

**Improving mealtime care for people with dementia:  
A training intervention for care homes**

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# **Abstract**

## **Background**

Many people living with dementia have difficulties at mealtimes, which can result in serious complications including ill-health, stress, hospital admissions and even death. However, current training in mealtime care for staff working with this population has been found to be poorly reported, with variable effectiveness. This thesis describes work to develop an evidence-based training intervention to improve mealtime care for people with dementia in care homes.

## **Method**

There were three phases to the study. The first phase was a literature review of relevant scientific papers and published guidelines. Evidence was synthesised from diverse sources to identify themes in mealtime care for residents with dementia. The second phase was an ethnography conducted in UK care homes, to explore current practice in mealtime care, and identify good practice. This included mealtime observations, and semi-structured interviews with care home staff, family carers, and visiting health and social care professionals. The third phase was a series of co-development workshops, in which key stakeholders worked together to create a prototype training intervention, using evidence from phases one and two.

## **Results**

The study found that priorities in mealtime care, such as providing choice, facilitating independence, and promoting adequate nutrition/hydration, were often in tension with one another. In addition, mealtimes operated within a complex system which constrained care. A person-centred approach, focusing on residents' history, capabilities, preferences and prognosis, helped to resolve tensions between competing priorities in mealtime care. Teamwork between care staff, kitchen staff, management, external health and care professionals, and family carers was key in overcoming contextual constraints. These findings informed the development of a prototype training intervention, in which collaborative learning was emphasised.

## **Conclusion**

This thesis contributes to the field through the co-development of a new prototype intervention to improve mealtime care for people with dementia in care homes. The intervention is informed by new knowledge about good practice in mealtime care for this population, and about how care home staff can overcome contextual constraints on practice. Future work will test the feasibility and acceptability of the prototype training intervention.

For my dad, whose love for people  
and curiosity about how things work  
are reflected in these pages.

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# Chapter 1. Introduction

## 1.1 Overview

Many people living with dementia have difficulties at mealtimes, which can result in serious complications including ill-health, stress, hospital admissions and even death (Abdelhamid et al., 2016; Manabe et al., 2019). However, current training in mealtime care for this population has been found to be poorly reported, with variable effectiveness (Faraday et al., 2021). Understanding the effectiveness of staff training on this topic is a top research priority (Pagnamenta et al., 2022). This thesis describes work to develop an evidence-based training intervention to improve mealtime care for people with dementia living in care homes. In this introductory chapter I present the context and justification for this research, and then state the research questions, aims and objectives.

## 1.2 Background

Difficulties in eating, drinking and swallowing can have serious medical consequences for people living with dementia. The risk of malnutrition and dehydration is high in this population (F. Bunn et al., 2016; Camina Martín et al., 2012), and can lead to more frequent hospital admissions (Natalwala et al., 2008) and increased risk of morbidity and mortality (R. A. Abbott et al., 2013). Unsafe swallowing may result in pulmonary aspiration (entry of food/drink into the larynx and lower respiratory tract); this can lead directly to asphyxiation or pneumonia (Torres et al., 2013). Of note, dependency on carers for feeding has been shown to be the dominant risk factor for aspiration pneumonia (Langmore et al., 1998). In addition, dementia is one of the conditions most strongly associated with deaths from choking on food among older people (Kramarow et al., 2014).

As well as impacting on physical health, mealtime difficulties can be detrimental to mental health and social well-being. Eating and drinking are fundamental human activities with significant social and emotional associations (Brush & Calkins, 2008; Burges Watson et al., 2018), and mealtimes have an important psychosocial aspect (Fetherstonhaugh et al., 2019; Keller, 2016). Difficulties at mealtimes can lead to anxiety, depression and isolation (Ney et al., 2009). This can be distressing for people with dementia – as well as for those who provide their care (Egan et al., 2020; European

Society for Clinical Nutrition and Metabolism (ESPEN), 2015; Pasman et al., 2003). There may also be changes in mealtime roles for the person with dementia and those around them (Mole et al., 2021), with mealtimes becoming more functional and less social.

People living with dementia are at risk of eating and drinking problems of various kinds (Abdelhamid et al., 2016). For example, dysphagia can occur due to impaired physiology, such as limited or weak mastication, or delayed swallow reflex (Alagiakrishnan et al., 2013). The Royal College of Speech and Language Therapists (RCSLT) defines dysphagia as “eating and drinking disorders in children and adults which may occur in the oral, pharyngeal and oesophageal stages of deglutition” (RCSLT, n.d.) The nature of dysphagia will vary, depending on the type of dementia. To illustrate, people with Alzheimer’s disease may experience increased oral transit duration related to sensory awareness of the bolus (Payne & Morley, 2018). In Lewy body dementia, pharyngeal function is more often affected – typically, delayed initiation of the pharyngeal swallow (Londos et al., 2013).

Eating and drinking problems in people with dementia are not only limited to dysphagia (RCSLT, 2018). Other difficulties at mealtimes are prevalent, because of the cognitive deterioration which characterises this condition (Kai et al., 2015). These may include difficulty recognising food and drink (Amella, 2002), problems using cutlery (Social Care Institute for Excellence, 2015), and reduced range of tastes and preferences (Ikeda et al., 2002). In addition, a fast and impulsive rate of eating and drinking may cause or compound swallowing problems. Mealtimes can also be impacted by changes in a person’s behaviour (such as agitation and restlessness), and changes in relationship with carers (Porter et al., 2021, p. 18). People with dementia may also be affected by age-related comorbidities, for example, stroke (F. Bunn et al., 2016) which can exacerbate poor oral intake (World Health Organisation, 2017).

By 2025, there are expected to be one million people with dementia in the United Kingdom (Department of Health, 2015). Many of this population will live in care homes. In the UK, USA and Australia, it has been estimated that more than half of all long-term care residents have dementia (Alzheimer’s Society, 2014; Australian Institute of Health and Welfare, 2010; Harris-Kojetin et al., 2019). Specifically in the UK, there are approximately 500,000 people living in long-term care (Carehome.co.uk, n.d.), and the

total prevalence of people with dementia in this setting has been estimated to be 69% (Alzheimer's Society, 2014). This equates to approximately 345,000 people living with dementia in care homes in the UK<sup>1</sup>.

Mealtime difficulties are particularly prevalent among people with dementia in care homes (Alzheimer's Disease International, 2014). Such difficulties will typically increase in severity as dementia progresses, and therefore by the time people with dementia are living in long-term care. Abilities to eat, drink and swallow are generally among the last functions to be lost (ESPEN, 2015, p. 3), and there is an increasing awareness that dysphagia has a significant impact at the end of life (including, for example, chest infections and possible unnecessary hospital admission (RCSLT, 2020, p. 3). Thus, people living with dementia are often dependent on the care of others at mealtimes. Typically, this is someone in a carer role (whether termed *carer*, *care assistant*, *certified nursing assistant*, *auxiliary*, *care aide*, and so on, depending on country), although qualified nursing staff may also provide this personal care at mealtimes. Through direct interactions with residents, care home staff are responsible for facilitating oral intake which is safe, adequate and enjoyable (Skills for Care, 2015). Staff may do this by providing physical assistance with eating/drinking (Abdelhamid et al., 2016; Mann et al., 2019), and by prompting and supervision at mealtimes or responding to signs of dysphagia to minimise risk of aspiration. In this thesis, I refer to activity of this kind as 'mealtime care'. Effective mealtime care is essential in maintaining or improving the health of people with dementia throughout the course of their condition (Divert et al., 2015).

These carer-resident interactions which comprise mealtime care are influenced by the care home context. The care home is a complex system comprising multiple actors, both internal (for example, kitchen staff and management staff) and external (such as family carers and visiting healthcare professionals). This context has important implications for mealtime care; sometimes enabling care, sometimes constraining it. I explore the way that carer-resident interactions operate within the care home context at various points in this thesis, in particular through the ethnographic study reported in chapters 4-6.

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<sup>1</sup> Different terms are used in practice and in literature to describe long-term care settings; these include *nursing home*, *care home*, *aged care setting*, and *residential home*. In this thesis, the term *care home* is used, and denotes a setting registered to provide residential care and/or nursing care.

Good mealtime care for people with dementia living in care homes is holistic and can improve quality of life (G. Evans et al., 2009), provide reassurance for families (Alzheimer's Society, 2013; Hanson et al., 2013) and may reduce hospital admissions (Richardson, 2015). Bunn et al. summarise this as follows:

It is likely that it is not just what people eat and drink that is important for their nutritional wellbeing, engagement and quality of life, but also how and where they eat and drink, the atmosphere, physical and social support offered, the understanding of formal and informal care-givers, support for using the toilet, and levels of physical activity enjoyed. (D. K. Bunn et al., 2016, p. 17)

However, evidence has shown that the quality of mealtime care for this population is variable. Milte et al. (2017) highlighted the negative impact that a focus on process, organisational systems, and structure can have on mealtimes. Lea et al. (2017) pointed to various aspects in which mealtime care could be improved, including increasing prompts to drink, and offering alternative meal choices. Of note, they also cited studies which have found limited staff training in, and knowledge of, the nutrition and hydration needs of people with dementia, especially those with swallowing difficulties (Bauer et al., 2015; Beattie et al., 2014).

Concerns about staff knowledge and skills in mealtime care and corresponding training provision reflect broader concerns in respect of all aspects of dementia care. Royston et al. (2020), in setting out the background for their work to develop a dementia care framework, articulated the importance of care home staff having specialist knowledge about dementia:

With an increasing proportion of people living with dementia residing in care homes it is paramount that health care workers (including nurses, care assistants, kitchen and domestic support workers) have specialist knowledge about dementia. This assertion is supported by the National Institute of Clinical Excellence, an organisation which provides national guidance and advice on how to improve health and social care in the UK. NICE (2015) highlights the importance of developing care home nurses to possess specialist knowledge in older people's nursing, such as dementia care. (p. 1317)



Despite this, studies of training to equip staff with specialist knowledge in dementia care have been found to be variable, both in the quality of evidence and reported efficacy (Surr et al., 2017). The need for better training in dementia care was highlighted by the first National Dementia Strategy (Department of Health, 2009) and then more recently by the National Institute for Health and Care Excellence (NICE) guidelines on dementia care (NICE, 2018). Significantly, there is a paucity of adequate training on mealtime care for people with dementia reported in the literature. Systematic reviews on this topic have found no effective interventions (including staff training interventions) to support food and drink intake in this population (D. K. Bunn et al., 2016). There is also a lack of studies which examine outcomes of mealtime care training (Fetherstonhaugh et al., 2019). A recent survey to establish the current practices of Speech and Language Therapists (SLTs) managing dementia-related dysphagia and mealtime difficulties in the UK and Republic of Ireland concluded that: “further research to develop efficient and effective training for care staff supporting mealtime difficulties and dysphagia is essential” (Egan et al., 2020, p. 777). Prior to undertaking the research reported in this thesis, I conducted a systematic scoping review to identify training needs on the topic of mealtime care in dementia, and to evaluate the extent to which existing training interventions correspond to those needs (Faraday et al., 2019). The review highlighted that more rigorous research is needed on the topic of mealtime difficulties in dementia, and in particular that future training interventions should be systematically developed, taking greater account of the views of stakeholders (for example, people with dementia, care home staff, and families), and with increased involvement from relevant professionals including SLTs and dietitians.

This need for further research into mealtime care training interventions was also identified in several recent priority-setting exercises. In its top ten priorities for dementia research, the James Lind Alliance included the question “What are the most effective ways to encourage people with dementia to eat, drink and maintain nutritional intake?” (Kelly et al., 2015). In an international survey of experts to determine the fifteen most important research questions to be explored in nursing homes, “dementia care” and “improving nutrition” were ranked first and fourth respectively (Morley et al., 2014). In a similar exercise to establish the top ten research priorities to improve the health of adults with dysphagia, the third-highest priority was determining the effectiveness of carer/staff training programmes in eating, drinking and dysphagia in dementia to (a) improve

referrals to SLT, (b) reduce hospital admissions for dysphagia-related illness and (c) improve health and wellbeing outcomes for people with dementia and dysphagia (Pagnamenta et al., 2022).

### **1.3 Aims, objectives and research questions**

The research described in this thesis sought to answer three related questions:

- What is good practice in mealtime care for people with dementia living in care homes?
- What are the factors influencing mealtime care for people with dementia living in care homes?
- What is the best way to support care home staff to care for people with dementia at mealtimes?

In answering these questions, the overall aim was to develop a staff training intervention to improve mealtime care for people with dementia in care homes. There were three phases to the work; each of these had individual objectives, which contributed to the overall aim.

The first phase was a literature review. This comprised a systematic review of research studies, and a scoping review of guidelines. The objective of the systematic review was to synthesise evidence from research studies on mealtime care for people with dementia living in care homes, in order to identify important categories of carer-resident interaction. The objective of the scoping review was to synthesise recommendations from guidelines on the topic of mealtime care for people with dementia living in care homes.

The second phase was an ethnographic study. This comprised observations and interviews in two care homes in northeast England. The objectives of this study were to critically examine current practice in mealtime care, to identify good practice, and to understand the factors influencing mealtime care.

The third phase was a co-development process. This comprised a series of workshops, and associated activity before and after the workshops. The objective of this process was to produce a prototype mealtime care training intervention, informed by evidence from the literature review and the ethnographic study.

## **1.4 Conclusion**

In this chapter I have described background information relevant to this thesis. In summary: problems with eating and drinking are prevalent in people living with dementia and have serious consequences; many people with dementia live in long-term care and are dependent on the care of others at mealtimes; the quality of mealtime care is variable and training provision on this topic has been found to be lacking. I have also set out the aim of the research, in response to this problem: to develop a staff training intervention to improve mealtime care for people with dementia in care homes. In chapter 2, I describe the scientific framework underpinning this research.

## **Chapter 2. A framework for intervention development**

### **2.1 Introduction**

At the end of the preceding chapter, I set out the overarching aim of the research described in this thesis: to develop a staff training intervention to improve mealtime care for people with dementia in care homes. I then summarised the three phases of work which have contributed to this aim: a literature review, an ethnographic study, and a co-development process. Each of these studies is reported in detail in the remainder of this thesis. Each has its own guiding methodology and methods, which I describe in chapters 3, 4, and 7. Before doing so, however, it is important to consider the way in which these discrete studies fit together, to form a cohesive whole. Therefore, in this chapter I present the scientific framework underpinning the work, and important concepts related to this: stakeholder involvement and positionality.

### **2.2 Complexity and complex interventions**

Giving due consideration to the complexity of interventions has become a major theme in healthcare research (N. C. Campbell et al., 2007; Petticrew, 2011; Richards & Hallberg, 2015). Complex interventions are sometimes differentiated from simple interventions by virtue of the features of the intervention itself – such as the number of different components contained within. For example, pharmacological interventions are typically classed as simple interventions, whereas non-pharmacological interventions (such as psychological interventions, or allied health professional interventions) are typically classed as complex interventions (M. Campbell et al., 2000). Other researchers have argued that the number of components is not in itself an indicator of complexity. A helpful illustration is provided by Glouberman and Zimmerman (2002), who suggest that sending a rocket to the moon, while complicated, is not complex – there are very many different components, but they are discrete, linear, replicable and predictable. They contrast this with raising a child, which is certainly complex – because the various components are unique and much less predictable!

In recent years, considerations of complexity have shifted from the intervention and its components, to the context in which it takes place. For example, interventions in schools or hospitals take place within complex systems (Moore et al., 2019). These systems are complex because they are influenced by various actors at various levels. To take the schools example: an intervention in a school may potentially interact with or be

influenced by students, teachers, parents, governors, the local education authority, the Department for Education, and wider society.

Complexity is pertinent to my research, which aims to develop a training intervention for care home staff. Firstly, the intervention itself is complex. Training interventions are complex because they include multiple components (facilitators, participants, means of delivery, and so on). At least some of these components are people, who may act in ways which are not easily replicable or predictable. There are also challenges in identifying the right way to measure outcomes for a training intervention. Secondly, the intervention context is complex. Care home staff operate within a complex system which has multiple actors at multiple levels, including but not limited to residents, management, external health and social care staff, families, the local council, and the Care Quality Commission.

### **2.3 Intervention development**

In search of an over-arching approach for my work, I was drawn to intervention development. This is a burgeoning field, and there is now an increasing number of published frameworks for intervention development within healthcare (see for example Bartholomew et al., 2006; Bleijenberg et al., 2018; Collins et al., 2007; Michie et al., 2014; O’Cathain et al., 2019, Croot, Duncan et al., 2019; Wight et al., 2015). The most prominent of these is the Medical Research Council (MRC) framework, which has now had three published iterations (M. Campbell et al., 2000; Craig et al., 2006; Skivington et al., 2021).

Intervention development was an obvious fit for my research. First, it has an emphasis on problem-solving, and on producing an output (Craig et al., 2006). Hodinott (2015, p. 1) characterises intervention development as a process which occurs from “the inception of an intervention until it is ready for formal feasibility, pilot or efficacy testing prior to a full trial or evaluation”. Thus, there is an end-point; not a finalised and fully-evaluated intervention, but a significant step in that direction. O’Cathain, Croot, Sworn et al. (2019, p. 3) suggest that this end-point is the production of a document or manual describing the intervention and how it should be delivered. I resolved to produce such a document as a primary output of my research, because I wanted to make progress towards a solution with application to clinical practice.

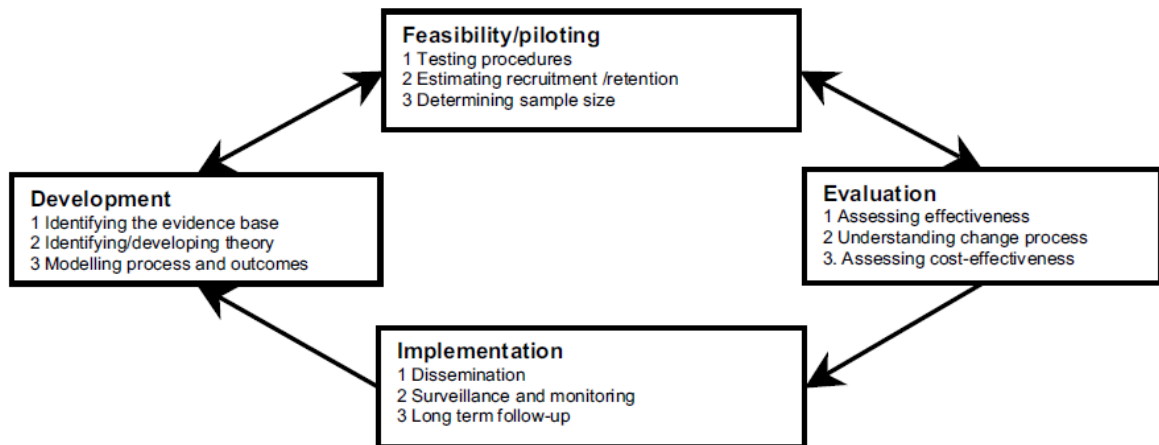
Second, an intervention development approach promotes teamwork. Working with others is widely considered to be an essential component of the approach, with multiple benefits:

Interventions are best developed through collaborations between interdisciplinary teams of practitioners, researchers, the effected population and policymakers. Such coproduction maximises the likelihood of intervention effectiveness by improving: the fit with the target group's perceived needs and thus acceptability; practicality; evaluability, including the theorising of causal pathways; and uptake by practitioners and policymakers. (Wight et al., 2015, p. 520)

This collaborative way of working resonated with me. There are many important stakeholders in mealtime care for people with dementia. Involving them in a meaningful way was key, and an intervention development approach provided a structured way to do this. (I expand on this in section 2.4 below).

Third, intervention development directly addresses the issue of complexity. The recent proliferation of intervention development guidance focuses on complex interventions. Simple interventions, particularly pharmacological interventions, already have well-established and tightly-regulated development processes (Hoddinott, 2015). Complex interventions, as described above, pose additional problems for developers (Craig et al., 2006). The science of intervention development is bringing increasing transparency to this process, so that complex interventions may be developed in such a way as to be robust, replicable, and easy to evaluate. This pertains both to the complexity of the intervention itself, and the complexity of the system in which it takes place (Anderson, 2008) – in the case of this research, the care home.

Thus, the research described in this thesis uses an intervention development approach. I broadly followed the MRC framework as outlined in Craig et al. (2006) in planning the project and writing the protocol. The MRC framework proposes that development is one of four key phases in an iterative process of intervention development and evaluation (see Figure 2.1).



**Figure 2.1: The MRC framework for the development and evaluation of complex interventions**

This research sits primarily within the ‘development’ phase. It lays the foundations for future work which would be located within the ‘feasibility/piloting’ phase.

I decided upon the MRC framework because it explicitly outlines an evidence-based approach to intervention development. I was determined that the prototype training intervention, which was to be the primary output of this work, would be evidence-based. I envisaged this as being partly about using existing evidence, by undertaking a literature review. The MRC framework recommends as a first step the identification of “what is already known about similar interventions” (Craig et al., 2006, p. 2). I also saw that it was important to generate new data about mealtime care for people with dementia living in care homes, so that I could understand the context better and develop a more effective intervention. Again, the MRC framework is relevant to this, as it calls for the supplementing of existing evidence by new primary research. In my case, I sought to generate new data through qualitative research: specifically, to use an ethnographic study to understand good practice in mealtime care, and the factors influencing this. I was aware that the MRC framework “demonstrates the usefulness of qualitative studies exploring the experiences people have of illness, health services and treatments in order to develop theory, identify need and evaluate the working of interventions in practice” (Griffiths & Norman, 2013, p. 584).

