not doing much at all, with it being invisibly incorporated into everyday routines. Elaine, a woman in her seventies, engaged in a range of voluntary activities. She shopped and did washing for her neighbour, suggesting this didn't seem like voluntary work:

I just include it with my own household things. (Elaine, Diary)

As a result of her various volunteering roles over the years, Elaine warned of the dangers of taking on more than could be realistically managed, as the result is disappointment on both sides, perhaps worse than no engagement at all. As she explained at the end of her diary account:

This is the end of my fortnight, although I have been please[d] to take part I feel a bit uncomfortable talking about it. To me it is a way of life and not difficult, but the one thing you have to be aware of is always to keep your word and not to over commit. (Elaine, Diary)

Elaine underplayed the value of the voluntary care she provides, perhaps out of a sense of embarrassment in talking about one's own 'meritable' acts. Being a churchgoer, this perhaps connects to a discourse of being silent when doing good. However, the fact that these practices were raised in Elaine's diary, and that she came forward as a respondent, meant she found them significant and defined her activities as care in some form. That Elaine does not see it as 'voluntary work' in the same way as she views other volunteering can in part be explained by the historical (gendered) invisibility of domestic work in the home. She makes a distinction between informal support at home and in communities with previously known others, and the more abstract form of volunteering in which the relationship developed out of a desire to 'do something'.

#### **4.3.2 *'I Think A Lot Of It's Just As Much About Me Really'***

Volunteering can be mutually beneficial and is increasingly promoted as one way of acquiring new skills and experience to navigate precarious labour markets (Perrons 2000; Fyfe and Milligan 2003; Baines and Hardill 2008; Ross 2008). In a study conducted in an economically deprived community in the Midlands, UK, Sue Baines and Irene Hardill sought to understand the motivations and experiences of volunteers in order to respond to a government agenda which was promoting volunteering as a means of combating social exclusion and worklessness. They recognised the importance of understanding volunteer motivations, in a wider context and situated within networks of informal support (Baines and Hardill 2008; Hardill and Baines 2009). They suggest mutual aid and altruism are the main motivations for voluntary activity:

Mutual aid is characterised by individuals with a shared experience or situation working together to bring about change. Philanthropy is associated with altruism towards people less closely identified with the giver. (Baines and Hardill 2008:312)

Mutual aid can be described as reciprocal caring activity, where both parties gain something from the process. Within this, explicit motivations of self interest may exist. In my study, these took a number of forms ranging from: building up a CV and improving work skills; combating isolation; and generating new and imagined 'family' members where these were absent (Morgan 1991, 1996). These motivations are embedded within the material circumstances at the start of the volunteering activity.

It's not like a burning desire or anything like that. I just. I think a lot of it's just as much about me really. It's given me this sort of, given me something. Given me sort of like an activity as well. And I can tell as well that, I can tell as well that they appreciate me visiting, so. So that sort of motivates me as well.  
(Ben, Interview)

In this research, both male volunteer-respondents Ben and Edward, clearly presented what could be described as motivations of mutual aid that on first glance might appear to be self interest if the wider context is not taken into account. They were unemployed at the start of their current volunteering activity, and this influenced their motivation as they hoped this would be a means to improve their CVs, gain experience, test their aptitude, take advantage of free training and ultimately find their desired employment. The desire for an improved CV is noted in literatures on volunteering, and implies acquisition of social capital (Coleman 1988, 1990; Putnam 2000; Fukuyama 2001; Woolcock 2001). In this response from Ben, there is a hesitation and discomfort in articulating CV building as a motivation, perhaps because this may be regarded as an inadequate reason, even though his volunteering background had helped him to gain employment as a residential support worker.

It was because I was unemployed. I was looking for, I was looking for work. And then I was also, I'd had time on my hands as well [...] I was looking for something that might...I really, sort of help me...help my CV. (Ben, Interview)

Edward's motivation was similar, but there was more confidence in presenting his motivations in this way. He is intending to commence a degree in Social Work after taking redundancy following a long career in the civil service. Volunteering for Edward was therefore a stepping stone giving him valuable experience of working with vulnerable groups, and allowed him to test his capability before embarking on a new direction through full time education.

As soon as I left, in my head I was a social worker, but I needed experience. And I also wanted to make sure I could actually do it. I felt the best way to do that was to do voluntary work  
(Edward, Interview).

These male respondents appeared more hesitant about their abilities to 'care' than the women volunteer respondents, some of whom regarded this as 'natural'. This

uncertainty about having the necessary aptitude or demeanour was shared by the two male family carers, but not apparent with the male care-workers or the women across the three samples. Since care for older people has traditionally been the domain of women, this is a common discourse. Whether based on essentialist beliefs about inherent or natural ability, or whether through learned embodied and emotional experiences over the life-course, care is seen as easier for women to take up without training. However, in areas of high unemployment, such as Tyne and Wear, care work is increasingly being promoted to men as a legitimate labour market option, and the caring professions in the public sector an opportunity for advancement. However, as McDowell (1991, 2001) work on male employment suggests, the capability to adopt the necessary emotional work and demeanour for service work presents difficulties for men from formerly industrial backgrounds, partly due to the local and historical expectations about masculinity.

Whilst the male volunteer carers in this research did not have a personal history of this industrial past, both were very keen to know more about it, expressing dissatisfaction with their working lives at various points in service and administration. They enjoyed the company of their befriendedees because of their links with shipbuilding occupations and these life-worlds, the traditional masculinities associated within the Tyne and Wear area (see Nayak 2006). To some extent caring represented a challenge to men, one which they felt required training, accreditation and testing of skill or aptitude before embarking on a career change.

Though gender appears to be a factor differentiating aspirations to acquire personal economic capital which form motivations for voluntary carers, particularly at the initial stages, the small number of respondents makes any inferences difficult to sustain. Also, the different material employment positions at the start of the volunteering blurs this claim as only one woman, Coleen, could be considered unemployed and, unlike Ben and Edward, was not actively seeking work. Coleen, a married graduate with school age children, was not motivated to improve her CV or learn new skills. But like Ben and Edward, and many of the women volunteers, she saw volunteering as a means of providing structure to her day - another motivation driven by mutual aid.

Structuring the day for those not in paid employment and combating loneliness and isolation are significant prompts to voluntary caring. Dawn and Elaine were both retired widows, and saw volunteering as a means of combating isolation and keeping active. Motivation and material circumstance combine to provide the impetus to get involved in a formal voluntary organisation. Dawn found inspiration in the strength of others. Though a regular church goer, Dawn never referred to caring in terms of ‘doing good’, ‘doing the right thing’, or observing religious duty. In fact, on my first visit, Dawn suggested it made her look awfully conceited to talk about herself in that way. Other volunteers expressed similar sentiments. When Elaine discussed her more formal volunteering work, she saw the reciprocal aspects of this, and the personal benefits she gained.

It is hard to put into words what I feel about being a volunteer I don't really think of it in that way. I get as much pleasure as I find it makes me feel happy. I'm sure there will be times when I might need a helping hand. (Elaine, Diary)

For June, who befriended an older woman in her late sixties in Newcastle, her caring role had a different temporality to appreciating loneliness. Rather than it providing structure to her day as with those befrienders who were retired, June as relatively new to the area and with little family, may or may not have experienced loneliness herself, but was nevertheless keen to learn more about its effects in later life and how to guard against it. This led to a degree of empathy for the position of older people as a group, and as part of the life-course she will face, which is discussed in the next section.

### **4.3.3 *Empathy and Affinity with Older People***

Deonna (2007) describes empathy as accurately representing another's emotion and having a congruent response to it. She suggests, in contrast to Levinas (Hutchens 2004) that empathy does not require visible perception or proximity. The notion of empathy can be used to describe awareness of and responsiveness to both embodied and existential concerns which emerge as a result of declining health and dwindling social connections. Existential doubts and concerns can occur at any time during the life-course. As Heidegger proposed, our lives are always in a state of being-toward-death (Heidegger 1962), which affects how we view everyday life. Yet, death's inevitability



can lead to it being an avoided topic. Phoebe describes how this may have detrimental consequences for planning ahead, which may (as June fears), be faced alone.

We tend to associate ageing with dying so we tend not to think about it. We don't really work out what we would do if we were left without a partner at that time in our lives. And really we should, we should think about it. (Phoebe, Interview)

This awareness of potential isolation, and the need to keep going to avoid disconnection and loss of structure was something Phoebe understood as difficult to deal with in later life. She described the experience of a friend who had been dreading retirement at the age of 70.

It's a huge transition. It's trying to find ways of allowing, for people who want to maybe take a back seat, allowing that to happen, but for people who want to continue and take on more responsibilities and take on more challenges, not just see it as a period of decline. (Phoebe, Interview)

June worked part time in retail, and was keen to develop links with the community as she had moved to the North East in recent years. She volunteered in a library but had never befriended before. She had been befriending for a few months when she took part in this research. She explained that she was hoping the befriending would help her to understand the people of the North East, as she was not born in the UK.

Curious, quite curious. And then I like to meet different people as well. Like to go inside and to see how they are thinking. And why, you know, this. (June, Interview)

She explained that she had difficulty with the Newcastle accent, and was pleased that she had been matched with an older woman, Rita, who was originally from the Midlands. She found this accent easier to understand, and had built up a good relationship in the few months she had been befriending. June wished to understand older people more, as this would be a means to acquiring knowledge that would help her in later life. She described how hiding feelings to protect family could cause depression. June's befriending enabled Rita to express frustration and sadness.

If I don't have this befriending, I'm never understand clearly. I understand but I never deep down understand the feeling, you know. They can be depressed sometimes, they can be very

lonely. But they won't tell you, they always say I'm fine. Fine. Deep down there is something. Just they don't want to burden their family. The children. They same I'm fine, but deep down they very sad, but they won't say. When I was there I will hear. (June, Interview)

June felt she gained appreciation of her own life-course trajectory by listening to her befriender, and sensing the loneliness of being without a long term partner following bereavement. Coping with such alterations in life-course trajectory was something June was learning from Rita.

I understand other people, after the loss, being together for a long time. And how lonely that can be. Sometime can be, they don't want to, you know...They like to stay in the house. They don't want to do anything. They're just waiting. If you have something for them to do, to actually help them. So it does make me understand that if I. Also when I talk to her I learn as well. I understand getting older, you really have to do something. You keep moving, your brain keep moving you know. Life is always, it could pass away ... You will in the end may live alone. And how do you cope? (June, Interview)

An aspect of empathy was about providing an alternative means of 'giving voice' to frustration. June felt that there was mutual benefit to her befriending activity with Rita, as giving time to listen enabled Rita to say things that she might not be able to say to family, and at the same time, knowing that she was helping was good for June's sense of worth.

I give my time to listen to her, and she give her time to talk to me. And for me it benefits both. One time I think I, someone to listen, she can tell that she cannot tell to her son, her daughter. Some of the thing that she will share with me. It's because it's quite hard for her to say oh, something something. But for me I'm an outsider, so she can just tell me. And then that's why it's good for me, I'm helping her. (June, Interview)

Similarly Danielle described how her befriending role was of more benefit than family when disclosing uncomfortable feelings or anxieties. Several respondents described the inside/outsider positionality which placed them in an interesting social location in relation to family, friends and paid carers. Danielle described herself as a friend to her befriender Vera, but her role as 'outsider' compared to family meant Vera was able to convey to Danielle how she sometimes felt like an inconvenience to her family, with Danielle acting as a sounding board for these feelings. At other times, however,

Danielle referred to her befriender as her 'new grandmother', since she performed a role which was missing from within her own kin.

As well as concern and appreciation for emotional wellbeing, showing concern for the material circumstances of older people includes helping them to manage everyday activities such as mealtimes and shopping. For Phoebe, the experiences she had with formal volunteering with older people, helping them with decisions about transitions from hospital to home, hospital to residential care, or residential care to home, had an impact on how concerned and attentive she was about older people within her immediate family. Though her father in law was in his early sixties, she noticed he wasn't taking care of himself. The local area being short of good quality food outlets, she found he was not eating healthily or regularly.

I looked in the cupboard and he had about three dozen pot noodles. And I came home and I said to Robin, I'm going to start and cook for your Dad, 'cause he is not living on pot noodles. He's flesh and blood, and he's not living on pot noodles. So now we cook for him two or three times a week, pop it in the freezer, and when we go up there here we are, you've got this in this box, and that in that box, I mean he's actually having better meals. He's still not terribly acquainted with vegetables...well I think sometimes it's the bother opening tins. We took him fishcakes last week and he just had the fishcakes on their own. (Phoebe, Interview)

This concern has led to Phoebe and her husband making regular visits. One consequence of this is that her father-in-law is showing greater interest in trying new foods, being more creative and more interested in things generally. He also reciprocated by buying the meat once a week for Sunday lunch, which got him out of the house to do the shopping at the butchers. Phoebe reflected upon this experience with her father in law and related it to the experience of the older people in her formal volunteering. She wondered whether being more creative with food was one way of enabling choice for those in residential settings, whose family had given details of likes and dislikes, but which were likely to be seen in a fixed way.

The midday meal is usually the standard meat and veg. I've not seen options like sweet and sour pork. Or even a chicken curry...there's a gap between what elderly people really

experience now and what we think the model for them should include. We haven't caught up. (Phoebe, Interview)

Being seen to have choice and control as a necessary condition of dignified human existence brought empathy to older people when it was felt this was not being provided. A perceived lack of choice and variety in care homes is one of the fears identified by family carers when making decisions about whether residential options are appropriate. More innovation in these, which take account of the changing needs and demands of older people today are likely to affect how these decisions are framed in the future. Cultural expectations and lifestyles change over time, and our impression of who older people are and what they want may be out of sync. Cost need not be a barrier to increasing the choices in such ways. As Phoebe remarked, if they stopped serving pie and mash one day, they could make sweet and sour pork. The same budget could give greater choice, but only if carers and staff stopped making assumptions about what is good for older people.

Beyond a broad empathy with older people and the human condition, affinity with older people was also suggested as a motivation to volunteering. Dawn is in her seventies, and is befriender to a woman in her eighties. As well as this, she also volunteers with asylum seekers and participates in reminiscence work in local schools. She began her diary explaining why she became a volunteer/befriender, and described how thirteen years ago she became very ill, suffering a stroke and meningitis. Whilst she was initially wheelchair bound and unable to walk, speak or write, she recovered to some extent with help from family and friends, though she continues to rely on use of a walking stick and occasionally a wheelchair. At the early stages of her illness, Dawn was entirely dependent on her husband, whose help and encouragement was instrumental to her recovery. She described how the many hurdles she has learned to overcome and live with have made her empathise with others in similar situations. It seemed important for Dawn to tell and re-tell people's stories. Overcoming misfortune or tragedy is held in high esteem, and therefore worth retelling. This diary entry summarised a longer conversation when we first met.

She is a wonderful person in her eighties. She is so cheerful and caring of others despite personal tragedy. A son and

granddaughter have died as well as her husband. Her other son visits regularly. (Dawn, Diary)

Danielle described her surprise at the affinity she had with someone considerably older than herself, but which was suggested by the befriending coordinator as being a good match.

It's almost like a sort of dating match, and she put Vera and I together because she thought that we would have lots in common. And I thought how on earth can you find things that a 29 year old woman has in common with 96 year old woman? But actually, we get on really well. We're both very very chatty, got a lot to say. In fact we, an hour goes past so quickly. (Danielle, Interview)

As with Neil's story in the previous section, Edward felt an affinity with and fascination towards older people due to his interest in history and local culture. Before his volunteering he began writing a book about old footballers from a lower division club within the region, and he had interviewed players, groundsmen and spectators about their experiences. This made him realise he connected well with older people.

I made a rapport with them, not just about football, but I just seemed to, understand their ways. I understand the old ways. I like local history, that sort of thing. So I thought I'd give that a go. So I got in touch with [organisation name], and eventually they matched us [sic] with a couple of people I now befriend. That's how I got into it. (Edward, Interview)

Edward's volunteering enabled him to open up a former world of shipyards and heavy industry, which fascinated him. He was equally interested in the sense of neighbourliness and close-knit community life, the family dynamics of a male work culture and the importance of friendship over material possessions, which he felt characterised an earlier Tyneside, but had now largely disappeared.

## **Conclusion**

This chapter sought to understand orientations of carers across three care economies. I argue that 'who they are and who they want to become' (Lucey 2004) can be facilitated by the caring role and the relationships that arise from it - in becoming an important

figure in someone's life; in moving up a family hierarchy; or creating new family memberships (Morgan 1991, 1996; Keating et al 2003). Caring responsibilities are involved in doing something necessary as well as achieving something difficult. As well as strengthening pre-existing relationships, care also has the capacity to move away from former or perhaps idealised notions of family and friendship in the negotiation of 'necessity' to create new possibilities. This is part of a process which is explored in the next two data chapters, demonstrating the way this impacts upon how carers negotiate with others, and what life-worlds result from these negotiations.

Some issues were raised by all groups which demonstrate the intersecting and contingent responses to care. For family members, an initial presence developed into substantial caring obligations, either through living near or with an older person, or becoming involved in wider networks of support. The caring which developed could reflect inter-personal reciprocity, or could reflect conjoined reciprocity across several generations. For some, involvement in care acted as a transitional marker towards responsibility and adulthood. One of the consequences of this in Joseph's case, however, was that intersecting factors of age, gender and family role made his caring invisible and in some sense under-estimated by others, but visible to him as unusual and therefore more reflected upon.

For paid carers, it became clear that organisational and material constraints shaped expectations and orientations to care. Occasionally, they drew upon factors similar to those of family carers in giving meaning to their work, complicating simple love/money distinctions. On the one hand, presenting themselves as doing work for love was regarded as diminishing their professionalism, as there was value in being able to create boundaries and limit the commitment. On the other hand, care done for love was regarded as better quality care, so this was also a prevalent discourse. Such distinctions were also affected by relational considerations within a care-network, as family carers were often afforded privilege as 'carers for love' (Keating et al 2003).

Not thinking about later life can mean that choices are made 'at hand' and are not thought through. This circumstance applies both to older people in need of social care, and carers who are faced with caring decisions. Care decisions may put a life-course out

of sync with the way a person had lived their lives so far. The notion of the life-course as a linear career is problematic, since social and cultural changes (such as divorce) may complicate the care expectations and choices open to older people. Respondents in this research often focused on maintaining a 'normal' life.' In doing so, older people and their carers challenged negative constructions of care practices, identities and spaces by critiquing understandings of what mid-life and old age are expected to be, framing the inter-dependencies of care as an equally valid stage in the life-course. This was shown by the concern for keeping true, giving back, and being there, all of which reflected upon evaluations of the 'right thing to do', and which were inflected by class, gender and other intersecting identities. Consequently, self-directed support may reinforce demand for cultural norms around patterns of eating, sleeping, getting dressed in appropriate places and at appropriate times rather than lead to greater demand for diverse forms of care.

## CHAPTER 5: NEGOTIATING CARE

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### **Introduction**

This chapter introduces decision making processes and factors which constrain and enable carers in pursuing their caring practice. These focus on the negotiation of new and the renegotiation of existing relationships with an older person and their social support network. These negotiations differ according to the type of relationships, but with some overlap in the way renegotiations were dealt with and reflected upon. This chapter presents data which highlights the various ways family carers, care-workers and volunteers negotiate and renegotiate their relationships in order to engage in appropriate caring practice. Drawing upon and building appropriate embodied knowledges and skills to engage in caring practice was one key element to this negotiation, with this and other factors serving to set boundaries and limits on what was possible and desirable. In one way or another, all carers drew upon support, either formal support of institutions, informal support from friends, neighbours and voluntary organisations, or support from within the care relationship itself. The chapter concludes by summarising the main issues, pointing to similarities and differences across three care economies.

### **5.1 (Re) Negotiating Family Relationships**

#### **5.1.1 *Reassuring Performances***

Family caring sits precariously as both a ‘normal’ expectation and an ‘abnormal’ category of experience in relation to individual and shared life trajectories. Family carers comply with or deviate from these expectations in their everyday routines and concerns. The inter-dependencies which stretch across the life-course are constantly negotiated between family members. As suggested by Kittay and Feder (2002), this can involve performances of disguise by givers and receivers of care, as the extent of



obligations and willingness to request or fulfil them are tentatively explored in order to avoid distress or undue pressure. These hidden aspects of caring at home are a common function within caring relationships (Kittay and Feder 2002; McDowell 2004b), yet understanding and articulating hidden tensions, inter-dependencies and reciprocities is perhaps a necessary condition to ensuring care for carers (see Kittay and Feder; and Deacon 2007, for a discussion of the concept of 'doulia').

Carol's mother had multiple and complex health problems until her death three years before our interview. Carol worked full time in a retail position when this caring began, and her hours declined as her mother's multiple health conditions deteriorated. Carol described in her retrospective diary and subsequent interview how she had not received formal support from social care, or any support from siblings, though she did have a brother living nearby. Eventually she took the decision to give up paid work and care full time for her mother. From this context, it would appear that a 'collective' understanding (Pyke 1999) of obligation was shared between Carol and her mother. Carol's story exemplified how both care-giver and care-receiver sought to hide their discomfort at the level of care being provided, and the impact this had. Carol's care could be seen to be taken up graciously' by her mother and therefore achieved (see Kittay 2011). However, Carol described how discussions about money had been extremely fraught on both sides, not acknowledged by either until the situation could be renegotiated through the introduction of Direct Payments.

It's the way we see things from the caring point of view, that sometimes no matter how close you are to the person that you look after, sometimes they don't tell you exactly how they're feeling... what I hadn't realised was prior to the Direct Payments, six or seven months prior to that, is how much my Mam was feeling herself that because of her I had packed work in, the kids couldn't get different things they wanted, we'd lost wer [sic] house, you know and it just, it seemed as if it had lifted a load off her shoulders (Carol, Interview)

Therefore, unease was disguised in order to 'care' for Carol. When an alternative presented itself, Carol's mother was able to then express the frustration she felt. Paying Carol for the care she provided brought reassurance and comfort. One consequence of such reassuring performances (for care-givers and care-receiver alike) is the opportunity to learn and gain confidence in one's own ability to cope. It is this silent coping that

makes the extent of caring roles difficult to fully appreciate, and which often goes unrecognised by those not proximate (Milligan 2005). From a carer perspective, caring roles are often conferred upon those regarded as most able to manage. This was read as such by many carer respondents, who saw themselves as able to respond when under extreme pressure, drawing acknowledgement from other family members, health visitors, social workers and friends for their determination and tenacity.

The ambiguity involved in negotiating care practices and intentions makes care difficult to establish as having being 'achieved' as Kittay (2011) proposes. Such ambiguities can stretch through time way beyond the performance of specific tasks, and can be subsequently undone. Carers' practices and relations emerge by negotiating the intentions and capacities of others. Compliance and intention, subordination and resistance, settlement and disruption are evident in the becoming of carer identities and practices. Carol's example demonstrates how the negotiation of meanings and intentions at the present moment is perhaps a more appropriate focus for attention. Care practices, routines and roles can be taken for granted and appear to reflect essentialised characteristics (of gender, age or family position), but are in fact the result of complex negotiations and compromises.

### **5.1.2 *Embodied Capacity, Skills and Knowledges of Family Care***

Care has been described as a combination of 'caring for' and 'caring about' (Milligan 2003; Grant et al 2004; Milligan 2005). This section considers the various elements to this, and then seeks to show how 'caring about' influences the way 'caring for' is negotiated. There is no clear dichotomy between embodied and emotional support, though as Fisher and Tronto (1990) suggest there is a means of validating the quality of care according to distinctive care ethics of: attentiveness, responsibility, competence and responsiveness. These can be performed in a one-one relationship or can be negotiated by coordinating various caring relationships.

Aspects of privacy, dignity and control inform the way caring practice is negotiated with the older person. There is a practical issue about the capacity to perform certain tasks which family carers negotiate. This involves both physical strength and dexterity,

but also skills and knowledges. Unlike care-workers, family carers are rarely trained for such tasks formally, but instead learn through experience. Despite their lack of formal training, because of the intense and extended duration of caring for one person, family carers can become more ‘expert’ in the care of that individual than anyone else (Arksey and Glendinning 2007; Glendinning et al 2008). Bourdieu’s notion of habitus (2004) suggests such dispositions are ‘created by’ the ‘field’ of social relations, which are accumulated and become settled so that an individual develops a ‘feel for the game’. This leads to the formulation of accomplished practices (Merleau-Ponty 2007), which Louise Holt (2008:231) has described as ‘embodied capitals’.

In Barbara’s diary she described how habitualised knowledges and practices had formed around her husband Bill’s bodily needs, and the critical time parameters of these. The complexity involved in a leisurely trip out in the car was described by Barbara.

...when A.. and S.. arrived, Bill refused to go. I reminded him that I wouldn’t take him out if he hadn’t urinated as there would be no toilet tho’ I take a bottle with me for emergencies. Also there is no way he can last out from 10.30 to 4pm and the slightest chill in the wind would more than likely trigger an accident and wet trousers. (Barbara, Diary)

Double-checking, accounting for resistance, conditional demands, contingency plans and avoidance of additional domestic work are all involved in this one simple decision to go for a drive. It was clear how much Barbara’s home and her identity as a carer had become infused with her capability to use medical terminology and handle medical technologies such as convenes, hoists and specialist beds. Similarly, Gayle described how she needed to be fully aware of her husband’s bodily needs, such as toileting, describing what he would need to feel comfortable throughout the day before she could leave the house or get on with housework. This involved checking the convene, checking there was sufficient water in the glass by his chair and making sure his reading glasses and remote control were ‘at hand’ as he was unable to move to get these himself. In her diary, Gayle remarked how her routine and embodied knowledges were very precise, and that the sequence was very important. Gayle made her husband a cup of tea shortly before the arrival of the care-workers, as she knew she could not manage taking him to the toilet herself.

9.00 sorted out washing for day as I get quite a bit of soiled washing per day as convenes leak or come off quite regularly.  
9.15 make Peter cup of tea to drink just before carers come as he daren't drink hot tea other than when is going to loo as I can't get him to the toilet without carers. (Gayle, Diary)

As Twigg (1999) argues, bathing is an intimate practice which positions an older person as 'like a child' and therefore is difficult to contemplate from an adult daughter's perspective. Carol described how she took a great deal of care when bathing her mother, as her skin was as fragile as tissue paper. She picked up tips from nurses how to pat down and create a warm environment to reduce the need for rubbing when drying her mother's skin. Besides the practical knowledges and embodied practices she picked up, she nevertheless felt uncomfortable doing this task, describing how she often stood behind her mother to preserve her privacy. She noted that several friends of hers had said they could not imagine having to cross the line in such a personal way, and would not do so. Carol argued that it was difficult to do, but nevertheless meaningful, serving to bring her closer to her mother in her final years.

There is a relationship between the embodied capacity of the older person in need of care and their carer's bodily capability. It can have consequences in terms of which tasks can be performed and which cannot, such as lifting; the time it takes to perform particular tasks, such as bathing; and the emotional stresses that are produced through the difficult embodied interactions. James noticed that tasks took longer to do as time passed, making him reconsider returning to work as planned. James helped his mother to perform everyday tasks and movements around the home by prompting regularly. The knowledge he acquired from carer training arranged by his local carer centre gave him additional confidence. This training, together with embodied knowledge of his mother's strengths and weaknesses, meant he was aware of when prompting was necessary:

I'll say to her 'Right, now if you put that hand on that arm', she won't naturally think that's the safe thing to do, and 'put that hand on there, and then you can turn round. Make sure your backs of your leg, the chair's on your leg before you sit down'. She won't do any of that herself. She won't. I would say she's not savvy anymore, she hasn't common sense in a way, as good as it was. (James, Interview)

This attention to detail was important in helping his mother into the kitchen for meals, and relied on embodied knowledge which many care-workers may not be able to acquire or sustain. Everyday activities were becoming slower, and required a great deal of patience as well as some physical strength for both.

It is taking longer to get mam onto the stair lift, it's taking longer to get her moving into the kitchen if I'm going to give her something to eat, but I can manage, I can do it. Lifting Mam isn't a problem, she's still got strength in her arms, so she's getting out of the armchair, she presses down on the arms at the same time as I probably help lift her as well, but again, getting out of bed, she can press on the bed, and she's got a bed rail which she can grab onto, and again I might just help her under the other arm. So, physically, no, we can just about manage. (James, Interview)

For Frances, a woman in her eighties looking after her spouse in his early nineties, the situation was very different. There were occasions when she felt able to strip wash her husband, but only when he cooperated. This was as much about inter-personal resistance to the support as to physical capacity to achieve the task.

And then at times when I think I can handle him, I give him a strip wash, take his pyjamas off, put his feet in a bowl of water, and wash up his legs. Cos he won't go in a shower, he won't. Well I couldn't get him in a bath anyhow. And I have to choose a moment when I wash his hair, or cut his nails. I've got to do all that for him. (Frances, Interview)

Lifting appeared to be a particular problem affecting many women carers. The physical strain of these activities day to day and the emotional consequence of dealing with resistance could be frustrating. It is unclear from the statement below whether Barbara's inability to deal with her husband's toileting needs was the result of physical incapacity or emotional fatigue.

I've come in to say to Bill 'Right, we'll do the convene' about half past nine, 'I'll come back and give you a hot drink at ten'. Which I do. Go in at ten, and I'm just about to give it to him. I had everything on, and he said 'I think I want to go to the toilet'. But the convene. He said 'no I need to go'. So twice he's wanted to go to the toilet at half past ten. So by the time I get the chair in, and I say 'Right mind, you're going to have to get out of the chair yourself because I CANNOT' [emphasised]. (Barbara, Interview)

Similarly, Hilary described a distressing situation when her husband fell after being in the bathroom and she couldn't get him up. Until that point, her husband's poor mobility following his stroke was not very evident, so this fall made Hilary aware of her limitations in providing physical support. Fortunately, they had a telecare service which they called upon to assist.

### **5.1.3 *Boundaries and Limits of Family Care***

Caring for older people is not a static situation – it requires a constant renegotiation of time, practices, and a redefinition of relationships. This section explores how family carers negotiate the limits and boundaries of the care they provide and receive.

Facilitators and constraints altering one's life-course trajectory can be interchangeable, influenced by particular material contexts and subjectivities. Having been through an intensive caring experience with her mother just a year before, Amanda articulated frustrations and uncertainty about where her future priorities should lie as her father's situation deteriorated. Though she often expressed guilt at not being there during the day, particularly at mealtimes, she was also very conscious of the loss of self-identity and restriction she had experienced when providing intensive caring for her mother, describing such a scenario as dangerous. Therefore she was resistant to the prospect of giving up her employment to care full time for her father, but unsure what the proper boundaries and limits should be. From an empathetic imagination of her father's position, she suggested if it came to a decision she would take responsibility herself rather than see him in a care home.

'Cause I'm like thinking, when I'm their age, I'm going to be in care, I find it quite scary that that, and I . It's probably horrible, but I, I think of them as old people's prisons. And that's probably awful but that's the way I think of them. And some of the experiences, of what I've seen in them, is pretty disgusting. I mean I'm sure there's good ones, and I've heard of good ones, but some of them, you know I wouldn't put a dog in. So no, it would be my last, my very very last resort. (Amanda, Interview)

For people who value caring practice as worthwhile, but who cannot put their time where their values are (Hochschild 1997:219) because of meeting paid work

obligations, this can produce negative affect, such as feelings of guilt arising from reflexive judgements on the self (Hochschild 2003a,b,c). The particular value systems and feeling rules of individuals differ, so the perceived normativity of particular actions and orientations affects the experiences of giving and receiving appropriate levels of care. The importance of keeping true to the sense of who the cared for is (and was) can mean negotiating boundaries with others. For Barbara, drawing on paid care-workers for support generated an additional negotiation in her caring practice with her husband.

They say well will you have a word? No, I know some days he might listen to reason, but mostly he says I'm not going to do it. I think it's his way of taking control of his life. (Barbara, Interview)

Compliance and resistance was particularly significant for spouse carers, who were renegotiating power relations of their existing relationships. For many, the inclination to support the agency of cared-for loved ones was balanced by their own need to get through everyday tasks and keep their own spirits intact. Frances described a shopping trip in her diary, in which her husband was in an 'awkward mood' which lasted all day.

Eventually succeed and get home tensed up. Decide to relax before getting dinner. Ham-salad and chips but husband won't eat it saying it is horrible, off he goes to sit in lounge. I finish my dinner – very stressed so go and lay on the bed. Fall asleep till 3.30. Get up have a cup of tea then go and bake some cakes. Husband has just sat talking to himself all afternoon. Will not take his shoes off. However have tea - sandwiches and cakes which he enjoyed. Watched television till bed time. Not the best of days. I feel like a good cry. (Frances, Diary)

The difficulty of maintaining a sense of control within everyday routines was matched by a difficulty in imagining a future which was beneficial for both. Frances described how she worried about current and future boundaries and limits of her ability to care, and also the uncertain consequences of not doing so.

And I think, yeah, we'll stay here, he's alright and I'll look after him as long as I can. And then other days, when I'm so tired and I think 'Oh why am I doing this, shall I sell the house, put him in a home'. And then I think to myself 'Well where would I go, what would I do? You know. I sometimes wish someone would just say to me 'Look, you're there, and do it for me you know

what I mean, it's all done for me, and I've got no say. But life's not like that is it? (Frances, Interview)

A focus on how to maintain relationships and respect the personhood of loved ones when the present conditions suggested eventual decline and loss was clearly a worry for Frances whose own health was becoming a concern. Having someone else make difficult decisions for her was perhaps one way she could come to terms with contemplating her husband going into a care home. In these circumstances, choice and control being in one's own hands was a burden rather than a benefit. For some carers, decline in health wasn't inevitable. Working together with her husband Jim who had suffered a stroke earlier that year, Hilary described how they didn't regard the situation as permanent, and for this reason they patiently tried to engage in conversation, which sometimes ended in frustration.

The thing is Jim sleeps a lot so I really miss all the great conversations we had but again he is patient and tries to make me understand, sometimes I can, sometimes I can't. So he will just say forget it, and we will try later. (Hilary, Diary)

Experiencing a slow 'loss' of the older person when memory and other mental capacities decline were similarly responded to James, by prompting, reminding and maintaining routines. As he described during his interview:

I have to try and keep giving Mam bits of news, or keep prompting her with things, keep putting a paper under her to read, or er, but she won't often do things herself now... I've got to actually help her to watch television, it seems a strange thing to say but. So I'm afraid I've noticed that increasingly, that Mam is less and less herself. It's not Alzheimer's disease where I know the character can change markedly, you know and sometimes somebody can become a different person altogether. It's just Mam sort of seems to be just withdrawing gradually I would say. (James, Interview)

An under-acknowledged renegotiation for spouse carers is levels of intimacy and sexual relations. These can be significant for shaping broader concerns about loss, since spouses in this study shared experiences with their partners across several decades. Redefining their sexual relations was an ongoing negotiation between Barbara and her husband, and one which continued through its articulation, if not in its practice.



Bill asked tonight why I was 'going upstairs to bed' and not getting in with him. He half queried once before but this was straight out and he didn't like the answer. I'm sure he'll come back to it. (Barbara, Diary)

On another occasion, Barbara described how Bill was 'feeling romantic'. At my first meeting with Barbara to hand over the blank diary, our discussion moved towards the loss of sex life, and loss of a loved one as a lover. She produced a book '*The Selfish Pig's Guide to Caring*' by H Marriott, which she had used to explore her loss and her frustration. I found it interesting that the book title appealed to her, perhaps indicating a negative self-identification, despite the round the clock caring she provides to Bill. Barbara revealed to me that even in her seventies, it was something she couldn't get used to. She was the only spouse to mention sexual intimacy and its loss, though this could occasionally be inferred from comments by spouses about the loss of the former relationship, and the difficulty they had forming new understandings of their future – for many as alone but not alone.

#### **5.1.4 *Negotiating Support: Options for Family Carers***

Barriers to making optimal consumer choices about care can be due to lack of information and other practical considerations, but can also be a moral decision (Lucey 2004). Information deficit, confidence in managing relationships with professional agents, or a misperception of available options all impact on the capacity of individuals to access resources (Arksey and Glendinning 2007). When navigating the pros and cons of taking up formal care support, family carers may experience dilemmas about the best possible care, with practical considerations of maintaining a stable sense of family life. These negotiations are often gendered, as 'doing the right thing' may be anguished over by individuals in different ways for different reasons. Those who have not been socialised into such roles and expectations may worry they do not 'naturally' possess the necessary aptitude or skills; whereas for those who view care as intuitive, this may predispose them to accepting caring roles.

Consumer practices can be used to demonstrate love and care within families (Miller 2004; Deutch 2008). Deutch argues traditional notions of good housekeeping valued

thrift and good management to enable luxuries, which can lead to a focus on value rather than quality for everyday expenditure. Quality of care is bound up in the assumed characteristics and intentions of carers, who face a 'pay penalty' themselves (England and Folbre 1999) as their intrinsic rewards are construed to outweigh their poor or absent remuneration. Family carers in this study who drew upon paid care-workers as part of their team were largely unaware of their pay, surprising given the extent to which they were involved in the most intimate aspects of their home and family life, but this perhaps allowed a certain distance from which to focus on the older person's care.

Being an adult daughter living in close proximity to her mother, Carol described how her caring was not a decision as such, but simply arose as a natural development of the existing mother-daughter relationship. She believed that taking this role automatically was a common philosophy among families where she lived. She was aware that some families acted differently, but in working-class families like hers, you 'looked after your own'. As Carol's mother's health conditions deteriorated, her caring role grew until it became the dominant aspect of Carol's life. Leaving her full time position in retail, and selling her family home to cover the lost earnings, Carol found it difficult to imagine doing otherwise.

Until you recognise yourself as a carer you don't realise what's there for support. You carry on, I don't know how to describe it. You carry on doing things as a family and as a daughter, without looking outside the home for help. (Carol, Interview)

For Carol, direct payments were an important development and a big change to the way she provided care. Because Carol was not living with her Mam, exceptional circumstances were granted to allow her to receive Direct Payments due to the extremely high level of care required.

The biggest help came from Direct Payments. Mam was assessed as needing 33 hours. It had been hard to persuade to accept this as we did not want strangers looking after Mam. It took Soc Ser from Feb 2004 to Nov 2004 to get Mam and I to accept them. To be honest once they started we wished we had done it sooner. Soc Services gave permission for DP's to be paid to me. I was told to take a step back from being a daughter, and see how much care I was giving to Mam. (Carol, Diary)

Carol's reluctance for strangers to be involved is a common issue, and was also articulated strongly by Amanda (as discussed below). In Carol's example, social services staff suggested the daughter relationship and the 'care tasks' should be seen separately, which does not equate exactly with official guidelines which presupposes unpaid care by family. This demonstrates the continuing importance of 'street level bureaucrats' (Lipsky 1971, 1980; Ellis 2007) to how social policies become established in places, influencing their effectiveness and outcomes. Carol was one of the first in the local authority to take up this option, and she described receiving a significant amount of support from social workers. They persuaded her to accept payment for her care, suggesting that there would not be a facility in the area which could provide care to the same standard or intensity she provided. Most of her time was spent at her mother's house, round the corner to her own, leaving little time with her husband and children; a situation which intensified in the last two years of caring. She believed that without her husband's understanding, caring for her mam in this way would have been impossible. However, Carol also felt it should be an automatic right for family members to be paid through Direct Payments, favouring a thorough assessment, as this option could be abused, and care might not actually be delivered.

Resistance by the older person to alternative support in the home can also make both formal and informal support difficult to conceive or access. Some older people with social care needs prefer formal over informal support from family or friends, as this helps to maintain existing relationships in their current form. However, for some, maintaining privacy was an important factor which made taking up formal options undesirable. Though Amanda recognised the value of respite care options available to her, her mother was resistant to paid carers being in the home. She shared her mother's unease at family privacy being invaded by strangers, but would have liked to draw on occasional non-personal respite care by friends:

I had friends saying, well we'll come and sit with her for a night so you can go out for the night. And I was thinking, she wouldn't have it, you know. She would have raised the roof, you know. So I don't really know. And I'd have to think about it long and hard to probably come up with something 'cause it's such a minefield, depending on what your individual situations are. (Amanda, Diary)

Amanda hoped her father's awareness of how much caring for her mother had affected her health would make him less resistant as his own needs increased, enabling Amanda to consider her options beforehand. She described how she felt able to advise others, in a similar way to the advice she received from her friends.

I could tell that her talking to me, having been through it, was helping her, and I also know, that having had a few years ago, spoken to like older friends of mine, who'd gone through it with their parents, I kind of, a lot of what they said helped me even though I'd heard it years before. And I can sort of see, but if you haven't got that, you don't know. (Amanda, Interview)

An important issue in accepting formal support is direct monitoring and regulation of caring activity in the home, which can be a source of strain and anxiety, particularly when things 'go wrong'. Barbara constantly monitored her husband's symptoms throughout the diary, and used her 'expert' knowledge to advise paid support workers (Twigg and Atkin 1994). In her diary, she described her worry over a lunchtime 'happening' in which physical aggression was displayed by her husband while she was assisting the care-workers. His 'hitting out' at them resulted in her using restraint, holding down her husband's wrists, which was then reported to Social Services as a matter of course. Needing to consider this situation from the 'outside viewpoint' was a consequence of agency staff being regularly present in her home. The increased surveillance brought about by the presence of external agencies led Barbara to seek advice from a knowledgeable person from the Alzheimer's Society, who provided sympathy and a sounding board to weigh up in her own mind the justification of her actions.

I told her how worried I was about the result of the Tuesday lunchtime happening and told her all about it. She seemed to think I was justified in trying to stop Bill from hitting out at people but we both could see how it would all seem to the outside viewpoint. Anyway, I just needed to talk, to someone I could trust, about it all. (Barbara, Diary)

Though Barbara described the utmost trust in the care agency staff (alternatively referred to as 'friends', her 'team' and 'family') she knew her caring practices were being monitored. She therefore felt she needed a trusted source of support from elsewhere. Barbara's friend at the Alzheimer's Society could be trusted most to see

things from her perspective, yet impartial enough to give real reassurance about her actions, as she didn't believe family or friends would be able to offer adequate advice. Several family carers described the benefits of sharing their experiences in carer groups or with people at work who were in similar circumstances. For Hilary, it gave support to her husband, who had suffered a stroke earlier that year. It gave Hilary time to chat to other carers which was welcome respite from her usual routine. In accessing such formal support for her husband, it generated a secondary benefit for her own wellbeing.

He really likes going to the stroke club. They make things, and again, I get to chat to the other ladies. (Hilary, Diary)

The importance of respite from the daily routine was a significant theme for family carers, much of which was obtained from formal support from voluntary organisations. One of the ways in which decisions to take up formal support is often deferred, is where family, friends and neighbours can be incorporated into everyday routines. As well as informal support to assist with caring for an older relative, informal caring involves supporting family carers too, sometimes as a deliberate intervention as a form of respite, but often as ad hoc gestures to supplement family care. There are some similar issues underpinning formal and informal support decisions, but also some important differences. The decision of family members to accept offers of support is influenced, not only by considerations about what is in the best interest of the care-receiver, or what would alleviate circumstances for themselves, but also by taking into account the existing relationship with the person making the offer.

Many family carers in this study had support from other family members to some extent, and most were primary carers who received ad hoc respite support from family. Carol revealed she had never been in touch with any carer support or other voluntary associations, relying instead on occasional respite from other family members. This additional support to her mother's caring routine meant Carol could spend some time with her own family.

Get some housework done when mam resting. Make some calls to Soc Services also Freeman's hospital. Shopping needed and bills to pay so waiting for Aunty to come sit with Mam. (Carol, Diary)

In home-based care, the role of the neighbour can take on greater significance in caring for older people, but this additional support is negotiated carefully by family carers. James' caring is supported by home-carers who assist with washing and dressing his mother. Support from neighbours also became a consideration to supporting her emotional wellbeing, when James realised there was a need to boost her daily interactions and interests to combat depression:

When as I say, mam is sitting, you know, with her head in her hands, I think well what else can I do to sort of alleviate this, try and you know make things better for her? We're hoping that, there's a lady in the next street. I haven't asked her yet but I think she might start to come back in, now that I'm here full time, I think she was probably a bit reluctant to come in when Mam was on her own. But I'm sure she'll start to come back again. That would be a bit of extra input for Mam. We're just trying to look for other bits of extra input. (James, Interview)

In considering offers of support from neighbours and friends, however, there is a negotiation in working out how the existing relationship might be reconfigured, depending on the closeness of the existing relationship. The perspective of the neighbour or friend is considered empathetically by Amanda, who felt her neighbour was offering more than they are obliged to 'as a neighbour'. These negotiations may take on particular classed and gendered rationalities as the privacy of family life and the home is often more highly regarded by middle class people than in working-class communities. As Campbell (1984) contends, the differential capacity to maintain privacy due to material and spatial arrangements of middle class and working-class homes and neighbourhoods contributed to this social or moral order. Amanda describes this tension:

I mean I know one of the guys a couple of doors up has always said if I need him to. I mean, at one point he said oh I'll come in every day. And I said no that's too much of a commitment for you, that's not fair. You can't expect someone to do that. But, I know he's there if I need him, so like he'll be getting the phone call when I'm away [laughs] for the week. And I know the neighbours will bring the bins in, so they're not lying round the streets, em that sort of thing. (Amanda, Interview)

Daily commitment is seen as problematic between neighbours, perhaps influenced by duration of residency and the length of relationship, but may also refer to the

expectations of the relationship itself - that neighbours have no a priori obligation to make a long term commitment to each other, compared with family members by implication. Amanda identified the level of appropriate support she would be willing to accept: to provide help in exceptional circumstances such as when she goes away from home overnight and for more 'light touch' impersonal but nevertheless critical help at street level – bringing the bins in. Concerns about safety and security during the day are also clearly relevant. Amanda had an alarm system installed at a height to enable her father to operate it himself. Furthermore, street indications of the vulnerability of their home were raised by Amanda, who was often at work during the day. This weekly gesture of support means her home does not stand out as vulnerable, and provides a visible reminder that further support is available when required.

## **5.2 (Re) Negotiating Care-Work Relationships**

### **5.2.1 *Imagining Family***

The negotiations of carers' everyday practices reflect personal histories and rationales which are mediated by current circumstances, and can mean a reorientation from previous modes of caring practice. The history of the gendered division of labour within Tyne and Wear working-class cultures is likely to accentuate the importance of gendered moral rationalities to care in particular ways, and construct the concern to be seen as a 'good enough' carer in paid environments. This was evident in care-workers whose had grown up in the local area, and for those who had settled in Tyne and Wear from elsewhere. In many ways, the moral rationalities of the migrant workers in this study corresponded and perhaps exceeded these concerns about the position of family members with regards to caring responsibility.

Marta suggested that back home, care homes and paid care workers were rare, because this was seen as a family responsibility. So in her role as care-worker, she tried to 'see family' in her clients. Even for those care-workers who were not prompted into the job from personal family experiences, once caring roles were established, family still played a role in the imagination of caring identity and practice:

But always even before I started this work, or in the care home I found that I want to look after those people as if they were my parents or my grandparents. So I always try to see like some relatives. But it's hard to say whether I would be better or worse work carer if I had that experience. (Marta, Interview)

Similarly, Gemma described how she considered how she would like her grandparents or parents to be treated in a care setting.

I've always just wanted to do the best, you know the best of my ability. And how I would want my Nana, or my Mam or you know, somebody that kids looked after. I always transfer that, and if it's good enough for mine, then it's good enough for other people. (Gemma, Interview)

The concept of family is drawn upon within care-worker accounts to describe the closeness of some relationships, or as described above, to step into the shoes of an imagined relative, though there is also concern to ensure these do not impinge on 'real' family ties. Ewa explained how building care relationships was a slow process, which in Ewa's case she put down to a perceived lack of trust in foreign people, overcome in part by the acknowledgement that her presence was beneficial to the clients. This was negotiated by building a rapport through what she describes as 'women gossip' such as shopping, home life and discussing television programmes.

Oh slowly slowly you know. From the beginning maybe they don't trust well foreigners, and now it's really good yes. She found this [laughs] I am good for her, so. (Ewa, Interview)

Describing how her embodied practices of domiciliary and personal care support required emotional engagement which involved giving and receiving positive feelings, Ewa suggested:

We have to love people. And really need to help each other, because this job really need, you have to be calm, and patient. And like people, like help. And I realise really when you give somebody something you are more happy, like you get something sometimes. So, and always smile, be open. (Ewa, Interview)

However, Ewa perceived the limits to the rapport and the relationship, which, rather than forming part of an imagining of family, she defined by her status as non-family.



She prioritised real family relationships of her client, and decided it was not appropriate to interfere. Deciding it was inappropriate to share her own problems, she chose to present a positive image, engaging in what Hochschild terms 'emotion work' by smiling and saying everything is okay (Hochschild 2003a).

When I think she's in trouble with family, I rather be erm, near and don't give her any advice just calm her. You know I don't want to interrupt in family problem, you know like family one day is battle and another day is good. So rather not. And the same, I don't tell her my problems, always smile everything is okay. Because I think when I would be in her case, maybe what it's like she sometimes, when she is in bad mood. Everybody has sometimes, has bad days so. (Ewa, Interview)

Beyond such imagined and real family relationship dynamics with the older person, there were other significant issues to be negotiated with the family of clients. Recognising the difficult circumstances of these family carers, some care-worker respondents described how they were positioned as also caring for family carers as much as the older people themselves.

They see, not just me personally but all the people, you know as a life line. A respite for them. Some of them don't get any break at all until we go in. And then once you get to know them, and you know, they do open up. You end up knowing all sorts about people. And it's just part, you just listen you know. I cannot tell them how to run their lives, but just sometimes for them just to talk and get it off their chest, and have a bit of a bit of a babble for a while. Just helps them doesn't it? (Gemma, Interview)

In turn, care-workers recognised the importance of support from neighbours and friends, not just as ad hoc or latent support for their clients and families, but for them personally. There was considerable reassurance brought by 'having good neighbours' for clients, but this also had a positive impact on circumstances for the paid care-worker.

Her neighbours, I mean she's got nice neighbours as well, and erm. I've seen me standing, maybe on my way from Jennifer's and standing talking to the neighbours as well. About anything, the weather, anything. General conversation, you know. Aye, I think yeah aheh. I think, I like my job, I just think I'm lucky at the minute touch wood [laughs touching head], touch wood, you know what I mean that I'm quite content at the minute. I really am, I really am. (Megan, I)

The reassurance to Megan that her client had good neighbours presumably made it easier to leave, safe in the knowledge that others were available to respond in an emergency. This is especially important when clients live alone and do not have strong ties with family members or friends. For care-workers who operated alone from one house to the next, like Megan, it suggests interactions with her client's neighbours can bring increased social contact during shifts. Megan suggests that she felt her role was recognised as valuable by her client's neighbours. This brought visibility and validation to her role as carer.

### **5.2.2 *Embodied Capacity, Skills and Knowledges of Care-work***

Skills associated with care can be regarded as intrinsic (often essentialised by gender) or learned and incorporated as embodied knowledge so that it appears instinctive. Tasks and relationships that are nurturing or affectionate are often construed as intuitive and done for love (Acker 1990), but these are also devalued and deskilled. Such embodied knowledge is assumed to belong to family carers who, in contrast to care-workers, have accrued their skills and knowledge in response to a particular individual and not in a generic way through formal training. However, care-workers develop caring skills and knowledges as a consequence of their own family caring which are utilised in paid contexts.

Balloch et al (2004) discuss the problem of securing minimum requirements by standardising and professionalising caring knowledge to NVQ level II qualifications. Small employers experience difficulties in arranging and affording training, viewing it as unnecessary for an older female workforce who have acquired skills over the life-course. They found older women themselves often did not perceive any direct benefit as they felt their skills were already beyond the minimum level. With little interest in career development, they were reluctant to seek to fit training around their other responsibilities. In contrast, Balloch et al (2004) found that younger employees were more keen to acquire qualifications, but this often led to a high turnover of staff as they sought to advance their careers elsewhere. Yet achieving formal care qualifications were not incentive enough to make a commitment to this sector long term – as many new recruits quickly

moved into less demanding work on similar (minimum) wage levels, such as in retail.