My qualitative work was informed by subtle realism and constructivist grounded theory. In chapter 4, I outline in detail this methodological approach to the ethnographic study

and its rationale, but I will briefly summarise here my reasons for adopting the approach. Subtle realism's position – that there is an independent reality which we do not have direct access to but are able to represent with reasonable confidence (Murphy et al., 1998) – was appealing to me. My stance was that good mealtime care for people with dementia is something real, whose characteristics I would be able to feel reasonably confident about through my research. Constructivism holds that our view of reality is influenced by our history and cultural context (Mills et al., 2006). I knew that in conducting this research I brought with me my own knowledge and experience of the topic, primarily as a clinician, which I would need to acknowledge and reflect on. I was drawn to grounded theory because of its constant comparative approach to data analysis. The iterative nature of this method – going back and forth between observations and interviews, and between data collection and analysis, would enable me to probe early findings and explore in greater depth the things I was seeing and hearing. Constructivist grounded theory, in particular, acknowledges that the researcher may have familiarity with relevant literature, and previous experience of the topic – and indeed that these things are a legitimate and important part of the research process. Thus, the MRC framework gave me a guiding structure to organise my work, with a view to making progress towards an output. Subtle realism and constructivist grounded theory helped me formulate my thinking in undertaking the qualitative research that informed intervention development.

Whilst it is credited with stimulating a constructive and enduring conversation about intervention development (Anderson, 2008), the MRC framework does have some perceived shortcomings. Not least, it provides only limited detail on how to conduct the development phase. There are three suggested elements in this phase: Identifying the evidence base; Identifying/developing appropriate theory; Modelling process and outcomes. These elements are not comprehensively specified, and may not by themselves be a sufficient guide for the novice researcher (Bleijenberg et al., 2018). Therefore, various researchers have sought to elaborate or expand on the process of intervention development. For example, O’Cathain, Croot, Duncan et al. (2019) propose a more detailed framework for intervention development, comprising various actions including: Plan the development process; Involve Stakeholders; Bring together a team; Review



published evidence; Undertake primary data collection; Understand context<sup>2</sup>; Design and refine the intervention. This framework was published soon after my research was already underway, so it did not explicitly inform my protocol. Nevertheless, because it synthesises and builds on previous work in the intervention development field, it closely represents the approach I have taken. To give some examples: I reviewed published evidence in the systematic review; I undertook primary data collection in the ethnographic study; I designed and refined the intervention (working with others) in the co-development process. In the following section I elaborate on another important aspect of intervention development: involving stakeholders.

## **2.4 Stakeholder involvement**

Stakeholder involvement is essential to healthcare research, and, as alluded to above, an established principle of intervention development (Boaz et al., 2018; Staniszewska et al., 2018). I have worked closely with key stakeholders during the research process; the term stakeholder including people living with dementia, family carers, care home staff, health and social care professionals, and the wider public (Pollock et al., 2018). Stakeholders have been involved at different times and in different ways throughout the work, as I will outline in this section. In each case I have followed relevant guidance for public involvement (Simons, 2012; Staniszewska et al., 2018). This guidance makes a distinction between involvement in an advisory capacity, sometimes known as Patient and Public Involvement (Greenhalgh, 2019), and involvement as a research participant. Both kinds of involvement were an important feature of this project, but I will focus in this section on the first kind. The involvement of stakeholders as research participants is reported in detail in chapter 4 (in relation to the ethnographic study) and chapter 7 (in relation to the co-development work).

In order to plan and design the research initially, I obtained input from two carers of people with dementia, whom I contacted through the Dementia and Neurodegenerative

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<sup>2</sup> After I had completed the intervention development work described in this thesis, the third iteration of the MRC framework was published (Skivington et al., 2021). This updated framework emphasises the importance of understanding how interventions contribute to change, including how they interact with their context and wider dynamic systems (p. 8).

Diseases Research Network (DeNDRoN; <https://www.dendron.org.uk/>) and the North East Dementia Alliance ([https://www.dementiaaction.org.uk/local\\_alliances/6390\\_north\\_east\\_dementia\\_alliance](https://www.dementiaaction.org.uk/local_alliances/6390_north_east_dementia_alliance)).

I spoke to the carers by telephone, outlining the aims of my research and seeking their views on how best to conduct it. They gave me valuable advice about various aspects of the project, including design of the mealtime observations, and of the co-development workshops. I also elicited important feedback on the research design from care home staff. I discussed the project with a group of staff at a local care home, asking their opinion on the research design. Their comments helped me appreciate the value of obtaining participants' trust – in all phases of the project, but particularly in the ethnography. In addition, I consulted with health and social care professionals. I presented my ideas to SLT colleagues at a meeting of the regional Dysphagia Discussion Group, to confirm the relevance of the research to current clinical priorities, and to obtain their views on how best to recruit SLTs to the co-development phase of the study. I met with a social worker from my NHS organisation, who helped me to understand better the way that care homes are registered to provide different kinds of care. Finally, I spoke at a meeting of VOICE, a public engagement panel in Newcastle (<https://www.voice-global.org/>). The panel members provided valuable advice about observation methods in the ethnography and recruitment to the co-development workshops.

At the beginning of the project, I established an advisory group, comprising four family carers of people with dementia. To do this, I advertised through local networks such as DeNDRoN and VOICE, and visited a regional dementia carers' group to talk about my study and present this opportunity. Each of the carers in the advisory group had first-hand experience providing mealtime care. I used relevant guidance (Simons, 2012) to help them feel able to make a full contribution in meetings, considering accessibility and familiarity of meeting venues, accessibility of materials and language, and appropriate ground-rules. This advisory group was retained throughout the project, and we met regularly at key points, with email communication between meetings. Specifically, we met in September 2018 (to discuss issues relating to ethical approval, review participant information sheets, and plan the systematic review), June 2019 (when they advised me on engagement with care homes and fieldwork methods for the ethnography), May 2020 (to share preliminary findings from the ethnography and seek feedback on this), and September 2020 (to gain their advice on how to maximise accessibility for participants in

the online co-development workshops). The first two meetings were face-to-face; the others were via Zoom.

## **2.5 Positionality**

The starting-point for this research was my clinical practice. I have worked as an SLT for over 15 years. For most of that time I have specialised in the care of older people. My caseload has been, to a large extent, people with dementia who live in care homes and have difficulties at mealtimes. I have visited care homes on a regular basis as part of my clinical work, to provide assessment and management of swallowing difficulties in people with dementia – liaising closely with care home staff and family members. My experiences in this context have inspired and motivated me to conduct this research. They have also informed the way I have gone about it.

There are various aspects of my clinical work which have shaped my approach to the research. One of these is the importance of problem-solving (Vordermark II, 2019; Yoo & Park, 2014). Clinicians are continually presented with problems to solve. In my case, I am referred people whose ability to communicate, or to eat and drink, is compromised due to neurological, medical, or other reasons. The role of the clinician is not only to understand what is happening, but also, if at all possible, to make it better. My ambition in this research has been to arrive at a solution to the problem set out in chapter 1.

Another influence from clinical work on my research was the importance of working with others. Teamwork is a vital element of healthcare, whether that be cooperation with professional colleagues, the wider multi-disciplinary team, families and so on (Rosen et al., 2018; Taberna et al., 2020). It is also integral to the SLT profession, which encompasses both direct work with patients, and indirect work with and through those key people in the patient's environment. Teamwork has in any case always been my preferred way of working. Thus, I approached this research in the belief that I could not solve the problem by myself. Rather I needed– and wanted – to work with others to develop a solution together.

Finally, I was aware that SLTs have a professional remit to provide training in this clinical area (RCSLT, 2014), but to date have had minimal or no input into the development of relevant evidence-based training intervention. This is to my knowledge the first SLT-led study to systematically develop a training intervention to improve mealtime care for people living with dementia.

## **2.6 Structure of thesis**

Having described the scientific framework underpinning this work, and set out how my own professional background relates to the research, I will now signpost to the content of the remaining chapters within this thesis.

In chapter 3, I review existing literature on mealtime care for people with dementia living in care homes. Two separate but complementary reviews are presented: (1) a systematic review of research studies; (2) a scoping review of guidelines.

Chapter 4 provides a detailed description of the methodology and methods used in my ethnographic study. I elaborate on the philosophical and methodological perspectives underpinning this study, and outline in depth the research methods employed. In addition, I explain my approach to ensuring trustworthiness in the research.

In chapters 5 and 6, I present the findings from my ethnographic study, which took place in two care homes in northeast England. By interrogating data from observations and interviews, I critically examine mealtime care for residents with dementia. In chapter 5, I set out various priorities of mealtime care, as pursued by care home staff in their interactions with residents. I note the tendency, at times, for these priorities to conflict with one another, and I propose that a person-centred approach can help to guide staff through the challenges that this presents. In chapter 6, I explore the contextual factors at play in mealtime care. I show how these factors constrain the care that staff are able to provide, and I suggest that teamwork is integral to overcoming constraints.

Chapter 7 describes the co-development work which generated a prototype intervention for mealtime care training. In the first part of the chapter, the methodology and theoretical framework underpinning this phase of the research is presented. After this, the methods are described; I explain how participants were recruited, and how the workshops were designed. Finally, the results from each workshop are reported, including decisions about content, mode of delivery and implementation which informed the prototype intervention. The prototype intervention itself is presented in Appendix X.

A discussion of the work presented in this thesis can be found in chapter 8. I identify the key findings in relation to good practice in mealtime care for people with dementia living in care homes, and the development of a staff training intervention on this topic. I also

consider strengths and limitations of my work, and highlight implications for research, policy and practice.

## **2.7 Conclusion**

The first two chapters of the thesis have provided background and justification for the work, stated the aim of the research, and described the scientific framework that underpins it. To summarise this framework: I used an intervention development approach, broadly following the MRC framework (see Craig et al., 2006, and Skivington et al., 2021). In chapter 3, I review the existing literature on mealtime care for people with dementia living in care homes. Two separate but complementary reviews are presented: a systematic review of research studies, and a scoping review of guidelines.

## Chapter 3. Literature review

### 3.1 Introduction

This chapter reviews the existing international literature on mealtime care for people with dementia living in care homes. Two separate but complementary reviews are presented: (1) a systematic review of research studies; (2) a scoping review of guidelines. The objective of the systematic review was to synthesise evidence from research studies on mealtime care for people with dementia living in care homes, in order to identify important categories of carer-resident interaction. The objective of the scoping review was to synthesise recommendations from guidelines on the topic of mealtime care for people with dementia living in care homes.

There are several previous reviews which have assessed the effectiveness of interventions aiming to improve some aspect of mealtimes for people with dementia (Abdelhamid et al., 2016; D. K. Bunn et al., 2016; Herke et al., 2018; Jackson et al., 2011; Liu et al., 2015). All but one of these reviews included studies with any setting. Lieu et al. (2015) narrowed the setting to long-term care facilities. The reviews considered a range of interventions, including: education/training for staff; education/therapy for people with dementia; changes to the dining environment; nutritional interventions; food modification; assistance with eating/drinking; social support for eating/drinking; changes to menu provision / food service.

The reviews which included any setting did not come to definitive conclusions about the effectiveness of the interventions. They either found no clearly effective (or clearly ineffective) interventions (Abdelhamid et al., 2016; D. K. Bunn et al., 2016), or they found at best moderate evidence for the intervention types (Jackson et al., 2011), or they rated the overall quality of evidence as low (Herke et al., 2018). The review by Lieu et al. (2015), which focused on long-term care, found evidence of effectiveness for intrapersonal training programmes for residents (spaced retrieval training, and Montessori methods), and for one-to-one assistance during eating. However, in both cases these interventions were implemented by trained research staff, rather than care home staff – this was acknowledged as a weakness by the reviewers, since the evidence was not generated in real-world conditions. The reviews provided some suggestions for future research, such as greater involvement of people with dementia and their carers (D. K. Bunn et al., 2016), and more studies taking place in care homes (Herke et al., 2018).

In designing this literature review, I sought to build on the work of previous reviews and further develop the evidence-base, in a way that was consistent with the overall aim of my research, which was to develop a staff training intervention to improve mealtime care for people with dementia in care homes. To this end, there are three distinctive features of the review.

Firstly, and unlike most previous reviews, this review takes long-term care as the setting of interest. This is because the project aims to improve mealtimes for people with dementia living in care homes. Mealtime difficulties are particularly prevalent among this population (Alzheimer's Disease International, 2014). Certainly, it is true that some principles of care transcend the setting, and are equally applicable in care homes, hospitals, and people's own homes. However, it is also true that there are factors specific to the long-term care setting which influence mealtime care (Amella, 1999).

Secondly, the review focuses on carer-resident interactions. This is because the project aims to use training of care home staff as a means of improving mealtimes. This focus contrasts with previous reviews which have taken a broader approach to interventions, for example by including oral nutritional supplements, food and drink texture-modification, and intra-personal training for residents. Whilst interventions of this kind may in some cases be administered by care home staff, the staff themselves are not responsible for prescribing or making clinical decisions about them; rather, they are implementing the directives of other professionals (such as dietitians, SLTs, or psychologists). This review focuses specifically on mealtime care interventions which are entirely within the remit and role of care home staff. The reason for this is that these interventions have the potential to be targeted through the training of care home staff.

Thirdly, the review is inclusive of a wide range of literature types. That is to say, it includes quantitative and qualitative studies of any research design, and it includes grey literature in the form of guidelines. Grey literature can provide an important complement to published research in literature reviews, to help with questions which cannot be answered only by quantitative or qualitative evidence (McArthur et al., 2015).

Traditionally, literature reviews (and in particular, systematic reviews) have focused on one form of evidence – for example, effectiveness studies. However, reviews of this kind are increasingly considered too narrow to produce useful findings for policy and practice (Pearson et al., 2015). Instead, reviews which include diverse forms of evidence are used,

to provide a richer and more practical understanding of complex interventions (Sheldon, 2005).

### **3.2 Methodology**

Whilst the inclusion of diverse literature can help to generate meaningful findings, it also necessitates careful consideration of methodological issues – in particular, critical appraisal and synthesis. There are various approaches to critical appraisal of grey literature (see, for example, Burrows and Walker, 2013; White et al., 2013), but as yet, none of these is firmly established. Techniques for combining evidence from grey literature and peer-reviewed research altogether in one synthesis are in a similarly emergent state. Reviews that undertake to do this will typically include only grey literature that is close in format to peer-reviewed research (such as unpublished studies), which enables the use of established synthesis methods (Mathieson et al., 2018; van Cauwenberghe et al., 2010).

For these reasons, I have chosen to conduct two separate (but complementary) reviews on the topic: firstly, a systematic review of research studies; and secondly, a scoping review of guidelines. This means that for both reviews I have been able to follow established and robust methods at all stages, as set out below. Finally, I have compared the findings of the two reviews by means of a synthesis matrix (Kavanagh et al., 2012).

### **3.3 Systematic review of research studies**

A version of this material has previously been published, as **Faraday, J., Abley, C., Beyer, F., Exley, C., Moynihan, P., & Patterson, J. M. (2021). How do we provide good mealtime care for people with dementia living in care homes? A systematic review of carer–resident interactions. *Dementia*.**

<https://doi.org/10.1177/14713012211002041>. Two colleagues outside of my supervisory team made contributions to the systematic review and were included as authors on the publication. These contributions included: duplicate screening; data extraction or critical appraisal, in line with robust systematic review methods; and, reviewing the manuscript prior to publication. Five other colleagues, acknowledged in the publication, made more minor contributions to assist with screening and critical appraisal. I led all aspects of the systematic review process and wrote the manuscript.



### **3.3.1 Aim**

The aim of this systematic review was to synthesise evidence from research studies on the topic of mealtime care for people with dementia living in care homes, in order to identify categories of carer-resident interaction.

### **3.3.2 Methods**

#### **Registration of the review protocol**

The protocol for this review was registered on PROSPERO (CRD42018114533).

#### **Eligibility criteria**

The following eligibility criteria were used for study selection:

- a) The population was people with dementia living in care homes. Dementia could be of any type and stage. If a study included participants with various clinical diagnoses, it was necessary for the majority of participants to have dementia, and for data on those participants to be presented separately from those with other diagnoses.
- b) The phenomenon of interest was mealtime care. Mealtime care was defined as ‘interactions occurring between care staff and residents at mealtimes, which may promote safe, adequate and/or enjoyable oral intake’. Activities outside of the direct control of care staff were excluded (for example: recommendation of PEG; oral nutritional supplements; and specialist training programmes targeted at people with dementia, such as Montessori, and spaced-retrieval therapy). Studies focusing on assessment of mealtime difficulties were also excluded.
- c) The publication types were peer-reviewed primary studies of any research design (quantitative, qualitative or mixed-methods). For practical reasons, sources unavailable in English were excluded from the review. There was no limitation on the date of studies, to capture as many studies as possible which met the eligibility criteria.

#### **Search strategy**

Seven databases were chosen to provide comprehensive and relevant multidisciplinary coverage: AgeLine, BNI, CENTRAL, CINAHL, MEDLINE, PsycINFO and Web of Science. Search strings suitable for each database were devised; these comprised the categories ‘dementia’, ‘mealtimes’, and ‘care’, and used both free-text and index terms.

Thesaurus headings were translated as appropriate between databases. An example search strategy, for MEDLINE, is presented in Appendix A. Databases were searched from inception to May 2020.

### **Study selection**

It is widely considered good practice that certain review tasks are done in duplicate by two people working independently, to minimise risk of bias (J. P. Higgins & Deeks, 2008). I followed this principle in the study selection and critical appraisal tasks. By way of a proportionate approach to the data extraction tasks, I ensured that all extracted data were checked by a second person. In this section and others that follow, I use the term “reviewer” to denote someone doing one of these tasks. In addition to myself, reviewers were my supervisors, and other clinical/research colleagues with relevant methods expertise.

Results were downloaded into EndNote<sup>®</sup>. Titles and abstracts of retrieved studies were screened independently by myself and a second reviewer, using the online tool Rayyan (<http://rayyan.qcri.org>). Any discrepancies were resolved via discussion. Full texts of remaining studies were then screened independently by myself and a second reviewer. Again, discrepancies were resolved via discussion, with recourse to another reviewer as needed. Reasons for exclusion were noted.

In addition to the database search, studies were sought by other means. Relevant non-indexed journals were hand-searched, from inception to present. These were: Journal of Nursing Home Research; Journal of Aging and Long Term Care; and Journal of Long-Term Care. Reference lists of related systematic reviews were searched. Experts in the field were contacted for recommendations.

### **Data extraction**

Separate data extraction forms were designed for quantitative and qualitative studies, with fields chosen to capture all necessary information. Data were extracted on study characteristics, outcomes and results. For qualitative studies, verbatim reports of findings were extracted. I carried out data extraction, and a second reviewer checked the data against the original papers to ensure there were no erroneous or missing data.

### **Critical appraisal**

Peer-reviewed critical appraisal tools published by the Joanna Briggs Institute (JBI) were used to critically appraise the studies (The Joanna Briggs Institute, 2014). The tools used

were: Checklist for Analytical Cross Sectional Studies; Checklist for Quasi-Experimental Studies, Checklist for Randomized Controlled Trials; and Checklist for Qualitative Research. Critical appraisal was carried out by myself and a second reviewer independently. Discrepancies were resolved via discussion, with recourse to a third reviewer as needed.

### **Data synthesis**

A convergent synthesis design was used: quantitative and qualitative evidence was collected and analyzed in parallel (Hong et al., 2017). Integration occurred at the level of the extracted data, so that studies were analyzed using the same synthesis method. The chosen method of analysis was Narrative Synthesis (Popay et al., 2007). In order to construct a common rubric for synthesis of quantitative and qualitative data, a textual summary of results was produced for each study. Verbatim extracts from the study reports were used, including principle findings. Data were interrogated to identify thematic categories of carer-resident interaction. Principles of constant comparative method were used (Glaser, 1965), which involved reading and re-reading data to search for emerging categories (Burnard et al., 2008). The synthesis process was undertaken by one reviewer, with regular discussion with other reviewers in order to cross-check the analysis.

### **3.3.3 Results**

The initial database search retrieved 5,729 articles. Reference management software was used to remove duplicates, leaving 3,268 articles. Title/abstract screening resulted in 680 articles. Of these, 526 were excluded because they were ineligible due to language, availability, publication type, or because of duplication undetected by the software. The remaining 154 articles were full-text screened, with 136 excluded at this stage (see Appendix B for a full list of these articles, and reasons for exclusion). This left 18 articles which reported eligible studies. Hand searches and other lines of enquiry did not yield any additional eligible studies. See Figure 3.1 for a PRISMA flow diagram summarising the study selection process (Moher et al., 2016).