The ubiquity of some of these personal and domestic tasks can lower the perceived importance of the skills attached to performing them, as they are done by many people in their everyday lives, or demeaned by many as 'women's work'. The drudgery and embodied messiness of some aspects of care of older people can 'other' those who perform this work (Ehrenreich 2000; Twigg 2000). The low pay in care work is perhaps connected to the nature of the tasks performed, with illness and degeneration of the body acting as a reminder of our own mortality (Douglas 1991). However, discourses of the abject conditions of embodied care work are less present in accounts of carers themselves. Most care-workers described their caring practices in mundane and pragmatic terms, rather than raising abject emotional responses. This suggests they were either unaffected by what others might find distasteful or difficult; or saw beyond it and were portraying a neutral demeanour to demonstrate their resilience and the value their care produced. Ewa pointed to the practical difference these tasks were making to the lives of their clients.

I have to hoist my client together with the other care assistant. So feed my client because she only can speak and she couldn't move at all. So I listen to her, what she like. So I feed her, sometimes change a pad. Dress, and we move her to comfy chair. I'm doing some shopping sometimes. If she like, and even I was with her once time to the centre, we've been together. What else? Some homework as well. (Ewa, Interview)

In performing this work, there was a certain empathy and imagination about the circumstances of older people, in which understandings of appropriate home and family life were drawn on.

That could be me or my husband. So you've got to realise that they can't clean their skirting boards, they can't clean up, they can't wash the dishes, and you know, you've got house. And I mean they do, they are good to the carers. They make sure the Hoover's there, the iron's there, dishwasher, do you know what I mean? There's only one house that I have to go in and wash the dishes. I get down on my knees and wash the floor. The way I look at it, I run it the way I run my house. (Lorna, Interview)

In Lorna's case, as described in chapter four, the unpleasant or apparently unrewarding aspects of the job were accepted in light of her intentions and former frustration over the care of her mother. Though the tasks are often perceived by those who are not involved with the care industry to be low skilled, unimportant, and undesirable, Lorna elevated the importance of the work, capturing the value and values inherent in her new role. The fact that she had 'got house' was seen as a huge responsibility, with significant meaning. Transferring her informal domestic work into a paid work setting to establish the appropriate quality, this benchmark was perhaps more imaginary or from past experience than current realities, as she described elsewhere how her own home life and routine was suffering as a result of the physically exhausting work she provided on behalf of the care agency.

I mean I haven't been well in myself for a couple of month and I've been going to the hospital and that. And I come in and just fall into bed. And he goes 'you're bloody mad'. (Lorna, Interview)

The tension between imagining family as described in the previous section, and the embodied capacities, skills and knowledges outlined in this often relates to the number of relationships a care worker is expected to engage in. This can affect how well care-workers can get to know their clients, and the level of fatigue or emotional 'burn out' that comes with care work. Currently working with four clients, but having worked with six since starting in home-based care, Elizabeth explained how this was preferable to a residential setting.

It's different because in the home there's just many people at the same time, but I felt in the home I couldn't work in the home, since there are too many. You don't get time to like know each and every person or time to talk to each and every person whose. It's just too many of them. But now with home care it's good, because you know it's a one on one thing, so it's just you and the client and you know you can talk, get to know the client more. (Elizabeth, Interview)

As with Marta and Megan who shared similar work histories, all found previous work in a residential care home to be less satisfying personally, and less supportive of clients' sense of personhood. As Elizabeth explained, the requirement to 'double up' when

toileting clients in their own home, and expressed a preference for one-to-one care in the residential setting.

E: We do the double ups for that. But in the care home we used to do it one-on-one, so we weren't allowed to do it double staff. Just me and the service user. I wash the service user. Unless it's someone who needs to be hoisted and stuff, but it used to be me a lot different times. That's how it's different.

A: and did you find that a struggle to do that?

E: No, no no. It was okay, really nice because I think for their privacy you know. It's good that way. You can't be two or three in a room, just to wash a person. I think it's good that way if there's just the two of you. (Elizabeth, Interview)

A range of skills and knowledges were required of carers who had multiple caring roles. Several care-worker respondents worked with older people and young disabled people. Daily tasks ranged from housework, personal care and peg-feeding for older clients to play and leisure trips with younger clients. Gemma, felt able to adapt to these roles because of her considerable experience, having worked as a carer for over fifteen years. She found her practical experience on the job was useful as a supervisor, suggesting the role would be difficult without it:

The office based you could. But even then, no. It's sort of knowing the people and putting the right people, so you've got to have that. And I mean people sort of ring, and say the bag's blocked or, you know it's something. If you haven't been out there you don't know. You cannot give them any ideas, as to how to deal with it. So (Gemma, Interview)

Emotional and embodied caring practice is often essentialised as a disposition which is gendered, classed or racialised. A complex interplay of wider economic restructuring, embedded histories of work and inter-personal relations over the life-course can influence the construction and relevance of differentiated gender roles in terms of socialisation and cultural expectation, affecting how individuals become enrolled into caring roles.

### 5.2.3 *Boundaries and Limits of Care-Work*

For some, escape from the confines of the home to more social contact with work colleagues, regardless of the job, is welcome (Miewald and McCann 2004). For others, this brings deterioration in life satisfaction (Hochschild 2003c). The multiple roles of the carer as perhaps mother, wife, sister, daughter, aunt, neighbour and friend show how complex care-worker roles can be, given the way they intersect and create tensions in meeting different care needs and desires.

Because it's not like I get shifts every day, so some of the days I'm here I can do the childcare for myself, like they go to school anyway. Well until three. And I have family who help me, family everywhere, brothers, sisters. (Elizabeth, Interview)

Gemma described how she worked most nights by choice. She relied heavily on her mother for childcare, which enabled Gemma to work till late evening. The terms and conditions of employment in this sector is not a significant pull factor in terms of motivation, but it does make a difference to the way the role is negotiated. Balancing paid caring and family caring necessitated difficult choices, and influenced the way paid carers viewed their relationships with their clients. Gemma saw great value in the independence her paid work enabled, in contrast to her domestic confinement as she had described it. The limits of what to accept when caring for older people were occasionally tested, even to the point of abuse.

I mean one of my clients got quite sort of nasty, and we have to have two carers with him. And I don't appreciate getting spat at. Spat in the face and stuff. But you know, [laugh]. (Gemma, Interview)

Susan is carer to two older adults with learning disabilities. Her caring role demonstrates how facilitating autonomy is not always about managing or resisting decline in older age. There are other sections of the older population who have managed disabilities throughout the life-course, and whose independence may be increasing in later life as the power of institutions and their parents wane. Susan's clients were receiving care in residential institutions until the Community Care reforms of the 1990s, and one man has little connection to his family. Both men live together in their own home, and are supported by Susan, who was formerly employed by Social Services but

now works for a private agency. Both men receive Direct Payments to support their care, and Susan helps them to manage their money.

I get up at 6.30am to carry out paperwork and sort out monies required by both men. Both men get up at 8.30am. Both men are off on a Thursday. 9am – both men bring remainder of washing down and do clearing in their own room. 11am – we go into South Shields to pick up benefits from bank, both men use personal cards at cashpoint, we collect medication from chemist, then have lunch out. Men get personal shopping and pay the bills. We return to the house at 2.30pm, have a coffee and chat, then I finish at 3pm. (Susan, Diary)

Though Susan's paid work was an important part of her life, and she often described her clients as kin, she felt more of a pull towards home and family obligations, especially when she felt the time away from her family was not appreciated by her clients.

Another tiring day, I am just pleased to get home. I felt the men enjoyed themselves but do not appreciate the time, effort and work we do and the time I have spent from my family (Susan, Diary)

Leece and Peace (2010) found a significant element of 'unpaid' labour within commodified relationships with personal assistants (previously known and unknown to the older person) which had a detrimental impact on the terms and conditions of the care-worker, as the pressure to 'go beyond' the usual duties to demonstrate 'over and above' commitment was more difficult to resist in such one-to-one employer-employee settings.

The emerging relationship can bring challenges where personal boundaries and limits are reached in other ways. Difficulties arose for Elizabeth when she experienced racism from her client. This occurred once during her time as a home-based carer, and she was the one who decided how to proceed, not only to protect herself, but because she believed it would affect the care quality.

I'm the one who had to make the final decision. If I wanted to go back there or. But we had to discuss it at the office and stuff, so I say I can't go back there. Because I don't want to go and do that job, in the, you know. I would love to do my job, happy every time, be happy do the right things, instead of me going there being grumpy. So I finished. (Elizabeth, Interview)

This issue was only raised by Elizabeth, the sole black respondent in this study; however Ewa described an initial wariness of ‘foreigners’. The manager of a care agency interviewed as a key informant explained that many clients refused to be cared for by migrant workers, with the most difficult carers to place being black men, as they were judged by colour and/or ethnicity or gender, as male clients presumed male carers would be gay and therefore deemed unacceptable for personal care. The consequence of these consumer choices were that in an environment in which the carers’ contracts were often zero-hours, it was black men who received the least hours or the most unfavourable hours and locations.

#### **5.2.4 *Negotiating Support: Options for Care-Workers***

Good and bad jobs are denoted according to range of factors, including pay, conditions, autonomy and performance demands (Phillips and Taylor 1980; Sengupta et al 2009). Care work is usually positioned as low in all of these, though home-based caring brings more autonomy than in care homes through less managerial presence. Beyond the purpose of managerial control, training and supervision brought an opportunity to socialise with colleagues. Support mechanisms by the employers of care-workers can enable care-workers to meet with others to discuss issues, experiences, and complaints – enabling an informal social network to develop which enhances the social capital. Marta described how the practical knowledge she gained was important in helping her build confidence to work alone, and the variety of training on offer meant she could develop in ways that suited her needs.

It definitely gives you, not only the knowledge, but also some practical...practical side of it, so. Yes they definitely raise your confidence. And then you see other carers, so you can share your experience as well. (Marta, Interview)

Since many paid care-workers worked solo in older people’s homes, or work in pairs within very constrained time parameters, any opportunity to meet up with others enabled valuable reassurance that they are working in the right way, from a practical point of view, and provided an opportunity to share experiences and stories, which raises confidence. Marta described how her previous job working in a residential care



home, working as part of a team enabled her to acquire skills and knowledges that helped her gain confidence and become more autonomous in her current role working alone. Ewa also explained how the ‘double up’ hour became an opportunity to chat with other carers, who were mostly friendly and happy to offer advice:

I’m not bothered, I can work by myself. And I feel really pleasure when I working with other because you know we exchange our experience sometimes and, for example, this woman which working with me on Sunday morning, she had a big experience because she used to work as a carer for more like ten years or twelve. So from the beginning I got from her a lot of advice, and really appreciate, yes. And we like each other so, yes yes. It’s good. (Ewa, Interview)

The confidence gained through practical knowledge, enabled through formal support from training could be thought of as ‘embodied capital’ (Holt 2008), which is the acquisition and retention of particular embodied skills and knowledges only acquired through physical demonstration and repetition. This would be particularly relevant in the paid sector, where embodied capital can be converted into economic capital by getting through work more effectively, or being more competent generally. Since all paid care-workers in this study operated within an appraisal system, positive feedback and demonstrable competence and efficiency would be the principal means of advancing through the rather flat organisational structures within care organisations.

Since informal unpaid carers also articulated the benefit from meeting other carers, in being able to share information, stories and so on, it is reasonable to suggest that the same benefits are also received by care-workers, and for similar reasons: an opportunity to get together to aide understanding of the work role; to combat isolation; for reassurance; to share funny or distressing tales; and to engage in ‘banter’ (Willis 1977; Crang 1995) rather than as a means to acquire particular individual convertible capitals. Opportunities for such gatherings with other paid carers may be as limited as the opportunities available to unpaid carers. Their motivations, as suggested above, may be similar. This may be particularly the case where the gendered and other intersecting identity constructions of paid carers align with those of informal carers – i.e. with middle aged working-class women. Shared habitus and shared values/moral rationalities

across the paid/unpaid divide may sharpen the similarity in the perceived benefits and motivations of accessing formal support beyond the requirements of the workplace.

### **5.3 (Re) Negotiating Volunteering Relationships**

#### **5.3.1 *Emerging Family and Friends***

For volunteer respondents, there was a desire to incorporate new people into their personal community in order to increase their social network, not only to combat isolation, but to substitute for family members who are otherwise absent in their lives. These formal and informal voluntary roles created a space of emergence by imagining family and extending their personal communities (Pahl 2000). Pahl and Spencer's (2004) use of the notion of suffusion can be drawn upon to understand the way in which these personal communities are constructed from a variety of sources, and which contain some overlapping functions and some degree of separation. Many of the younger respondents felt they either missed having grandparents around, or missed their parents and wider family networks if they lived away from 'home'. Others felt they were able to connect with the community through their volunteering activity, often as their sense of belonging was not as they imagined it should be. Danielle described how it connected her to the life-worlds of older people, which were not part of her own family life.

I felt like I wanted to do something, and was actually because, well all my grandparents are dead so. And I felt like, I sort of missed something for me, and I just saw an advert in one of the local papers that just said do you have a spare hour that you can give to an elderly person? And I just thought that is exactly what I want for me. (Danielle, Interview)

For the most part, however, the relationship type most commonly articulated by volunteers was friendship. There was considerable tension about defining their emergent relationships as friendship and for some 'care' was not seen as an appropriate description (Andrews et al 2003).

I think because it's such a small part of my, I dunno. Well we call it befriending at [befriending organisation], which I think is quite nice. Especially because the lady that I befriend, she's a

very proud woman. And she would probably hate to think that I was a carer. And I don't see myself as doing anything to care, we basically sit down and chat, and I'll maybe make her a cup of tea. And we'll just gossip about things, so I wouldn't look at myself as a carer, more sort of, maybe a volunteer I would say. Not so much a carer. (Danielle, Interview)

June described her befriending role as a job, which may have been an issue of language rather than intent.

You ever to do this the job, patience and listening skills, communication skills... And then to befriend you are willing to give your time. That's the character. And the opposite way, you have to have some you know, some erm, some line between. For example, if they say oh you are so kind! Give you some money. You say no. Because you have to have some. Yeah. (June, Interview)

Finding the 'line between' was usually described by befrienders in relation to money. Being given gifts of any kind was seen as contrary to the terms of the relationship, and affected the boundaries and limits. This influenced the extent to which the relationship could be regarded as 'true' friendship. The line between was negotiated in a complex way, ranging from the refusal of money as a professional code of conduct, as a character trait which is innate, and as a mutual friendship which develops over time. June described the relationship with Rita as a friendship.

She is my friend [...] that's why I really need to be there, so really to listen to her. That's really my motivation because, not because I want to get a job, but because I like her. I'm happy to do the job, and I'm happy to accompany her. And benefit each other, accompany her. (June, I)

Though she makes it clear she doesn't want a 'job' out of the volunteering, and positions Rita as her friend, at the same time she describes that she is happy to do 'the job' - this demonstrates the difficulty in naming befriending as clear friendship, even when inclined to think of it as such. She explained that the befriending organiser paired older people with volunteers, and it was important that this pairing was a good match in order to feel comfortable with each other, and also for the befriender to be a good listener. In comparison, Ben often found conversations with his befriender a bit strained. However, he still felt there was a qualitative difference between the

relationship he was building with his befriender and those which were already established with residents at his paid work.

I think the basic difference actually going into the family home. Being invited into the family home. And when I'm working in my job, residents live there, it's not a family home for any of them, they've been referred there. And it is an institution, no matter how you dress it up really. You know, so it's different, being invited into somebody's family home. (Ben)

The site of the caring therefore influenced the way the relationship was perceived. Being invited into a family home enabled Ben to view it as more of an informal relationship than those engaged in within a residential setting, his befriending placing him somewhere between a formal and informal identity. Though it took place within an organised and structured environment, the practice had an informal character, which he found difficult to reconcile:

I would say...I wouldn't say I was a friend, well, prob, well yeah it is sort of a friendship really. I see it perhaps as more, I dunno. I'd say it, I would say it's a friendship. I'd say it's less...less. Although you've still got boundaries, like there's a boundary policy and things you know with volunteering. It's less, it feels less formal than work. (Ben, Interview)

In contrast, Danielle was more certain about describing her new relationship as a friendship, though like Ben, there is still some hesitation over the word in her discussion, and a superimposed label resembling 'fictive kinship' by her mother.

I would say she's a, she's a friend, she's, she's... that's like how I talk about her. My erm, my Mum says when are you going to see your new grandma? That's what she calls [laughs]. So at home she's called like your new Grandma. Erm, but to me she's just like a lady that, she's a great excuse to go and have a natter, and to be there, and to listen to her moans and groans and things. Because they're so different to mine. And it's quite nice to listen to somebody else's issues that aren't to do with work and schedules, and you know boring stuff. It's really interesting. (Danielle, Interview)

The enrolment of care-workers as 'fictive kin' by clients is apparent in care literature (Rae 1992; Barker 2002; Andrews et al 2003), yet less well known how far carer-workers themselves attribute clients as fictive kin. Pennington and Knight (2008) found

in their study of an Australian befriending scheme that both friendship and family attributes were assigned by both sides of caring dyads. 'Doing' friendship and family by volunteer carers in this study was often tentative, and dependent on wider structures of support which was available to the older person (see Keating et al 2003). It is perhaps seen most visibly in the negotiation of such the 'artificial' construction of friendship between befriender and befriended. Derrida (1997:45) proposes it in the rarity and 'perhaps' of friendship that sustains its value (Derrida 1997:42). The formal organisational structures which help to initiate the relationship made it difficult for Ben to see his relationship as a friendship. Relations which are designed to approximate friendship struggle to acquire this status in practice, unless one's social network is weak that this rarity becomes attached to the befriender-befriended relationships, and there is suffusion to negotiate this within the care network

### **5.3.2 *Embodied Capacity, Skills and Knowledges of Voluntary Care***

Accounting for carers' capabilities and resources, social capital is a concept often utilised to measure capacity and connection, including the ability to navigate information and access welfare support and care provision. However, though this may be a useful starting point, it is not unproblematic. Assuming that people's choices are motivated by desire for individual gain associated with the notion of 'capital' contains a rationality mistake. The value and values (Lee and Smith 2004; Lee 2006) of various 'capitals' are not universal, but are only pertinent and realisable in particular places and with particular people. I argue these as 'contingent capitals' as this recognises diverse socio-economic practices, values and expected social roles in which we negotiate with others in context.

In contrast to family caring and market-based caring, there was very little embodied interaction in volunteer care. It was more likely that volunteers would engage in physical activities which did not involve personal care, such as shopping, housework and cooking. Most of the volunteer respondents were befrienders who were guided by limitations placed upon them by the befriending organisation, restricting the tasks they could engage in. Coleen described playing games, cards, looking at photographs and chatting. This was common among all the volunteers, though some did go beyond this

to pick up prescriptions, do shopping, cleaning and other tasks. It was felt by most of the respondents that the tasks involved in their caring did not require training or professional knowledge; instead the concern was to understand the personal histories and circumstances of the person they befriended. Some training had been provided in the use of wheelchairs for some befrienders. Danielle felt initially this was unnecessary, as it would be self evident, but found that it was more difficult than she thought and demanded some strength. The risk management concerns of formal volunteering organisations may have contributed to the feeling that the role was emotional rather than physical support.

For Dawn, her physical support to older people was restricted due to her own embodied capacity. In her diary, she often commented on feeling tired, and having to restrict the volunteering she performs because of her lack of mobility brought on by successive health problems over the years. Instead small gestures of support, often made by telephone were Dawn's way of overcoming this limitation, providing sympathy and a listening ear. Administrative support was a large part of her volunteering contribution, which she was able to do from home. She described one such occasion, undertaken as part of her duties as church secretary.

I telephoned an elderly member of the congregation who had fallen & hurt her arm/shoulder. I spent some time talking to her [... ]Late afternoon I had a seizure so lay down for a while to recover as I feel really disoriented for some time (Dawn, Diary)

Beyond physical capacity, there was discussion by volunteers of knowledge and skills. Nearly all mentioned listening skills as the key requirement to be a good befriender. The men in the study were more likely to share concerns about their level of skill, and how they were being evaluated. Edward's desire to become a social worker was reflected in his negotiations within his volunteering. He took on multiple roles as driver, day care centre organiser as well as befriending two older men. He reflected on how this gave him a range of experiences to draw upon in his future career. He described how walking up the path for the first time to meet his befriendees, and chatting to family, neighbours and health professionals gave him a sense that he was capable of undertaking paid work in this environment, and that the role he was performing as a befriender had considerable responsibilities. Rather than actively seeking to test his capabilities, Ben

was concerned with how his conversation ability was impacting upon the negotiation of the relationship he had with his befriender, and had mixed opinions during the diary and interview discussions about whether his befriending skills were under scrutiny by family carers or by the voluntary organisation. Ben described how the regular silences in the conversations made him anxious that he wasn't fulfilling his role properly. Though he felt the older man got something out of it, he worried that his family judged his ability to maintain conversation.

I have realised in time that the silences are ok and that he will talk when a memory or story comes back to him. There is no pressure for me to instigate conversation. (Ben, Diary)

However, he was interested in the older man's industrial working past, and learned about the local area from his reminiscences in a way which 'brought it to life a bit', yet remarking that he was rarely asked anything in return.

He tends to talk about the same, his working life and his history, like reminisces, but he does observe things on the street, outside and that. But most of the time it's his working past, and his family past and that. Then sometimes, sometimes it'll just dry up, and sometimes it's quiet. (Ben, Interview)

The desire to share relevant experience and knowledge of dealing with health and social care professionals prompted Elaine to situate herself in several voluntary networks. She wished to share with others how she fought institutions and professionals to secure adequate care for her mother. Though part of several formal voluntary organisations herself, she distrusted the formal rules associated with them, preferring the informal community support networks she had become involved in. This she felt reflected her personality and caring demeanour. She remarked that if she been a care-worker professionally, she would act in a similar way, as this would arise from her inclination to go beyond what is strictly necessary.

If I was a younger person and I'd done it as a job, I would have probably been still, regard it as the same. Because I have, it's my failing that I make friendships with people that I'm doing. You know, I can't be impartial, which is what you're supposed to be. So I would have difficulties with that, so. I would always probably do a bit extra or a bit, something that wasn't strictly on the, on the list. (Elaine, Interview)

### 5.3.3 *Boundaries and Limits of Voluntary Care*

Danielle, June and several other volunteer respondents found that their befriendees' relative immobility meant their role was restricted to the home. June found that spending two to three hours going through old photographs and sharing family stories was a good way to help, and she gained a lot from this.

She just want me to be there, listen to her, and we have the afternoon tea together. One time she went to the shopping mall near her house, so we have the shopping. If the weather is bad, we just sit out, cup of tea, something like that. (June, Interview)

June described how in the beginning, discussions were challenging as the befriender was quite shy. She persisted in asking questions because she was curious and interested, and tried to make her feel comfortable. Eventually she gained her trust, sharing stories and problems. June thought it was an indication of their closeness that she now felt willing to 'introduce her family to me' though she explained she hadn't actually met them in person. One aspect of these conversations June particularly enjoyed was finding out about the past, and what her befriender was like in her earlier life.

How she was like as a teenager. When she was aged like me or how they look like, what they do. So obviously she showed me the picture and family, how she looked like. And her husband and children, all the pictures, when she goes for her holidays. We talk about this. And she really really miss the time then. A: so is her husband dead? J: that's why she moved here, and lonely. A: did she move from outside? J: yeah, outside. Somewhere near Lancaster, but I'm not sure. I wouldn't ask too much. At least three hour, four hour drive from Newcastle. And her daughter live beside her, not far from her (June, Interview).

Though they often spent several hours discussing the past and family relations. June nevertheless felt there were aspects which could not be broached, such as exactly where she was from. She was always cautious about sharing any actual information with me about the older woman she was befriending, as this might appear to be breaching the trust. This caution was shared by many of the volunteer respondents. The main concern June had about her volunteering was keeping the commitment going. Though the usual practice for befriending was to stay for a couple of hours, often June stayed longer. She



usually managed to fit her visits twice a week into her work and other routines, but felt she would not like to let Rita down if something got in the way.

I don't want her to feel that way. So I try my best to come, me and her. (June, Interview)

June usually planned her visits two weeks in advance, marking it on Rita's kitchen calendar, with a telephone call ahead of the visit, which was the usual practice for befrienders taking part in this study. Similarly, Coleen described how when she was unable to make the visit face to face, she would often telephone and chat for an hour or so, so that her befriender was receiving some interaction. She described feeling guilty doing this, and avoided it whenever she could, though she worried that the school holidays would mean that she would need to telephone instead of visiting. Negotiating changes to existing relationships with family and friends may also be necessary to accommodate voluntary caring into everyday routines.

Considering the position of existing relationships can shape the boundaries and limits of emerging ones, and can create tensions. Elaine describes how her attachment to her local community through her various voluntary commitments created difficult negotiations with her adult children, who lived some distance away.

My family were getting a bit upset about it. It was interfering with me being able to go down to my daughter's so I retired from it. But I'm not a person that, really, that likes to just sit around. So I'm automatically drawn, I mean. I just, I'm drawn... I don't think of it as voluntary work to be honest, I just think of it as friendship. (Elaine, Interview)

Elaine felt that she had to give up some volunteering in a local lunch club to free up some time to make her diary more flexible, though she commented that her family did not think she should need a diary, as she had retired. However, Elaine felt it was these volunteering commitments which were giving her a sense of purpose day to day. In her case, this brought tensions with her daughters, as she was reluctant to leave her caring routines involving her ill friend, disabled neighbour and voluntary groups, to visit family for any length of time. The hierarchical importance of family over friend relations was therefore challenged by Elaine's account.