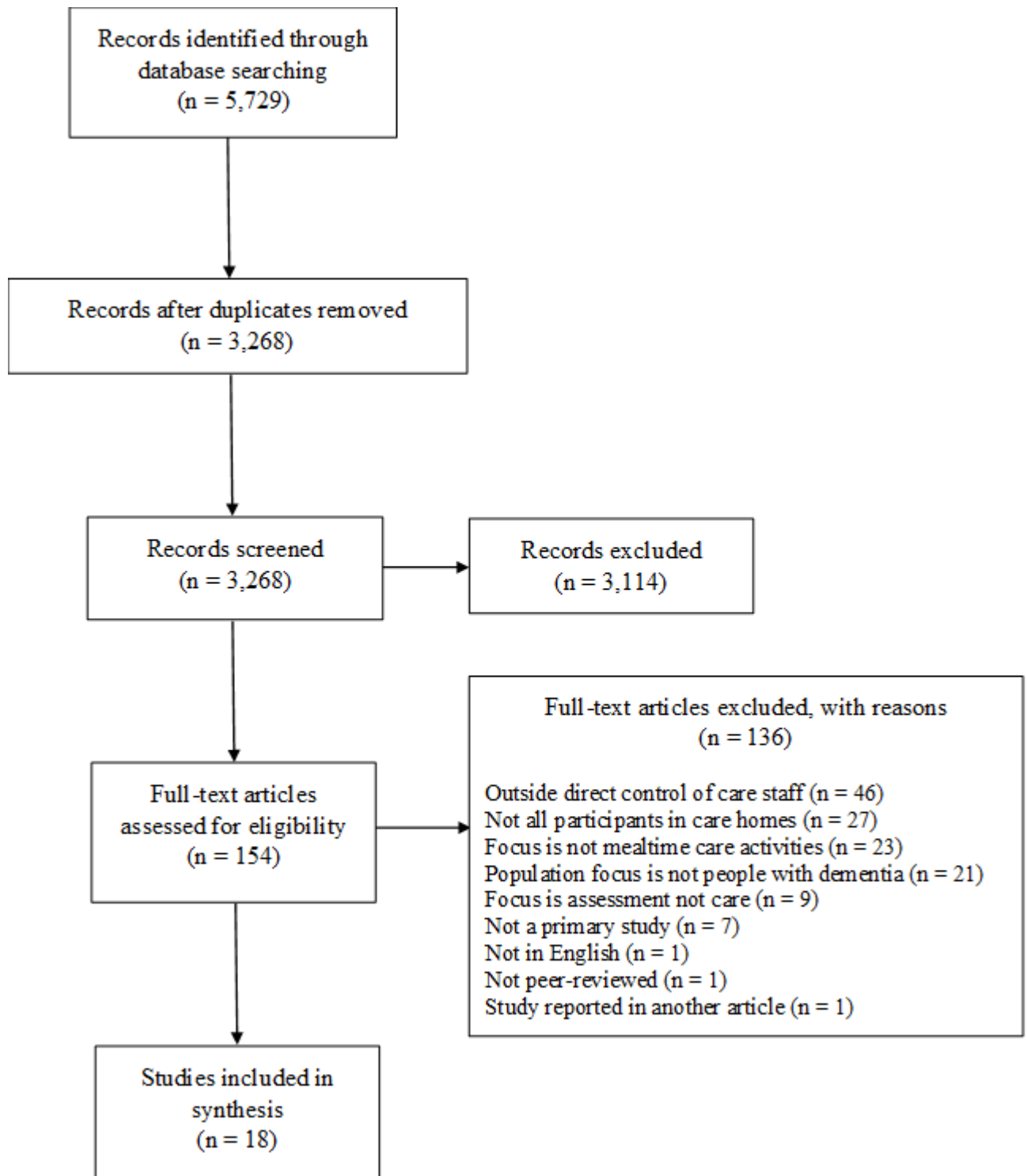


Figure 3.1: PRISMA flow diagram of study selection process

## **Study characteristics**

Study characteristics are presented in Appendix C and summarised here. Nine different countries are represented in the studies: Australia, Canada, Italy, New Zealand; Sweden, Taiwan, the Netherlands, UK, and USA. All of the studies took place in care homes, with the exception of Murphy et al. (2017), where a neutral venue was used for focus groups and interviews. Ten studies recruited residents and care home staff as participants; four studies recruited only residents; four studies recruited only care home staff.

The studies were varied in design. Two studies were randomized controlled trials (Batchelor-Murphy et al., 2017; Coyne & Hoskins, 1997); one was a quasi-experimental study (Engström & Hammar, 2012); two were cross-sectional studies (Amella, 1999; Suski & Nielsen, 1989). Eleven studies were qualitative. Of these, nine included observation of mealtimes in their data collection (Driessen & Ibáñez Martín, 2020; Gibbs-Ward & Keller, 2005; Hung & Chaudhury, 2011; Kayser-Jones & Schell, 1997a, 1997b; Palese et al., 2018; Pasma et al., 2003; Pierson, 1999; van Ort & Phillips, 1992), and two used focus groups and/or interviews only (J. L. Murphy et al., 2017; Nell et al., 2016). Two studies used mixed methods: Chang and Roberts (2008) (2008), and De Bellis et al. (2003). Both of these conducted cross-sectional studies and collected qualitative data. De Bellis (2003) reported only the qualitative data. In Chang and Roberts (2008), the quantitative data focused on residents' eating difficulty, while the qualitative data investigated mealtime care – for this reason, only the qualitative data from this study were included here. Thus, these two papers are bracketed with the qualitative studies in the review.

The three experimental / quasi-experimental studies assessed the effectiveness of a care staff intervention at mealtimes. Batchelor-Murphy et al. (2017) compared three techniques for eating assistance (direct hand, over hand, and under hand), by using the Edinburgh Feeding Evaluation in Dementia scale to assess eating and eating assistance behaviours. Coyne and Hoskins (1997) assessed the efficacy of directed verbal prompts and positive reinforcement, using their own Level of Eating Independence scale. Engström and Hammar (2012) assessed the effect of carers humming during mealtimes, measuring the amount of food/liquid consumed in grams.

The two cross-sectional studies investigated the association between quantity of oral intake and possible influencing factors. Amella (1999) used weight to measure proportion of food consumed, and assessed the influence on this of interaction between resident and carer,

carer empathy, and carers' level of perceived power (these were measured using, respectively, the Interaction Behavior Measure, the Interpersonal Reactivity Index, and the Fundamental Interpersonal Relations Orientation – Behavior. Suski and Nielsen (1989) used researcher rating of proportion of meal consumed as the outcome measure, in considering the impact of time of day, type of food, and technique for eating assistance.

The 13 studies reporting qualitative data explored mealtimes from various perspectives. De Bellis et al. (2003), Kayser-Jones and Schell (1997b), Nell et al. (2016), Palese et al. (2018), Pasma et al. (2003), and Pierson (1999) investigated care staff's perceptions of, and approaches to, mealtime care. Gibbs-Ward and Keller (2005), and Murphy et al. (2017) used qualitative data to develop a conceptual understanding of mealtime care. Kayser-Jones and Schell (1997a), and Van Ort and Phillips (1992) described and analysed carer strategies to assist residents at mealtimes. Hung and Chaudhury (2011) explored the concept of personhood (see Kitwood (1997) in the context of mealtimes, with particular reference to the influence of care staff activity. Chang and Roberts (2008) investigated mealtime difficulties, carer strategies, and mealtime environment. Driessen and Ibáñez Martín (2020) considered how mealtime care is tailored to address differences in residents.

### **Study quality**

The results of the critical appraisal are presented in Appendices D (quantitative studies) and E (qualitative studies). The methodological quality of included studies was varied. The highest-scoring quantitative study (Batchelor-Murphy et al., 2017) was rated Yes for all applicable criteria, except for one criterion which was rated Unclear. The lowest-scoring quantitative study (Engström & Hammar, 2012) was rated No for three applicable criteria. The other quantitative studies were all rated No for one applicable criterion. The failed criteria were different in each case and included: “Were the outcomes measured in a valid and reliable way?”; “Were confounding factors identified?”; and “Were treatment groups similar at baseline?”. The highest-scoring qualitative study (Gibbs-Ward & Keller, 2005) met all criteria. The lowest-scoring qualitative study (Chang & Roberts, 2008) was rated No for three criteria, and Unclear for six others. The other qualitative studies achieved a range of scores in between. The most common failed criterion amongst the qualitative studies was “Is the influence of the researcher on the research, and vice versa, addressed?” The impact of study quality on the review synthesis is discussed in more detail below.

## **Synthesis of study findings**

The findings of individual studies are presented in Appendix F. Using Narrative Synthesis, these findings were analysed to identify thematic categories of carer-resident interaction. Four broad categories of carer-resident interaction were identified: *Social connection*; *Tailored care*; *Empowering the resident*; and *Responding to food refusal*. These are presented alongside relevant study findings in Appendix G, and described below.

### *Social connection*

Social connection refers to interactions which build relationship between carer and resident, and which facilitate social connection at mealtimes. This sense of relationship and social connection featured in findings from five studies. Two studies identified the importance of carer-resident relationship (Amella, 1999; Hung & Chaudhury, 2011). Three studies found that social interactions were key at mealtimes (Kayser-Jones & Schell, 1997a, 1997b; Palese et al., 2018).

### *Tailored care*

Tailored care denotes interactions which are tailored to the individual. The idea of tailored care was represented in findings from nine studies. Some studies emphasised tailoring the amount of direct assistance to suit the resident (Batchelor-Murphy et al., 2017; Kayser-Jones & Schell, 1997a, 1997b; Palese et al., 2018). Other studies highlighted the importance of knowing residents' preferences (Driessen & Ibáñez Martín, 2020; J. L. Murphy et al., 2017; Nell et al., 2016). Focusing on the individual resident – rather than the task – was identified in other studies (de Bellis et al., 2003; Hung & Chaudhury, 2011).

### *Empowering the resident*

Empowering the resident is about interactions which promote the resident's autonomy and independence. Empowerment in this way was represented in the findings of several studies. Encouragement of independent eating was advocated (Hung & Chaudhury, 2011; Kayser-Jones & Schell, 1997a). So too was ceding control to the resident in mealtime interactions (Amella, 1999; Batchelor-Murphy et al., 2017; Hung & Chaudhury, 2011). Provision of choice was a key theme in Driessen & Ibáñez Martín (2020).

### *Responding to food refusal*

Responding to food refusal is concerned with interactions which carefully and skilfully address the challenge of food refusal. Some studies promoted the use of skills and techniques in dealing with this challenge (Pasman et al., 2003; Suski & Nielsen, 1989). The balance of encouraging oral intake without using force was also highlighted in studies (Kayser-Jones & Schell, 1997b; Pasman et al., 2003).

### **3.3.4 Discussion**

This systematic review has investigated the published evidence on mealtime care for people with dementia living in care homes. It has taken an intentionally broad, inclusive approach to study selection, and as a consequence the included studies are heterogeneous in design. The review has focused on ways in which care staff interact with residents whilst providing mealtime care. It has identified four thematic categories of interaction across the studies: *Social connection*, *Tailored care*, *Empowering the resident*, and *Responding to food refusal*.

These findings may be informative for practitioners, researchers and policy-makers seeking to optimise mealtime care for this population. Firstly, the findings point to social connection as an important part of mealtime care. Care home staff are able to foster social connection at mealtimes, not only through their own interactions *with* residents, but also by facilitating interactions *between* residents. For some staff, this may be a very natural undertaking; others may have to be more intentional about it. Interventions promoting social connection at mealtimes should be considered (Watkins et al., 2019), but these also need to take account of residents' individual characteristics (Cherry et al., 2008).

Secondly, and following on from this, the findings indicate that mealtime care should be tailored to the resident. This means knowing the resident's needs and preferences, and prioritising them during mealtimes – but also being receptive to the idea that they may change (Driessen & Ibáñez Martín, 2020). Thirdly, the findings say that good mealtime care helps residents to be empowered. This can happen when residents are given choice at mealtimes (whether this is choice of what to eat, where to eat, when to eat, and so on). It can also happen when care home staff allow residents to be in control at mealtimes – for example, to eat without assistance, even if this takes longer. Complexities may arise from this, particularly when a resident's choice is perceived as unwise. An understanding of the Mental Capacity Act is likely important here (Manthorpe & Samsi, 2016a). Fourthly, the findings suggest that responding well to food refusal is a significant element of mealtime



care. Skilled care home staff may be able to respond in a way that encourages (but does not coerce) a resident to eat more. Further work is needed to find ways to articulate and delineate this skill, so that it can be replicated (Pierson, 1999).

In reporting review findings, it is important to consider strength of evidence, the context of other literature, and review methods (Moher et al., 2016).

### **Strength of evidence**

The strength of evidence for these thematic categories was varied. The category *Social connection* was supported by five studies. Some of these had significant shortcomings in their design or reporting. For example, the qualitative studies by De Bellis (2003) and Kayser-Jones and Schell (1997a, 1997b) provided only brief or minimal illustrations from data to show the basis of their conclusions. By contrast, both Hung and Chaudhury (2011) and Palese (2018) used plentiful direct quotes and data extracts to support their themes.

The concept of *Tailored care* was supported by ten studies, easily the most of all the categories. Again, however, the quality of evidence was mixed. There was variation, for example, in the reliability of outcome measures used in the quantitative studies. Some measures of oral intake were precise and objective (Batchelor-Murphy et al., 2017), while others had greater risk of unreliability (Suski & Nielsen, 1989). There was also variation in the extent to which qualitative studies reported a congruent philosophical perspective and research methodology. Some studies clearly articulated a link between the two (de Bellis et al., 2003; Hung & Chaudhury, 2011), while others did not (Driessen & Ibáñez Martín, 2020; Kayser-Jones & Schell, 1997a, 1997b; J. L. Murphy et al., 2017; Nell et al., 2016; Palese et al., 2018).

Evidence for the third category – *Empowering the resident* – was also varied in quality. The quantitative study contributing evidence for this category (Amella, 1999) met all criteria except identification of confounding factors. The qualitative studies (Driessen & Ibáñez Martín, 2020; Hung & Chaudhury, 2011; Kayser-Jones & Schell, 1997a), however, were each marked down on more than one criteria – for example, none addressed influence of the researcher on the research, and vice-versa. It should be noted that evidence for this category came from only four of the included studies.

*Responding to food refusal* was supported by the lowest number of studies: three. Moreover, two of these studies achieved only half of the available criteria in quality

appraisal. Kayser-Jones and Schell (1997b), a qualitative study, was unclear on philosophical perspective, data analysis, and ethical approval – and did not adequately represent participants’ voices. Suski and Nielsen (1989), a quantitative study, was unclear on how the condition was measured, and on how to deal with confounding factors – and did not measure outcomes in a reliable way.

Five included studies did not contribute to the thematic categories, for various reasons. In Engström and Hammar (2012), study results were inconclusive. In Van Ort and Phillips (1992), the study produced initial categories of carer and resident behaviour at mealtimes, but the authors concluded that further work was needed to examine relationships between these categories. In Coyne and Hoskins (1997), the intervention was trialled as a training programme targeting the resident, rather than as a mealtime care intervention. In Chang and Roberts (2008), and in Pierson (1999), qualitative data were presented narratively, not as explicit themes amenable to synthesis in this review.

### **Comparison to other literature**

The thematic categories generated by this review are for the most part echoed in other related literature – for example, broader mealtime care literature, and dementia care literature. A number of recent studies have pointed to the importance of social interactions at mealtimes in long-term care (Chaudhury et al., 2017; Keller et al., 2018; Watkins et al., 2017). Also, current guidance has emphasised the value of social relationships and interactions more broadly for people living with dementia (National Institute for Health and Social Care (NICE), 2018; Alzheimer’s Society, n.d.). In dementia care and more widely, relationships and interactions are considered central to quality care – see, for example, relationship-centred care (Nolan et al., 2004; Tresolini & the Pew-Fetzer Task Force, 1994).

Similarly, the idea of tailoring care to the individual resident is prevalent both in broader mealtime care literature (Reimer & Keller, 2009; Slaughter et al., 2020; Wu et al., 2018), and in dementia care literature (Fazio et al., 2018; Manthorpe & Samsi, 2016b). It also features prominently in guidance and regulation in this area (Social Care Institute for Excellence, n.d.; Care Quality Commission, n.d.).

The importance of empowering the resident is a common theme in previous work on general mealtime care. Several studies have emphasised the need for interventions which maximise independence and autonomy at mealtimes (Iuglio et al., 2018; Mann et al., 2019;

Palese et al., 2018; Reimer & Keller, 2009). The topic also features in studies which explore dementia care more broadly (Boumans et al., 2019; McCormack, 2001), and in various published guidelines for dementia care (Alzheimer's Association, 2009; Irish Nutrition and Dietetic Institute, 2016).

The way that carers respond to food refusal is less prevalent than the other categories in recent papers on mealtime care (although it is found in some older literature, particularly from Scandinavia (see Athlin and Norberg, 1987; Jansson et al., 1995), and in published guidance (Voluntary Organisations Involved in Caring in the Elderly Sector (VOICES), 1998). At a broader level, the idea of refusal of / resistance to a care act of some kind – and the way in which staff respond to this challenge – is well-documented in the dementia care literature. There are examples in the context of medication (Haskins & Wick, 2017; Young & Unger, 2016), oral hygiene (Jablonski et al., 2011), and general care (Konno et al., 2012; Mahoney et al., 1999). It is not clear why there is a relative absence of this theme in mealtime care literature. Perhaps it is taken for granted (and therefore sometimes unstated) that mealtime care includes response to food refusal. New research in this area may be beneficial, to better understand the challenges of food refusal, and optimal ways to respond.

### **Strengths and limitations of the review**

As well as considering the strength of evidence provided by included studies – and the relationship between these studies and other literature – it is important to evaluate the robustness of methods used in the review.

The review has included heterogeneous study designs. This decision was taken in order to maximize findings and the ability of those findings to inform policy and practice (Harden, 2004); an appropriate strategy to address the complexity of healthcare research questions (Bressan et al., 2017). By synthesising data from a variety of sources, the review has been able to identify broad categories of carer-resident interaction in mealtime care. It does not, however, provide an estimate of the effectiveness of a current intervention (or type of intervention). Instead, it is intended to identify relevant principles which may help with intervention development and thus improve practice.

In keeping with this inclusive approach, the decision was taken to accept for synthesis all studies meeting the eligibility criteria for the review; that is, there was no cut-off score for quality. Instead, quality assessment was used to gain an understanding of the strength of the evidence, and taken into account during the process of synthesis (Center for Reviews

and Dissemination, 2009, p. 227). There is a range of quality within the groups of studies supporting each thematic category in the synthesis, and for each category the methodological strengths and weaknesses are reported narratively. It is therefore possible to draw only provisional conclusions about the thematic categories, and further robust evidence is needed because of the mixed quality of included studies.

A qualitative approach has been used in the review synthesis. Following Popay et al. (2007), it was necessary to use a common rubric for synthesis of quantitative and qualitative data, and in this case a textual summary of results was produced for each study. There is the potential for reviewer bias in this method, but this was mitigated by using only verbatim descriptions of explicit study findings and themes whilst developing the synthesis, and through regular discussion of emerging thematic categories by the review team.

The decision was made to specify people with dementia as the population of interest, rather than care home residents more generally. It is possible therefore that some studies have been excluded with useful findings on the broader topic of mealtimes in care homes. However, the particular nature of the challenges faced by people with dementia at mealtimes – and their carers – is the reason why the review focuses on this population.

Finally, the review has focused on carer-resident interaction at mealtimes. This focus has allowed for detailed analysis of this aspect of mealtime care, as it is reported in the literature. At the same time, it must be acknowledged that there are other, organisational, factors which may impact on the way people with dementia experience mealtimes – for example, physical environment, food service, and menu provision. These factors are not explored here, because they have been covered in previous reviews (Abdelhamid et al., 2016; D. K. Bunn et al., 2016; Herke et al., 2018; Jackson et al., 2011; Liu et al., 2015). Nevertheless, it would be essential to consider such organisational factors in future intervention studies on this topic. Carer-resident interactions are, after all, influenced by care home environment, staffing ratios, company policies, staff training, and many other things outside the immediate control of the care staff themselves. Complex interventions literature is a useful reference-point here, to help researchers take account of systems and context (Hawe et al., 2009; May & Finch, 2009; O’Cathain, Croot, Duncan, et al., 2019).

In conclusion, this systematic review has synthesised evidence from peer-reviewed research studies, to identify how mealtime care for residents with dementia is expressed

through carer-resident interactions. This is complemented by the findings of the scoping review of guidelines, presented below.

### **3.4 Scoping review of guidelines**

#### **3.4.1 Aim**

The aim of this scoping review was to synthesise recommendations from guidelines on the topic of mealtime care for people with dementia living in care homes.

#### **3.4.2 Methods**

Scoping reviews – like systematic reviews – can be conducted using explicit and replicable methods (Shemilt et al., 2013). This review was broadly organised around a well-established framework for scoping reviews described by Arksey and O’Malley (2005). There are five mandatory stages to this framework: (1) Identifying the research question; (2) Identifying relevant studies; (3) Study selection; (4) Charting the data; (5) Collating, summarizing, and reporting the results. In addition, there is an optional, parallel stage – Consultation – in which stakeholders may be consulted to suggest additional references. This optional Consultation stage was used in this case. Whilst this framework provides a helpful structure for scoping reviews, it does not explain in detail how to conduct each stage. Nor does it provide any specific recommendations for reviewing guidelines, which were the focus of this review. Therefore, various other relevant precedents were followed within the stages, as set out below.

#### **Identifying the research question**

The research question was: What recommendations do guidelines make about on the topic of mealtime care for people with dementia living in care homes?

#### **Identifying relevant studies**

The Google search engine was used to conduct an internet search, using broad and inclusive search strings, with a view to achieving high sensitivity. The use of mainstream search engines such as Google is a recognised strategy for scoping reviews of grey literature, in order to retrieve useful resources which may not be stored in research databases (Adams et al., 2016; Godin et al., 2015).

Searches were done in the Chrome browser, instead of Internet Explorer (which was the default browser for all other searches conducted in day-to-day work during the time of

this project). Because Chrome was used specifically for this search, this reduced the risk of personalisation of results (Blakeman, 2013). The search string included terms relating to the following concepts: care, dementia, meals. In full, the search string was:

*(care OR carers OR caring OR carer OR nurse OR nurses OR nursing OR caregiver OR "care home" OR "care worker" OR "long-term care") AND (dementia OR Alzheimers) AND (meal OR food OR drink OR feed OR swallow OR eat OR dysphagia)*

### **Study selection**

I viewed results within the search engine, and stopped screening when two consecutive pages of ineligible results were screened (Adams et al., 2016). Relevant websites identified by the search were navigated and read in more detail to locate eligible material (Godin et al., 2015). In addition, a list of relevant organisations was collated, in consultation with topic experts in the areas of dementia care, and nutrition/hydration in care homes. These organisations included professional bodies, government departments, charity/non-profit organisations, advisory committees, and regulators. The website of each organisation was navigated to locate any further eligible documents (Godin et al., 2015). This process took place between November 2018 and February 2019.

Included documents were then checked for eligibility by a second reviewer, with any differences of opinion resolved by discussion.

The following eligibility criteria were used for study selection:

- a) The phenomenon of interest was mealtime care for people with dementia living in care homes. Mealtime care was defined as ‘interactions occurring between care staff and people with dementia at mealtimes, which may promote safe, adequate and/or enjoyable oral intake, and which may occur within a care home’.
- b) The publication types were guidelines documents.
- c) The source of material was an organisation operating at the national level at least.
- d) The material was intended for dissemination outside of the organisation itself.

The decision was made to focus on guidelines, rather than grey literature more widely. Grey literature has been described as any information not produced by commercial publishers (Jordan et al., 2011). Clearly this is a broad scope, which for any given topic could potentially encompass huge numbers of resources with varying levels of authority –

ranging from, for example, World Health Organization publications to personal blog posts. In order to ensure the review was practicable, guidelines were chosen as the publication-type of interest.

The parameters of what constitutes a “guidelines” document were carefully considered prior to searching (Johnston et al., 2019). Any document providing “information intended to advise people on how something should be done” was considered eligible. For credibility, the guidelines source had to be an organisation operating at least at national level, and the guidelines had to be intended for dissemination outside of the organisation itself.

Guidelines documents were included if they were judged to be relevant and applicable to the care home setting, whether or not they were not explicitly addressed to that setting. Documents were excluded if they were explicitly addressed to another setting, for example hospital or domiciliary care.

### **Charting the data**

Characteristics of the guidelines were extracted and tabulated. These characteristics were: Name of organisation; Type of organisation; Title of guidelines; Date of publication; Country; Author(s); Field(s) of expertise. For the purposes of this review, and with a view to answering the specific research question, the findings of interest were the guidelines’ recommendations (Noyes & Lewin, 2011). In line with recent guidance for reviews of clinical practice guidelines (Johnston et al., 2019), the term “recommendation” was defined a priori. In this case, it was applied as per the Oxford English Dictionary definition: “A suggestion or proposal as to the best course of action, especially one put forward by an authoritative body” (Oxford University Press, 2020), and such recommendations could be located in any part of the guidelines text. Each recommendation for mealtime care was extracted verbatim into an Excel spreadsheet.

### **Collating, summarizing, and reporting the results**

Extracted recommendations were analysed using thematic synthesis (Thomas & Harden, 2008). This is an established, flexible and accessible approach to the synthesis of qualitative literature (Flemming et al., 2019), which is based broadly on the principles of thematic analysis (Braun & Clarke, 2006). It has been used in several scoping reviews (see Birchley et al., 2016; Kim and Lee, 2017; Threapleton et al., 2017), and has potential

to generate meaningful findings for practitioners, policy-makers and intervention-developers (Booth et al., 2016).

First, I coded each recommendation according to its meaning and content. Codes were inductive, and not based on an a priori framework. Examples of codes were: *Cut up food first; Place food where person can see it; Keep food visible*. Next, following Thomas and Harden's method, I organised similar codes into themes. For example, the above codes (along with some others) were grouped together to form the theme *Set up for independence*. Then, these themes were also organised according to their similarities and differences. For example, the themes *Set up for independence, Keep things simple, Use prompts, Provide graded support, and Prioritise independence* were grouped into the overarching theme *Independence*. Thus, a hierarchy of themes was created, comprising themes and sub-themes.

### **3.4.3 Results**

A total of 143 results were retrieved by the internet search and initial screen, before reaching the pre-determined cut-off point of two consecutive pages of ineligible documents (Adams et al., 2016). Sources of these results included government departments, regional/local healthcare organisations, professional bodies, commercial organisations, charity / non-profit organisations, expert working-groups, news organisations, professional magazines, on-line communities, and personal blogs. The results also comprised a variety of different types of material, including opinion pieces, PowerPoint presentations, factsheets, and guidelines.

After the second more detailed screening, nine guidelines documents were included in the review.

#### **Guidelines characteristics**

Characteristics of the included guidelines are shown in Appendix H. The majority (five) of the guidelines originated from the UK, two were from Ireland, one was from the USA, and one was from a working group spread across several European countries. Three guidelines were from charitable / non-profit organisations (Alzheimer's Association, 2009; Irish Hospice Foundation, 2016; Social Care Institute for Excellence, 2013). Two were from expert working-groups (ESPEN, 2015; VOICES, 1998). The remaining sources were a higher education institute (Bournemouth University, 2018); a care homes



provider (Barchester Healthcare, 2016), a professional body (Irish Nutrition and Dietetic Institute, 2016), and a national health and social care service (Health and Social Care Northern Ireland, 2015). Expertise of the guidelines authors covered various fields, including nutrition and dietetics, geriatrics, speech and language therapy, and social care. Five guidelines explicitly stated that they were informed by evidence (Alzheimer's Association, 2009; Bournemouth University, 2018; ESPEN, 2015; Irish Hospice Foundation, 2016; Social Care Institute for Excellence, 2013).

### **Guidelines recommendations**

Recommendations from the guidelines are presented verbatim in Appendix I, and as themes and sub-themes (following synthesis) in Appendix J. Six overarching themes were generated by the synthesis. These were: *Independence*; *Oral intake*; *Respect*; *Safety*; *Atmosphere*; and *Social well-being*. These themes and their sub-themes are described and exemplified below.

#### *Independence*

Recommendations within this theme are intended to help the resident to eat and drink independently. There are five sub-themes:

1. *Set up for independence* refers to setting up the mealtime to be conducive to independent eating/drinking – for example, ensuring food is visible and accessible to the resident.
2. *Keep things simple* refers to simplifying aspects of the mealtime appropriately, so that it is easier for the resident to be independent – for example, only providing cutlery that is strictly necessary.
3. *Use prompts* refers to prompting the resident in a way that encourages them to be independent – for example, placing cutlery into the resident's hands.
4. *Provide graded support* refers to assisting the resident when they need it, and to the extent that they need it – for example, stepping in to provide direct physical assistance only when needed.
5. *Prioritise independence* refers to putting the resident's independence at mealtimes ahead of other concerns – for example, concerns about how long the meal might take, or about the resident eating in an unconventional manner.

#### *Oral intake*

Recommendations within this theme are intended to encourage the resident to eat more. I use the term *oral intake* to mean the amount of food or liquid the individual is able to take in by mouth (Irish Hospice Foundation, 2016). There are five sub-themes. *Address underlying factors* is about checking and managing possible reasons for poor oral intake – for example, factors like depression or other health conditions. *Encourage, don't force* is about finding ways to encourage oral intake which do not transgress into coercion – for example, providing appropriate physical assistance, but not force-feeding. *Use sensory stimulation* is about using means such as temperature, flavour, and physical touch to encourage oral intake – for example giving ice-cold drinks before a meal. *Remember the accessories* is about ensuring the resident has all necessary accessories in place for a mealtime – for example glasses, dentures or hearing aids. *Describe the meal* is about giving the resident verbal cues to orientate them to the meal, and help them anticipate it – for example, explaining the elements of the meal, and describing its smell and taste.

### *Respect*

Recommendations within this theme are intended to ensure the resident is treated with respect at mealtimes. There are three sub-themes. *Pay attention* is about focusing attention on the resident and not elsewhere – for example, giving appropriate eye contact during the meal and not talking 'over' the resident to others. *Maintain dignity* is about ensuring the resident's need for dignity is met – for example, protecting clothes with an apron as needed. *Respect choice* is about providing and facilitating choice at mealtimes, and respecting the resident's wishes – for example, allowing the resident to choose where they eat their meal.

### *Safety*

Recommendations within this theme are intended to keep the resident safe when eating and drinking. There are five sub-themes. *Alertness* is about making sure the resident only eats/drinks when sufficiently alert – for example, pausing the meal if the resident becomes sleepy. *Positioning* is about helping the resident sit in a good position to eat and drink safely – for example, ensuring they are as upright as possible. *Temperature* is about checking the temperature of food or drink is suitable, and safe – for example, taking into account the fact that some residents may have sensory impairment. *Bolus size* is about regulating the size of mouthfuls the resident takes, where necessary – for example, cutting up food into smaller mouthfuls if needed. *Pacing* is about moderating the rate at which the resident eats or drinks – for example, providing verbal prompts to slow down, for a resident who eats too quickly.

### *Atmosphere*

Recommendations within this theme are intended to create the right atmosphere at mealtimes. There are three sub-themes. *Keep calm* is about promoting a calm and relaxed atmosphere – for example, not communicating stress or agitation to the resident. *Allow enough time* is about taking an unhurried approach which affords the resident all the time they need when eating/drinking – for example, not rushing the resident on to the pudding if they are still finishing the main course. *Avoid distraction* is about minimising unhelpful distractions at mealtimes – for example turning the television off.

### *Social well-being*

Recommendations within this theme are intended to promote and capitalise on social interaction at mealtime. There are three sub-themes. *Connect with the resident* is about relating to the resident in a personal way at mealtimes – for example, sitting at the same level as them, and conversing with them during the meal. *Model eating and drinking* is about joining the resident to have a meal with them – for example, to model eating/drinking behaviour, as well as to socially interact with them in the process. *Facilitate resident interaction* is about enabling residents to successfully socially interact – for example, arranging the seating so that socially-compatible residents sit together at mealtimes.

### **3.4.4 Discussion**

This scoping review has identified nine guidelines documents that provide recommendations relevant to mealtime care for people with dementia living in care homes. A synthesis of the recommendations has generated six over-arching themes: *Independence*; *Oral intake*; *Respect*; *Safety*; *Atmosphere*; and *Social well-being*.

For the most part these are familiar themes in dementia care literature, so it is perhaps unsurprising to see them represented in these guidelines. The importance of maintaining independence in activities of daily living – and its impact on quality of life and well-being – is well-documented for this population (Chan et al., 2015; Harris, 2016). Adequate oral intake is clearly essential to life (R. A. Abbott et al., 2013), and for many people with dementia, meeting nutrition and hydration requirements is a significant challenge (Camina Martín et al., 2012; Natalwala et al., 2008). Respect is a central component of the ‘personhood’ theory of dementia care (Kitwood, 1997), and yet there remain questions about whether people with dementia receive the respect they deserve (Hammar et al., 2021).

Eating and drinking problems in people with dementia can have serious consequences for safety, leading for example to choking episodes and aspiration pneumonia (Kramarow et al., 2014; Sura et al., 2012). The value of a calm atmosphere at mealtimes has been previously highlighted (Hargreaves, 2008; K. H. Lee et al., 2017). Recent guidance on dementia care has emphasised the importance of social interaction and relationships (National Institute for Health and Social Care (NICE), 2018).

### **3.5 Comparing the reviews**

By comparing the findings of the systematic and scoping reviews, it is possible to explore the extent to which guidelines recommendations match up with what research evidence says about mealtime care. I have done this by adapting an approach previously used to integrate the findings of quantitative and qualitative syntheses (Kavanagh et al., 2012). This approach, known as a synthesis matrix, has been used here to juxtapose and compare the findings from my reviews – see Appendix K.

#### ***3.5.1 Similarities between the reviews***

##### **Social connection / Social well-being**

The synthesis of research evidence identifies the importance of carer-resident interactions that build relationship and social connection at mealtimes. This corresponds directly to the theme of *Social well-being* in the synthesis of guidelines. Within this theme, carers are recommended to connect with the resident, to model eating and drinking, and to facilitate interaction between residents.

##### **Empowering the resident / Respect, Independence**

Interactions which empower the resident by promoting autonomy and independence are highlighted in the synthesis of research evidence. This corresponds to two themes found in the synthesis of guidelines: *Respect*, and *Independence*. The first of these themes relates to autonomy, in the sense of the resident's ability to make their own decisions and exercise free will. The second theme relates to the resident's ability to eat and drink independently.

##### **Responding to food refusal / Oral intake**

The research evidence synthesis emphasises the value of interactions which carefully and skilfully address the challenge of food refusal. This corresponds to the theme of *Oral*

*intake* in guidelines synthesis. Within this theme there are practical suggestions of how to respond to food refusal.

### **3.5.2 Differences between the reviews**

#### **Tailored care**

Tailored care is a category in the synthesis of research evidence which does not have a direct match in the guidelines synthesis. This is surprising, since tailored care – or person-centred care – is widely considered to be integral to all aspects of dementia care (NICE, 2018). However, it is arguable that the notion of tailored care *is* actually integral to many of the themes in the guidelines synthesis, including *Respect* and *Independence*. This idea is developed and refined through the ethnography (chapter 5) and the co-development work (chapter 6).

#### **Safety**

Safety is a theme from the guidelines synthesis which has no equivalent in the synthesis of research evidence. One possible reason for this has to do with authorship. Adverse health outcomes such as choking and aspiration pneumonia are of particular interest to SLTs (RCSLT, n.d). Three of the guidelines have authors from this profession, but none of the research studies do.

#### **Atmosphere**

Atmosphere is another theme in the guidelines which does not directly correspond to the research evidence synthesis. Of note, there are some elements of this theme which may be towards the edge of (or even outside of) our definition of ‘mealtime care’ – remembering that it precludes activities outside of the direct control of care staff. For example, the theme includes the sub-theme *Allow enough time*; decisions about how much time to allocate to mealtimes are not necessarily within the gift of care assistants. Nevertheless, the other sub-themes – *Keep calm*, *Avoid distractions* – are more clearly in their remit. Although this overall theme does not have the same direct correspondence to the research evidence as seen in other cases, all of its sub-themes may in themselves have relevance for *Responding to food refusal*.

### **3.6 Dementia-specific learning**

Although the focus of the literature review (and this thesis) is people living with dementia, it should be acknowledged that some findings will have relevance to other care home residents who do not have this diagnosis. Indeed, it is important for anyone living in a care home to experience social well-being, to exercise autonomy and independence, to be treated as a unique individual, and to eat and drink well (Netten et al. 2012).

However, it can be argued that people with dementia are at particular risk of these needs not being met. For example, symptoms such as memory loss, difficulty in recalling names and events, apathy, communication problems and distressed behaviour negatively affect social interaction (Birt et al., 2020). Loss of autonomy is considered a core challenge for people living with dementia (de Waal, 2014). It is estimated that over 80% of people with dementia will have difficulty with eating and drinking (Anantapong et al., 2021).

Moreover, there are findings in the literature review with particular pertinence to dementia and dementia care. Because of deficits in cognitive domains such as attention, initiation, orientation, recognition, executive function and decision-making, people with dementia may experience different mealtime difficulties from other care home residents (Hansjee, 2022). Reduced awareness of the mealtime situation, poor visual recognition of food, disorientation, agitation and other cognitive symptoms can all adversely impact on intake of food and drink (Borders et al., 2020). The systematic review of research studies identified that carer-resident interactions at mealtimes are often about responding to residents with dementia who are eating less, or not at all. The scoping review of guidelines provided practical recommendations to address this, including addressing underlying factors, using sensory stimulation, compensating for visual difficulties, simplifying the table setting, and minimising distraction.

### **3.7 Update to reviews**

Because the literature review was the first of several workstreams to be undertaken in the course of this PhD research, the original searches for both the systematic review and the scoping review finished many months before the point of thesis submission (the searches finished in May 2020 and February 2019 respectively). For this reason, in July 2022 I conducted a rapid review to identify any relevant literature published after the original searches. To look for research studies, the search string *dementia AND mealtimes AND care* was entered into the PubMed search engine, with the search date being June 2020 to

present day. This retrieved 20 articles, which after title-abstract screen and full-text screen was honed to 3 eligible articles, summarised as follows. Douglas et al. (2021) used focus groups to investigate individual and interpersonal barriers and facilitators which care home assistants experience in providing mealtime care to residents with dementia. Several barriers and facilitators were reported, including their individual skills and personal characteristics, the training they received, and their relationships with residents, family members, and other health care professionals. Villar et al. (2022) explored the perception of common and best practices for dealing with resistance to eating of persons with dementia living in long-term care facilities. Participants were presented with a vignette in which a person with dementia showed resistance to eating, and were asked how a situation like that is managed - and how it should be managed. They found no obvious commonality in responses, and reported that less than half of participants considered person-centred strategies as best practice. In another qualitative study, Liu et al. (2020) identified barriers and facilitators at resident, caregiver, environmental (facility), and policy levels in optimizing mealtime care. At caregiver level, barriers included lack of preparation and training, competing work demands, time pressure and frustration; facilitators included strategies such as providing finger foods, verbal cues and prompts, and asking for preferences.

### **3.8 Conclusion**

In this chapter, I have synthesised evidence from diverse sources to identify important themes in the literature on mealtime care for residents with dementia. Focusing on carer-resident interactions, I have reviewed findings from peer-reviewed research, and recommendations from published guidelines. This has provided useful knowledge about good mealtime care expressed through interactions between carer and resident. However, I was keen to augment this knowledge by seeing at first-hand how mealtime care is implemented in the complex setting of the care home. In order to develop a relevant staff-training intervention, it was important for me to understand the challenges of enacting mealtime care in practice, and to explore how staff may overcome those challenges. To this end, I conducted the ethnographic study described in chapters 4 to 6. Next, in the first of those chapters, I set out the methodology and methods used in that study.

## **Chapter 4. Methodology and methods for ethnographic study**

### **4.1 Introduction**

This chapter provides a detailed description of the methodology and methods used in my ethnographic study. First, I elaborate on the philosophical and methodological perspectives underpinning this study. I go on to outline in depth the research methods employed. Finally, I explain my approach to ensuring trustworthiness in the study design.

### **4.2 Philosophical and methodological approach**

The aim of this study was to explore current practice in mealtime care for people with dementia who live in care homes, to identify good practice, and to understand the factors which may influence mealtime care. This aim has informed my philosophical approach, and in turn my decision-making about methodology and methods.

The ontology underpinning this work is subtle realism. I want to obtain useful knowledge about mealtime care, and I contend that it is possible for me to do so, even if I do not have direct access to the reality of mealtime care (Hammersley, 1992). In regards to how this knowledge is generated: I take a constructivist stance, which assumes that people – including researchers – construct the realities in which they participate (Charmaz, 2006). This is consistent with subtle realism; it is possible to believe that concepts are constructed rather than discovered, yet maintain that they correspond to something real in the world (Andrews, 2012, p. 40).

The literature review reported in chapter two provided me with some of this knowledge. In the study described in this chapter, I sought to add to this by understanding better “the complex world of lived experience from the point of view of those who live it” (Schwandt, 1994, p. 118). This meant seeing participants’ experiences as they see them, and understanding the meanings that are experienced by participants in that context (Jeon, 2004). (By participants, I mean care home residents, staff, and all others involved in care home mealtimes.) For this reason, I used symbolic interactionism as a theoretical perspective in this study. A term first coined by Herbert Blumer in the 1930s, symbolic interactionism is a sociological theory which emphasises the importance of ‘meaning’ in understanding human behaviour, interactions and social processes. The theory’s three tenets are that people act towards things on the basis of their meanings, those meanings derive from social interaction with others, and those meanings are modified through an



interpretive process used by the person in dealing with the things they encounter (Blumer, 1969). To apply this theory to the context of mealtime care: the actions of carers are based on the meanings they attribute to them, those meanings are derived from carers' social interaction with others (including, but not limited to, residents and colleagues), and those meanings are modified through carers' interpretation of the things they encounter in providing mealtime care.