The boundary policy of the voluntary organisation imposed limits on the expectations of the befriending relationship. In some senses, this gave Ben a security that his role was appropriate, and that he need not be too concerned that he was not fulfilling his obligations and expectations. However, it also made him reluctant to consider his relationship as a friendship, it being partly a job and partly a social activity for him to disrupt long periods alone. As Danielle described, the rules stipulated that once a befriender became a 'friend', indicated by the desire to give gifts, invite to dinner etc., they should declare they were no longer in a befriender-befriended relationship and therefore not requiring any further input from the organisation to manage, and should therefore seek another befriender to support.

#### **5.3.4 *Negotiating Support: Options for Volunteer Carers***

This section suggests that volunteer carers negotiated their caring practices and relationships in a way which enable support to themselves as well as to those they supported. Volunteer relations have been termed the 'third category of life experience' (Ashcraft and Kedrowicz 2002:96) in contrast to work and home-life, as there is no particular contract which formalises their relationship. In a study of volunteers in a domestic violence shelter, they found that by lacking specific or regular ties to their voluntary organisation (in comparison with employees), volunteers were found to display a high degree of uncertainty and ambiguity about their role, legitimacy and relationships (Ashcraft and Kedrowicz 2002:91). Furthermore, they felt reassured that ultimate responsibility lay with someone else. In contrast, whether formal or informal, volunteers in this research were not usually volunteering at centres alongside paid staff, but were usually engaged in sole volunteering in the homes of older people. Therefore, the negotiation of the relationships differed, their sense of responsibility altered, and their own understandings are elevated in importance. In this sense, volunteering for some became a form of self support, as well as being a source of support to others.

Finding ways to negotiate the appropriate level of engagement and commitment for individual volunteers was a concern for Phoebe. She described from her experience how older people often became church wardens following their retirement, as they looked for replacement responsibilities. With increasing life expectancy and consequently a longer

period between retirement and death, which can sometimes span 30 or 40 years, having no obvious direction for this stage of the life-course is challenging. Giving as little thought to mid-life would be regarded as odd or even irresponsible, yet there is much uncertainty and little consideration beforehand because later life is associated with illness and loss. Being unable to make adequate financial provision is also a factor positioning this as an undesirable part of the life-course for some, though for a privileged sub-set of 'Third-Agers' who have adequate pensions and relatively good health and mobility, later life can act as a springboard to new possibilities.

## **Conclusion**

The purpose of this chapter was to consider the range of negotiations, constraints and facilitators which are involved in establishing caring relationships with older people. Negotiating existing relationships and situating care within these can be problematic for family carers who wish to maintain the representation of their existing relations as normal and equal for as long as possible. In Frances' case, the existence of the care relationship, deeply troubling as it often was to her, nevertheless provided some sense of purpose and direction in her life, without which, she feared a very uncertain future. Family carers engaged in 'reassuring performances' to hide difficult circumstances and to equalise relations, sometimes at a significant cost to themselves. Care-workers often 'imagined family' in order to diminish the rule bound and impersonal nature of their caring practice, which served to raise its quality in their own eyes, and in the eyes of clients and family members. However, it was important that some distance was maintained, for their own psychic protection, but also to afford family carers with a privileged and distinct place where this was necessary (Pahl 2000; Keating et al 2003). Volunteer carers often engaged in care if there was little family involvement in an older person's life. Their position as 'befrienders' was a difficult one to negotiate, it being part crafted by an institution and its norms and rules, but part emergent from the interpersonal dynamics of their respective personalities and interests. Unlike paid care-workers, they were not undertaking personal care which complicated understandings of friendship. So long as the institutional beginnings were not discussed, a genuine friendship could be perceived by both sides.

The ways in which embodied capacities, skills and knowledges were negotiated across care economies was interesting, with blurring and overlap in many cases. The trajectories of some family carers was to 'professionalise' their relationships and their skills, becoming the 'experts' which other professionals consulted (Twigg and Atkins 1994; Arksey and Glendinning 2007; Glendinning et al 2008). The formal skills and knowledges of paid care-work, being codified and regulated upon entry was, however, often valued less than informal experiences of care in their own families. The values of professionalism were thus overturned, which may be increasingly important as care agencies seek to 'individualise' relationships with clients, drawing on specific (cultural) knowledges and practices. The position of volunteers was mixed, with less focus on embodied caring skills relating to personal care, but a high degree of concern about intuitive listening skills. For some, volunteers saw themselves as standing outside of formal structures, providing an alternative space for older people to air their concerns. For others, volunteering was a route into formal structures, as this is increasingly being promoted as a route into paid employment in the caring and service professions.

Finally, this chapter discussed the multiple and uneven ways that support was drawn upon and reflected upon across different care economies (Tronto 1993; Sevenhuisjen 1998, 2000). Existing and intended identities were drawn upon to establish practices, relations and spaces in the negotiation of boundaries and limits to care. There was significant concern to establish appropriate boundaries and limits in the caring role. The insider/outsider positionality of voluntary carers was most evident in this concern. Attention to the inter-subjective negotiations, power relations and identities offers a critique of policy discourses in a way which considers inter-subjective rationalities influencing choices and negotiations. Being situated (initially) within different structures, with different expectations for practices and relations of care, often generated different needs, some of which meant looking to formal support systems and institutions, including negotiating the presence of other carers in their routines. However, others found informal support from family, friends and neighbours was more useful or appropriate. Care contains reciprocities, even if these are uneven within care relationships. These were seen in different ways across care economies as older people and the wider care network served to raise the esteem of family, care-worker and volunteer carer. The suffusion described by Pahl and Spencer (2004) in the way

relationships are constituted within the personal communities of individuals is evident in the accounts of family carers, care-workers and volunteers in this research. The room for manoeuvre in the performance and negotiation of different caring roles and relationships is mediated however, not only by the constraints of institutional rules and regulations which impede certain practices, but also by the presence of others who may be established within given roles. Each carer 'type' negotiated the space that was made available by the older person and their wider personal community. Sometimes this meant straying beyond the boundaries and expectations of their given role.

## CHAPTER 6: LIFE-WORLDS OF CARE

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### **Introduction**

This chapter presents data which describes the ‘life-worlds’ of care across three care economies. This concept draws together the experiences of care, how these are felt and expressed by carers, and how these expressions in their totality constitute a life-world which can in turn influence future orientations. The main elements to be explored in this chapter are the temporal rhythms and settlements of carers’ everyday practices, usually presented as routine, but which can be disrupted intentionally and unintentionally to assert familiarity and control. The temporalities of day-to-day living with an older person with social care needs are different from the temporal horizons which form imaginations of past and future as seen through current realities. These histories and trajectories constitute ‘pathways of feeling’ (Hochschild 2003a) which influence, not only the decision-making in accepting a carer role as described in chapters four and five, but also the lived experience of care.

### **6.1 Life-Worlds of Family Care**

#### **6.1.1 *Maintaining and Disrupting Family Routine***

This section considers how family carers’ established routines create particular temporal rhythms which shape the experiences, relations and spaces of care. Having multiple family carers involved in the day-to-day caring routines was not common in this research. For most respondents, caring was performed by one family member, with or without support from external agencies. The duration of caring for respondents in this research was often unquantifiable, as it seeped into every aspect of the day and night, if not in tasks then in planning, listening or worrying. Family carers’ days often ended

very late in the evening, sometimes as late as 2am. Most family carers who lived with the older person described late nights and early mornings as a regular feature.

For Barbara, much of the late evenings were spent catching up on housework, administration or cooking batches of meals for forthcoming days. During the daytime, the focus was often on caring for the older person, but this was interspersed with general housework duties. Barbara described the quick pace of her domestic tasks between personal care for her husband as 'butterfly sessions'. Gayle described in her diary how her routines were organised around her husband's physical needs and the shift patterns of the agency care-workers.

12.15 Dash home to give Peter his medication and to make his lunch and a cup of tea for carers coming to put him on toilet.

12.30 One carer arrives first so give her a hand to get Peter onto commode and into bathroom. Carers have to be at next address at 1.00pm so will usually give first carer to arrive a hand if one has been delayed as they arrive separately. (Gayle, Diary)

The requirement to respond during the night puts particular pressures on carers, as a time when the older person needs most physical support, such as help to the bathroom, or responding to disturbed sleep (see Kraftl and Horton 2008). Some of my respondents slept in separate rooms from those they cared for, which generated anxieties and regular checking, as described here by James.

I think it's in the night time hours that she is more shaky, in the early morning hours. So what we are arranging to do, somebody's coming this afternoon to assess to see if we can have a pressure pad put in the bedroom there. So as soon as Mam puts her foot down, it'll ring my mobile phone [laughs]  
(James, Interview)

Rather than active checking or listening at regular intervals through the night, the alarm notifies when action is required. Waiting for an alarm would allow James the possibility of sleeping right through. Currently, he worried about allowing himself to sleep heavily as he occasionally woke in the morning to find his mother upright and out of the blankets shivering, as she had obviously got out of bed but couldn't put herself back. He hoped the installation of a pressure pad would alert him to such episodes during the

night, so the technology would help him to respond only when required (Milligan 2005).

For those who worked full time, being present at the right time required significant co-ordination with others. Isabel cared for her mother at home after finishing nightshift work as a care-worker in a residential care home for the elderly. Her employers were aware of her informal caring which meant she was able to reconfigure her shifts to avoid Wednesday to Friday nights which was her share of the routine split with her two sisters. When Isabel's time with her mother was sleep disrupted, this made her tired for starting her paid work, which added to the continued pressures of her routine, especially as her mother's health declined from one week to the next.

Mam has had a restless night, talking and shouting, not much sleep for myself or daughter. Carers came at 9.30am and helped me get mam up, washed and dressed. Once carers had gone I done the breakfast for Mam, fed her and she nodded off in chair. I got some ironing and housework done. Mam not looking too well today, she is very sleepy and her colour is very yellow, due to her liver failing. It is now 1pm waiting for a carer to come and give me a hand to change Mam's pad. I will then make her dinner and feed her, as she cannot do anything for herself.  
(Isabel, Diary)

The consequences upon paid work of this overnight support could be felt in terms of constant tiredness and rushed pace. For Amanda, the rushed routines she engaged in to manage her caring with full time employment was persevered with to ensure she was able to spend quality time in the evenings with her father. This was especially significant, as she had been unable to give much attention to her father in recent years during the time when she had cared for her mother. Sitting in front of the telly together was a way of demonstrating commitment and love, which Amanda saw as perhaps 'overcompensating' for the period of intensive caring when she could not do so. Family respondents who were supported by care-workers described how their care was affected by these additional temporal rhythms and constraints. Barbara, whilst very supportive of the individual carers who were part of her 'team' as she described it, was nevertheless frustrated that sometimes the paid carers would be in and out in fifteen minutes.



The lunchtime pair 'J' and 'M' were gone in fifteen minutes. Not exactly a record, but pretty quick all the same (Barbara, Diary)

The combination of resistance by the older person and the time constraints of the care-workers made keeping to a routine a challenge. Barbara described how if the breakfast wasn't prepared at the right time, due to resistance during toileting, showering or dressing, she wouldn't bother, as it would mean putting all the other meals out of sync. The need to keep to an appropriate sequence was also expressed by Rachel, who saw this in respect to her aunt's mealtimes. Rachel believed agency care-workers had too many older people on their schedule, and this was creating quality issues, lack of choice, and meant underlying health and wellbeing problems were missed. She described breakfasts going on till lunchtime, and on one occasion she witnessed the breakfast and lunchtime carers passing each other at the front path, expecting her aunt to eat 'rubbishy frozen stuff' at inappropriate times of the day.

I think they shouldn't have so many that they're running in and out of people's homes, and the breakfasts are going on until the late, nearly dinner time. So, they need to have far fewer people that they care for, and more time so that everybody gets a reasonable level of care. And consistent care, so that people get to know the ones, the carers, get to know the ones who need the care, and that way they can pick up quicker if there's something wrong with them (Rachel, Interview).

Disrupting routine can be as significant as the routine itself, for different reasons. Hilary often wrote of 'the same procedure' in her diary, acting as shorthand once the routine had been adequately described. Similarly, Frances notes 'the usual routine' as shorthand. She illustrated the significance of breaking from these routines at home by taking part in dinner dances and other events organised by carer organisations such as the Alzheimer's Society.

Have dinner then we are off to a tea dance run by Alzheimer's society. We take advantage of all events offered. It is about the only time I meet people. Looking after husband is rather a lonely time. Home again, relax- have tea-watch television and read till bedtime. As you will note life is very routine. (Frances, Diary)

Many family carers described being at home most of the time, with only brief interludes of respite. In James' case, short windows were available, and these brief episodes were organised around his mother's toileting needs. He described being 'on call' most of the time. If he needed to go out he made sure his Mum had recently been to the toilet, which afforded him up to an hour and a half, just enough time to get to town and back, or visit a nearby friend. Taking up offers of respite could be difficult for those working full time however. Amanda was aware of the possibility of support at the local carer centre, but found it difficult to fit this around her routines as she balanced work and caring for her mother.

That seemed to offer all sorts of things from you know, aromatherapy, massage, organises respite care and so on, but certainly when I was looking after my mum. I didn't have time to go (Amanda, Interview)

Barbara received a respite service which was added onto the usual caring routines for Bill, which enabled her some personal time. She questioned whether her Friday afternoon 'free' time was in fact her own in her diary, as she often used it to do essential shopping, though she did fit in visits to the hairdressers during this slot. However, Frances did not wish to have a sitting service to enable her to go out, as her dearest wish was to have time alone at home, to listen to the radio, read or 'bake in peace'. Her husband often followed her around, and talked to himself, which she found difficult to deal with all the time. A support worker from a voluntary organisation came once a week to take her husband out for a drive to the coast or local places of interest or for a few hours, providing support to him and respite for her.

Disruption to routine can allow personal time for the carer, enabling engagement and sociality beyond the home and quiet time inside the home. As Ehrenreich (2006) notes, the joy of togetherness and spontaneity of dances, gatherings and sporting events with strangers is as much part of the human condition as inter-personal and close relationships of family and friends. Arendt (1958) also contended that disruption to routine brought possibilities – a result of being-in-the-world with others, and from which we weave our own stories. Without others, our stories have no audience and no wider significance. It is with this sense that keeping routine as a form of ontological

security is experienced as positive on one hand, but its disruption to introduce newness and possibility is equally valued.

Family carers established routines which created particular temporal rhythms. These were often concerned with maintaining former family practices, routines and modes of living (Finch 2007; James and Curtis 2010) in an attempt to reinscribe family in contexts where caring practices were blurring this.

### **6.1.2 Pathways of Feeling: Changing Moods and Life-Course Sensibilities**

Pathways of feeling is a term used by Arlie Hochschild (2003a) to describe the accumulated effect of past histories and imagined futures upon our felt lives, our current routines and relationships, and the way we plan for future events. Frances wrote a poem titled 'A Selection of Thoughts, Feelings and Emotions of a Carer Looking after a Husband who has Mixed Dementia' to describe the range of feelings she encountered as part of her everyday life. She described these feelings in an A to Z list to describe the complexity of managing her thoughts and coping with her current role, showing how the pathways that develop over the life-course are difficult to sustain day-to-day, creating considerable tension.

Anxiety in case he hurts himself or becomes violent
Anger
Bewildered as to how this has happened
Cry whether in self pity or pity for him I can't decide, perhaps a little of both
Doubt and Despair about the future
Embarrassment
Frustration when he can't understand what I am saying
Grief for the husband that was
Hit Out when he is awkward or stubborn
Impatient
Jacking it all in- then telling myself to
Keep Calm
Laugh at the silly things he does
Love him still
Malice in Mind when he starts his constant talking
Needing company and comfort
Overwhelmed at the responsibility
Patience

Query how long I can cope  
Resentful that my life has been limited  
Shout when he won't respond or follows me around  
Tearful  
Not Understanding what he is saying  
Very Very thankful for the help and support I receive  
Weary  
What is the X factor that keeps me going?  
Yearning for peace and quiet  
Zero tolerance at times.

(Frances)

Frances gave me this poem to help me understand the contradictions at the heart of what it meant to care for her husband. By considering this poem, it is clear that the emotional world of this respondent was inextricably bound up with the wellbeing of her husband. Moods and emotions were often described as shifting quickly in response to the situation or according to place. Many carers felt they were on a downward decline emotionally, as circumstances became more difficult over time rather than easier, creating a dissonance with the way they felt things ought to be, leading to questioning of the impact of their significant efforts to make things better. Amanda commented on how common it was for her to feel frustration, tiredness, guilt, being rushed and sometimes overwhelmed by the responsibility. However, whenever she expressed these feelings in the diary or the interview, she regularly dismissed them, commenting that her feelings were 'rubbish' or illogical as lots of people feel the same, and things weren't as bad for her as they had been or were for others.

I can feel a bit swamped with having to do it all, even though  
logically I know when I am on my own I will be doing it all too!  
(Amanda, Diary)

Barbara described how her usual positive disposition was being undone by the weight of the responsibility and the stress involved in caring, and she was not always able to hide negative emotions. She also expressed negative feelings about caring for her husband, Bill, in her diary. This articulation was perhaps only possible because of the enormous level of care she provided over many years, giving her powerful moral authority from which to speak. It is worth emphasising that Barbara was speaking to me, someone outside the usual situation, and not to her husband. Though she expressed these feelings

to me, she had to 'walk away' from the situation in practice to avoid her husband having to confront these frustrations.

You feel you could push them downstairs, well I don't even have that luxury. He's not upstairs [laughs] but there are times when you think I could easily hit them. And you have to walk away. But, in that time you are feeling oh, like this. Now yesterday, my head hurt. It felt so tense, so tight that it almost frightened me. (Barbara, Interview)

The diary perhaps provided an outlet for expression of such difficult feelings not often expressed face to face. Barbara wondered whether bottling up emotions may have contributed to the development of her husband's condition (Lewy Bodies disease). She wrote in the diary that she worried that her son was also bottling up his feelings, and was concerned might lead to the same condition.

Don't be like your father, keep it all in. And where it might come out. And I think underneath that he is worried it maybe something that's hereditary (Barbara, Diary)

Barbara described her previous experience of caring for her mother and father, and how this impacted on the way she cared for her husband. She described her father as similarly 'wilful' and 'aggravating', and when Bill acted in this way, it brought back memories of her father. For most of the time, and in day-to-day interactions, it appeared to be an important element of caring subjectivity to disguise and underplay such negative feelings and consequences, but these articulations of histories of feelings of anxiety and frustration surfaced occasionally.

Being able to plan and organise for the future was an important aspect of the life-worlds of family care. The calendar as a planning tool to organise time and 'look forward' was commented on by some respondents as being more significant than a means to co-ordinate the routine of care in a practical sense. Hilary described how her calendar had taken on greater significance since her husband's illness. She shared similar stories with others about the consequences of getting older and how health becomes a focus for future plans rather than leisure pursuits, often the preoccupation at an earlier stage in the life-course.

Oh aye, all your appointments, physio, God nars [knows] what. That's what Bessie was saying in the hairdressers. She's in her eighties but she's really funny. She had a stroke. She says, I used to have on my calendar Hilary, going to the cinema, going to the Empire, she says now, ga'an [going] to the hospital, ga'an to doctors, ga'an to the eye infirmary [laughs].  
(Hilary, Interview)

Joseph described how planning ahead was significant. His visits were usually pre-arranged by telephone a few weeks in advance, and marked on his Gran's calendar. He suggested that having a physical notation of his arrival as a permanent visual feature in her home would have been comforting, knowing there was always something 'penned in' rather than having nothing to look forward to. Joseph explained how arriving unexpectedly was sometimes met with irritation, which he initially found upsetting and as rejection of his attempt to care. But he came to understand that his Gran was asserting her autonomy by establishing control over her routine. As Joseph was not involved in embodied personal care (this being done by his Aunt) it is possible that advance notice was desired to clearly establish a boundary, separating his caring support from more intimate aspects of her care routine, perhaps a form of impression management. Beyond these everyday temporalities of care, when the older person's health condition was changing and/or declining, this could make seeing ahead and considering the future difficult, as James explains:

It might get to the stage where I can't cope any longer, and Mam would have to go into nursing care. I know she doesn't want to do that, but erm, and for as long as possible I'll try and help her to live at home. I suppose it's just the changing nature of things as well, trying, sort of, I try to sort of pre-empt it, but I don't, I just react to what's happened. It's very difficult to see ahead.  
(James, Interview)

As with other family respondents, Gayle commented that she found the early hours of the morning the most difficult, as it was at this time she felt most isolated. During the night all non-medical sources of support were absent, and she felt there was no-one she could call unless it was an emergency. She found the telecare package with the private provider which had been arranged via Social Services was very useful for assistance with physical needs, if her husband needed to visit the toilet, or had fallen. Peter's complex medical needs meant a minor epileptic attack or health problem could have other serious consequences. Despite this support, fears were heightened by past

experience, and she described a pathway of feeling towards anxiety which developed about decisions about the level of ‘threat’ posed by her husband’s physical symptoms. Gayle found emergency services were unwilling to send an ambulance during the night for chronic cases, asking her to wait until regular daytime hours, and was often unsure whether an ambulance was necessary. This caused her a great deal of concern because it was a delay in calling for an ambulance which caused her mother to die some years before, in her view unnecessarily. This memory made her more wary of the ‘wait and see’ attitude being suggested in the here and now. For Gayle, it was the feeling of responsibility for another life which she found overwhelming. She suggested it would be beneficial to have a carer support line so that concerns could be talked through, or frustration shared, similar to the Samaritans service, but dedicated to carers. Around the time this study took place, a strategy document ‘Building a Society for All Ages’ (HM Government 2009) proposed such a carers helpline and website. Most respondents, however, relied on secondary caring support from relatives and friends, both for emotional support and for respite. This allowed the family carers to regain some perspective and sense of self, or this could be just finding time to do domestic chores and return the home to ‘normal’ to do everyday tasks as going to the hairdressers.

### **6.1.3 *Spaces of Family Care: Meanings and Consequences of Home***

The home was often considered ambivalently by family carers. Amanda found that the spaces of the home limited her horizons, and could have detrimental emotional consequences upon the life-worlds of care.

It becomes all you think about, and your world slowly contracts. And I’ve sort of described to people how I’ve seen my parents’ world contract as they got older. And slowly but surely it kind of crept in from being very very outgoing and everything to being just a couple of rooms, and nothing but, you know, well towards the end not even watching the telly. It’s very...very tight. And your own world kind of contracts with it because, bit after bit, drop off doing that, drop off doing that, drop off this, don’t go there anymore, don’t do this. And to the end, so you got to the point where I was going to work, looking after my mam, that was it, that was my life. And I think it’s dangerous. (Amanda, Interview)

Carers persisted with these restricted life-worlds, attempting to create a sense of togetherness and normality as the older person's health declined and their ability to recognise familiar people, objects and routines that constituted their family life were fading. The changes occurring inside the house, when managing illness in old age were most likely to be experienced as decline.

I do worry long term about the changes because as I say it's not a static situation, things have changed even in the last couple of months, and I think 'well now, another two months down the line, where will we be?' Will Mam have to go and be in a wheelchair all the time, or will mam have to just stay in a bed all the time? Will she just, the strength is going, will she not be strong enough to weight bear, to sort of walk around at all? And then how will I manage if she's, or will she just live upstairs? Will she just stay in her bed all the time? (James, Interview)

Holding together routines meant keeping things the way things used to be, if only in the short term. This was significant in terms of the timing, pace and sequencing of events. The spaces in which such routines were enacted were critical to establishing meaning and keeping things 'normal'. It also signified and displayed the continuation of family practices, such as eating at the family dinner table (see Finch 2007; James and Curtis 2010).

He ate his lunch badly. He slumped in the chair all afternoon – I cut the grass. At the 4pm toilet break he refused to go to the toilet, use the bottle or move at all. I prepared dinner and pointed out that he was then in the wrong chair to go into the dining room to eat it so I wheeled the black chair in beside him and after removing the near arm told him he'd have to transfer himself. At first I thought he couldn't but next minute he was up and sliding across into the seat. Thus he was able to eat the meal at the table. (Barbara, Diary)

Proximity is not always required, as can be seen in the growth of assistive technologies which enable more autonomy for the older person, and allow remote checking and interaction by carers (Rose 1999; Sixsmith and Sixsmith 2001; Percival and Hanson 2006; Rose 2006). Telephones are frequently used to communicate at times when physical proximity is not possible, and were most often used by non-resident carers, such as Joseph. However, most family respondents were involved in intensive caring in the home of the older person. In Isabel's case, this was done on a rota system with her



sisters, moving between these homes, which often resulted in difficult sleeping arrangements. Isabel describes how she and her youngest daughter regularly stayed overnight at her mother's house, which was a one-bedroomed bungalow.

After carers had been in I gave mam her tea. It was a struggle but we managed. We then went to bed ourselves on the airbeds in the sitting room. (Isabel's sister Donna, Diary)

As older people are increasingly encouraged to stay in their homes for longer into later life, small one-bedroomed bungalows usual in social housing provision become inadequate or undesirable, as older people increasingly need to accommodate visiting family (who may live away) and carers who stay overnight (Lansley et al 2004). Beyond the internal spaces of the home, outdoor spaces did not feature much in this research, as many of the family carers were managing the care needs of older people who had mobility problems, making trips outside too difficult. Carers occasionally venture beyond the home to accompany the older person to hospital visits, opticians and the like. There were various obstacles to overcome in doing this. For instance, Amanda described the difficulty she had taking her father to an optician appointment, which required significant 'ringing round' to find one with nearby parking as her father would have difficulty walking long distances.

Amanda also encouraged leisure trips, such as visits to the coast to watch the sea, and less frequently, to meet up with wider family. Her father was reluctant to use a zimmer, and mostly stayed in the car when they made visits to the coast. Amanda described how she often refused invitations from family as her father was resistant to travelling too far, fearing getting 'caught short' or needing to negotiate stairs to go to the bathroom. For Barbara, getting her husband to raise his feet over the threshold of the front door and then climb into the car was an ordeal, and relatives made temporary ramps to assist with this. It was therefore easier to make routine trips alone, such as shopping or to pay bills. Barbara commented that she went into town by car to do shopping and had to pay for the parking fees, but had her husband accompanied her, this would be free. Since Barbara herself was in her late seventies and would struggle with heavy shopping, it was important to her to find a spot which would make carrying less burdensome. Barbara went to the same shops regularly, and described how heartening it was to be asked about Bill's health by shopkeepers. Sometimes these shopping trips led to short

excursions and diversions to explore roads she hadn't driven down before, extending her spatial horizons briefly before returning home.