Blumer describes research as “lifting the veils that obscure or hide what is going on”, and goes on to say that “the veils are lifted by getting close to the area and by digging deep into it through careful study” (1969, p. 39). My aim in this study was to lift the veils around mealtime care, by studying it carefully to understand the meanings experienced by those people who are involved, and ultimately to generate theoretical insights into mealtime care for people with dementia living in care homes. With this in mind, I used Constructivist Grounded Theory to inform my approach to data collection and analysis, and to theory-building.

Grounded Theory has evolved in various ways since it was first developed by Barney Glaser and Anselm Strauss in the 1960s (Glaser & Strauss, 1967). Of note, Constructivist Grounded Theory (CGT) has become popular in recent years (Charmaz, 2006). CGT assumes that researchers construct categories of the data, rather than the theory emerging from the data. Taking this standpoint, meaning is created through an interaction of the interpreter (the researcher) and the interpreted (the phenomenon to be observed) (Crotty, 1998). Thus, the phenomenon is not approached as a blank canvas. Instead, theory is constructed through the researcher's past and present involvements and interactions with people, perspectives, and research (Charmaz, 2006).

This is an appropriate perspective here, not least because I came to this study with many years' clinical experience as an SLT. My professional role has included working regularly in care homes, to provide assessment and management of mealtime difficulties for people with dementia. Thus, I brought knowledge and experience to this study which I cannot simply discard or ignore. Indeed, it is this knowledge and experience which has motivated my research interests in the first place. As described by Holton (2009, p. 38), “when the practitioner turns researcher, he/she carries into the field his/her own espoused values and accumulated experience”. I have taken a reflexive approach, scrutinising my research

decisions and interpretations so that they are transparent and accountable. (I expand on this at the end of the chapter, in the section 4.8.)

I chose ethnography as the method for this study. Symbolic interactionism, constructivist grounded theory and ethnography are complementary. A symbolic interactionist approach requires the researcher to actively engage in the world they are studying. Through the researcher's interaction with and immersion in this world, theory is constructed.

Ethnography is well-suited to this task, since “more than any other research method, [it] allows entering the lifeworld of others and observing how they make sense of the world around them” (Timmermans & Tavory, 2012, p. 497). In this way, the researcher is able to explore the culture, perspectives and practices in a particular setting, and can – for example – generate rich and detailed accounts of care workers' interactions and approaches to delivering care (S. Reeves et al., 2008). In my case, by immersing myself into the real-world context of care homes, I aimed to discover and make sense of the complexities of mealtimes in that setting (Jones & Smith, 2017), and to identify what matters most to people (O’Cathain, Croot, Duncan, et al., 2019).

Engaging with participants and the setting is a fundamental part of this process. Indeed, in conducting the ethnography I sought not simply to engage with participants, but to become a participant (of sorts). To this end, I adopted an approach called *moderate participant observation* (Spradley, 1980). This entails that the researcher be present and identifiable, interacting to some extent with the people they are observing. This type of participant observation allows the researcher to obtain a high level of involvement while maintaining a level of detachment (DeWalt & DeWalt, 2011). It differs from *non-participation* or *passive participation*, where there would be no interaction with those being observed, and from *active participation* or *complete participation*, where the researcher engages in almost everything that those being observed are doing, to the point of becoming a member of the group.

### **4.3 Ethical approval**

I gained ethical approval for this study from the Social Care Research Ethics Committee (reference 19/IEC08/0020) in June 2019 (see Appendix L).

#### **4.4 Sampling and contacting care homes**

To select care homes for the study, I used purposive sampling. This approach to sampling allows the identification and selection of information-rich cases for the most effective use of limited resources (Patton, 2002). I employed a type of purposive sampling called ‘maximum variation’, in order to explore diverse variations that have emerged in adapting to different conditions, and to identify important common patterns that cut across variation (Palinkas et al., 2015). My intention was investigate mealtime care in care home settings that differed in certain respects, to see if those differences had any impact on care.

In particular, my plan was to have variety in size (number of beds) and ownership (national/regional/local). I obtained a list of all care homes in Newcastle upon Tyne, by reference to the Care Quality Commission (CQC) website. I removed from the list any home not registered to provide dementia care – since the focus of the study was mealtime care for residents with dementia. I then removed any home with a CQC rating of “Requires improvement” or below – since an objective of the study was to identify good mealtime care. I separated the remaining homes into a list of large homes (which I defined as homes having 50 or more beds), and a list of small homes (fewer than 50 beds). I ordered these lists so that, when juxtaposed, each pair of homes differed in at least one other characteristic (in addition to number of beds). For example, one pair comprised a home from a small, local company (which at time of selection owned two care homes), and a home from a large, national chain (which at time of selection owned more than 300 care homes).

I wrote to the managers of the top pair of care homes, outlining the study, inviting them to participate and explaining the risks, burdens and benefits of participation (see Appendix M). After approximately one week, I followed up by telephone, and arranged one-to-one meetings with both managers. At these meetings I discussed the study in more detail, and answered any questions. Both managers gave verbal agreement in these meetings for their care homes to take part in the study. I subsequently requested from them – and received – written confirmation of this.

(Whilst I was collecting and analysing data from care homes one and two, I began the process of selection, orientation and recruitment for a third care home. I selected a home that was different from the others: it was in the middle range, both in bed-numbers and

ownership. It had approximately 60 beds, and belonged to a regional chain which owned 12 homes. I was able to build on previous experience, and gathered relatively quickly a number of consents from residents, staff and family carers. In March 2020 I was about to start data collection in that home, but at that point national restrictions were introduced due to the COVID-19 pandemic – which meant that non-essential visits to care homes were not permitted. I stayed in touch with the manager of care home three during this period (as I did with the other managers), and although I did not manage to collect data from care home three in the way I had expected, I was able to interview the manager by phone. This was helpful in the course of establishing theoretical saturation, which I describe in section 4.8.)

## **4.5 Recruitment and consent**

### ***4.5.1 Orientation period***

After receiving agreement from each care home manager that their home would take part in the study, I arranged to spend a period of orientation in each care home. The purpose of this was threefold. First, it allowed time for me to develop rapport and trust with staff, and to help residents become used to my presence. This fitted my underlying ethnographic approach, as I became present and identifiable in the setting. This was important not only to prevent staff and residents feeling any distress or discomfort about the study, but also to mitigate against the Hawthorne effect (a change in behaviour of research participants in observational studies) (Chiesa & Hobbs, 2008). Second, it gave space for me to adjust to my own transition from clinician to researcher (described by Lawlor (2003) as “gazing anew”). In other words, to become used to the idea that I was in the care home not as an SLT, but as an ethnographer. Third, it enabled me to obtain useful background information (for example about the physical layout of the home, the timings of meals, and approximate staff numbers). This was helpful later in making decisions about optimal times to be in a home, and optimal places to position myself within a room or on a unit. No research data was collected from any individuals during this time. Instead, I used the time to begin the process of obtaining consent. The orientation periods in each home lasted approximately twenty hours, and in each case was spread over approximately two weeks.

During this time, care home staff seemed in general happy to be approached and to engage in conversation with me – provided they were not too busy carrying out their daily

activities. I noted an apparent difference between the homes in this respect. In one home in particular (the home with fewest beds), staff were often immersed in direct-care activities, (such as assisting a resident with toileting, or transferring a resident from chair to walking frame). Thus in this home I needed to be mindful about when to attempt conversation with staff, so as not to distract or inconvenience them or the residents. By contrast, in another home (the home with most beds), staff seemed to have more time outside of care tasks – and therefore it was easier to find an appropriate moment to sit and chat to them.

In my initial conversations with them – in which I introduced myself and briefly outlined the purpose of the study – care home staff sometimes began talking about mealtime care almost straightaway, reflecting on practice and giving their opinions about it. This was not consciously solicited by me, but probably an understandable response from them when I explained the topic of my research. Much as these contributions were interesting (and promising), I felt the need to explain that I was not yet collecting data as consent had not been obtained, and effectively told staff to “hold that thought”. Staff were generally accepting of this, but it was a helpful indication to me that the orientation period had been effective, and the time had probably come to start recruitment.

#### ***4.5.2 Types of participant***

There were four types of participant in the study: care home residents; care home staff; family carers; visiting health and social care professionals. These participant-types were intended to encompass anyone who could have involvement in mealtimes. Care home residents were eligible if they had a diagnosis of dementia in their care records. All care home staff in the homes were eligible to participate. Eligible family carers were defined as family or friends who visited participating residents in the care home. (‘Family carer’ was used in participant information and consent documents as a generic term to describe these participants, but it was not necessary for them to have a carer role – formal or informal – to be eligible for the study). Any health and social care professionals visiting the care homes were eligible; it was anticipated this would include SLTs, dietitians, nurse specialists / community nurses, and General Practitioners (GPs).

### ***4.5.3 Obtaining consent***

#### **Care home residents**

The approach to identifying and consenting care home residents was developed in consultation with my Patient and Public Involvement (PPI) advisory group. During my initial visits, I explained the study in more detail to senior staff in the care home (the manager, deputy manager, registered nurse, and senior carers), so that they could identify eligible residents to recruit. I had initially expected that only managers and registered nurses would perform this activity. However, it quickly became clear from discussion with the managers that deputy managers and senior carers also had the requisite authority and insight for the task. This was in fact helpful, since these other staff often had more availability. It tended to be easier for me to develop a close working relationship with them, conducive to recruitment activity.

Residents with a dementia diagnosis were identified by senior staff, with reference to care records held within the home. I asked that staff exclude residents with a documented preference to be excluded from research studies, and residents they felt it would be inappropriate to approach (e.g. people at the end of life). This last exclusion criteria was intended to minimise risk of distress or inconvenience to these residents and/or their families.

Senior care home staff made the initial approach to eligible residents. I suggested a form of words to use, to help them verbally communicate key messages about the study succinctly and clearly. I also gave them a study summary sheet (see Appendix N) to show to the resident. This was an abbreviated version of the Participant Information Sheet (see Appendix O), containing brief, accessible information, developed in conjunction with my PPI advisory group. They asked the resident if they would be happy to meet me, to find out more about the study. The intention was that staff members would make this approach while I was out of sight, to prevent the resident from feeling undue pressure from me. In practice, this aspect of the protocol was not always rigorously applied. Rather, the staff's approach to recruitment activities varied between individuals, and tended to be pragmatic – which was to be expected, given this was an extra task added to an already busy workload. I endeavoured to strike a balance in this which upheld study protocols (designed to safeguard participants), without exhausting the goodwill of staff.

If a resident indicated they did not wish to meet me to find out more about the study, they were not included, and were not approached again. If, on the other hand, a resident agreed to meet me, I was informed of this, and then I approached them. I did this as soon as possible after their conversation with the senior staff member – often directly afterwards – so that it was fresh in their memory. I gave them a Participant Information Sheet, explained the study and their participation, using accessible, inclusive language, and offered to answer any questions. During the discussion, I assessed whether they had capacity to make a decision about consenting – by following the guidelines of the Mental Capacity Act (MCA) Code of Practice (2007). If I assessed that they had capacity, I asked them whether they would like to participate, offering them a period of time to consider their decision, if appropriate. Those who agreed to participate signed a consent form (see Appendix P). Where people had difficulty signing the form (due to impaired upper-limb mobility, or impaired writing skills), I asked a senior staff member to witness the participant giving verbal consent, and to record their own initials and signature on the consent form. I asked residents regularly during the study if they remained happy to participate, to check that this was still the case.

### **Care home residents without capacity**

Some care home residents were deemed to lack capacity to consent to the study, even with supports in place to aid understanding and communication. In some cases, this decision was made by senior care home staff, through informal assessment during their initial approach to the resident. In other cases, it was made by me, when having a more detailed discussion with the resident. That is to say, some residents were assessed by care home staff to have capacity, and agreed to meet with me, but then subsequently were assessed by me to lack capacity for the specific decision about consenting to participate. Sometimes, assessment of capacity was straightforward, particularly for those residents in the more advanced stages of dementia. But sometimes it was finely balanced. For example, one of the four principles of the MCA test of capacity is “the person must be able to hold the information in their mind long enough to use it to make an effective decision”. In practice, it was not always easy to discern whether the resident had demonstrated this capability, and the MCA Code of Practice (2007) is lacking here. On several occasions, a resident appeared to understand the main points as I took them through the Patient Information Sheet, and expressed that they were entirely happy to participate in the study. But when I asked them immediately afterwards to recall anything

about the topic of the study, they were unable to. If I had any doubts about a resident's capabilities against the principles of the capacity test, I assessed them as lacking capacity to consent.

For residents lacking capacity, I asked senior care home staff to identify a suitable personal consultee. A personal consultee is defined as someone who knows the resident well, who either cares for them or is interested in their wellbeing, and who is willing to be asked their opinion of the person's view and feelings about being involved in the project (Goodman et al., 2011). If such a person could be identified, I asked staff to contact potential consultees (either by post, or in person if they visited the home), and to provide them with a resident Participant Information Sheet and a covering letter explaining the personal consultee role. If the identified personal consultee was happy to meet with me to discuss further, a meeting was arranged where I explained the study and they decided whether or not to agree to the resident's participation.

I did have provision in my protocol to use nominated consultees, where personal consultees could not be identified. A nominated consultee is someone who has no connection with the research project, and who is willing to be consulted about the participation in the project of a person who lacks capacity (Shepherd et al., 2019). However, in most cases, the problem was not that a personal consultee could not be identified – it was that they were not contacted by the care home, or did not respond to contact. In this eventuality, the resident was excluded from the study.

It is acknowledged that there were various 'gatekeepers', operating at different levels, in this process of recruiting care home residents to the study (C. L. Reeves, 2010). Care home managers determined whether I would gain access to the research sites in the first place. Senior care home staff identified, and made an initial approach to, residents. Administrative care home staff contacted potential consultees. It was important to build a constructive working relationship with each of these gatekeepers, in order to make progress with recruitment (Crowhurst, 2013).

### **Care home staff**

After the orientation period, and having had the chance to develop some early rapport with residents and staff, I began to seek out appropriate opportunities to recruit care home staff. This process played out quite differently from care home to care home.



In Care Home 1, I was given permission by the manager to attend the daily staff meetings, where I outlined the purpose and nature of the study, and circulated Participant Information Sheets. I followed this up by approaching individual staff members – when they were not too busy – to discuss the study further, invite questions, and ask for their consent. My over-riding concern here was to avoid coercing staff in any way. I stressed that their participation was entirely voluntary, and offered them as much time as they needed to think it over. I was careful not to rush the consent process, in order to build a level of trust with staff which was important in the ethnographic data collection which followed. Some signed-up straightaway; others took time to consider it and subsequently signed-up. Very few directly declined consent – instead, several staff said they were too busy to talk to me, or they had not had time to read the information, or they were still thinking about it.

In Care Home 2, the manager was proactive in facilitating the recruitment process by bringing together groups of staff on each floor, so that I could talk to them together about the study. In doing this, the manager set an expectation that staff would take time to listen to me, and would consider participating in the study – without unduly influencing them. This was very helpful in giving credibility to me and the study. In addition, conducting the consent process in a group setting, rather than one-to-one, seemed to be beneficial. My observation was that some staff felt more confident to ask questions about the study in that setting, in a collaborative way with colleagues. It is possible also that some staff were more reassured to give their consent if they knew that a trusted colleague had given consent. In any event, staff recruitment proceeded more quickly in this home.

### **Family carers**

When designing the study protocol, I decided that if a resident was not a participant, their family carer(s) would not be eligible to participate. This was to avoid causing any distress or disrespect to non-participating residents. Thus, once a resident was recruited to the study, I asked care home staff to put me in contact with their family carer(s), to invite their participation. Staff were able to do this either by post or in person. I also put up posters in the home, with my photo, a brief description of the study, and contact details, so that visiting family carers could contact me directly. In addition, each home held regular family meetings, either monthly or quarterly, as a forum for communication with family carers. I attended at least one of these meetings in each home, describing the study and answering questions.

Just as with personal consultees, face-to-face contact between care home staff and family carer was the most common route of referral. Family carers were almost always willing to talk to me, were receptive to the study, and consented to participate.

### **Visiting health and social care professionals**

I wanted to recruit visiting health and social care professionals to the study, to obtain a broader perspective on mealtime care. Coming from a speech and language therapy background, I was aware that several different professions could have a role in, and insight into, the nutrition/hydration needs of residents with dementia – or their eating/drinking needs in a wider sense. These professions could include (but not be limited to) SLTs, dietitians, dementia nurse specialists, and GPs. I planned to recruit visiting health and social care professionals by approaching them during their visit, introducing myself, outlining the study and providing them with a Participant Information Sheet – then giving them sufficient time to decide whether or not to consent.

In the event, this type of participant proved to be the hardest to recruit. This was primarily because their visits were infrequent. With all other participants, there was opportunity to recruit in a gradual, unhurried way – giving time for the potential participant to become familiar with me, to develop a sense of trust in me, and to consider their participation. With visiting professionals there was much less scope for this. In fact, in some homes I barely saw any visiting professionals at all – and if I did, their visit was usually very rapid, and it did not feel appropriate for me to delay them by approaching them about my study. The exception to this was one care home which received regular weekly visits from two healthcare professionals – a GP and a Community Nurse – who came on the same morning each week, working together to see any patients who needed attention. In this context, it was relatively easy for me to introduce myself and the study, and to seek and obtain their consent to participate.

### **Consenting to observations or interviews**

When recruiting care home staff, family carers, and visiting health and social care professionals, I gave them opportunity to consent to participation in observations, semi-structured interviews, or both. I decided not to include residents in semi-structured interviews, and opted instead to use the more informal context of mealtime conversations to elicit their views and ideas. Informal conversation with residents with dementia can be

tailored to cognitive ability, and avoids privileging those residents able to participate in long conversation (Bamford & Bruce, 2000).

## **4.6 Data collection**

### **4.6.1 Observations**

Observations were an important element of the ethnography, permitting me to study participants in their own environment in order to understand things from their perspective (Baker, 2006). I began to carry out observations when I had recruited enough participants so that at any given mealtime there would be at least two participating residents, and at least two participating staff. This was to prevent participants from feeling they were being closely scrutinised – my priority in data collection was the comfort and dignity of participants (Schuster, 1996). It also allowed me to observe a greater number and variety of interactions during the mealtime. I continued to recruit when data collection was ongoing, but the rate of recruitment was highest in the first few weeks of the study, and decreased over time.

In the early stages of data collection, I visited Care Home 1 only. I visited the home several times a week for several weeks, carrying out observations at each visit. I did this partly so that participants could quickly become used to my presence and behave as naturally as possible during my visits. I also did it so that I could quickly become used to the home, and its occupants; so that it was easier for me to recall what I had seen, and make sense of it – without being confused or distracted by another home. Once I had a clear and established understanding of Care Home 1 and its participants – formed by multiple hours of observations and conversations – I moved onto Care Home 2, to undertake the same process there. I then felt confident to return to Care Home 1, in order to conduct further observations. In each case, new observations were informed by what I had seen so far; this iterative method highlighted areas for me to probe in more detail.

I spent time in every unit within both homes, which included residential units, nursing units, units for residents with advanced dementia (sometimes known as EMI units), and units for residents with early onset dementia. I observed residents eating/drinking at all times of the day, including at breakfast, lunch and tea – and snacks in between meals. I was occasionally present for residents' birthday celebrations. I visited on different days of the week, including at weekends. I observed meals in different rooms, including dining rooms, lounge areas and bedrooms, but only if this was acceptable to the resident.

The observations focused on interactions between participating residents and staff. On occasion, participating family carers were also present, and sometimes directly involved in the mealtime care – interacting with or in some way supporting one or more of the residents. When that happened, they were part of the observations too. I also intended to include visiting health and social care professionals in the observations – but in the event, those participants were not present at mealtimes (perhaps in part due to a ‘protected mealtimes’ ethos, although for some professionals – such as SLTs – mealtime would be the most appropriate time to visit).

Inevitably there were people present during some observations who had not been recruited to the study, and therefore were not participants.

### **Informal conversations**

Observations often included informal conversation with participating residents, staff members, or family carers, and as such, these conversations were an integral part of the ethnography. Sometimes I sat next to residents during a mealtime; I was guided in this by staff, and the residents themselves. Some residents were very hospitable towards me, and enthusiastically invited me to sit next to them. On other occasions, it felt more appropriate to sit quietly at a distance, perhaps in the corner of the room. When it felt appropriate, I engaged in conversation with participants – either during the meal, or afterwards. This allowed me to gather more information and ask about some of the things I observed.

After an observation finished, I quickly wrote field-notes, either directly onto my password-protected laptop, or in a notepad (and later typed-up on the laptop). I did this discretely, typically out-of-sight of residents, in case this would have caused distress to any residents who may have been unsure who I was and why I was writing notes. Sometimes, if it was not possible to write in situ, I wrote the field-notes elsewhere (typically at my university desk), as soon as possible after the observation. Field-notes were stored in Word documents on a secure network drive. For an example of a field-note, see Appendix Q.

#### ***4.6.2 Semi-structured interviews***

Semi-structured interviews are an appropriate method to reveal information about under-researched topics, because they allow flexibility to investigate issues that had not been predicted (Fielding & Thomas, 2001). A widely-used method in qualitative research,

semi-structured interviews focus on specific themes but cover them in a conversational style (Raworth et al., 2012). I used semi-structured interviews to explore in detail participants' views on mealtime care, and in particular what helps and hinders people with dementia to have a good experience at mealtimes. I used topic guides in the interviews (see Appendix R), developed in consultation with my supervisory team and informed by relevant literature. These were slightly different depending on participant-type, but common topics included:

- What helps residents with dementia have positive experience at mealtimes?
- What gets in the way of residents having a positive experience at mealtimes?
- What would you change about mealtimes?
- What kind of training would be useful?
- What would be a helpful way to deliver the training?

I used the topic guides to steer discussion in interviews, rather than to strictly prescribe it (Ritchie et al., 2013). During each interview, I noted down salient points to allow me to probe issues in more depth within the interview, as appropriate

I began the interviews once the observations phase of data collection was already well underway. This meant participants were for the most part quite familiar with me, and it was hoped that they would therefore be more forthcoming in interviews as a result. It also meant that I was able to tailor questions – within the broad parameters of the topic guide – to find out more about some of the things I had observed. Initially I used purposive sampling to explore the views and experiences of a broad range of participants (Patton, 2002). This meant I intentionally chose different participant types including care assistants, kitchen assistants, head chefs, senior carers, registered nurses, care home managers, and family carers. Later in the iterative process of data collection and analysis, I adopted theoretical sampling, as I sought pertinent data to elaborate and refine categories in my emerging theory (Charmaz, 2006). Interviews took place in a quiet, private area of the care home. Almost all interviews were one-to-one. The exceptions were two interviews where, for the convenience of the participants, I interviewed two family carers together as a pair (in one case, a husband and wife, and in the other case, a brother and sister). Interviews were audio-recorded, and then transcribed by a professional transcription service, using intelligent verbatim (a level of transcription in which elements are omitted if they add no meaning to the script – such as filler words).

All personal identifying information was removed from transcripts, and files were stored on a secure network drive.

I encountered some challenges in arranging the interviews. With family members, it was a straightforward process – by and large, they were in control of their time, and able to arrange a convenient day/time. With care home staff – and in particular, care assistants – the situation was quite different. Even if they were very willing to be interviewed, they were less able to allocate time for the interview. If at all possible, I wished to avoid interviewing them in their own time (for example, at the end of their shift) – although in some cases, staff readily volunteered to do this, and I accepted their kind offer.

Otherwise, I was reliant on their manager to make provision for them to be released from their duties for the duration of the interview. After some negotiation and false-starts, I reached a situation in both care homes where I was able to conduct interviews at relatively quiet times in the working day, returning to the homes at the same times each day to conduct multiple interviews.

Even with this arrangement, I felt a certain awareness of the ‘ticking clock’ during staff interviews. At no point did any staff member or their manager express that an interview was taking too long, but nevertheless I was mindful it was happening in work time.

Consequently, I may have rushed some interviews, or even cut some short. In general, though, I felt able to interview participants thoroughly and in depth, developing in my interviewing skills over time.

#### **4.7 Data analysis**

Data analysis was iterative, and used the constant comparative method (Glaser & Strauss, 1967). This means I did not wait until all data were collected before beginning analysis. Rather, during the data collection phase – periodically after observations and interviews – I stepped back from data collection to review the information gathered so far, to explore the data, to look for early patterns, themes and connections, and to refine the data collection process accordingly. This process was informed by interaction with my own worldview and standpoints (Charmaz, 2006), and to some extent by my knowledge of relevant literature.

To give an example: I became interested in the idea of social interaction early on in the study. I noticed the way staff interacted with residents, and with each other, in mealtime observations. I frequently observed a degree of informality in these interactions. I noticed

that the nature of social interactions was sometimes different on different floors/units, with verbal jokes and “banter” being more prevalent in some circumstances, and tactile affection being more prevalent in others. I noticed that staff sometimes – though not always – sat and ate with residents. I also observed the social dynamics at play among groups of residents, and the impact of this on mealtimes. I saw many examples of positive social interaction between residents (such as friendship, and care for one another), as well as examples of negative social interaction (such as arguments, cliques, and territorial seating arrangements).

I explored these ideas in detail during interviews and informal conversations – with staff, family, and (where possible) with residents. I asked about the differences I had seen in interactions, to uncover reasons for this. I asked about staff eating with residents, to probe why I had seen an inconsistent approach to this. I asked about the social dynamics between residents – how this affects mealtimes, and how staff respond to this.

Now I will outline in detail the process I used to move from data to categories. My method here was informed by Charmaz’s description of Constructivist Grounded Theory (2006).

#### ***4.7.1 Coding the data***

After observations, I printed out my field-notes, read them and annotated them by hand, writing initial codes and focused codes in the margins. Following Charmaz (2006), for initial codes I endeavoured to “stick closely to the data” (p. 47), and to use actions words where possible. My focused codes were more selective, and conceptual – to explain larger segments of data. An example of coded data from observation field-notes is reproduced in Figure 4.1 below; initial codes are in blue font, focused codes in green.

Aversive behaviour	17	Jeff is eating a sandwich from a plate. Abruptly,	
	18	and before he has finished, he throws the plate	Resident throwing food onto floor;
Staff supporting residents;	19	onto the floor. StaffA12 picks it up and then	Staff providing same food resident has rejected;
Staff knowing the resident;	20	fetches another sandwich on another plate.	Staff advising colleague;
Staff communicating / working as a team;	21	StaffA10 says he might not want it and might want	Resident ready to move on to pudding;
	22	pudding instead. StaffA12 takes away the	
	23	sandwich and puts the bowl of ice-cream on the	? Food badly positioned
Importance of positioning food correctly;	24	small table in front of him. He ignores it. Shortly	
Staff facilitating independence	25	afterwards, StaffA10 goes over and moves the	Staff re-positioning food
	26	bowl closer to him, and verbally encourages him	
	27	to have some. He begins to feed himself steadily.	Resident eating independently
	28	Sometimes he gets distracted by his bib again and	Resident becoming distracted;
Staff communicating / working as a team;	29	begins to fiddle with it. StaffA10 asks StaffA12 to	Staff advising colleague;
Staff knowing the resident	30	get him a second pudding, as he often has two	Resident having two puddings
	31	puddings.	

**Figure 4.1: Example of coded data from observation field-notes**

I also wrote brief memos on the transcripts, and developed these into longer memos in separate documents. I used the same approach after interviews, with the additional initial step of listening back to the audio-recording and simultaneously reading the corresponding transcript – both to check for accuracy, and to familiarise myself with the data.

Next, I typed-up my annotations into tables in Microsoft Word documents – using a different document for each interview and observation. In doing so, I cross-referred to other annotated transcripts in an effort to produce consistent codes. At this stage I refined codes, added new codes, and deleted others. I juxtaposed or conflated the same or similar codes. I refined or expanded some memos, and added new ones. I marked codes by using a different colour font for each participant-type, and by appending a different superscript number for each participant.



### 4.7.2 Organising the codes

I copy-and-pasted all codes and memos into PowerPoint documents, using a different document for each participant-type (care assistants, family carers, kitchen staff, etc.). I clustered together similar codes, to begin (tentatively) to create categories. At this stage I again refined, conflated, added and discarded codes – by bringing them together into clusters I was able to see more clearly which codes were redundant, weak, or incomplete. I also changed the rank of some codes (either from initial code to focused code, or vice versa).

During this process I also moved codes around from page to page. Sometimes it was obvious straightaway that two codes belonged together, or apart; sometimes I needed to see other codes to have a better understanding of the relationships between them. While this was happening, I allowed codes to be in more than one category. An example of clustering together similar codes is reproduced in Figure 4.2 below.

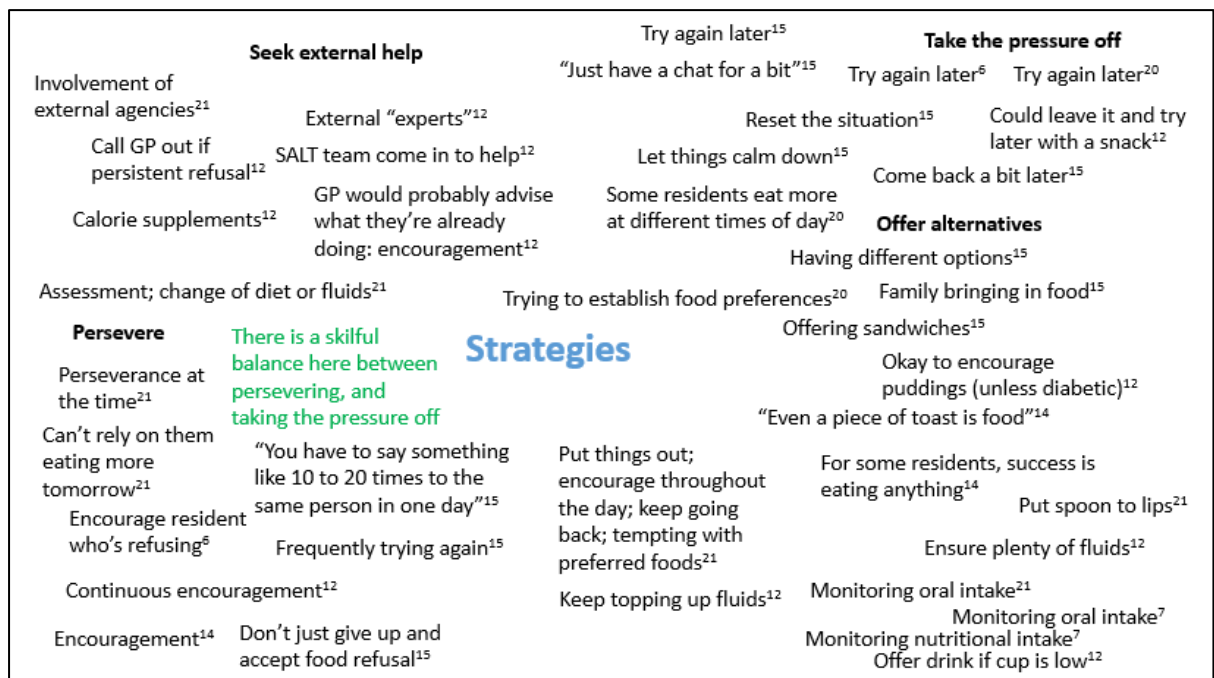


Figure 4.2: Example of clustering together similar codes

### 4.7.3 Developing categories and constructing theory

In doing this work, I was seeking to answer some broad research questions specified by the study:

- (i) What is good practice in mealtime care for people with dementia living in care homes?
- (ii) What are the factors influencing mealtime care for people with dementia living in care homes?

Thus, I used these questions as a framework to help with organising the codes. I moved aside data which did not pertain directly to these questions – for example, data about a resident’s early life. This kind of data was interesting in itself, but not relevant here.

Up to this point I had kept apart codes from different participant-types. Now, I brought them together to develop conceptual categories. I printed off all the PowerPoint slides and looked at the codes, memos and tentative categories as a whole. I used large sheets of flip-chart paper to sketch out connections between codes and categories, making decisions about which of these fitted together, and which were sufficiently strong and coherent to stand alone. I developed sub-categories under each category. I transferred the resulting diagrams back to PowerPoint, to facilitate the writing-up process.

I wrote textual descriptions of categories and sub-categories, expanding on existing memos and adding new ones. I chose data extracts to illustrate categories and sub-categories, and created PowerPoint slides to document this.

In the course of these successive levels of analysis, categories became more theoretical, providing a “conceptual handle” on the studied experience (Charmaz, 2006, p. 3). I gathered additional data to check and refine emerging categories – a process I describe within section 4.8 below.

#### **4.8 Trustworthiness of research**

There is a long-standing debate about how best to assess the “quality” of qualitative research – and, indeed, whether it is even possible to do so (see, for example, Altheide and Johnson (1998), Johnson et al. (2020), Sandelowski (1986), and Smith (1984). As I have already outlined, my ontological perspective for this study is subtle realism, and I take the view that a judgement can be made on the trustworthiness of qualitative research. In particular, I have sought to follow the work of Hammersley (1990), who proposed that research should be judged on its validity and its relevance.

In keeping with subtle realism, validity is not about research being true beyond all doubt; rather, it is about research standing up to scrutiny so that we can be confident about it

(Hammersley, 1990). To this end, I regularly discussed the data with my supervisory team, to explain my thinking in respect of codes and categories. I did the same in meetings with my PPI advisory group, and with our Institute's qualitative data group. These discussions were invaluable in providing opportunity for me to develop, refine and test the analysis. During the period of data collection, I wrote reflexive notes (Davies et al., 2004; Watt, 2015) in order to maintain perspective and minimise professional bias from my perspective as an SLT. I was conscious of bringing various perceptions and experiences from my clinical work which had potential to shape the way I conducted and thought about the research. For example, my clinical role has previously involved observing care home mealtimes – but in a different way (looking only at one resident on each visit), and with a different focus (considering specifically the safety of swallowing). In transitioning from clinician to researcher, I was careful to acknowledge and reflect on previous experiences. Finally, in writing this chapter I have articulated the research process in detail (including consent, data collection and data analysis). This in itself makes a contribution towards the validity of the research, creating a record which can stand independently of the observer, so it is public and reproducible (Dingwall, 2020).

Whether or not research is relevant pertains to the extent to which its findings can be generalised beyond the setting in which they were generated (Patton, 2002). This is a vexed problem in qualitative research, but Hammersley (1992) and others (see, for example, Yin (2009)) suggested “theoretical inference” as one means of solving it. This is the idea that inferences from the research setting to other settings cannot be statistical, and instead must depend upon the adequacy of the theory on which they are based. But how do we determine whether a theory is adequate? In keeping with Constructivist Grounded Theory, I turn here to the notion of theoretical saturation.

#### ***4.8.1 Theoretical saturation***

In describing theoretical saturation, Charmaz writes “categories are saturated when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of your core theoretical categories” (2006, p. 113). This was my aim in data collection and analysis – to reach this point. Thus, I began to use theoretical sampling as I progressed further into the ethnography. Charmaz differentiates theoretical sampling from other types of sampling commonly used in research, such as sampling to reflect population distributions, and sampling until no new data emerge. When conducting

theoretical sampling, the researcher moves back and forth between data collection and data analysis, constructing preliminary ideas about the data, and then examining these ideas with further empirical enquiry. To illustrate this, Charmaz refers to ethnographic work by her colleague Jane Hood: “Codes became categories. Early categories were suggestive but not yet definitive. Further data collection strengthened them but Hood saw new gaps in her nascent analysis. She returned to the field and asked further questions – and kept writing and analysing” (Charmaz, 2006, p. 103).

I have adopted the same approach. I collected data through a series of observations, conversations and interviews. During this process, I noted tentative patterns and connections in the data which had the potential to develop into categories. I wrote memos and reflections. I shared and discussed ideas with supervisors and other colleagues. All of this informed subsequent data collection: it provided a degree of focus for later observations, and allowed me to refine my questions in later interviews.

The COVID-19 pandemic interrupted this iterative process. Because of the national lockdown, I was unable to continue with data collection in the way I had planned. I could no longer visit care homes to do observations. In addition, in the early weeks of the pandemic (when care homes were particularly impacted), I took the view it would be inappropriate to arrange remote interviews with care home staff, family carers, or healthcare staff – because of the challenges they were facing. In retrospect, this interruption was helpful. It gave me more space and time to carefully consider whether I had reached data saturation in my study. I concluded that my categories were, in general, well-developed – with explicit properties, and clear relationships between categories. However, there were certain aspects which less well-specified, and would benefit from further exploration. On this basis, I decided to resume data collection in a particular way, which I outline below.

#### ***4.8.2 Refining categories with key participants***

I took an approach proposed by Albas and Albas (1988,1993), whereby categories are refined through conversation with key participants. These researchers, whose work focuses on education, asked students to read their analytic reports – to assess the validity of the conclusions from their points of view. This would sometimes cause the researchers to modify and recast their theorizing, based on the feedback received (Albas & Albas, 1988, p. 263). In my case, I conducted phone interviews with the managers of all three

care homes, including the home which had agreed to take part in the study, but in which I did not conduct observations because of the onset of lockdown regulations. (First, I took advice from colleagues and relevant authorities on the appropriateness of re-engaging care homes in research at this point in the pandemic – the consensus was that this was now appropriate. I also obtained approval for a protocol amendment to make remote consenting and data collection easier. I had not previously approached two of managers for interview consent, so obtained this from them now remotely). During the interviews, I presented my thematic categories, and asked participants to what extent the categories fitted their experience. I explored in particular those aspects and categories which I considered to be less well-developed. Interviews were audio-recorded and transcribed. The new data was used to refine categories and their properties. For most categories, the participants responded with straightforward agreement, indicating that the categories were consistent with their own experiences. For two categories, participants brought a degree of challenge to my findings, which led me to make small but meaningful refinements to the category properties.

#### ***4.8.3 Testing findings against extant literature and theory***

Finally, I located my theoretical categories within relevant literature. This enabled me to test and refine the findings (Dey, 2012; Dick, 2012). In the course of writing the ethnography, I referred to findings from my own literature review, as well pertinent ideas from related fields. I was necessarily reflective about the fact that I had carried out a literature review prior to beginning the ethnography. In doing so, my intention was that this would orientate me to current thinking in the field, but not serve as a defining framework for my research (Urquhart, 2007).

#### **4.9 Conclusion**

In this chapter, I have explained the philosophical and methodological approaches which inform the ethnography, and set out in detail the research methods – as well as my rationale for using them. In the following two chapters, I present the findings from the ethnography.

## **Chapter 5. Good mealtime care is person-centred**

### **5.1 Introduction**

In the next two chapters I present the findings from my ethnographic study, which took place in two care homes in northeast England. By interrogating data from observations and interviews, I critically examine mealtime care for residents with dementia. Firstly, in this chapter, I show how mealtime care attends to various priorities, how these priorities appear sometimes to be in tension with one another, and how a person-centred approach can help to resolve such tensions.

The ethnography was situated in the context of my existing knowledge and experience. Inevitably, I took with me into the study both the knowledge I had acquired from my literature review, and the experience I had gained from my own professional practice (as outlined in chapter 2). In the tradition of constructivist grounded theory, I attempted to hold on to these things lightly – acknowledging them (Charmaz, 2006), and allowing them to orientate me (Urquhart, 2007), but also aiming to keep my mind “sufficiently open so as to allow new, perhaps contradictory, findings to emerge from the raw data” (Dunne, 2011, p. 117).

Before presenting in detail the study findings, I will describe the care homes in which the study took place, and provide quantitative data about the study participants.

### **5.2 Study setting**

#### ***5.2.1 Care Home 1***

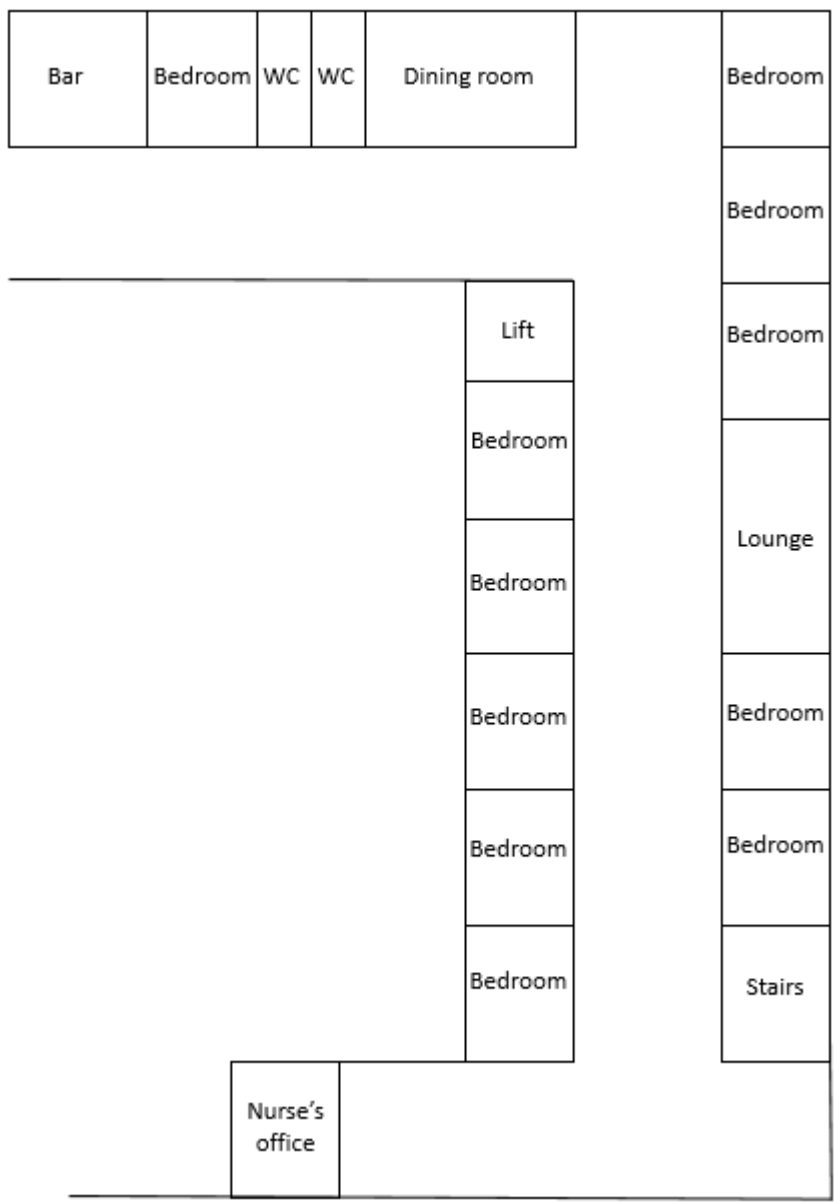
##### **Characteristics**

Care Home 1 was situated in a west-end suburb of a large city in the north of England. It had approximately 35 beds. This is slightly below the average number of beds in UK care homes, which was recently reported as 40 (Competition & Markets Authority, 2017). Almost all the beds were occupied; this compares with a national care home occupancy rate of approximately 88% at the time of data collection (a rate which subsequently dropped to approximately 80% during the COVID-19 pandemic) (Michas, 2020). Care Home 1 was part of a large, national chain of care homes, which at the time of my fieldwork comprised approximately 350 homes in total. The chain has a page on its website outlining its approach to mealtimes in general, without referring to residents

living with dementia in particular. Care Home 1 was registered to provide dementia care, and had a Care Quality Commission (CQC) rating of ‘Good’.