Some respondent discussions focused on the garden as an outdoor space. It was perhaps seen as an intermediary space between the private hidden world and external world beyond, providing an opportunity to engage with wildlife, plants and enjoy sunshine. For Barbara, the garden was her refuge, an escape from the feelings of inside, which occasionally became intense or frustrating since she shared her home four times a day with two carers operating on rotation, the garden may have been experienced as a 'private' space for Barbara.

Amanda did not regard the garden as a retreat, but saw its potential to encourage her father to move around, escape the confines of home and soak up the sun. He had given up tending to the garden, and Amanda employed a gardener infrequently to keep on top of it, as she didn't have time. Her father often spent all day indoors, and could never get warm despite the heating being permanently on high, even during summer months. Amanda bought a garden seat so that they might be able to sit and enjoy the sunshine together. Furthermore, the garden creates a general impression of the house to others, which can be a cause for concern. Amanda and Isabel both commented on the state of their gardens. Isabel explained how the grass was overgrown, and she complained that the social housing provider who managed the small front garden was not responsible for the large back garden. Since there was no one in the family able to do this, it became unkempt and she feared this would attract attention and make the house vulnerable.

## **6.2 Life-Worlds of Care-Work**

### **6.2.1 *Shift Patterns and Everyday Temporalities***

The boundaries between domestic and public spaces are often blurred when working in someone else's home. The everyday routines of care-workers were much more tightly regulated than family carers in this study. Ensuring a number of carers reached their appropriate destinations on time meant strict adherence to schedules, operated as regular

shift patterns with emergency call outs to cover illness etc. Because of the marketised nature of this provision, time is money and each care worker is allocated time with a client based upon a contract, which in turn was often the result of a needs assessment by Social Services, though increasingly agencies were managing contracts with individual personal budget holders.

Care-workers operate according to shift patterns which are efficient for the organisation but often undesirable for care-workers and their clients. Family carers often complain about support which is untimely, and paid care-workers are often moving across the city for short sessions. Whereas some are more able to secure beneficial work routines, others seem to have inconsistent working hours, being stretched to capacity one week and then under-utilised the next. Factors such as ethnicity and gender may impact upon the way these routines are constructed and managed. Personalisation may intensify pressures for timeliness, if not more time itself, as more time costs more money from a limited budget. Care-worker respondents in this study were involved in care which ranged from an hour for toilet stops to overnight stays. As was described in family respondent accounts, care-workers can appear for only 15-minute slots, but none in my research described this sort of shift pattern.

The plural temporalities of caring labour as opposed to linear, clock-time understandings of 'work' means that both paid and unpaid forms of labour should conform to these bodily rhythms i.e. the carer should be a permanent presence in the daily routines of care-receivers. Therefore, particular spatialities emerge from these constraints. This can be distinguished from the task driven nature of work; where the needs of a particular body are perhaps attended to in brief moments, with the same tasks usually performed upon multiple bodies over the course of a working day. Though there was a real concern to promote individualised care, this was in tension with the necessities arising from the time-space constraints of their employment across different sites. For those with long-term relationships with individual clients, personal support was negotiated and individualised in a relational way, often reflecting their own moral rationalities of the right thing to do, or how they would want their family members to be treated, yet respecting the wishes of family members, and clients.

One potential respondent who failed to return a diary after an initial meeting had described the intensive work patterns, which meant she was on foot or travelling by bus for most of the day, rushing from one house to the next. Not being given enough travel time between calls meant she was harried and often received complaints on her arrival, making the job less enjoyable. Care-worker respondents in this study were recruited from more than one care agency. These differed in the client profiles, with some doing domiciliary and personal care for low support need clients, and another which did not do domiciliary work, but had a range of clients with high support needs. This often required stays of longer duration and therefore fewer clients. One of the care agencies who were participants in this research monitored the shift patterns of care workers using specialist IT care programmes. Gemma, explained the importance of this:

We need to know at the click of a button where people are, where they should be, you know who should be there. Who's coming next, we need to have all access to that information. Especially because we do twenty-four hour care. So through the night one of us always got a mobile, so you need that information. Somebody's ringing you late last thing at night, you cannot come rushing into the office. (Gemma, Interview)

Because of the fine grained knowledge that is brought to bear in personal and domiciliary care, particularly at an agency dealing with high support needs, Gemma explained that it would be very difficult for someone other than a former or current carer to be sufficiently capable of working in a care agency office environment. Having an awareness of the value of timeliness and doing things in the right order was something best learned on the job. This tight scheduling is illustrated by Wendy's diary account. She worked for a domiciliary care agency in Gateshead:

Left house at 7.45am to catch the bus to client no 2. Arrived at client no 2's house about 8.25am. Made a cup of tea, tidied up and hoovered, wrapped some Xmas presents. Left client no 2's house at 10.30am arrived home at 11.15. Took washing out of washer had a sandwich. Polished and hoovered bedrooms, cleaned bathroom, and hoovered stairs and sitting room. Finished at 2.15pm. Felt nice and relaxed knowing everything was done, had tea at 4pm. Washed and dried dishes had a bath at 5.30pm. Left house at 7pm to catch the bus to client no 3 to meet work colleague. Client no 3 is house bound and needs help with most things. Arrived at client no 3 at 7.25pm, gave client no 3 her medication, prepared breakfast tray for the next

morning, took client no 3 to bathroom and left her for a few minutes to give her a bit of privacy before getting her undressed and ready for bed. Put client no 3 to bed at 8.25pm, gave her her glasses and remote for TV. Left client no 3 at 8.35pm got a lift home from work colleague, arrived home at 8.45pm. (Wendy, Diary)

Nearly all of Wendy's diary was similar in tone. Her diary noted very detailed timing, was incredibly repetitive from one day to the next, and for the most part, offered little expression of the feelings she had during the day. There was a clear sense of regimentation in her description of her routine, and a mirroring of her 'work' and her 'home' life with similar tasks being performed across these various spaces. Working for a small domiciliary care company, Wendy's relatively close proximity to her clients meant she was able to integrate her paid work and home responsibilities throughout the day, rather than as distinct shifts. Rather than implying dissatisfaction, the repetition could be read as a sense of accomplishment in getting through this demanding schedule without complaint. For other care-worker respondents, their day was spent doing domiciliary care tasks for numerous clients at a number of places. Others had fewer clients, and spent considerable time at the clients' homes alone, with brief interludes with other care-workers to 'double up' for certain tasks. Kelsey explained how the shift patterns meshed with other carers' rotas.

Like a Monday, I do a dayshift its half eleven I start,...and we'll get like the hour double up, then get her up, sit her on her chair, and then. The other carer would leave and then, if she's sleeping I would do like a bit of housework that hasn't been done, or ironing...

A: so the other carers come in, they are coming in for that hour? Do you know what they are doing in terms of their day?

K: No, like they're finishing. Like if I start at half eleven, on a Monday, I start at half eleven, so the carer's there until half twelve, but she's been there since eight.

A: right, so it's like an overlap hour, aheh.

K: yeah, but like at 'Deidre's' on a Thursday there is just like an hour pop in, where they just come for like the pop in, for like personal care. But they might have been somewhere else for their shift. (Kelsey, Interview)

As a single mother, Kelsey opted to work nights because she found it easier to get childcare from family and friends at this time. Similarly, Gemma's mother helped her out with childcare, ensuring that her children were given their evening meal, though she

explained the consequence of this was she rarely cooked a meal just for herself, as she felt it wasn't worth the time or effort. She explained that it would be difficult to imagine not working the hours that she did, as she often found annual leave frustrating and boring, particularly spending time at home dealing with housework. For Gemma, her paid work identity gave her a lot of personal satisfaction.

I mean I do a lot of hours, and I get a decent wage for doing them. And it's my choice to do the hours. (Gemma, Interview)

In contrast, Elizabeth found that working hours were outside of her control. A refugee from Zimbabwe in her early 20s, Elizabeth has been working for three years as a care support worker. This was Elizabeth's second job in the UK, the first being in a residential care setting. The agency gave her hours week to week, and this could fluctuate significantly, impacting on her ability to plan and manage her income and childcare arrangements.

A: So what's the most and the least that you work in a week?

E: Maybe sixty five if it's more, and if it's less maybe its twenty five or twenty, and sometimes I get no shifts for a week or two, so.

A: Right, so it's very variable.

E: Yeah.

A: So how do you manage that in terms of your own, managing your income?

E: It's hard, that's why now I've been looking for another job.

So if I don't have shifts on one side, I can. You know, I have bills to pay, and so. Kids to look after. (Elizabeth, Interview)

The rates of pay do not vary within the industry; however other factors influence the terms and conditions of work, mostly around temporality in some way. The choice of number of hours, type of shift, the intensity of the shift, the number of clients and the regularity of hours was variable for care-worker respondents, differing according to size of agency, the personal circumstances of care-workers, and the choices of clients favouring certain carers.

### 6.2.2 *Pathways of Feeling: Emotion-Work and a Caring Demeanour*

As outlined earlier, one of the motivations for paid work for Gemma was keeping active and getting away from home. This responds perhaps to a need for respite from her own family care, even if some aspects were similar. The cross-circulation of skills and knowledges between care economies is an important aspect of conceptualising orientations and negotiations of care, and is most clearly demonstrated with attention to the life-worlds of care:

I just get there, I mean even when there's sort of problems and that at home, you just paint a smile on your face. I'm not one for, you know, whinging on about things, I just come in and get in and get done (Gemma, Interview)

The 'emotion work' was explained differently by Elizabeth, who described that a large part of her job was to provide comfort to her clients, though they did not have a particularly close or friend-like quality described by other care-worker respondents.

Some of them sometimes they are upset and they're just crying and. So emotional on the day, you just sit there and give them a cuddle, or just hold their hands and talk to them and stuff, so. Just try something to you know make them comfortable. (Elizabeth, Interview)

Feeling valued as a carer was important for many care-workers. Megan understood this was expressed in a number of ways by different clients. One younger client appreciated her direct input on personal matters, seeing her as an advisor and advocate when negotiating with doctors and officials. An older client often underplayed the level of care she required, perhaps due to variable health and wellbeing, but also due to a sense of pride, preferring to see Megan more as a visitor than a care-worker. Allowing the client to control the level of care provided was described by Megan.

And sometimes I'll say to her like, 'Do you need a hand? Do you want a hand? 'Sit on your arse!' I mean that's what she says to me. I says 'Now, do you need a hand? 'No, no you're okay the day, you're okay the day' (Megan, Interview)

This care towards the care-giver by the presumed care-receiver gave some autonomy and control to her client who had no family or friends. In the interview, Megan

described earlier experiences working in a care home where she witnessed abuse and neglect. Negotiating this freedom for her clients was balanced with a concern to be seen to be offering support over and above what was expected. Susan also expressed concern to act in a safeguarding role, which often meant treading upon the autonomy of her clients. Having a caring demeanour meant for Megan being supportive but not directive, and this often took the form of advocacy when accompanying her clients to GP surgeries or being present during social worker visits. Megan described how she felt strongly that professionals often ‘looked down’ upon care-workers and their detailed knowledge of the client which had built up over time. This experience concurs with the empirical work of Twigg and Atkin (1994) which describes how the organisational and physical boundaries between care supporters often marginalise those most closely associated in the lived realities of care when making decisions. In this case, this marginalisation is felt by a paid care-worker rather than informal carers as found in Twigg and Atkins’ study. Megan compares her intensive everyday support and advocacy, to professionals who assumed they knew best following ‘ten minute’ reviews with clients. The low status of the role of care-worker made it difficult to express her knowledge as more informed than professional knowledges.

### **6.2.3 *Spaces of Care-Work: Boundaries of Work and Home***

This section considers the way space makes a difference to the experience of giving and receiving care. For care-workers, this often means travelling between several sites, engaging in several caring relationships, with a consequent impact on the negotiation of boundaries between multiple caring relationships at home and at work. Megan described the way she marked the separation between her paid caring role and her personal time. Describing the need to consciously tell herself to switch off between shifts, she found this difficult to do, but something she was capable of. She uses the front door of her own home as the marker to start thinking about her caring work. Her bus journey was a space of transition which allowed her to make a mental journey from thoughts of work to thoughts and worries of home.

And how I do it I says ‘Right! I’m outside my front door now. Work!’ And that’s it. And I cut off. Yeah you deal with it when you come back, but it’s. And then sometimes, sometimes that’s



difficult as well, you know. But I do it. I do it. And then when I come back I worry about whatever was on my mind then [laughs]. Or sitting on the bus, you know going 'oh' [laughs]. Coming back. (Megan, Interview)

Being capable of switching off was emphasised so strongly by Megan during her interview that it seemed to be an important work expectation of being a good carer. That it is not an easy accomplishment was perhaps emphasised to demonstrate commitment, care and thought in the work that she does, but it being surmountable was part of the professional demeanour expected of her, and which she had accomplished successfully. Switching off had to work both ways, and was spatialised according to physical location. She described elsewhere in the interview that the personal concerns she may be dealing with at home needed to be kept out of the paid care work. Her conversations at work with her clients were intended to support their needs, and not an opportunity to share her problems. The lack of reciprocity within the paid work sets up the role as professional, rather than as a form of friendship, though she suggested that she would like to think her clients positioned her as providing a friend-like role.

Keeping personal belongings in the home of clients was usual for some care-workers but not for others. The difference seemed to be whether the work was scheduled as a waking night or a sleepover, though other factors may have made it more difficult for some to feel 'at home' in their clients' home. Elizabeth and Martha were the only carers who reported working 'waking nights'. Elizabeth explained that she had no designated space in her clients' homes to sleep, sit or to keep any personal belongings. She explained if it was a sleeping night, carers were usually provided with their own room, but as Elizabeth worked mostly waking nights, she didn't get this. Unlike other respondents who kept personal belongings at their clients' homes, Elizabeth's experience was that:

You have to carry around with you. If you want something for yourself, you have to carry it (Elizabeth, Interview)

In contrast, if the care work involved sleeping over, or was a long shift, Ewa described how she had her own space to relax and do her own thing, and where she kept personal belongings like books and slippers. Her primary role was to give her client painkiller tablets during the night, and water if she is thirsty, and apart from this at quiet times she

was able to spend reading. She had a baby monitor so she was able to hear when her client was calling her or becoming restless. Kelsey also kept slippers and other personal belongings at her client's house, describing it as like a second home to her. She was on very sociable terms with her client, and they often sat down together to watch DVDs on an evening. Megan also described how she felt comfortable in her clients' homes. Though she didn't bring any personal belongings with her as she did not stay overnight, occasionally she brought family holiday photos, which was appreciated by the clients, and made her feel at home in their company as she felt they were interested in her as a person.

### **6.3 Life-Worlds of Voluntary Care**

#### **6.3.1 *Finding Time and Filling Time***

Creating structure in an otherwise unstructured day, Dawn spoke a lot about loneliness since the loss of her husband, the lack of children of her own, and how volunteering helped to fill her days and brought her good times.

Apart from helping them I help myself as I get to meet people and it gives me a reason to get out of the house. (Dawn, Diary)

Similarly, Elaine described her volunteering and befriending as a means of building structure into her day. She felt she would miss being useful to people if she was not involved in the range of activities – such as befriending for a cancer bereavement service, helping a neighbour and an ill friend with shopping, cleaning and picking up prescriptions, volunteering at a hospital library, helping out at a lunch club and so on. However, though she found it easy to find the time, and it was an important element of filling in her day, it brought difficulties with her family. Elaine planned her activities with a diary, as she needed to write things down so she didn't forget arrangements or appointments, wishing to ensure she was consistent and reliable. Elaine thought it was vital to ensure she didn't over commit, though in reality she found it hard to say no.

I have to sort of always be aware when I was last in touch with her so I don't sort of. 'Cause a week can go by before you know

it. But to a person by themselves, and unhappy, that's a long time. (Elaine, Interview)

However, this physical indicator of her routines alerted her family to the level of support and responsibility she had taken on, and was a cause for concern for them. Elaine described how this irritated her daughter who lived some distance away. She remarked that her daughter would often say 'Mother, you're retired, you don't need a diary'. Coleen had a different kind of issue with the timing of her voluntary activity. This was easily incorporated into her daily routines and helped her to build structure into her day, as she had a car and did not work full time, which enabled her to devote considerable time to a range of volunteering activities. However, she described how her befriending became a problem during school holidays, as she would need to arrange childcare to maintain her commitments. This she felt would be difficult, so she was unsure how this would work out in the long term.

Befriending was one of very few attachments Ben had to the region, other than an Aunt and his paid employment as a residential support worker. Missing friends from his home town in the Midlands, Ben described how he struggled to coordinate time to socialise with new friends due to shift working. He usually received social offers at times which conflicted with his paid support work, so his times off were usually spent on his own. He described visits to libraries, cinemas, bus rides and so on noting on one occasion how 'it was noticeable that the bars seemed to be well frequented by lonely older men'. He was reluctant to share the details of his routines of the day as a residential support worker in the diary and in his interview pointed out he found the shifts at work (particularly nightshifts) uneventful and that they did not warrant further comment. This brief diary entry reveals how Ben perceived his paid did not warrant any further description when this involved sleepovers, but that dayshifts were his main opportunity for socialising with others.

Tuesday - On finishing work I walked down [street name] into Newcastle. Although it is nice to finish a long shift I have noticed that my mood gets lower on leaving as part of me will miss the social side of talking with residents and colleagues.  
Friday - I worked a 24 hour sleepover shift and felt quite tired from yesterday. I often feel tired at work even when I haven't been out or away the day/night before. (Ben, Diary)

Sleepover shifts generated dead spots in his diary and his routines, which is perhaps not common in other forms of work. The dayshifts enabled some degree of socialising with colleagues and clients, and contrasted with his leisure time which was often marked by time spent alone, wondering how he might fill his days. The befriending therefore became embroiled in a dilemma about whether this activity constituted real friendship and community involvement, perhaps more so than it would have done for others.

### **6.3.2 *Pathways of Feeling: Responding to Loneliness***

Most volunteer respondents engaged in their caring responsibilities out of a desire to do some good for older people, and to obtain some positive benefits for themselves, often focused around combating loneliness. Several respondents described how, as Sartre (2003) suggests, the possibility of bad faith was used as a mask to disguise actions, practices and circumstances which might otherwise be considered shameful (Andrews et al 2003). Those volunteer respondents who engaged in befriending activity usually did so with the proviso from clients that this formal set up was not discussed or referred to within the relationship. However, it was not only the response to the loneliness of others that prompted the caring activity, or shaped its experience. A significant number of volunteer respondents described their own social isolation or loneliness.

Prior to her retirement, Dawn had worked in a public library and was used to meeting people all day. She found getting on with people easy, so this prompted her to take up several voluntary roles in her local community. Elaine also described the satisfaction she gained from simply hearing the noise during the lunch club, not only in the hall but in the kitchens too. This was not only an occasion to support patrons who came to receive a cheap meal and enjoy some company, but also provided much needed confidence to some volunteers. As she explained:

I did that community wise because I tried to pick people who didn't feel valued to help. (Elaine, Interview)

Those who didn't make friends easily found a role, if not in chatting to older people in the hall, then by cleaning and clearing the tables. What Elaine got greatest joy from in

doing the lunch clubs was getting to know other people's families and stories. She could picture their holidays, friends and family. She explained how she would hate to live somewhere where nobody spoke to anybody:

...and you just did your shopping and you went in your front door and you, you know. I don't think I could survive in that.  
(Elaine, Interview)

Elaine wondered whether because she was an only child, she envied people with large families and liked to hear all about their lives. The experience of volunteering for some, however, brought additional worry. Many of the volunteer respondents described how they found some aspects of the role distressing or stressful. Danielle described how there was a spatial aspect to her emotions. She described how she would leave negative emotions behind before she went to visit Vera, as Vera was not there to look after her. Yet in other instances, Danielle described the relationship as reciprocal, and this marked a difference between befriending and friendship. As well as guarding unpleasant emotions, the caring itself could introduce it. Several respondents described 'dread' when informing their befriendedees they were not able to meet their usual time commitment. Danielle described how she dreaded telling Vera she was going away for a few weeks, more than anyone else, as she felt responsible for her wellbeing, and did not want to be the cause of any concern.

Beyond the personal aim of establishing new relationships of family, friend and community, there was sometimes a faith-based commitment to forging such community ties. As well as being an advocate for older people in transition from hospital to long term care, Phoebe was involved in building community links with older people through her local church. Her intention was to use the church as a catalyst for allowing older people to be active for longer, and for bringing a spiritual dimension to care, which was often missing from medicalised assumptions about care provision for older people. She described how many churches have an ageing population. For some, this was regarded as a threat, with younger people suspicious, seeing older people as an obstacle to change and innovation. For Phoebe, she saw the emphasis on younger people as 'tomorrow's church' as unhelpful, and she didn't want older people to 'fall off the end'. Instead, Phoebe intended to engage with older people through alternative models of spirituality.

I want to get good links within the parish to elderly people so that if a time comes when they can't go to church, or church is just no longer for them, for whatever reason, that there are alternative models of spirituality so that they can still be involved. That they don't become separate units, whether that's going into homes, whether that's conducting home visits, whether that's going to discussion groups and just getting this whole issue of spirituality aired amongst older people, so that the spiritual element of their thinking is taken into account. I just feel as if you get to a certain age in the church and you either join the prayer list, or your role is seen as being essentially just prayer, when in fact it needn't be (Phoebe, Interview)

As Phoebe was training for the ministry, she saw older people as the potential to re-engage the church with local communities by taking more seriously the spiritual element of thinking, which is perhaps more relevant at later stages of the life-course. She was interested in opening up dialogue between older people of different faiths, and from around the world, in order to reconnect older people to wider communities.

I think if people don't work, once their children and their grandchildren have grown up, there aren't that many natural connections left. If they're still working, even just part time, they've got a network of friends that they stay in touch with. And I think in terms of job, occupation. A lot of larger firms, they tend to have retirement fellowships, you know the NHS has got one. Marks and Spencer's has got one. They're great for keeping older people connected. But you don't hear of them that often now (Phoebe, Interview)

In post-industrial regional economies such as the North East, employment patterns may increase these disconnections. Work-based community organisations for former employees to keep in touch with friends and colleagues is likely to decline in significance as jobs become more varied, precarious and mobile (Beck 2000). This makes other forms of community building into later life more important to establish and maintain. As Phoebe explained, there are considerable benefits that older people can provide to society. Thinking of older people in terms of their embodied needs is inappropriate – they have acquired important assets and knowledges which can help improve community life.

### 6.3.3 *Spaces of Voluntary Care: Finding Community*

Some volunteers who befriended in people's homes found that their role complemented those of other carers, especially if there was no family to look out for the older person. Dawn described how her befriended received regular support from a care-worker, who assisted with meals, personal care and domestic tasks, but simple things were not part of this assistance, such as changing curtains from one season to the next. Being another person who entered into the befriended's home meant another pair of eyes to watch for problems. Elaine provided regular domestic assistance to her neighbour, as being so close at hand meant she was able to incorporate his household into her own, as she described it. As with others in the research, previous experience of caring for her mother and choosing a care home gave Elaine a determination to help others. Feeling that she had chosen the wrong place for her mother, and seeing the consequences of this for her mother's wellbeing, made her want to share her knowledge to enable people to stay at home and to make the right choices for them.

My Mum hated where she was. Part of it would be her dementia but part of it, I knew, I knew I'd done. I'd chosen the wrong place. Practically immediately after she'd moved in... little young people looking after. (Elaine, Interview)

This sense of finding an appropriate space of care influenced her own volunteering. Other volunteers provided one-to-one support in an older person's home, often because this was most suitable for people with limited physical mobility. Danielle described how she wanted to go on walks and shopping trips with her befriended, but that mobility problems and chronic pain made this difficult. The issue was not a physical one for Coleen, rather it was the older person's depression which made it difficult to conceive conducting their befriending relationship elsewhere. Her befriended's hospitalisation caused a disruption to the volunteering activity for several months. The benefit of being invited into the home space of the older person, however, was that it allowed volunteer respondents to get a better sense of the life-world in which they inhabited day-to-day - their photographs which could be used as prompts, comings and goings of the neighbours, and the sense of being invited in was important to some, particularly Ben, who felt this distinguished his befriending from the paid caring he did at a residential home. The spaces of care are not only connected to the home-space of the older person,

but extend to the wider life-world of the volunteer, and how this is experienced and reproduced during everyday practice. Ben described how, outside of his befriending and his paid employment he tended to ‘stay inside my own little orbit’. He struggled to fill the time between shifts, as he was usually free during the day when most of his friends were working.

On arriving at [local area] I walked to the family home of the gentleman who I have befriended. I stayed for 1½ hours and chatted with him mainly about the past. He talks about how children used to play in the back lanes and yards of [local area] and entertained themselves before the days of TVs and computers. It reminded me of how I used to play football till it was dark with my friends. We used to use jumpers for goalposts and it’s something that I don’t see children doing now.  
(Ben, Diary)

Ben’s diary also revealed his sense of place and low attachment to the region which informed his experience of befriending. Walking the streets made him think of his future as not in Newcastle, as someone who does not belong, and does not wish to belong, prompting a wish to drift around. Ben’s ties to the local area were weak, and befriending was perhaps an attempt to become more established within the community, but which he felt was not sufficient to achieve a sense of ‘belonging’. Here, he places himself in the middle of a continuum of belonging to the area.