### **Layout**

There were three floors in this care home. Each floor housed residents with a different level of care needs. The ground floor was for residents categorised as ‘Residential’, and had approximately 15 beds. The first floor was for residents categorised as ‘Nursing’, and had approximately 12 beds. The second floor was for residents categorised as ‘EMI’, and had approximately 8 beds. (EMI stands for Elderly Mentally Infirm – somewhat old-fashioned terminology but the acronym remains in common use.) As well as bedrooms and bathrooms, each floor contained a dining room, a lounge, and administrative areas. The ground floor also had an activities lounge, and the first floor had an additional small lounge in the theme of a bar. Figure 5.1 provides a plan of one of the floors in this care home, by way of example.



**Figure 5.1: One of the floors in Care Home 1**

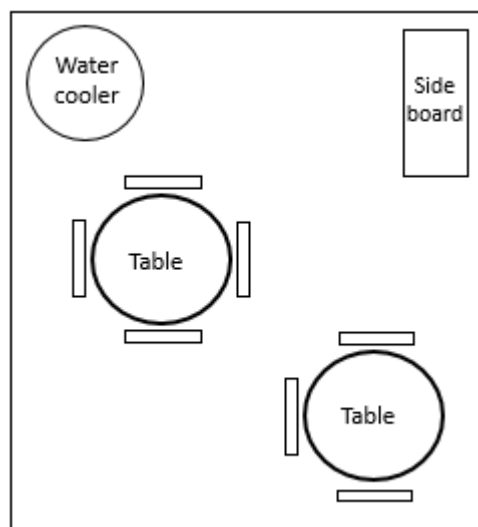
**Staffing**

Care Home 1 was staffed by a manager, deputy manager, a registered nurse, senior carers, care assistants, activities co-ordinator, head chef, kitchen staff, and domestic staff. Senior care staff / nursing staff were in general responsible for a particular floor. Some care assistants were based on predominantly on one floor; others tended to rotate, working shifts on different floors as required. Kitchen staff, including the head chef, also acted as care assistants on various floors as the need arose – particularly at lunchtime.



## Mealtimes

Breakfast in Care Home 1 was at 8am, lunch at 12pm and tea at 4pm. Some residents ate in the dining room, some in their bedrooms, and some in the lounge. Food was delivered to each floor by kitchen staff using a heated trolley, and then plated-up and served by care staff. Dining rooms were small. The ground floor dining room had room for three tables, with seating for approximately nine residents. The first-floor dining room had four tables and seating for approximately twelve residents. The second-floor dining room was the smallest, with room for only two tables and seating for approximately six residents. In each case, space was tight, with tables close together and circulation room at a premium. As an illustration, Figure 5.2 shows the layout of one of the dining rooms.



**Figure 5.2: A dining room in Care Home 1**

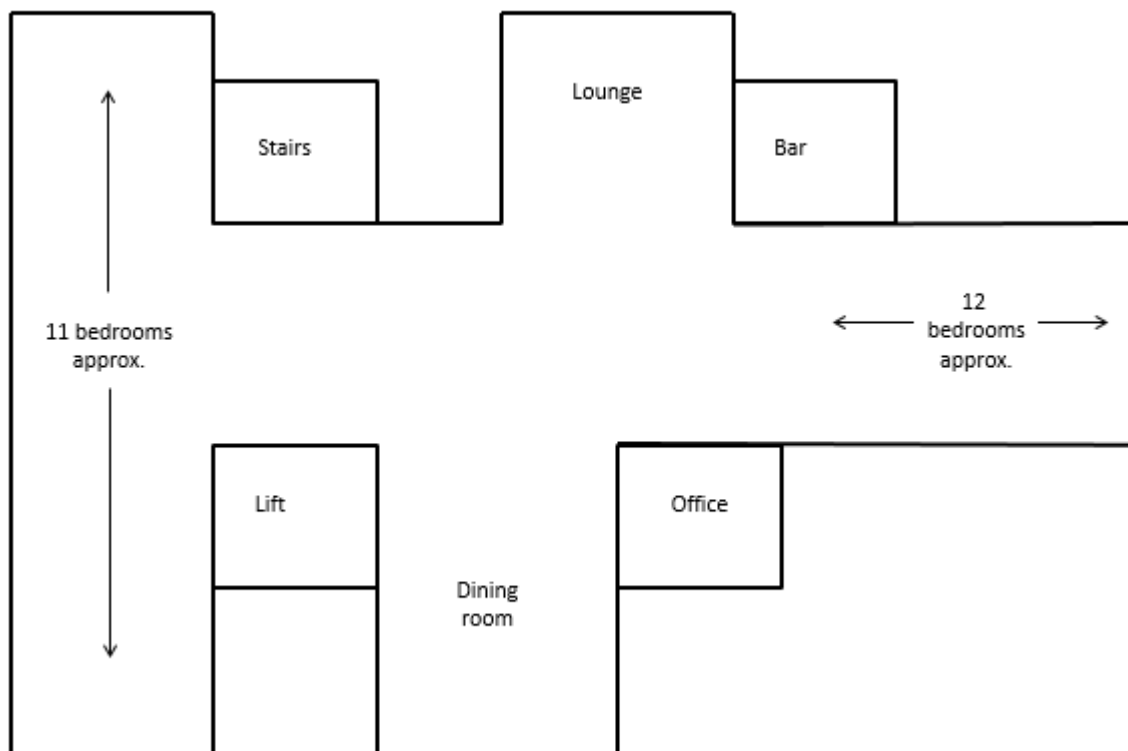
### *5.2.2 Care Home 2*

Care Home 2 was situated in an east-end suburb of a large city in northeast England. It had approximately 95 beds, almost all of which were occupied. It was therefore significantly bigger than the UK average. It was part of a small, local group of care homes, which at the time of my fieldwork comprised two care homes in total. It was registered to provide dementia care, and had a Care Quality Commission (CQC) rating of 'Good'.

### **Layout**

There were two wings in this care home. These were connected by an atrium which contained the welcome desk, manager's office, and administrative office. Each wing had

two floors, and each floor housed a different unit. Thus there were four units in total, each one intended for a different category of resident: Residential, Early onset dementia, Nursing, and EMI. Each unit was home to between 20 and 25 residents, and also included a dining room and at least one lounge. Some of the lounges were themed, for example to resemble an old-fashioned sitting room, or a pub. The floor plan of one of the units in this home is shown in Figure 5.3.



**Figure 5.3: One of the floors in Care Home 2**

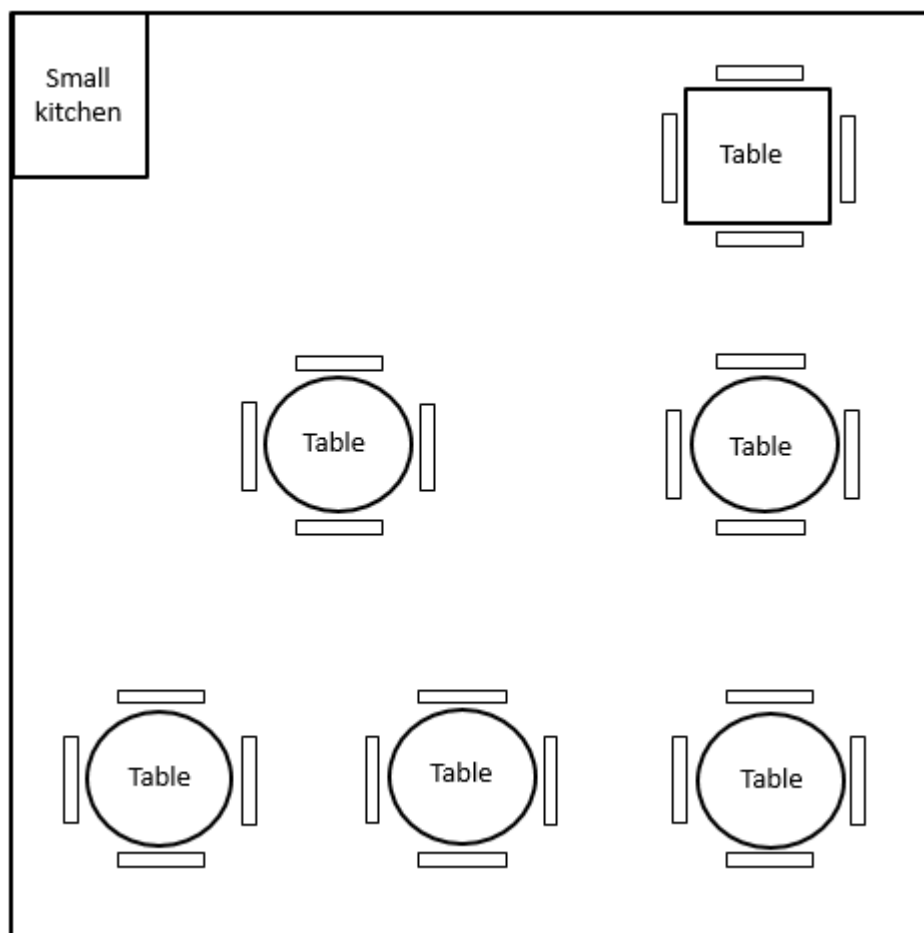
### **Staffing**

Care Home 2 was staffed by a manager, team leader, three registered nurses, senior carers, care assistants, head chef, kitchen staff, and domestic staff. Like Care Home 1, senior carers or nurses tended to be based on specific units, while many (but not all) care assistants spent time on various units. Unlike Care Home 1, kitchen staff did not take on any resident care duties at mealtimes (or other times).

### **Mealtimes**

Main meals in Care Home 2 were served at 9am, 1pm and 4:30pm. Residents typically ate in the dining room, or in some cases in their bedrooms. Sometimes, a small number of residents ate in the lounge. Food delivery worked in the same way as Care Home 1, with

heated trolleys taken onto each unit by kitchen staff, containing food to be plated-up and served by care staff. In contrast to Care Home 1, the dining rooms were relatively large and spacious. They each contained at least five tables, with seating for approximately 20 residents, and a good amount of space to allow staff (and residents) to move in between tables comfortably. The sense of space was heightened by the fact that, on most units, the dining room and lounge were adjoining, with no dividing wall (these walls having been removed some years ago in a refurbishment). In Figure 5.4 there is a schematic of one of the dining rooms. In common with other dining rooms in the home, it featured a small kitchen in one corner which served primarily as a beverage bay for staff to prepare hot drinks for their breaks. This was not intended for use by residents, and nor was there any kitchen facility for residents' use in Care Home 1.



**Figure 5.4: A dining room in Care Home 2**

### **5.2.3 Participants**

A total of 87 people were recruited to participate in observations in Care Home 1 (30) and Care Home 2 (57). Across the two homes, these people comprised 27 residents, 51

members of care home staff, 7 family carers and 2 visiting health and social care professionals. There were 13 hours of observations in Care Home 1, and 15 hours in Care Home 2. These observations were spread across a time-period of four months, and took place at different times and different days of the week.

In total, 25 people took part in interviews: 11 in Care Home 1; 14 in Care Home 2. (Thus, there were slightly more hours of observations, and more interviews conducted, in Care Home 2.) Across the two homes, those taking part in interviews were 17 members of care home staff, 6 family carers, and 2 visiting health and social care professionals. A more detailed breakdown of interview participants is provided in Table 5.1.

<b>Participant type</b>	<b>Number</b>	
	<i>Care Home 1</i>	<i>Care Home 2</i>
<i>Care home staff</i>		
Care assistants	3	5
Senior carers / Nursing staff		3
Management staff		2
Kitchen staff	1	3
<i>Family carers</i>	5	1
<i>Visiting health and social care professionals</i>	2	

**Table 5.1: Interview participant types**

12 people from Care Home 1 declined to take part in the study, as did 7 people Care Home 2.

Having provided demographic data on the study participants, in the remainder of this chapter, and in chapter 6, I present the findings from the ethnographic study. These findings are organised into the following sections: priorities in mealtime care, tensions in mealtime care, the symbolic nature of mealtime care, the importance of a person-centred approach, contextual constraints on mealtime care, and teamwork in mealtime care. (In order to preserve anonymity of participants, whilst at the same time presenting data in a meaningful way, the following naming convention is used for the data: pseudonyms are used for residents, and descriptive alphanumeric labels are used for other participants (denoting broad participant type, care home, and number of participant). For example: StaffA10 stands for the tenth member of staff to be recruited in Care Home 1.)

### 5.3 Priorities in mealtime care

I knew from the literature review that good mealtime care could be characterised by its effect on the resident. Thus, I had found in the research literature that good mealtime care may lead to the resident experiencing empowerment, independence, social connection, and adequate nutrition and hydration. These were identified as priorities in mealtime care. Through the ethnography – by observing mealtimes in the care homes, and talking to residents, health and care staff, and family – I saw these priorities acknowledged and enacted in practice too.

Firstly: I noted that good mealtime care was associated with residents having choices – and being empowered to execute them. Residents (like everyone) had preferences and opinions about various aspects of eating and drinking. In a care home setting, multiple people living in the same place meant that multiple options were needed. A member of kitchen staff in Care Home 1 emphasised the variety available on their menu:

*“Breakfast here is everything from – you know, they get boiled eggs, porridge, there’s a cooked option, cereals, juices so there’s quite a lot going on. Literally as soon as I’ve finished that I’m straight on to preparing for dinner. Obviously we’ve got to give them options all the time, so you’re talking two full dinners, two desserts, even two options on potato, two options on veg.”*

[Interview\_StaffA14\_Home1\_10/03/20]

Varied menus was one way of providing choice, however it became clear that choice at mealtimes was about more than just food and drink. Residents had preferences about other things – such as when to eat. Both care homes operated set mealtimes, and most residents ate at these times – but I learned from care staff that there was flexibility in this:

*“If someone’s just not in the mood, sometimes it is a case of just moving things later. For example, in the home we do lunchtimes and they’re generally about – I can’t remember how long the period is, I think it’s maybe an hour, hour and a half. Maybe a bit longer. But the idea is kind of – rather than going, ‘This is mealtime,’ it’s sort of having a large period in which someone can have a meal.”*

[Interview\_StaffA6\_Home1\_10/12/19]

*As lunchtime draws to a close, I talk to StaffB17 about a resident – Hannah – who did not come for lunch today. StaffB17 explains that she tends to have a lie-in and a late breakfast, so she’s often not ready to eat again when lunch is served. “We knocked for her but she didn’t want any – we’ll save her some.”*

[Field-notes\_dining-room\_Home2\_lunchtime\_23/11/19]

Secondly: staff told me about the importance of independence; specifically, helping residents to eat and drink independently (or as independently as possible):

*“It’s also that soft approach, where you’re trying to assist but you’re trying to encourage. You know, like gentle encouragement – and also, if they’re also able, to try and help them to be independent. ... Because you know, although they can’t tell us, that, for them, is important, regardless of the Alzheimer’s or the dementia; some of these things of wanting to do for themselves is still there. So we’re not here to take it away from them just because they happen to come to a nursing home. We try to encourage it for as long as we can.”*

[Interview\_StaffA3\_Home1\_09/01/20]

I often saw this kind of encouragement of independence at mealtimes:

*StaffA10 is kneeling next to Gracie. She is sitting at the same level as Gracie, assisting her directly with a spoon. It’s a soft meal – pureed or well-cooked meat; mashed potato. StaffA10 is going at quite a fast pace but Gracie is coping with this. StaffA10 gently tries to encourage independence: “Come on [Gracie] you could be doing this yourself” She places the spoon in Gracie’s hand, and withdraws. Gracie seems uncertain about using the spoon, holding it the wrong way round. StaffA10 re-positions it in her hand, to be the right way, and withdraws again.*

[Field-notes\_lounge\_Home1\_lunchtime\_03/10/19]

Thirdly: I noticed an emphasis on the social aspects of eating and drinking. This care assistant believed that without social interaction, mealtimes were diminished:

*“Just imagine if you’re sitting at home and you’ve got your family all around the table but nobody speaks. Everybody’s just eating and nobody speaks. It’s just deadly silence. It’s a bit awkward isn’t it? And uncomfortable. It’s not nice – so we try to just put some effort into it really to make it pleasurable.*

[Interview\_StaffB33\_Home2\_05/12/19]

When I asked about their involvement in this, the carer’s response indicated they considered facilitating social well-being at mealtimes as integral to their role:

*“There’s two ladies upstairs and one is in her bedroom all the time but she’ll come out for her meals. She comes to the dining room and she gets on particularly well with this other resident. I’ll say, ‘Are you not going to go and sit with your friend?’ you know, and sort of prompt them to sit together and they get along like a house on fire. To me, that’s my job to do that. It’s alleviating loneliness, because that lady is in her room, on her own, all the time.”*

[Interview\_StaffB33\_Home2\_05/12/19]

I also saw many examples, such as in this extract, of staff instigating a sociable atmosphere during mealtimes:

*StaffA12 is working as a kitchen assistant today. From time-to-time he stands at the hatch, which is near to Daisy and Elsa's table. There are various jovial exchanges between StaffA12 and the two residents. Elsa lifts up her empty glass and waves it in his direction. He asks if she'd like a glass of whisky; she says "I would! That'll make me sit up straight!" (She does sit up straighter.) StaffA12 comes out of the kitchen: "She wouldn't refuse it you know!" He rubs her back and pours her a glass of juice. The mood is lightened, and Elsa eats a bit more of her dinner.*

[Field-notes\_dining-room\_Home1\_lunchtime\_09/10/19]

Fourthly: I found that promoting adequate nutrition and hydration was a priority in mealtime care:

*"You try your best to go around and make sure that people are eating or drinking. Really that's the importance of it. You know people will think 'Oh well she hasn't done very well but she might do more tomorrow', well, depending on who's on, that person might have the same day as they had that day, and before you know it they might have had a full week of it, where they haven't done well simply because there hasn't been that little bit of extra care in making sure. I know that sounds probably not important, but it is important."*

[Interview\_StaffA3\_Home1\_09/01/20]

In the same home, I observed staff persevering to encourage residents to eat and drink:

*StaffA2 sits opposite Frida, and begins to directly assist her to eat her pudding (mousse). Frida is poorly positioned in an easy chair, leaning to one side. StaffA2 tries to reposition her, and manages to assist her into a more upright position. As she offers her the spoonfuls of pudding, StaffA2 is gentle but persistent. She calmly asks Frida to open her mouth; if Frida resists, she says "Frida do you not want it?" and tries again.*

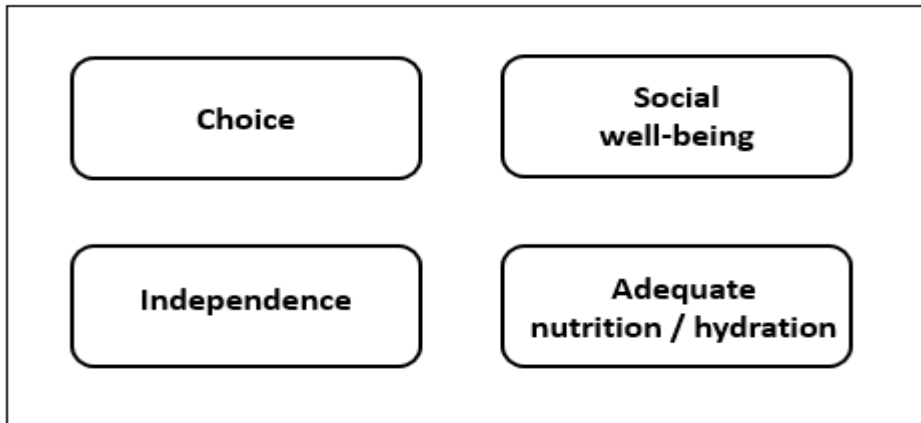
[Field-notes\_dining-room\_Home1\_teatime\_27/11/19]

In Care Home 2, a care assistant alluded to the need to be proactive and intentional about this aspect of mealtime care:

*Just encourage them to eat as much as they can, but I think fluids are really important as well. ... If you leave them, they'll not ask for one. But if you've got common sense and you see their cup low, then you offer them one and they'll drink it.*

[Interview\_StaffB31\_Home2\_04/12/19]

To this point, the ethnography findings were consistent with what I had drawn from the literature. They confirmed the idea that mealtime care pursues various priorities; in other words, outcomes that are considered beneficial for residents – these being choice, independence, social well-being, and adequate nutrition and hydration, as shown in Figure 5.5 below.