I always think of how my future is not in Newcastle. You have to be a Geordie to belong here. I don’t like the parochialism as if the place is somewhere ‘special’. I don’t actually want to belong anywhere and look forward to selling my flat so that I can drift around. But I know that I’m spoilt in that I have a nice home. There are people in Newcastle who are refugees and asylum seekers who have seen their families killed in wars. To them Newcastle may seem like a fair place which it probably is when I think of the bigger picture. (Ben, Diary)

The negative attachment and defensive stance to the region, articulating an intention to ‘drift around’ suggests displacement and ontological insecurity, his sense of self and his relationships fragmented and uncertain (Giddens, 1991). Several days later in his diary, he described a trip to his parents in the Midlands for a relative’s funeral, which he enjoyed as a change of scenery, despite the sad occasion. He believed he was living in the wrong place as his family and friends lived elsewhere. The difficulty for ‘outsiders’



to penetrate strong regional identities and notions of community was evident. Sometime after Ben completed the diary, he contacted me, concerned that it may have been written too negatively. He also advised that he would be leaving the area as he had sold his flat, and was moving back to his parents' home town. I wondered to what extent the reflexivity of the diary writing process had made him more conscious of his daily routines and limited sociality, which perhaps unsettled his sense of belonging to the area.

## **Conclusion**

A significant element of this research has been focused upon important existential concerns. People choose to bracket off or revise aspects of past, present and future horizons to make sense of their routines and life-worlds, maintaining a sense of ontological security. As Giddens describes, already existing spaces, objects and relations of everyday life have emotional connotations and evaluation by others, creating 'symbolic residues' (Giddens 1991:39) which affect caring decisions, practices, experiences and geographies in ways which follow conventional or unconventional pathways. I would argue that there is a desire for predictability and routine in order to comprehend life-worlds as secure, to believe that knowledge is shared with others when acting in the world, that existing family or friendship practices are held intact (Finch 2007; James and Curtis 2010), and ultimately that one's life narratives can be told in a coherent way. Much academic and personal discourse over recent years has been generated as a result of poststructuralist theories which represent identities and social phenomena as multiple, fractured, disjointed or in some way incomplete. This has been a very valuable contribution to destabilise essentialist constructions. However, though the complexity of processes and the incompleteness of knowledge are assumed in this thesis, I would caution against inferring from everyday performances and practices of carers that individuals desire such a fracturing and fluidity. Rather, they discussed a desire to maintain some sense of control, a concern to stay still, slow down and hold on to rather than a desire to enhance, build and improve.

The temporalities of everyday caring practice differ significantly between family carers, paid care-workers and volunteers. Family members were more connected to the

‘cyclical’ temporalities focused on the needs of the body of the older person they cared for. The rhythms of care during the day and at night were organised around the embodied needs of their relative or spouse, but needed to be coordinated with those of paid care-workers coming into the home. Finding respite time was important for family carers, which became a disruption to the everyday practices of care. Other disruptions, however, were avoided wherever possible, to maintain some sense of order in everyday life. Disruptions to this order (such as through inconvenient timing of paid carers or resistance of care-receivers) brought frustration to the activities of the day.

Similarly, paid carers’ work patterns were arranged to be timely to such bodily needs, but not in an inter-personal way. Rather, these were pre-arranged times for bathing, toileting and putting to bed. They were not always attentive to the social expectations attached to such everyday practices, such as the appropriate time for such routines (Finch 2007; James and Curtis 2010). They were unlikely to be present for the whole cycle of the daily routine at an older person’s home – instead moving across the local area to attend to the requirements of several older people in the course of a shift. Their concerns included finding adequate time to get from one client to another, and the achievement of such tight scheduling. Co-coordinating with clients’ family, other care-workers’ shift patterns and their own family care responsibilities made these routines important to establish and maintain. For volunteers, the temporalities were different, more concerned with filling in time than finding time. In contrast to the experience of most family respondents who were mostly confined at home, volunteers often used these caring responsibilities to build routine into the week, as a means of getting out of the house, and as a means of socialising.

Gendered and classed dimensions of aspirations (towards paid employment for example) can make a huge difference to how ‘pathways of feeling’ develop and how caring work in the home is perceived, experienced and performed (Hochschild 1997, 2003a,b). For some ‘work’-focused people, losing this aspect of their identity is unwelcome and produces dissatisfaction, though for others who prioritise care over paid work, continuing paid work through necessity can cause uncertainty if they are not putting their time where their values are (Hochschild 1997:219). This tension between values and time afforded to valued practices and relations is also found in empirical

studies by McDowell (2005, 2006). The space in which care occurs was significant for the way this is experienced across different care economies. Family carers talked of condensed life-worlds as a result of their caring, whereas volunteers' life-worlds were opened up. Care-workers' positions were uncertain in the spaces of the home, requiring negotiation to find an appropriate balance, and to achieve a sense of belonging and familiarity.

## CHAPTER 7: RESPONDING AND CORRESPONDING TO 'NECESSITY'

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### **Introduction**

The preceding data chapters raise issues of choice and control for carers by framing data from semi-structured interviews and solicited diaries around pathways of feeling which influence the orientations, negotiations and life-worlds of care. The concept of orientation describes subjective understandings and desires in relation to given contexts, and is used to explore why and how carers respond to older people with social care needs. These orientations shape care decisions, and the negotiated, routinised and spatialised life-worlds carers inhabit. By looking across diverse care economies including family, care-worker and volunteer roles, this thesis argues care experiences and subjectivities can overlap in their practice (see Pahl 2000 and the notion of suffusion), as individuals draw upon experiences beyond their given roles to negotiate boundaries and inform caring practice. By looking beyond caring dyads, this thesis suggests care roles are negotiated in response to the intentions and capacities of care-receivers and complementary carers. However, attention to the spaces and temporalities of care reveal how material and organisational constraints continue to assert real (if porous) boundaries in care relations.

### **7.1 *Evaluating and Exceeding Necessity***

This thesis suggests that key to understanding the process of accepting and interpreting a carer role is the 'necessity' of care as an embodied and emotional practice. As embodied subjects, we are mortal and suffer pain, and our lives involve mundane and sometimes abject conditions, such as managing bodily fluids, eating, sleeping, that form a necessary part of everyday life (Twigg 2000). We may respond to tiredness or hunger differently in different contexts, but due to the limitations of our bodies, we cannot

escape it. According to Arendt, the human condition is characterised by this embodied reality and existential desires and fears of living in the world with others, rather than achievements in our 'productive' lives:

Man cannot be free if he does not know that he is subject to necessity... the enormous changes of the industrial revolution behind us and the even greater changes of the atomic revolution before us will remain changes of the world, and not changes in the basic condition of human life on earth. (Arendt 1958:121)

Most family carers in this research adopted current caring roles in mid-to-later life, whilst paid care-workers and volunteers spanned a wider age range. For family carers in particular, decisions taken in response to 'necessity' were either in response to such medical emergencies (of a spouse, parent or other relative) or as a gradual accumulation of responsibility rather than in fulfillment of an imagined future or life project. Contradictory assumptions in contemporary welfare discourse that the state would make necessary provisions for old age, and at the same time that it is a family responsibility, have shaped responses to the necessity of care for and by older people.

Given the infrequent public discourse surrounding care of older people, there are no clear culturally defined pathways to good caring practice, or symbolic markers recognising the adoption of a caring role as a significant and valued moment in the life-course, such as occurs when leaving school, childbirth, marriage and retirement. There exists a wealth of cultural displays of 'good' childcare practice often set within highly moralistic, and often classed and gendered terms. For example, the care of children is built into conventional understanding of family life which informs an individual's life trajectory from an early age (often acted through play) and these expectations are brought to romantic relationships and marriage. In contrast, decisions about caring for older family members are more likely to arise as caring needs become apparent, or during some crisis such as a fall or as a result of diagnosis of illness. This may not necessarily imply an alteration to life-course intentions (Bury 1982), rather, the timing may be at odds with current circumstances. As a result there may be less planning (financially and emotionally) by prospective carers as they engage with their responsibilities. The choice of carer is often 'naturalised' according to the enrolment of those who are emotionally and spatially 'at hand'. This is reinforced by assumptions

about necessary (gendered) skills, knowledges and demeanours, positioning some subjects as more 'capable'. Choices then become constructed after this fact.

Care might be characterised as a stance of engagement and orientation to the perceived needs of others, most often associated with a leaning towards (Arendt 2003:81). It can also be characterised by absence or turning away from, such as parental response to children's transition to adulthood in order to facilitate a sense of freedom, autonomy and personal growth; when discouraging detrimental dependencies in mental health contexts; or in deploying 'light touch' or unseen techniques or technologies to facilitate a sense of autonomy of older people. This suggests care is practiced as individuals orient themselves in contextual judgements based on their moral rationalities of the right thing to do, rather than reflective of particular tasks or behaviours. Appropriate timeliness and pace is intimately connected to caring practice at home, and is to some degree expandable, collapsible or squeezable, affecting perceived quality standards and the display of personal values (Hochschild 1997; 2003a,b,c). Carers in this study suggested that, whether in terms of the care they provide themselves, or the care they expected from others, timeliness and pace are significant elements which influence their evaluations of what is necessary to provide 'good enough' care.

The data chapters suggest dissatisfaction with the care role can be difficult for carers to express, but is nevertheless evident in many accounts. By focusing on meanings derived from caring practice, the data contradicts suggestions that care is intrinsically unsatisfying or undervalued by revealing the value and worth to both givers and receivers of care. Whilst valuing care as a 'labour of love' can risk reproducing dominant discourses that women are suited to mundane, caring, repetitive tasks of care, Delphy (1980) argues positionality is critical to understanding the 'truth' of this statement. For those who are not called upon to engage in caring labour to argue it is morally rewarding has quite different political effects than if this same statement is made by those who are called upon to do so. I argue with Folbre (2001) that these contradictory characterisations of care as both rewarding and marginalising form the basis of a care paradox.

Going beyond the necessity of bodily needs and appreciating existential concerns is an important means of ensuring the personhood of the older person is held intact for as long as possible.

It's not about wiping bottoms and giving baths, it's about spending time providing hands on care for *real people* [emphasised] who have experience, and who have opinions, and who can pass on something to the next generation. (Phoebe, Interview)

Existential concerns may include keeping 'true to self', life projects and relational commitments. Sometimes it is about having the ability to live a 'normal' existence, in which mundane everyday routines are practiced regardless of their necessity, to promote variety, enjoyment and affective satisfaction. Going to the shops, getting public transport, having a coffee while you are there, wearing a winter coat, feeling the weather, and getting wet in the rain - such practices are examples of positive experiences of everyday life which are missed when they are taken away through illness or confinement in the home. Many respondents discussed attempts to encourage older people to get outdoors, to take part in everyday activities as part of 'normal' life. The data reveals evidence of relational concerns across all carer types in that their satisfaction was often tied to the satisfaction and comfort of the person they cared for. However, as Pyke (1999) argues, whether families are individually or collectively oriented influences how such concerns will be articulated and acted upon.

## **7.2 *Ontological Security: Maintaining (and Disrupting) Routines***

Regularity and routine can be comforting when dealing with changes caused by the onset of illness. At a stage in the life-course when older people may be losing control over their bodies (Dawson 2002), through dementia and other illnesses, carers respond by seeking to maintain and protect their routines, relationships and life-worlds. The 'dread' described by Kierkegaard (1944) of the unknown, and of death itself, generates fundamental anxieties concerning the reality of the world around us. Berger and Luckman (1967) argue that shared meanings are essential for human beings to conceal the contingency of action, and the uncertainty and fragility of our embodied selves. Giddens (1991) calls this 'ontological security'. This requires individuals to adopt: 'the

natural attitude' which 'brackets out questions about ourselves, others and the object world which have to be taken for granted in order to keep on with everyday activity' (Giddens 1991:37). Sharing understandings of 'reality' with others is, Giddens argues, increasingly relevant in the context of 'high modernity' in which individuals are confronted with choice and endless possibilities. Those experiencing loss of control of their bodies, or of those they love, may respond to such changes anxiously. Securing and maintaining regularity and sense of purpose may be particularly desired under such circumstances. Arendt (1958) describes the regularity of social reproduction through embodied routines, which may not bring pleasure as such, but brings a satisfaction from being alive in the capacity to breathe, to sleep, to eat and to feel. Phenomenological accounts suggest regularity and familiarity with material objects and in relations with others are important constituents of the human condition.

Certain spaces, places and practices can sustain ontological security, and some can disrupt them. The site of the home is an ambivalent space, since its familiarity is challenged by the accoutrements of managing illness in old age. Since many family care-givers and care-receivers were largely confined to the home, this ambivalence takes on greater importance. Several family carers commented on the benefits of the seaside, and visited the coast as often as possible – a landscape significant for its regularity, familiarity and sense of the sublime in its vastness. This pleasure derived from witnessing the 'monotony of the sea, the desolation of moorland and the quiet, unchanged fall and rise of an engine beam' (Ruskin 2007:176) reflects a phenomenological approach to embodied existence. Care-workers and volunteers saw trips outside the home, even if only in a car journey or a walk around the street as beneficial, significant and necessary.

In conducting our relations with others, there is often a sense of accomplishment and comfort in simply rubbing along, not standing out in a crowd, living a predictable, regular existence. Routine is understood to be both a coping strategy and a constraint imposed by the complexity and volume of the multiple tasks and responsibilities involved (Wiles 2003a). Differences may be seen between those carers who feel their place is to be a full-time carer, and those who have a pull towards employment outside the home. The highly precarious character of care routines are often overlooked when



support options for older people are considered. Rigid care plans can be framed around highly contingent and informal caring practices. Achieving set routines and ensuring predictability may conflict with other responsibilities and commitments. These routines are often sub-optimal (Jarvis 2005:213) in order to build in flexibility, as sustainable routines need to be both reliable and adaptable. When finances, time and other resources are scarce, and carers face fatigue and emotional challenges in their everyday lives, dealing with a lack of adaptability can be detrimental for care-givers and care-receivers. The consequence of a desire for routine and familiarity is that agency care is likely to remain a popular 'default' choice, when compared with the uncertainty and risk of employing personal assistants enabled by personalisation policy. This resonates with the work of Baxter et al (2008) who found that customers tended to stay with existing agencies even when measures of 'quality' positioned them as inferior.

### ***7.3 Invoking Family, Friendship and Community in the Care Imagination***

One of the ways that caring roles elevate status is in strengthening and creating actual and imagined family ties in a process of 'doing family' (Morgan 1996,1999) and 'displaying family' (Finch 2007). The invocation and display of family and friendship is important across care economies in different ways. For family carers, it is evident that Joseph's family status was enhanced through his caring role, and in another example, Carol described becoming the 'head' of the family as other older relatives turned to her for advice and support as a result of her responsibilities.

The motivations and orientations of volunteer carers in particular are influenced by imaginations of relational commitments from which authenticity is desired on both sides of the care dyad and beyond, into how these relationships are perceived by others within the support network. In this study, establishing authentic family or friendship connections were less important for those whose primary motivation for volunteering was as work experience, but for those who befriended in order to extend their own social network, or who wished to alleviate the loneliness of others, the relational aspect was important to establish. Drawing on Ben's example, befriending gave him a connection to an older generation and an involvement, however minor, into a family setting. Living alone and working unsociable hours, befriending allowed this sense of

belonging to some extent. In Ben's case, the desire for an improved CV (to increase experience and attain certain desirable and employable demeanours and skills) was only one aspect of a more complex rationale and orientation based upon reduced social connection and lack of fulfillment.

There is a stigma attached to befriending schemes where paid workers or volunteers act as surrogate friends (Andrews et al 2003). Some older people:

...indicated that they felt a loss of self respect and dignity in having to pay someone to come into their homes for company  
... the voluntary nature of the befriending service was an important feature (Andrews et al 2003:355-6)

Therefore, relationship boundaries are carefully negotiated in order not to appear artificial on the one hand, or place too much emotional or time-burdens on the visitor. These friendship groups and visiting schemes are likely to be in more demand as kinship ties loosen. Self-directed support and personal budgets may be mechanisms which potentially bind family and friend relations for the first time within contractual relations in the delivery of welfare support. From a carer perspective, demands for care given 'authentically' (usually imagined as given freely for love) remains important, yet increasingly complicated within contractualised relations, as has been demonstrated by Leece's (2006) findings on the amount of 'free' care provided to older people within direct payment relations.

#### **7.4 *Idealised and Disrupted Spaces of 'Home'***

In policy as well as public discourse, the most desirable site for providing care for older people is the home. The promotion of community-based options coincides with media stories and word-of-mouth accounts which raise awareness of bad practice, abuse and neglect within residential care. Failing to enable an older person to stay at home may generate distress and unhappiness for carers as evidence of failure. This concern may exert pressure to cope and disguise difficulties or discontent, in order to secure the social expectation to enable an older person to stay at home, seen as the place most likely to secure contentment.

By contrast, care-homes are perceived as unhappy places. As Amanda and other family carers described, ordinary questions such as having choice over what to eat, when to go to bed, whether or not you have your own key to protect your privacy and possessions, whether intimate relationships are encouraged, are of great concern. This concern reflects a fear of a loss of freedom and control. The experiences of Phoebe, who acted as an advocate for care-home residents, illustrated some of the issues which family carers, care-workers and volunteers were attempting to ameliorate by aiming to keep people in their homes for longer.

I have yet to hear a conversation about whether the dinner was nice. And I think it's because people feel as if they have to be quiet. It's a bit like a library. They feel as if they have to be quiet. (Phoebe, Interview)

Phoebe argued that residential care settings may be communal, but they are not necessarily a community. Phoebe described staff concerns about the 'risks' attached to friendships, which may explain why friendships are not often evident in these spaces, as older people felt they were being watched by staff. Her account of a discussion with care staff about two residents who were reunited after many years apart indicates her belief that institutions seem unable to respond adequately to questions of personhood:

They recognised one another instantly, and because they were on their own, they wanted to strike up their friendship again. And the staff were saying to me, you know, 'we can't leave them alone in the lounge'. I said, 'well why?' 'Well you know, in case something happens'. And I really wanted to say, well define something. They're both in their eighties. They're not suddenly going to dive behind the sofa. And it was at that point that I began to think, I wonder if friendships don't develop because people feel as if they're being watched... from where I was standing, all I could see was two elderly people who'd found one another after all of these years, and simply wanted to sit on the sofa and hold hands. The lady had quite severe dementia, and yet every afternoon he would sit next to her, and he would hold her hand, and he would read things out of the newspaper. (Phoebe, Interview)

Such accounts reinforce negative associations about residential care. However, during a visit to a church lunch club as part of my fieldwork, I spoke to older people who lived in supported housing (sharing some communal areas, but with their own small flats). They

argued that their current living arrangements were preferable to being 'in streets'. The women described living in conventional housing as isolating and unfriendly these days. The interstitial space of supported housing environments (between communal care home and conventional family home) illustrates the possibility for options outside of binaries, demonstrating that privacy and sociality can be negotiated in degrees. Unpicking assumptions that being in one's own home is necessarily more desirable prompts questions about its connection with the current policy agenda. Gott et al (2004) in their empirical research on preferences for home as opposed to hospital as a site for end of life care, suggest the characteristics of these sites should not be taken for granted, since they are dependent on how practices, spaces and experiences are constructed within them, and the way these enable or constrain agency and choice. This point could be made concerning the preference of home-based care more generally. Over-emphasising the value of home-based care over care homes may be counter-productive, as negative discourses and scare stories may overshadow the benefits of residential care, and trivialise the profound difficulties and compromises involved in caring for older people at home.

An important strand in this research was the way carers were concerned with combating loneliness for both older people and themselves. Home-based care may not be best placed to alleviate this issue alone. The boundaries of the home were challenged and supported in various ways by the presence of paid care-workers, volunteers and others. External support (outwith the family) could provide reassurance during the day for those family carers in paid employment. Amanda outlined the benefits she found in the meals-on-wheels service in terms of enabling the monitoring and regulation of care routines. The guilt of leaving her father unattended, particularly and symbolically at meal times, was assuaged to some extent by the midday meal provided by meals-on-wheels. By arranging something superior to what she could have provided herself (a hot meal mid-day) compensated for her absence and displayed her concern to others (see James and Curtis 2010). Amanda also describes the other positive benefits beyond the immediate satisfaction of a bodily need to eat. The visit provides a check on general wellbeing – and a system of alert for her during the day whilst she is at work should they not gain access.

Similarly, for paid care-workers, the presence of neighbours was a source of reassurance when it was time to leave clients on their own. However, this direct monitoring and regulation of caring activity in the home can be a source of strain and anxiety for family carers, particularly when things ‘go wrong’. Barbara’s experience following a distressing incident with her husband, which was reported back to social services, demonstrates this clearly. Barbara described needing an ‘outside viewpoint’ other than the care-workers who had disrupted the privacy of Barbara’s domestic space of the home - the consequence of accepting formal support. Although she described elsewhere the paid workers being ‘like family’, in other circumstances she needed to find a trusted source from elsewhere. Living day to day, sharing intimate knowledge and abdicating even limited responsibility for the care of a loved one to paid others, whilst not being able to fully trust them, was clearly cause for some anxiety.

### ***7.5 Relational Agency and the Ambiguous Spaces of Care***

Relational agency is explored in this section to propose that choice and control do not necessarily reflect the individualised actions of rational consumers. Rather, choice and control for care-givers and care-receivers draw upon the needs and desires of others within a given support network. Relational agency is a concept which is defined by Edwards and D’Arcy (2004:147) as ‘the capacity to engage with the disposition of others in order to interpret and act on the object of our action in enhanced ways’. This is a useful way to understand caring encounters, and suggests there is a tension with policy discourses of self-direction and personal choice, which rarely takes sufficient account of the situated circumstances of carers. There is a relational agency at work in caring practice which incorporates intersecting power relations into the ways carers negotiate their caring roles. The enrolment or ‘hailing’ of carers and the construction of care routines is an engaged and intentional process. However, set in a context where moral discourses valorise self-sacrifice as an attribute of authentic care underscores the difficulty of addressing the position of carers in policy and practice (Folbre 2001). Carers may rely on the care of others to protect their interests if the very essence of their caring identity is derived from their proximity to satisfaction of others.

This section discusses debates about power, subjectification and resistance involved in human agency, and considers how care fits into these debates. The work of Michel Foucault (1977) has been important for understanding power as both positive and negative in its dimensions. Foucault argued that power is not solely the attribute of dominant agents coercing others, though this has been the predominant focus of his work. Foucault is influential because his work accounts for the historical shift in the way power is exercised by the state. Rather than (or as well as) physical force, Foucault describes how power flows through everyday embodied practices, organisational structures and agents of the state, creating particular types of subjects who respond to this power, in compliance or resistance. His focus on the state has led to suggestions that Foucault equated notions of power too closely with domination. However, Heller (1996) critiques this view, arguing resistance informs his theory of subjectification.

This is developed empirically in geography literature which seeks to account for the way power operates in space. According to Sharp et al (2000:2) in *‘Entanglements of Power: Reflections’*, interplays of power creates a messy entangled process through which subjects emerge. In this edited collection Jenny Robinson (2000) notes how Foucault’s description of top-down subjectification from state organisations implies that mastery and control of individuals, and the construction of subjects is uni-directional. She argues that this is in fact a two-way process, since resistance exerts a subjectifying power towards dominant agents. She also suggests that power is ‘noisy’ since it draws on genuine emotional engagement and the interiorisation of the desires of others, which cannot be produced by imposition.

This concern is shared by Jassanoff (2004:25) who cites Benedict Anderson’s (1991) *‘Imagined Communities’* to argue that successful enrolment of citizens into the idea of belonging (to a nation) is only possible by the active imagination and agency of its subjects. In seeking to demonstrate this notion empirically, Robinson (2000:86) considers relations between tenants and rent collectors, arguing that the process of encouraging tenants to make regular payments suggests the possibility of ‘power as friendship’, and in order to persuade a subject to co-operate, an agent must first understand their concerns, and this implies power is always ‘contaminated by resistance’. This interplay is fragile since it involves conflict, acquiescence, mutuality

and is subject to re-negotiation. This enrolment of subjects in the exercise of power has been variously described as: 'permanent provocation' (Foucault 1982:222, cited in Robinson 2000:87); 'co-production' (Jassanoff 2004); and 'essential agonism' (Robinson 2000). The need for constant negotiation within care networks suggests the agency of care-givers and care-receivers are complex - neither a quiet conformity to meet social expectations, nor an active resistance to established markers of individual achievement or career.

Furthermore, carers stand in an ambiguous position in relation to individualised notions of agency and choice as both providers and consumers at various times and places. Landscapes of care which involve several organisations, individuals and resources coming together, make adult social care a particularly complex set of arrangements. This complexity and precarity in negotiating various relationships within a support network has implications for enacting choice and control. This can be understood with reference to Derrida's (1997) notion of the 'constitutive outside'. Derrida proposes that our identities and subject positions are framed within a relational context, often in response to conditions of possibility performed by the 'other'. For carers, this other may be the care-receiver; a complementary carer involved in the daily routines of the care-receiver with whom one needs to co-ordinate and negotiate; or some other individual who is not involved in providing care but nevertheless exerts an influence on the life-world of care, such as co-resident family members or geographically distant relations.

This is evident in several accounts by respondents as they sought to establish and negotiate their roles with other carers and with the care-receiver. Twigg and Atkin's (1994) typology, suggests the agency and power of carers is relationally and spatially contingent. This is evident in the way family carers can sometimes become co-workers or experts, drawn upon in moments of resistance to paid-workers' intentions (as in Barbara's account), but which may incur risk should this intervention goes beyond acceptable limits as decided by formal institutional guidelines. If the family carer had a less active care role, or perhaps in the absence of family entirely, care-workers often built closer, friend-like or kin-like relationships. In these instances, as Twigg and Atkin (1994) suggest, family may be viewed as individuals to be encountered and superseded.

Such an interventionist stance was considered appropriate by Megan, for example, to ward off coercion, or neglectful or inappropriate care by family.

Finding coherent ways of acting in the world is part of an individual's moral project, and forms the basis for caring activity towards others through everyday inter-subjective encounters. The perspectives, intentions, wishes and fears of others are likely to be taken into account in a care context over the singular intentions of a given agent. When encountering resistance from a client, the distanced position of care-workers (informed by organisational rules and guidelines) may limit their agency. In a continuum from passive acceptance of an older person's will as client/consumer towards active persuasion to do what is regarded as 'in their best interests', family carers and care-workers can move across this continuum, but from different default positions, with each accounting for the presence of the other in the extent to which their position can move. Consumer imperatives are likely to increase the power of care-receivers, but this may be tempered by the incorporation of the concerns of the wider support network who are affected by these decisions.

## **Conclusion**

This chapter has discussed some issues pertinent to understanding choice and control for carers across a range of contexts. A number of markers distinguish family caring, paid care work and volunteering, but there are several ways in which these overlap in time and space. Family carers adopt some of the features of care-worker practice to manage their identity and their changing relations with those they care for; care-workers draw upon real and idealised family experiences to configure their caring practice beyond the requirements of the role; and volunteer carers inhabit a space of in-betweenness as insider/outsider, demonstrating the blurred boundaries between care and non-care or authentic and inauthentic friendship most effectively.

Adhering to social expectations across the life-course can generate feelings of anxiety when our motivations and orientations are misaligned with everyday practices (Giddens 1991; Himmelweit 1995). These can be influenced by classed and gendered dynamics, never resting on one identity marker entirely. Values influencing carer subjectivity may



mean that a carer may endure difficult caring roles and be convinced of the 'rightness' of their action, whether or not this is against their own apparent interests or previously imagined life trajectories. Successfully accomplishing the care of older people may create a sense of achievement and meaning. However, it is important to critically explore the processes of perpetuation, disruption and renegotiation of obligations and responsibilities toward older people in need of care (Finch and Mason 1993). This takes on added significance in a dynamic social context which has seen the increased prevalence of women in paid employment and its discursive association with notions of 'care deficit'. Negotiating 'work' and 'care' responsibilities are usually not either/or choices but exist in considerable tension (Deven et al 1998). Even when enrolment into caring roles (paid and unpaid) reflect classed and gendered rationalities of the 'right thing to do', these roles may be embedded in spatial and temporal life-worlds which are at odds or out of sync with individual aspiration or social expectation.

Gender continues to influence the construction of carer identities (Tronto 1987), yet this thesis suggests that other intersecting factors, such as age, class, ethnicity and family position can also be relevant. Furthermore, the spatiality and temporality of caring practices are important in defining and framing the lived experiences and material consequences of accepting caring roles. In this thesis, attention to support networks (see Wenger 1991, 1997; Wenger et al 1996; Keating et al 2003) demonstrates the necessity of looking beyond care dyads to consider how choice and control is negotiated in a relational way which exceeds the concerns and attributes of the particular care economies in which individuals are situated.

## CHAPTER 8: CONCLUSION

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### **Introduction**

The concluding chapter reflects on the policy implications of this research, acknowledging the limitations of small scale study which affect the reliability of findings, and makes recommendations for the future direction of research in this area. By promoting individualised options for older people away from 'one-size-fits-all', personalisation could be an important policy, enhancing and facilitating choice and control and encouraging diversity of provision. As a form of identity-based politics, personalisation opens up a realm of individualised opportunities and choices, and is a means of thinking beyond normalising structures, particularly universalising tendencies of state and private provision (Young 1989).

However, by presenting the perspectives of carers across social support networks and care economies, this thesis suggests that the individualised focus could be problematic. The concern to establish and maintain reliable, predictable care routines needs to be complemented by attention to the needs of carers. These needs include: regular respite and support for family carers; adequate terms and conditions of employment for care-workers which take account their other care responsibilities; and the personal development and fulfillment of volunteers. This is a significant challenge for the personalisation agenda, and one which may require more resources. In an era of budget reductions, taking control of resources may bring additional risks as well as opportunities to older people and carers living in economically marginalised communities. A greater focus on how personalisation agendas strengthen care relationships, rather than on bolstering consumer power, may be one means of understanding the implications of personalised budgets for care.

## 8.1 Implications for Policy and Practice

There are three important processes at work in choice and control agendas towards social care for older people: commodifying informal caring; individualising market-based caring; and expanding voluntary caring. Clear divisions between care economies and dichotomies such as love/money are challenged in this thesis to reveal significant overlap between family, care-worker and volunteer accounts of care in relation to skills, demeanours, motivations, negotiations and lived experiences. However, distinctions between these categories are not entirely without basis, as the constitution of support networks influence the experiences and orientations of care in particular ways. This research may inform personalisation policy by taking account of such issues, and by considering the spatially and economically marginalised contexts of caring at home in working-class neighbourhoods in Tyne and Wear. Attention to embodied and affective relations of care has particular policy relevance to personalisation, even though most respondents did not engage with it in discourse or in practice. To reiterate Anderson and Smith's (2001:7) assertion: 'relevant policies may have to be small in scale, humanising in intent, embedded in context, enacted through bodies'.

Encouraging more preventative community support in later life is one of the stated aims of health and welfare policy as it is believed to reduce the need for high cost caring (HM Government 2009). However, there is a tension with this aim and the state spending squeeze which diminishes resources, targeting the most acute cases only. As Bloor's (2005) findings suggested, the 'modernisation' of social care does not as yet appear to generate the anticipated efficiency savings, though as has been suggested more recently, people who have personal budgets are now spending slightly less than local authorities on their own care and support, making personal budgets 'cost neutral' (Brindle 2010). However, progress in delivering personalised support is still 'patchy' across England (Arksey and Glendinning 2007), and it is perhaps inevitable that the current economic climate will jeopardise the emancipatory potential of choice and control.

### 8.1.1 *Commodifying Family Care*

This thesis argues along with Tronto (1987) that care has a legacy which is exploitative of gender, class and other inequalities. As Lawson argues:

...social relations of love, connection, mutuality, commitment and so on are not an idealised terrain; rather they are fraught with power relations that are worked out in specific contexts. (Lawson 2007:4)

This may have implications for the construction of choices and constraints of carers across care economies in the future. Extending choice and control through the promotion of more marketised and individualised relationships in adult social care may bring considerable benefits to some older people and their carers, but may also generate anxieties, limitations and risk for others. Personalisation has the potential to enhance consumer power in negotiations with care agencies, but may introduce risk and frustrate expectations for paid and unpaid carers alike. As was argued in the literature review, satisficing rationalities may be more reflective of care consumers, since the capacity to negotiate improved care may be contingent on particular knowledges and capacities to access these resources and opportunities from the market, and may be influenced by concerns to minimise disruptions and co-ordinate effectively with other care arrangements. Cash by itself does not provide knowledge of the commodified care market; nor does it entirely recompense individuals who are enrolled into informal caring positions which continue to socially and economically marginalise them upon receiving payment.

Personalisation in adult social care could bring financial reward and recognition to previously invisible and 'unrewarded' practices of family care since commodifying informal care is one aspect of the choice and control agenda. This appears to deliver a care equivalent to a 'wages for housework' (Dalla-Costa and James 1975), repositioning carers at home more favourably in monetary terms, but which may impact on social relationships and obligations in positive and negative ways for family, friends and neighbours. The original 'wages for housework' demand was critiqued in the 1970s as perpetuating the gender division of labour (Rowbotham et al 1979; Coultas 1981) and this critique could also apply to remuneration structures for carers within self-directed

support options. The commodification of pre-engaged informal caring is unlikely to introduce an individualistic economic rationality, as other intentions and moral rationalities are always already enmeshed in these relations. It may be that previously non-engaged informal carers (family, friends and neighbours) have the potential to become motivated by payment itself, perhaps more so than in other marketised forms.

The three data chapters in this thesis suggest that the marginalisation and inequity of family care may not be altered by financial compensation alone, by considering how individuals are drawn into care, how caring relationships and practices are shaped by family position, and how relational subjectivities sustain marginalised and restricted spaces and life-worlds. For family carers who took part in this research, concern was expressed about the level of intrusion in terms of administrative responsibility with personal budgets. The need to change the care plan as circumstances alter and providing cover for leave (of personal assistants) or respite (for themselves) were important concerns. Existing benefits and allowances are currently of low financial value, so their replacement in the form of wages for care through the personal budget may be a beneficial move for some, particularly those currently on benefits or low income. However, given that individual personal budgets bundle together several health, social care and income funding streams and entitlements previously administered separately, this may act to reduce the overall care resource available to an older person in need of social care support.

### **8.1.2 *Individualising Market-Based Care***

Standardisation and use of economies of scale through centralisation is the typical response to promote efficiency in the provision of services, yet such a move goes against the grain of the personalisation agenda to individualise provision. Whether extending consumer-led social care will lead to alterations to the structures of the industry is unknown. However, in the wider economy, agencies are increasingly the means through which flexible work is carried out, especially in sectors that have a high proportion of ‘difficult-to-fill’ positions (Theodore and Peck, 2002). Glucksmann (2008) points out that the UK is now one of the largest importers of professional health care workers in the world. This provides the context for the emergence of a care deficit

which self-directed support policies seek to resolve. The majority of paid care-workers are middle-aged women (Glucksmann 2008), which may not be sustainable as other forms of employment may attract women from the care industry. The social care sector is characterised by a flat structure with very little chance of promotion. Experienced carers with 25 years of service earn on average a maximum of 20p per hour more than new starters, and senior supervisors no more than £2.00 an hour more for their extra responsibility (CSCI 2006). Such pay and conditions have led to inferences that care quality is compromised.

In a political sense, historical approaches to care have been critiqued by the disabilities movement, which points to the ways disabled and older people have been positioned as passive recipients (Charlton 2004; Hughes et al 2005). Moves away from medicalisation and institutionalisation towards community support began with the Community Care Act 1990 (Milligan 2001, 2006), and continued through various health and social care reforms to introduce market mechanisms. The introduction of financial control through Direct Payments was an important moment in redefining the power relations of care-receivers. Self-directed support and personalisation measures have become key mechanisms for ensuring that the consumer gains more choice and control over the care they receive, limiting professional power and introducing more individualised, marketised relations in a contractual way.

This has implications for the way care is conceived and practiced. Empirical research from other European countries implementing consumer-based social care is instructive. Eichler and Pfau-Effinger (2009) argue that traditional care values (e.g. family based caring) are preferred over marketised care in Germany, and this can create significant obstacles - since older people and care agencies differ in their understandings of what constitutes good quality care. This raises the question whether cash-based markets for care are better positioned to encourage organisations to respond to and realise demands for improved quality and choice, rather than what is most convenient or cost effective. In a UK context, personal care and domiciliary care agencies are faced with similar challenges. Baxter et al (2008) suggest personal budgets have impacted on social care in terms of: recruitment and retention; increased competition in attracting personal budget holders to their services; threats to small independent agencies from larger firms;

differential charging and regulation; and risks of de-skilling the sector through use of personal assistants being employed directly by budget holders.

The increasing diversity of the way people live their everyday lives, and the diverse aspirations for old age has consequences on notions of 'good enough' care. As Phoebe asks:

Are they [older people] demanding, or are they just from a different strand of experience? (Phoebe, Interview)

Perceived quality is bound up in subjective experiences and preferences of older people, but requires an appropriate supply of carers to meet future demands. This depends upon the continued orientation of individuals to work in this sector. Ehrenreich and Hochschild (2003) suggest that the growth of domestic agencies has been accompanied by a symbolic association with idyllic pasts of servitude in names of franchises and in styles of uniforms and so on. She argues the industry is arranged remotely because clients experience discomfort when acting as employers. However, care for older people cannot be remote in the same way as domestic cleaning services, since the quality of care is bound up with the successful establishment of inter-personal relationships. As a result, the relationship between a care-giver, care-receiver and complementary carers can be complex and varied. As chapter five demonstrates, negotiating the boundaries of privacy, friendship, professional practice and autonomy become more difficult when care takes place within the home-space of the older person and their co-resident family. Upon the introduction of Direct Payments, Leece (2006) found a similar wariness to possessing knowledge of, or control over, care-workers' payment terms. Consequently, this alters the closeness of the relationships between consumers, complementary carers and care-workers.

The rates of pay allowed within Direct Payments is currently set at around £10 per hour for personal assistants within personal budget arrangements and agencies alike, though this usually equates to £6-8 per hour for agency care workers when allowing for agency overheads and profit. According to a manager of a care agency in Tyne and Wear, the rate given leaves little room for manoeuvre in improving their services when competing with personal assistants who are employed directly by the older person, which may lead to difficulties recruiting in the future as this option is taken up more widely. The

requirement of agencies to: provide payroll services; carry out CRB checks; keep abreast of legal/health and safety/safeguarding responsibilities which are always changing; provide office space and staff training; increase their costs and put them at a disadvantage. Driving down unit costs of social care through self-directed support is perhaps made easier by brokerage arrangements in which responsibility for payment falls on an institution willing to enter less emotionally engaged relations with care-workers. In Tyne and Wear, managing employment terms has largely been retained by local authorities or transferred to Age UK rather than independent agents.

Care-workers operate according to shift patterns which are efficient for the organisation but often undesirable for the clients and themselves. Family carers often complained about support which is untimely, and paid care-workers are often moving across the city for short sessions, whereas others are more able to secure beneficial work routines. Personalisation may intensify pressures for timeliness if not more time itself as more time costs more money from a limited budget. What older people and their carers demand in terms of quality relates to respect and dignity, which are put in jeopardy by standardised and hurried caring practices. The pace of care is very relevant to understanding how care is experienced, and timeliness is equally important for certain tasks. Pace and timeliness are related to the available time afforded to paid care-workers, and this is directly related to resources made available to individual older people (usually through the social services assessment process) in establishment of budgets and care packages. As funds are squeezed in the current economic climate, the potential to improve care quality and experience by slowing the pace and ensuring it occurs at a time most convenient to the older person may further decline. Choice and control may bring risk and uncertainty rather than improved provision.

As some key respondents noted, meeting the expectations of older people and family carers may mean care agencies have to organise and market themselves differently in the future, and they may need to be more responsive to appropriate and desirable timing of care. This may alter working hours and the number of care-workers in a particular geographical location, perhaps involving more split shifts. This may be more attractive to parents if it can accommodate school times, but less attractive as a full-time option. The result may be a two-tiered workforce split according to time-split shifts, leaving



large gaps between the shifts. Such shifts may miss out undesirable times such as 11-12am and 2-5pm and 8-10pm for getting up, giving meals, or putting to bed. These times may be required for toilet stops, which could mean the same workers or another shift of workers. This pattern of work might suggest very small local agencies or very large organisations may be able to organise themselves this way, but medium-sized organisations may struggle. Informal carers are much more likely to be able to respond as and when required, but a lack of supporting infrastructure in public spaces creates an unwillingness/inability for care-givers and care-receivers to leave the home too often, with a resultant loss of social contact for both. A shortage of public toilets, disabled access etc., curtails the social activities that can be performed, so this is very much an issue of values in the way older people with social care needs are positioned within society, and how this impacts upon access to and availability of resources to live a desired lifestyle.

As Hockey and James (2003) have suggested, creating alternative constructions of ageing can destabilise stereotypes and present more positive imagery of ageing - by presenting retirement as an increasingly active, empowering phase of the life-course for example. This can alter the way ageing is constructed in cultural life, and can shift power between generations. In doing so, a challenge is posed for maintaining the social standing of the proportion of older people who will require care support because of physical or mental decline – and not to regard this as an inevitable progression. Successful and unsuccessful ageing may be characterised with reference to the individualisation thesis of Beck and Beck-Gernsheim (2001), that an individual life-course is a reflexive encounter in which risks are continually negotiated and overcome by utilising personal resources and social networks to secure benefits and advantages (see also Arksey and Glendinning 2007). However, by understanding the life-course as marked by a series of inter-dependencies between family, friends and community (Bowlby et al 2010), the social position of older people in need of social care can be maintained given sufficient resources to achieve desired outcomes. This understanding positions decline in old age as neither inevitable nor unusual.

The shift towards personalisation in adult social care is intended to support individually defined outcomes for successful ageing. For informal carers and older people who

require social care, the reality is often that there are limited resources to support inter-dependent living and desired outcomes, whether formally disbursed through local authority needs assessments, or informally through availability of informal carers, both of which are influenced by environmental constraints and facilitators. Limited resources can mean balancing the need for adaptability and the desire for choice. Care routines may need to be both reliable and adaptable. Personal budgets may make this more difficult, as the onus is on the individual to organise any change to the care plans with authorities providing the finances and service providers (either personally employed or purchased from the market). When finances, time and other resources are scarce, and carers face fatigue and emotional challenges in their everyday lives, dealing with a lack of adaptability in the system can be detrimental.

Agency care will therefore remain a popular choice against self-direction through employing personal assistants. This has been found in the work of Baxter et al (2008) in their study of personal budget holders' navigation of market care options, as customers tended to stay with existing agencies even when measures of 'quality' positioned them as poorer. In conclusion, the size of care agencies, their geographical spread, number and residential location, motivation and work preferences of its workforce become crucial to the way in which agencies respond to personal choices, which will inevitably focus on the timing and pace of care. Whilst timing is a logistics issue (getting the right number of care-workers to the right home at the right time), pace (delivering care with sufficient attention and respect) is an issue of quality which depends on carers' capability as well as adequate resources. The concern for ensuring quality can introduce pressure upon carers to go beyond their scheduled tasks and allocated times.

### **8.1.3 *Expanding Voluntary Care***

Formal and informal volunteer carers were interviewed in the research to better understand motivations for providing support to older people, and to understand the facilitators and constraints influencing voluntary caring practices. Recent trends in volunteering include efforts to professionalise and expand the provision of support. The Joseph Rowntree Foundation highlight a development known as 'Slivers of Time' (Rowan 2010:13), whereby volunteering and micro-working practices could be

incorporated into ‘fluid, participatory, informed capitalism’ (Rowan 2010:13). This possibility reflects a concern by Hardt and Negri (2000) that practices formerly conceived as outside the realm of capitalist control (such as informal care, emotional life, sociality) are becoming increasingly drawn in and subsumed within capitalist relations. Personalisation in social care could be viewed in this light, as neighbourliness, informal caring, and volunteering become drawn into formal, commodified practices overseen by state bureaucracies. However, this subsumption theory is refuted in this thesis in favour of a diverse economies approach which proposes informal economic practices and social relations can be resistant, divergent or associated with, but not always incorporated by, capitalist relations - as each articulate the other in everyday life.

In this research, voluntary carers were the least aware of personalisation agendas and least connected to the established structures of state adult social care. Their volunteering for older people often coincided with other types of volunteering with other age groups and across a range of settings. They articulated more than family or care-workers how their practices of care were as much about their own fulfillment, as they were the least ‘obligated’ to provide support, materially or emotionally. Therefore, the reciprocal aspect of care became more prominent. This is an important challenge to the notion of individualisation at the heart of self-directed support. Carers are also self-directed, and if the mutuality and reciprocities of care are not acknowledged, there may be an issue for the future orientation and motivation of carers, particularly volunteers.

Individuals and communities are considered to be successful if they contain high levels of ‘social capital’ and have bonds between members within and beyond communities. Expanding voluntary capacity by encouraging association and support in a context of reduced public spending on welfare and social care support may influence levels of inequality, as some individuals and communities differ in their reliance on state resources and vary in their ability to raise voluntary activities from within their own capacities. Economically deprived neighbourhoods with fewer resources of formal or informal support may face increasing pressures under a decentralised and diminished welfare system, as this approach may rely upon the utilisation of existing personal social capital and effective local markets for care in particular places. Accepting voluntary

support may be less appealing than accepting support as an entitlement, as notions of deserving and undeserving poor and respectability within welfare structures resonate through generations within families, and are structured by particular habitus norms in particular places (Moffatt et al 2007). Amin (2005) describes how notions of 'community' and 'social capital' have been applied in relation to economic development in deprived neighbourhoods in a way which increases inequality rather than resolving it, as the aspirations of policy do not reflect the situation 'on the ground' (see also Miles and Tully 2007). Social support networks are contingent and subject to situated circumstances, orientations and capacities of its members. Different moral rationalities and value systems within different groups make evaluating social capital difficult using standardised measures.

There are considerable implications for volunteering in the shift from block contracts to 'spot contracts' with individuals as a result of personalised budgets (Acevo 2010). Unlike traditional health services which require high capital expenditure (on hospital buildings and equipment), social care is one area where the market may diversify more easily, which may present an opportunity for smaller charities. One key informant who managed a small local faith-based befriending scheme described how her organisation faced current difficulties in securing local authority contracts. She noted how isolated older people were often referred to them by local GPs who had heard of their service. Therefore, she felt the potential for money to follow individuals could be advantageous to them in supporting the work of their befriending scheme, which relies upon church and charitable donations and minor grants. The barriers to small and medium sized social enterprises and Third Sector organisations through existing contracting processes are likely to decline, enabling them to take advantage of a more open market-place. However, for medium-sized charities who currently hold local authority social care contracts, as was the case with one key informant, there was fear that increased marketisation towards 'spot contracts' would mean greater competition from large private-sector operators who may squeeze them out of the market by superior marketing and economies of scale. Whether this may result in a 'squeezed middle' across private and voluntary care (with comparative advantage to small/niche providers and large operators) is a potentially interesting research avenue once personalisation has been more fully embedded into social care.

## **8.2 Limitations and Recommendations for Future Research**

It is important to recognise the regional specificity and structural limitations of the research process and the findings discussed in this thesis. As described in chapter three, the research sample sought and subsequently included ‘hard to reach’ individuals from working-class communities who may not access formal support services. The majority of family and volunteer respondents identified as working-class, and most respondents who identified as middle-class lived or volunteered in working-class communities. I also hoped to attract more attention from friends and neighbours, and drafted recruitment literature which was inclusive of these terms. However, though some respondents did describe friendship and neighbourliness with older people, these tended to be discussed as an aside, and were not usually the principle focus of the research participation. It may be that the discursive domination of ‘care’ when researching older people, despite efforts to move beyond this, was influential in keeping friends and neighbours from taking part, as they perhaps understand ‘care’ as something done by others. Research which sought participation from, and was exclusively framed with friends and neighbours in mind, may have had more success. As a result, the respondents in this study who were not family or care-workers tended to consider themselves as either as a ‘befriender’ which is a more formal term than friend, or as a volunteer, as they all participated in formal voluntary activity with older people of one form or another.

### **8.2.1 *Researching Pre-existing Networks of Support***

A research design which recruited an entire social support network of an older person was considered carefully before arriving at the final research design. Care worker A brings a different perspective on the care to family carer X, and when combined produce one ‘inter-subjective relationship’ influencing the practice and experience of care. Bringing these relations into view would shed light on the complexity of the experiences of both (as the perspective of A towards X is likely to be consequential to the perspective X takes towards A), and would be effective in understanding the negotiated social support networks of an older person (see Wenger 1991, 1997 for a typology of the extent and strength of such networks). This approach would have

provided an excellent framework to conduct a study on life-worlds of care, being well positioned to reveal how routines intersect and overlap to create an integrated carescape. However, for ethical reasons and to avoid further delays, my research design did not recruit via older people, from whom carers involved in their routines could be accessed. It was also likely that not all members of a care cluster would have agreed to participate, and there was a fear that some carers may feel coerced into participation if their client is involved in any such study. Even where all might agree, there is a great challenge in dealing with anonymity, and consequent honesty of responses when each person could identify the other, including the client. As a result of these ethical challenges and time constraints, the research design changed to open recruitment in the community, so the carers in this study were not known to each other and were not integrated into the care routines of the same older person. However, if it were possible to find a way to resolve the ethical issues in multi-perspective and inter-related clusters around one older person in need of care, this could provide a nuanced and situated account integrating the diverse economies of care in place.

### **8.2.2 *Exploring the Intersections of Caring for Older People***

Due to the low number of male carers in this study, it was not possible to derive conclusive findings about the dynamics between gender and class within and between carer types. For instance, four of the five male carers identified as middle class, compared with the sample as a whole which was evenly distributed by class. It might be interesting to explore whether this is evident across a larger sample. The designation of middle-classness was the respondents' own, and did not entirely correlate with educational attainment as women in the sample with similar qualifications often self-identified as working class. It could be suggested that men entering into what is traditionally a woman's role elevated their class status to 'professionalise' the role. Alternatively, there could have been an unidentified barrier to working-class men in coming forward to take part in this research, such as the language used in publicity material.

Assumptions about wider family support may be hetero-normative, as 'family' may in fact be a source of strain. This research attempted to recruit carers from within the local

LGBT communities, but none came forward after extensive advertising in magazines and support groups. One of the fundamental principles of personalisation is to move away from a ‘one size fits all’ approach, so it would be beneficial to purposively focus exclusively on LGBT experiences of care for older people as there may be significant regional variations in the way this is being delivered and experienced, given the particular social geographies around LGBT migration to metropolitan cities, and poor support services in rural areas (Weeks et al 2001; Binnie 2004). Over the course of this research, it was clear that local authorities and voluntary organisations in the region were working with BME communities to inform how personalised services were being implemented, but not within LGBT communities<sup>25</sup>.

A key informant in this study described his experiences of caring for his male partner who was living with dementia. Living outside of Tyne and Wear he was not eligible as a respondent, however, his story highlighted the value in undertaking research on same-sex caring for older people. He received significant informal support from friends, and found organisational support within his locale in the South East of England to be supportive of him as a same-sex partner. However, the validity of their 40-year long relationship was contested by his partner’s family who claimed to be unaware of it. His partner’s relatives had organised a care home and wished to sell his house to cover the costs. A difficult series of legal disputes arose at the point the key informant moved in to his partner’s home as the caring requirements increased. It is not to be assumed even within a long term relationship that partners have always been co-resident. Discrimination and criminalisation of homosexuality experienced by older gay men in their earlier lives perhaps offers an explanation for such living arrangements, but there may be other cultural factors for being ‘together-apart’ long term (Weeks et al 2001). The key informant’s experience demonstrates that research with LGBT carers and/or carers of LGBT people would be a worthwhile undertaking, particularly in locations where such targeted service provision is likely to be less well developed.

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<sup>25</sup> A representative from Sunderland Council advised that a partnership with the local Bangladeshi community was in place to help shape personalisation of adult social care. Similarly, an event in October 2010 organised by voluntary sector organisation in the North East, VONNE, linked the issue of Big Society to personalisation, and what this might mean for BME communities.

### 8.2.3 *Participatory and Reflexive Methodologies*

Fuller and Askins (2007) propose that geography should be engaged and participatory, and more time and resources could have been employed to engage in participatory methods with carers of older people in this research. This approach was initially considered, but is often difficult to achieve under the constraints of PhD research. Reworking embodied interaction into written or verbal forms loses much in the translation, since written accounts can lack the resonance of care as an emotional, relational and embodied practice. Though much of this thesis has been concerned to reveal mundane everyday practices of care, artistic representations can sometimes offer a sense of distance and make explicit core concerns (Arendt 1958:370).

I considered participatory focus groups which might incorporate dance or other creative/dramatic methods to engage respondents and draw upon concepts of emotional and embodied capital and performativity in understanding mundane geographies and practices of care; as well as materialising the emotional and intangible aspects of care work (Craig 1980; Jameson 2000; Kindon et al 2007). Drama can encourage participants to reflect upon their experiences and negotiate their realities with other participants – in order to share, learn, re-evaluate and articulate new understandings and possibilities. The work of Mike Kesby (2007, 2008) in radio drama techniques demonstrates how participants are empowered to examine complex cultural and moral issues in an environment perceived as less judgemental than individual interview alone. In the end, what I had once thought were useful methods were dropped due to pragmatic issues of time, effort and cost, and by a lack of confidence in my ability to carry out these plans effectively. However, this approach may be developed by others with more resources and experience to great effect. For example, a project by Newcastle University researchers called '*A Lion's Face*', included interview material from doctors, older people, carers and social workers which were successfully reworked into an opera. Carers were then able to leave feedback on their way out, expressing their own realities and their experience of the complexity of the different perspectives presented.



## Summary and Conclusion

This thesis began by outlining the political context which has brought personalisation and self-directed support to the forefront of adult social care policy. These policy moves connect to academic debates about the individualisation of ‘modernity’ and the notion of reflexive selves. This thesis argued that by applying these discourses in the realm of care of older people, there may be difficulties reconciling notions of choice, control and individuality with the relational, inter-dependent and ambiguous circumstances of care. Considering the existing circumstances of carers from a range of care economies in working-class areas of Tyne and Wear, this thesis sought to understand some of the contingent factors associated with the current caring practices of carers, and the life-course issues which situated the meaning of these practices.

Rather than conceive of the life-course as a series of unproductive/dependent and productive/independent stages, I have drawn on feminist critiques of life-course representations to come to a position which argues for inter-dependencies and uneven mutuality in our relations with others. However, rather than focus on gender as the defining category of life-course experiences of care, I argue uneven mutuality and power relations are experienced according to categories of age, class, ethnicity, sexuality and so on. In drawing together conceptual ideas linking orientations, negotiations and life-worlds of care for family, friends, care-workers and volunteers, this then uncovers the inter-dependence of subjectivities and experiences of carers, though they may draw upon different objective circumstances. Often the intersecting subject and identity positions of individuals produce overlaps in experience, motivation and embodied practice, sometimes delineated by gender, sometimes by class, but most often by family position and age in structuring the expectations and responsibilities of care across the life-course.

Carers were enrolled, sustained and reproduced as familiar subjects, which to a large extent continues to reflect a persistently gendered dimension. It could be argued that processes of subjectification across the life-course encourage the continuation of responsibility towards working-class women (paid and unpaid); unmarried family members within a negotiated family hierarchy; and workers with limited labour market

options. Social influences and moral boundaries are contingent across a number of axes, particularly in relation to life-course trajectories, most often framed around work and career in the paid economy. This drives classed and gendered negotiation of the right thing to do when responding to the necessity of care. This thesis has shown that similar life-course trajectories and socialisation processes produce similar orientations to care, but that these are inflected through the material circumstances of carers within different economies. The boundaries between family, care-worker and volunteer are blurred as a result, but their material and relational differences to the particular older person being cared for require different negotiations and have different experiential outcomes. This thesis has argued that the emotional geographies of caring for older people are heavily influenced by differentiated constructions of time and space, produced according to various (sometimes misaligned) social roles or social expectations surrounding care.

## Appendix A - Policy Timeline

Date	Type	Details
1948	National Assistance Act, Section 29	Provision of a range of state services to support social care needs
1990	Community Care Act	Local Authorities have sole responsibility for assessing need for care services.
1996	Community Care (Direct Payments) Act	Enabling cash payments to social care service users
1999	The Community Care (Direct Payments) Amendment Regulations 1999	Extended Direct Payments to over 65's
2001	Health and Social Care Act, section 51	Direct Payments can be opted for when clients are able to consent to them. Local Authority retains safeguarding and assessment role.
2005	Mental Capacity Act	Capacity to make choices limited, but extends to user representatives. Statutory obligation remains for commissioning public bodies to monitor risk
2006	Our Health, Our Care, Our Say White Paper	Describes the vision for personalised services, and

		provides budget for transformation of health and social care services
2007	SCIE Research Briefing 20	Found positive benefits, but concerns to balance safeguarding and worker regulation with choice and control still struggled with; infrastructure not yet set up for brokerage function; mixed picture for pay and conditions of Personal Assistants; international experience suggests health and financial gains, but not yet apparent.
2008	Health and Social Care Act	Removes constraint of 2001 Act for informed consent to a Direct Payment option to allow payments to third parties.
2008	IBSEN Report, SPRU (Glendinning et al 2008)	Findings of the 13 pilot studies of Individual Budgets. Older people most reluctant to take up option; complex administration and greater costs, but potential for improved choice for older people and carers
2011	Individual Budget Implementation Deadline	Government set a target of 30% uptake of IB by 2011, though several LA's aim for majority of social care users to take this option

## **Appendix B - Diary Instructions**

### Why am I being asked to complete this diary?

The purpose of the diary is to tell me what is happening in your life in the course of two weeks. What you choose to include in the diary is up to you. It can be as detailed or as brief as you like, but the more you can say, the more I will be able to understand what happens in your week and how you feel about it. It would help me if you could write the date each day at the top of the page. You may use as many or as few pages as you wish.

I have listed some examples below of things you could include. You may choose some or all of these, or add some of your own. The main purpose is to describe and reflect upon each day. You could even note down occasions when you reflect on your past or think about the future. I am interested in your thoughts and feelings at the time you write the diary.

### In this diary, you could include:

Times you do certain tasks or activities

Why you do them

Where you do them

Who you do them with or who you do them for

How certain people, tasks or places make you feel

...or you could write about anything else you think best describes your day's activities and feelings

Please see the back cover for details about what to do next.

### What will happen next?

Once completed, the diaries should be returned to me at the address below.

A stamped addressed envelope should have been provided to you.

Please refer to the information sheet you received earlier for guidance about the purpose and limits of your participation in this research, and for details regarding confidentiality.

For any further information or advice, please feel free to contact me:

Mobile: 07758 939508

Email: [caring@ncl.ac.uk](mailto:caring@ncl.ac.uk)

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## **Appendix C - Respondent Profiles**

Amanda – provides non-personal daily support to her father. Amanda is in her early 50s, and describes herself as working class, and works full time in the public sector. She is single, and has always lived at home. For three years prior to supporting her father, Amanda provided intensive support to her mother at home until her death.

Barbara – cares for her husband, a former shipyard engineer, who was diagnosed with Lewy Bodies Disease several years ago. They live in a semi-detached home in the outskirts of Newcastle. In her late seventies, Barbara is a retired teacher with three adult children, all of whom live some distance from the North East. She is an active member of the local branch of a charity concerned with dementia. She receives additional support from paid care-workers.

Ben - is single and in his mid thirties. He lives alone in a terraced flat in the west end of Newcastle. He is employed in a residential care environment, and often works night shifts. He is originally from the Midlands, and has an elderly aunt who lives nearby. He is volunteer befriender to a former shipyard worker with dementia, providing respite for his clients' wife.

Carol – is a former civil servant from South Tyneside, who worked in retail until her mother's health deteriorated. Married with two daughters, Carol was full time carer for her mother until her death three years ago. Carol provided a retrospective diary account of the care she provided to her mother, based on the information she retained for the direct payments she received for her mother's care.

Coleen - lives in a large terraced house in North Tyneside, and is married with children of school age, and is not currently in paid employment. Coleen is a graduate who is involved in a range of voluntary activities. She recently began befriending an older woman in North Tyneside, who lives in a deprived ward of the borough. Due to medical circumstances, this befriending has been intermittent, with the older woman involved in a lengthy hospital stay. Her befriender is now living in a supported living environment, which Coleen has found to be hugely positive move. Coleen's experience of befriending has led her to realise the importance of maintaining old friendships, but also the possibility of forging new ones in later life.

Danielle – is in her late twenties, and works full time for a small charity in central Newcastle which creates volunteering opportunities for young people in Africa. She lives with her partner in an established middle class area of Newcastle. They do not have children, but Danielle is an aunt, and spends as much time as possible with her nephew. She currently befriends a woman in her eighties in a deprived area of North Tyneside, and describes their relationship as close.

Dawn – lives in Wallsend in a warden-controlled bungalow. Dawn has diabetes and other health conditions which limit her mobility and activities. Despite this, Dawn is an

active member of her local church and volunteers in several projects in the local area. She befriends an 84 year old woman once a week.

Edward - is a father of school-age children. He lives in Northumberland, and volunteers to befriend two older men, one in Newcastle and one in North Tyneside. He is currently unemployed after leaving an administrative role in the public sector. He hopes to train as a social worker, and together with his interest in local history, this led to his involvement in befriending older people.

Elaine - is in her seventies, and lives in North Tyneside. She has two adult daughters, one of whom lives in the South of England with her partner and their children. Before retirement, Elaine was a shopkeeper in North Tyneside. Following the death of her husband, Elaine moved into a supported living flat. She has been active in many voluntary roles, including bereavement counselling, supporting the library service in the local hospital, running a lunch club for older people at her local church, and assisting a neighbour and a friend with shopping and picking up prescriptions.

Elizabeth - is a young mother of two children living in a rented upstairs flat in Newcastle. She is a refugee from Zimbabwe who has had previous experience of care-work: first in residential care; and currently with a home-care agency. Elizabeth prefers a home-care environment, since she finds she has more time to make connection with older people compared to residential care. Her favourite element of home-care (which often involves waking nights) is being able to cook for her clients, as she enjoys sharing with others. She is a Christian who believes the work she does is necessary and valuable.

Ewa - is a Polish woman in her mid fifties who lives alone in an attractive upstairs flat on a large council estate in North Tyneside. Previously employed in a technical role, Ewa came to the UK following her divorce. She chose the North East because her daughter lives here. Ewa began working for the care agency having no previous experience. Her friend worked in care and helped her move into the industry. She often works nights, and is involved in domestic as well as personal caring for her client, who needs support with communication as well as all aspects of daily living. Ewa enjoys her work and regards her client as a good friend, and her home as a second home as she spends more time there than in her own flat. She enjoys watching television and 'gossiping' about daily news with her client.

Frances – is in her late eighties, and was married to her ninety year old husband for sixty three and a half years at the time of the interview. Her husband has been diagnosed with Mixed Dementia. She lives in a modern semi-detached home near the coast in North Tyneside. She was formerly an office manager, and her husband is a retired engineer. Frances does not have children, and describes receiving support from neighbours as well as formal support from a local Carers' Centre. Frances considers herself to be a resilient woman, but finds the isolation of caring difficult to deal with.



Gayle – has provided ongoing support for several years to her husband, a former local government officer, who has been diagnosed with epilepsy and other health conditions which make him house-bound. Gayle lives in an outer district of Sunderland. She has two daughters, one of whom lives in the south of England. Her other daughter lives locally, and has a young child. Gayle has back problems as a result of lifting her husband in and out of bed in the years before she received additional support from paid care-workers.

Gemma – is a care supervisor in her mid thirties, working for a care agency in a deprived area of Newcastle. Gemma described how her school years were disrupted, and she is able to identify with young people. Her career started in a young people's care environment initially. She moved into caring for older people as the shift patterns suited her. Her work involves carrying out spot checks of other care-workers, as well as care shifts herself, and spending some time in the office dealing with scheduling of rotas and staff supervisions. Gemma is a single parent with a child with ADHD, and her father is recovering from cancer.

Hilary - lives with her husband, whom she married within the last ten years. They have children from previous relationships who they see occasionally. They describe themselves as working class, and live in a terraced cottage in Sunderland. Hilary was formerly employed in a local shop, and her husband was formerly in the armed forces and subsequently became a driving instructor. They are both active church members, particularly her husband. A year prior to interviewing Hilary, her husband had a stroke. He is slowly recovering from this, and Hilary has sought out various activities to help her husband with his speech and memory. They often used public transport and went for walks in the local area.

Isabel – is one of three sisters who provide care to their mother at home in a council estate on the outskirts of north Sunderland. Isabel lives in a nearby area, a former mining community in the north of Sunderland, which ranks highly according to Index of Multiple Deprivation. In her late thirties, Isabel is a mother to four children, and has recently become a grandmother. She has a twelve year old daughter who accompanies her during her visits to her mother's home. Her mother is in her early sixties, and has been diagnosed with Alzheimer's disease. Isabel lost her father to cancer six years previously, and since that time, she has cared for her mother along with her two sisters. Isabel works full time as a care assistant in a residential home for the elderly, which makes her daily routine very challenging. The three sisters operate on a rota system, and are supported by care-workers throughout the day.

James – is single and in his late fifties. He has always lived at the parental home, and currently cares for his mother, who has been diagnosed with vascular dementia. His father died several years previously, and James has taken responsibility for the household since that time. They live in an established private residential estate in Sunderland. James is supported by care-workers who help to get his mother out of bed,

bath and dress her. James described how his mother was unable to carry out basic tasks, and was becoming increasingly depressed. James reduced his hours from full time work as a local government officer to part time due to his caring responsibilities. He is a keen local historian.

Joseph - is a twenty one year old student in Newcastle, whose family is currently living in Edinburgh. His maternal and paternal grandparents live in the North East, and he is a regular visitor. He provides weekly support to his Gran, who has reduced mobility following a stroke. He describes himself as middle class. He describes providing support to his grandparents out of recognition of happy childhood memories, and to act as surrogate for his father, who lives away.

June – is an Asian migrant who lives in Newcastle. She took up volunteer befriending in order to make connections with the local community and to help her to understand the local accent and culture. June has befriended an older woman in North Tyneside for the past few months, and enjoys the opportunity to share family photographs and get to know about her earlier life. June is keen to understand more about ageing and how to combat isolation and loneliness in later life.

Kelsey is a young single mother with a young daughter, living in a modern house in a large council estate in Newcastle. She has worked in a care environment all of her working career, since taking work experience in a care home when at school. Following the birth of her daughter when Kelsey was eighteen, Kelsey moved into home-care as the shifts met her childcare arrangements. Kelsey often works nights, which makes it easier to get childcare during the day from nearby relatives.

Lorna - is a married woman with an adult daughter who works as a carer. Before working in home-care, Lorna worked in the finance sector. Her experience of care provided to her mother within a residential setting led Lorna to switch careers in order to work as a carer, since she wanted to support older people to stay at home for longer. Lorna provides domiciliary and personal care in her local neighbourhood. She describes how her own health has suffered in recent months, making the role increasingly challenging, and creating disagreements with her family about continuing in this role.

Marta lives in a high rise flat in central Gateshead with her husband and young child. She moved to the UK from Poland with her husband to look for work. Upon the birth of their child, Marta moved into the care industry because the hours were more suitable, and could fit around her husband's shift patterns. In Poland, Marta worked as a teacher, and would like to train as a teacher in the UK. However, she was uncertain about this, as it was unclear whether they would remain in the UK for the foreseeable future.

Megan - is in her early fifties and works for a mid-sized care agency in Newcastle. She lives in a modern semi-detached home on the outskirts of a large council estate in Newcastle. She lives with her husband, who was formerly in the armed forces, and has an adult daughter who lives in her own home. Megan described her early working

career as revolving around her husband's armed forces, spending many years abroad. She has experience working in residential care, which she found distressing and eventually led to her reporting abuse of vulnerable adults. She moved back into care on her return to the UK, but within a home-care environment.

Neil – is a single man living in Newcastle, who was raised in local authority care. He has dyslexia and described the personal challenge he overcame in passing the NVQ qualifications to work in a care environment. Neil is also interested in local history. His work involves providing respite care to family carers of older people, and also providing assistance to disabled adults. He enjoys the varied nature of his work, going to the cinema, taking part in craft activities, and providing stimulative support to older people by taking tours around the city to elicit memories and stories.

Oliver - is a local authority employee who works in a Day Centre in a working-class area of South Tyneside. He had previously worked in residential care, and prior to this, worked in heavy industry in the shipyards. As well as his paid care work, Oliver was also involved in the care of his father, who was diagnosed with Alzheimer's disease. He has siblings living nearby, and described how the bulk of caring responsibility and decision making was deferred to him as a result of his paid caring roles.

Rachel - works full time in a finance environment for a charity in South Tyneside. She is single and lives on her own. She provides occasional support to her father since the loss of her mother some years ago. Rachel cared for her mother until it became necessary for her to enter residential care. The majority of caring activity in recent years has been an advocate for her aunt, who has had many problems with care providers and social workers. Since her aunt is visually impaired and has learning disabilities, Rachel found that her care was being mishandled, and so Rachel intervened to resolve issues.

Susan - has supported two adults with Down's syndrome for many years, and has remained with them through transitions from institutional care settings to a supported living accommodation environment. Susan moved from being a care-worker in a local authority to working in a small private care agency. She supports the two men, who are in their fifties, to maintain their homes; cook; shop and manage finances, as well as accompany them on leisure trips. Susan is married with adult daughters, and describes the men she assists as part of the family. She regularly invites one of the men home over the Christmas period as he is without nearby kin.

Phoebe –was formerly a nurse in the NHS. She describes how a distance-learning degree course led her to question the medical model of disability and the impact this was having on care of older people in the health service. She left this role following serious illness, and decided to move into an advocacy role for older people on a voluntary basis. She has provided over ten years of support to older people who are being moved from hospital to various care environments. She also provides informal support to older people in her local community, including her father-in-law. Phoebe is training for the clergy in the Church of England. She considers older people as an

essential element of church life, but whose needs are not being met when they become less mobile and house-bound.

Wendy – is in her 40s, and works for a small care agency in the outskirts of Gateshead. She lives in a village in a semi-rural, deprived area of Gateshead. Most of her caring takes place within walking distance or a short bus ride away from her home. Wendy was careful not to reveal details of her clients to maintain their anonymity in the research, and described her routines according to tasks completed in her diary.

## Appendix D - Gatekeeper Letter

[gatekeeper]

**School of Geography,  
Politics and Sociology**

5th Floor, Claremont Tower  
Newcastle University  
Newcastle upon Tyne  
NE1 7RU United Kingdom

Professor A E Gillespie  
Head of School

05.08.09

Dear Sir/Madam

I am a PhD student in the field of Social Geography at Newcastle University, conducting research on carers who provide support to older people in Tyne and Wear. The main aspect of my research is to illustrate the views and experiences of carers, and to understand their everyday routines and challenges. I am defining carers broadly: they could be anyone from family, friends, neighbours, employees or volunteers. The only condition is that they are over 18, live in Tyne and Wear and care for older people in some way.

Therefore, I would like to be given the opportunity to provide some further information about my project. I would be grateful if I could arrange to visit to leave some leaflets with you, or to introduce myself to people who use your service. If you feel you can assist in any way, I can be contacted by post at the above address; by email at [caring@ncl.ac.uk](mailto:caring@ncl.ac.uk); or by telephone on 07758 939508. I look forward to hearing from you.

Yours faithfully

Angela Abbott



## Appendix E - Research Information



You are invited to take part in a research study

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### About me and my research

My name is Angela Abbott. I am a student researcher at Newcastle University, and I will be conducting research in your area from January 2009 - March 2010. I am looking at the everyday lives, routines and life journeys of people who provide personal or emotional support to older people in their homes and within in the community. Caring and friendship for older people could include assisting with things like:

preparing meals - personal care – housework - dealing with finances - picking up prescriptions – befriending

### Why this research is important

The aim of my research is to understand the experiences and motivations of people providing support to older people. The findings of my research will contribute to academic knowledge about carers' lives. It may also in a small way, help to raise awareness and perhaps influence how service organisations and policy makers respond to carers' needs.

At a personal level, having an opportunity to share experiences and have these experiences taken seriously can be beneficial to those taking part.

### Getting involved

I am interested in hearing from you whether you support older people for a few hours a week, or if you do this full time. You could be a member of the family, a friend, an employee or a volunteer. It does not matter whether you are paid or unpaid. If you are over 18, live or work in Tyne and Wear and you provide support to an older person, please consider taking part in this research.

### Taking part would involve:

- spending a short amount of time each day for two weeks completing a diary of your everyday routines.
- taking part in an interview to discuss the diary, and to discuss other aspects of your life, which should take 1-2 hours. The interviews will take place in your local community.
- Optional - discussion with other carers.

While the duration of your active involvement is quite limited, the research programme itself will take several months to be fully completed.

### Issues

There is no need to give your real name to take part. Even if you do, your personal details will remain anonymous, and what you tell me will be treated as confidential. The interview will be held in private, and you can choose not to answer any question you wish, without giving a reason. More detailed guidance concerning procedures to ensure ethical conduct of this research is available by request.

### How to contact me

Please get in touch if you would like to take part, or if you have any queries. If you leave your name and number, I will get back to you.

My mobile number is: 07758 939508. Alternatively, you can email me or write to me at the address below:

Email: [caring@ncl.ac.uk](mailto:caring@ncl.ac.uk)

Angela Abbott

Care and Friendship Project

School of Geography, Politics and Sociology

Daysh Building

Newcastle University

Newcastle Upon Tyne

NE1 7RU

Thank you for taking the time to read this information sheet. I hope you will participate in this research.



### Research Participant Consent Form

‘Understanding care and friendship: exploring the social geographies of home and community support for older people

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I confirm that I have read and understood the accompanying information sheet for the above study. I have been informed of the aims, methods and duration of the study, and what part I will play in this.

I understand that my participation is voluntary and that I am free to change my mind and withdraw from the study at any time without giving a reason.

I understand that any data I have provided for this study may be published.

I agree to take part in the above study.

#### Your contact details

The following information will NOT be used to identify you in the research, but will only be used when making interview or group discussion arrangements.

Full name of participant: (you need not give your real name)

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Telephone number: \_\_\_\_\_

Email (optional): \_\_\_\_\_

Address:  
(optional) \_\_\_\_\_



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If you would like to contact either me or my academic supervisors, please see details below:

Angela Abbott  
Postgraduate Research Student  
School of Geography, Politics and Sociology  
Daysh Building  
Newcastle University  
Newcastle Upon Tyne  
NE1 7RU

Mobile number: 07758 939508

Email: [caring@ncl.ac.uk](mailto:caring@ncl.ac.uk)

For further help, please contact my academic Supervisors: Dr. Helen Jarvis & Dr. Alison Stenning

School office: 0191 222 5200

School of Geography, Politics and Sociology  
Daysh Building  
Newcastle University  
Newcastle Upon Tyne  
NE1 7RU

Researcher: \_\_\_\_\_

Date: \_\_\_\_\_

## **Appendix F - Interview Schedule**

### SECTION ONE – Infrastructures of everyday life

#### **A Identifying the relationship**

- Q1 Can you explain the circumstances of when you began caring xxx and why?  
Prompts: do you do this paid/unpaid/hours per week?
- Q2 Are you in paid employment?  
Prompt: terms of employment, pay, length of service. If unemployed, retired, incapacity etc, duration/history
- Q3 (If paid carer) how would you describe your occupation to others?  
Prompt: job title you normally use, is this how others describe what you do?
- Q4 Would you describe to others what it is you do for Xxx, what your relationship is?  
Prompt: identity as friend, neighbour, care worker etc,

#### **B Duties and responsibilities**

- Q1 Can you describe what support you give to Xxx?  
Prompt: where, when, how? Frequency per week? Duration?Less frequent activities?
- Q2 How many hours per week do you provide care for Xxx, and provide care to other older people?
- Q3 Can you describe what physical tasks or activities, if any, you are involved in when providing support to older people?
- Q4 Can you describe what emotional support, if any, you provide to older people?
- Q5 Do you have any worries about how you perform the support you do?

#### **C Everyday Routines, everyday places**

- Q1 Can you describe a normal day in your life? [add supplementary questions from day diary where applicable]
- Q2 How many people are involved in your everyday routines?  
Prompt: social networks/isolation. Interaction with others daily, weekly etc.; where, why.
- Q3 How do you manage your time when getting through your usual routine?  
Prompt: tensions, advance preparation?
- Q4 If you have difficulties managing to meet all your responsibilities, how do you get round these?

Prompt: people helping out regularly

Q5 Has your routine changed when Xxx's needs have changed? How?

#### **D Constraints and enabling factors**

Q1 Where do you and Xxx spend most of your time together?

Q2 Which other places do you go to and why?

Q3 What gives you most problems or obstacles when trying to get through a normal week caring for Xxx?

Prompt: physical barriers, people and organisations, finances

Q4 What gives you most assistance when trying to get through a normal week caring for Xxx?

Prompt: information, other services etc.

Q5 How do you usually travel to support Xxx?

Prompt: to get to Xxx's home, whilst out and about

Q6 In your opinion, what would most improve the lives of older people and carers in your community?

Q7 Do you access any support from organisations for yourself, such as online discussion forums, volunteer groups etc.?

#### **E Spaces of emotion**

Q1 When you are supporting Xxx, what tasks or activities do you like the most?

Q2 When you are supporting Xxx, what tasks or activities do you like the least?

Q3 Which places do you go with Xxx where you feel most relaxed or happy?

Q4 Which places do you go with Xxx where you feel most anxious or upset?

Q5 Can you describe how your mood changes through the day, depending on where you are or what you are doing?

Q6 Overall, can you tell me what motivates you to provide support to older people, and how do you feel about what you do, most of the time?

#### **F Making personal time**

Q1 Do you make time for your own health and leisure needs in your usual routine?

Q2 If there are other things in your life that need your attention when you would usually be supporting Xxx, how do you deal with this?

Q3 How do you manage holidays and respite, if any?

SECTION TWO – Connecting the Life-course to Social Support Network

A Family history

B Work History

C Friendship Ties

D Significant events

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