**Figure 5.5: Priorities in mealtime care**

However, as I spent more time in the care homes – as I was able to observe more closely mealtime care in practice, and to ask participants about it in more detail – I began to understand that the reality of mealtime care was more complex than this. In particular, I noticed that these identified priorities appeared sometimes to be in conflict with one another – leading to tensions in mealtime care which were challenging to resolve.

#### **5.4 Tensions in mealtime care**

I heard about, and observed, several different situations in which priorities of mealtime care seemed in some way to be in tension with one another. One such tension existed between independence and adequate nutrition/hydration. Put simply, some residents were able to eat more of their meal if directly assisted. From interviews and observations, my inference was that nutrition and hydration was generally considered the higher priority:

*“I think that’s where the staff intervene, and then you’ll have maybe a staff member doing the right thing which is start the feeding process ... because you need to eat.”*

[Interview\_FamilyCarerA4\_Home1\_08/10/19]

*Gracie tries to eat the pineapple upside-down cake, but has difficulty with maintaining the food on the spoon. So StaffA8 helps her by cutting up the pudding*



*into smaller pieces and placing a piece onto the middle of her spoon. Shortly afterwards StaffA8 steps in again, takes the spoon, and begins to directly assist Gracie. Gracie looks unhappy about this initially, but then accepts some spoonfuls.*

[Field-notes\_dining-room\_Home1\_lunchtime\_01/11/19]

I also noticed a tension between choice and social well-being. To illustrate: in both homes there were residents who preferred to eat in their rooms instead of in communal areas. The common view from staff was that this preference was understandable, and to be respected – as articulated here:

*“I’d say that if they’re in their own room it’s because they want to be on their own. Because the mealtimes can get really loud, and for some residents it’s really annoying. They just want to be on their own so we do give them that opportunity if they want to.”*

[Interview\_StaffB38\_Home2\_23/11/19]

At the same time, however, there was a sense that residents should be encouraged to come out of their rooms, if possible – because of the perceived value of social interaction at mealtimes:

*Well, there’s certain residents that just don’t want to come out of their room and sometimes it’s a case that their carers manage to persuade ... there’ll be times where you can persuade someone to come out of their room because obviously it’s much better when someone’s – it’s just more social, you know, when there’s more people in the dining room – so we promote that. That’s obviously something that the carers promote.*

[Interview\_StaffA06\_Home1\_10/12/19]

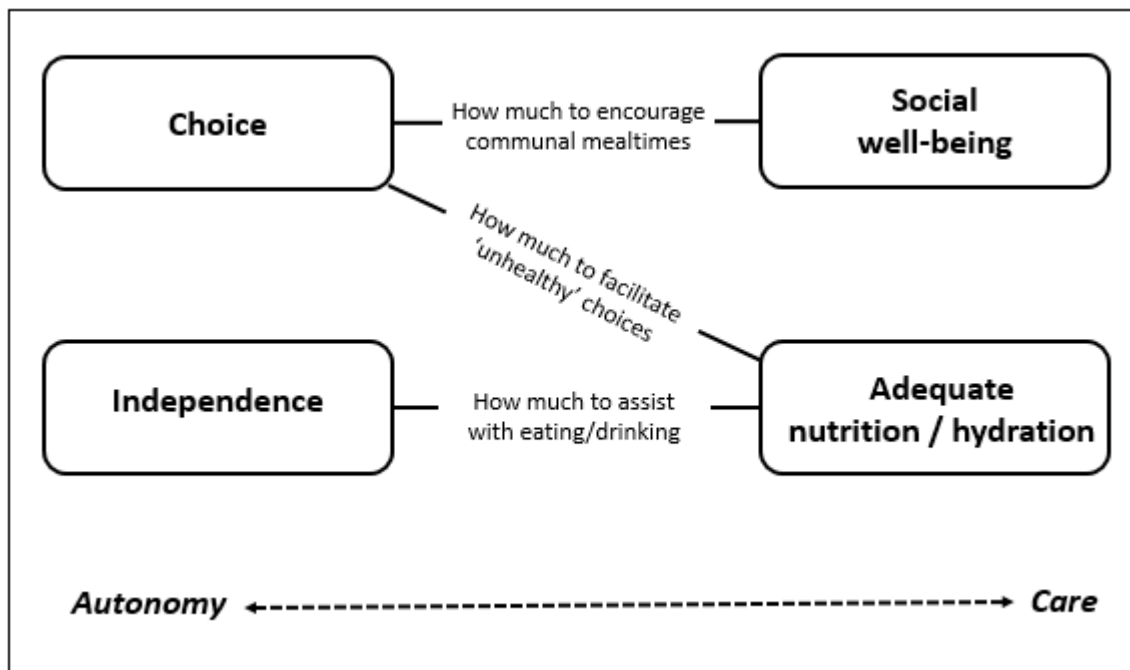
The challenge lay in how *much* to encourage. A family member felt that staff did not go far enough in encouraging her mother to leave her bedroom:

*“She needs to be encouraged more.’ I don’t feel as if she’s encouraged enough to go and kind of socialise. Now I’ve just asked her there, I says, ‘we’ll go along the other end and have a cuppa.’ Now she’ll do that because I’ll say, ‘Come on. Stand up.’ And I really firmly encourage her. The staff will say to me, ‘Well she doesn’t want to.’ ‘Well no she doesn’t want to because she doesn’t realise it’s isolating her, so you need to encourage her – find a strategy to use.*

Interview\_FamilyCarerB1\_Home2\_14/11/19

The resident had expressed a preference to stay in her room for meals – but her daughter believed her best interests were served by firmly encouraging her to leave.

I started to conceptualise these kind of individual tensions as being, in broader terms, a tension between autonomy and care (see Figure 5.6 below).



**Figure 5.6: Examples of tensions in mealtime care**

I noticed that carers were faced with making frequent decisions about ‘what is best’ for residents. Cognitive impairments meant that many residents may not have had capacity to make informed decisions themselves. Challenges arose when a resident’s implicit or expressed preference was perceived by others to be detrimental to their well-being. (*Others*, in this context, being care staff, family or other healthcare professionals.) For instance: one resident, Keith, liked a lot of salt on his meal, but staff were careful to moderate this:

*At the next table, Keith requests salt for his meal. Staff B33 shakes some over his plate. Clara and Daphne notice this, and comment that “They won’t give him it” [the salt cellar] in case he puts too much on. Later in the meal, Ken requests salt again twice. The staff don’t provide it, but say it’s on its way.*

[Field-notes\_dining-room\_Home2\_lunchtime\_12/11/19]

It was apparent here that staff were prioritising Keith’s nutritional needs over his ability to choose. When I discussed the topic of healthy eating with a senior member of staff in the home, they explained their policy was one of moderation. (There was no mention of the role of capacity, and so perhaps it was implicit that the resident in question lacked capacity to make an informed choice.)

*“If it’s with regards to too much of something... we’ve had somebody who insistently would only eat certain foods and again, we ensured that got incorporated into their diet so as long as it didn’t have an impact on a medical condition such as diabetes, then we would allow it within moderation.”*

[Interview\_StaffB41\_Home2\_19/12/19]

It occurred to me that the name of the setting encapsulated this tension between autonomy and care. The residents lived in a care home. As such, they were under the care of staff – but they were also in their home. I regularly heard staff make the point in interviews that ‘this is the resident’s home’, when they were emphasising the importance of resident autonomy:

*“Because it’s their home at the end of the day. If they were at home and they made themselves something...and they thought (I’ve done it before): ‘I don’t really fancy that’, then they’re able to go and get something else, make something else. So why can’t they have that here?”*

[Interview\_StaffB42\_Home2\_19/12/19]

However, I also observed that – in reality – residents did not have those same freedoms they would have experienced in their own homes. Notwithstanding the care assistant’s suggestion above, they were not really able to go and get something for themselves – such as a cup of tea:

*Keith is unhappy about his cup of tea: “The tea’s cold and strong. They just haven’t got time.” Alison goes over to Keith’s table and offers to make him a fresh cup. He accepts the offer, and she brings him the tea. There is a problem with this one too, so he goes into the kitchen to make his own. Alison and Margot both monitor this, and then Margot encourages him to leave the kitchen.*

[Field-notes\_dining-room\_Home2\_lunchtime\_12/11/19]

I explored this further when I interviewed the senior carer working on that floor:

*“Of course it would be lovely in an ideal world for everybody to have all of that independence and be able to do the things they want to do, but you’ve seen yourself, it can be quite hectic in that kitchen at a mealtime and all it takes is a member of staff to turn around too quickly and we’ve got a resident scalded, and for me, that wouldn’t be something I would be comfortable with. So it’s not about taking away their rights as such or anything like that, but protecting them and trying to make the best decision to make sure these kinds of things don’t happen.”*

[Interview\_StaffB39\_Home2\_05/12/19]

To paraphrase the senior carer: residents' autonomy was important, and to be promoted – provided it did not jeopardise their health and well-being. This connects to work by Evans et al. (2018), who describe two dominant and seemingly contradictory themes in dementia care: on one hand, a paternalistic concern with resident safety; on the other, advocacy for the individual as a free agent (p. 261). They note that the first theme tends to take precedence in practice, with care home staff erring on the side of caution. In my analysis of mealtime care, this seemed to depend on the perceived level of risk. If staff thought a resident's preference to be both unwise and harmful – for example, wanting to have a lot of salt on meals – they tended to be paternalistic and restrictive in their response. If they thought a resident's preference to be unwise but (relatively) harmless – for example, wanting to stay in their bedroom for meals – they were more likely to facilitate this. Within this decision-making, there was an apparent danger of infantilising the resident. This was exemplified during a mealtime I observed in a resident's bedroom (the resident, Edward, was at that time cared for in bed because of his medical status):

*Edward says "I wish I was back in the house. Good place to be." He tells me he used to cook for himself: "Anything; anything and everything. I've done Yorkshire pudding, roast dinners – many times on a Sunday." StaffB04 comes in with jam roly-poly and places it on his table. Seeing the remaining main course she exclaims: "Edward! Is this all you're eating?!" She opens the top drawer of his bedside table and pulls out multiple packets of crisps, and chocolate bars. She chastises him in a good-natured way. "This doesn't help! I'll take some of these away. And we wonder why he doesn't eat! I feel like a mother sometimes."*

[Field-notes\_resident's-room\_Home2\_lunchtime\_25/11/19]

Notwithstanding the language used here by the carer, it felt that their actions took limited account of the resident's wishes. However, I was wary of being judgemental. I saw that carers faced difficult dilemmas on a daily basis – often whilst managing multiple other demands, in the midst of a busy and dynamic environment. And it was clear that they were, in many cases, emotionally attached to their residents: they cared *about* them, as well as caring *for* them. Decisions and actions were typically – it seemed to me – well-intentioned, and motivated by that feeling of care. Moreover, I came to understand that this caring instinct was heightened at mealtimes – because of connotations of eating and drinking which I will address in the next section.

## 5.5 The symbolic nature of mealtime care

I became aware from talking to participants that mealtime care seemed to arouse strong emotions, and present particular challenges; my sense was these were somewhat different to those associated with other types of care. In conversations with care staff, I heard people express their desire for residents to successfully eat and drink, and their frustration when this did not happen:

*“It’s very difficult, because obviously you can’t make somebody open their mouth if they don’t want to. You can’t make somebody eat if they don’t want to eat. It’s one of those things: you want them to eat and you just try to encourage. You can’t do anything else, other than try to tempt them, encourage them. You know what I mean? Obviously, we do – we put the spoon to their lips, we’ll tell them what it is on their plate, we’ll try to put a spoon in their hand even.”*

[Interview\_StaffA3\_Home1\_09/01/20]

It was clear to me that this care assistant felt a responsibility for ensuring residents ate and drank well. At times, this feeling of responsibility seemed to cross over into a feeling of burden. As our interview was drawing to a close, I asked her if there was anything else she would like to say about mealtimes.

*“Well no, I just – I mean, [sighs]... It’s always hard to get it right, I think because not one day is the same and us girls – if somebody has a bad day we always get upset and worry about it. Because one thing about caring is wanting somebody to eat well and drink well because, you know, it’s all part of you being well, isn’t it?”*

[Interview\_StaffA3\_Home1\_09/01/20]

I knew from the literature that if residents or patients do not eat or drink, this can be perceived as a rejection of care (Featherstone et al., 2019; Hopkins, 2004). The adverse impact of eating and drinking difficulties on carers is well-documented in other clinical areas, such as cancer care (Burgess Watson et al., 2018; Nund et al., 2014). This speaks to the idea that provision of food and drink has a psychological and emotional significance, related at a deep-seated level to concepts of nurturing and protection (Jefferies et al., 2011; Wright, 2015). I noticed in both care homes there was pressure to encourage residents to eat and drink well. It seemed that this pressure could originate internally (that is, from a care assistant’s own personal and professional duty of care), and/or externally (for example, because of family expectations). A member of senior staff in Care Home 2 recognised this in colleagues:

*“Staff can take it personally. They take it as a problem and then of course what doesn’t help and exaggerates everything is the fact that families are, ‘Well, are you trying her with that? Are you trying him with this and that and the other?’ ‘We’ve got beans, he likes beans,’ and they’ll try, and it might work once, so they think that was the answer, that staff aren’t doing their job and so you can get suddenly a melt-down of confidence and then – it feels pressured and: ‘We must get him to eat!’”*

[Interview\_StaffB28\_Home2\_12/12/19]

Part of the challenge appeared to be determining what ‘eating and drinking well’ actually looked like. I understood that reduced eating and drinking was common in residents with dementia (Alzheimer’s Disease International, 2014), and I sensed there was potential for expectations around this to be unrealistic – perhaps based on what life was like before a resident had dementia, or before it was at an advanced stage. The literature suggests that carers’ understanding of the natural progression of dementia, and its impact on eating and drinking, is often limited (Barrado-Martín et al., 2021). I wondered if this may exacerbate their feelings of worry and uncertainty at mealtimes, and as I continued the interview with the member of senior staff, I asked them to say more about how staff respond to reduced eating and drinking. They told me:

*“When a person has known that a resident has been eating, it’s difficult suddenly that they’re declining and they’re going off their food and because you’re in the situation yourself, it’s sometimes difficult. ... They may say, ‘Oh Johnny doesn’t eat any more. What can I do? I feel useless.’”*

[Interview\_StaffB28\_Home2\_12/12/19]

When I spoke to a visiting professional in Care Home 1 about this, they echoed the idea that care assistants were at times caught in a conflict between reality and expectation:

*“We know that a lot of patients with dementia, their appetite subsides so I think that’s sometimes quite difficult for the staff if people are refusing to eat and we’re trying to promote that they should be eating and drinking.”*

[Interview\_VisitingProfessionalA1\_Home1\_08/10/19]

I also found that this pressure to encourage eating and drinking could, potentially, create a narrative about residents which was negative and unhelpful. That is, reduced eating and drinking was sometimes equated to ‘challenging’ or ‘difficult’ behaviour:

*“If there’s a resident that’s being quite difficult, like say if they’re on a food or fluid chart, and we need to get something down them specifically because they’re on that chart, and if they refuse to eat – then that puts us in a bad position as well, because we know that they are on this, they need this.”*

I was aware that the language used in dementia care was evolving (Alzheimer Society, 2017; Wolverson et al., 2021), such that terms like ‘refuse’ and ‘resist’ were acceptable to some people but not others. Notwithstanding this, it was evident from these conversations that carers construed a key part of their role as ensuring adequate nutrition and hydration for residents. They wanted residents to eat and drink. Thus, those occasions when residents stated (or demonstrated) they did *not* want to eat or drink seemed to epitomise the tension between autonomy and care. Residents were expressing their will, whilst staff were attempting to care for them in one of the most fundamental of ways.

I sensed that this was difficult terrain for care home staff to navigate. There were various priorities to consider when caring for residents at mealtimes. These included empowering residents to choose, encouraging them to eat and drink independently, facilitating their social well-being, and meeting their need for nutrition and hydration. Sometimes these priorities appeared to compete with one another. In addition, there seemed to be particular emotional investment by carers in the priority of adequate nutrition/hydration, which made their work still more challenging and complex. However, as I continued with data collection and analysis, I noticed something which was potentially transformative to mealtime care – something that enhanced all aspects of the mealtime, and served as a guiding principle where there was tension or uncertainty.

### **5.6 The importance of a person-centred approach**

In my review of the literature, I had sought to identify salient features of carer-resident interactions during care home mealtimes – with a particular focus on residents with dementia. In so doing, I noted it was important for carer-resident interactions to be tailored to the individual resident: to take account of residents’ preferences, characteristics and capabilities. My initial conception, from the literature, was that this tailored, person-centred approach was a goal of mealtime care – equal to and alongside other goals such as social well-being and adequate nutrition/hydration. Thus, I hypothesised that we could recognise good mealtime care if it was person-centred, if it empowered residents to choose, if it encouraged them to eat and drink independently, and so on.

During the course of the ethnography, I began to see person-centred care in a different way. I noticed from interviews and observations that it was not necessarily an end in

itself; rather it was important because it could facilitate and enhance other aspects of mealtime care. To take provision of choice as an example: I had previously heard about the varied menus in Care Home 1, from a member of the kitchen staff. As our conversation developed, and we talked in more detail about menus and menu-planning, it was evident the staff member felt more could be done to cater to residents' preferences:

*“We approached our area chef, the area chef went to head office and we said basically our menus should be set by region, because what they like down London is not what they like up here and we were saying it should be site specific so we get to choose what we have on our menu – because we know our customers.”*

[Interview\_StaffA14\_Home1\_10/03/20]

The kitchen staff member aspired to be able to design the menus themselves, based on their own understanding of what the residents enjoyed. In Care Home 2, I found that this was put into practice. In fact, the staff member responsible for menus took the process a step further. They did more than pre-empt or predict residents' preferences; they regularly consulted their residents:

*“Initially when I first started, I let the menus stay and remain the way they were. I got an idea: put food surveys out which go out every six months. So it's getting that general idea of what the residents' preferences are. What goes down well, what doesn't go down well – and devising a menu based on that.”*

[Interview\_StaffB41\_Home2\_19/12/19]

This seemed to represent a more person-centred approach to menu-planning. However, even with consultation, set menus could not be truly person-centred. By their nature, they were a compromise; an amalgam of many residents' preferences. It became clear that staff still needed to be responsive and flexible, in order to accommodate preferences in the moment – so that food and drink was genuinely tailored to the residents. This was articulated by staff members from both homes:

*“If they don't want the two choices that are on offer, we do our best to try and get them what they would fancy to eat, you know. Rather than just saying, ‘Well that's what's on offer. If you don't want it...’ You know, we don't do that and I think that's very important.”*

[Interview\_StaffB42\_Home2\_19/12/19]

*“Me personally – if anybody wants anything they can have anything. I was asked the other day for dinner time if someone could have a salad, and I was like ‘that's not a problem’. It's what they want.”*

[Interview\_StaffA14\_Home1\_10/03/20]



This kind of responsiveness was particularly valuable because residents' preferences were often not definitive or settled, but based on daily circumstances. A care assistant in Care Home 1 described a resident whose preference of where to eat was influenced by the level of dining room noise:

*“For [resident’s name] we ask maybe now and then ‘do you want to come along or not?’. If it’s too loud for him then he won’t enjoy it. If it’s intimidating, then he just doesn’t like that ... but sometimes he will say ‘yeah’, so obviously you need to keep asking just in case he does change his mind and wants a change of scenery.”*

[Interview\_StaffA8\_Home1\_08/01/20]

Moreover, sometimes residents might change their mind about a choice within moments of making it. It felt important that staff were open to this, and understanding of it:

*“You always give them choice, and whatever they chose you give that to them. But they will tell you they didn’t ask for that. They want the other, so... just patience.”*

[Interview\_StaffB33\_Home2\_05/12/19]

Thus, enabling residents to choose at mealtimes required a person-centred approach that was responsive and flexible. I discerned that good communication between carers and residents was an important element here. Carers needed to be proactive about this, particularly in view of the cognitive-communication difficulties experienced by many residents with dementia. There was acknowledgment among staff that current practice in this was sometimes imperfect:

*“I’ve worked in homes in the past that’s been a lot more [residents with] dementia than this and when I first started it was like, ‘What does this gentleman take with his tea?’ ‘What does this lady take with her tea?’ and they just say, ‘Put a sugar in everybody’s’ Something which I don’t think is nice. I mean I’ve never took sugar in my tea so if I get dementia, I don’t want a sugar stuffed in my tea.”*

[Interview\_StaffB25\_Home2\_05/12/19]

*“Not just assuming and actually speaking to the residents because that’s another thing that is one of my bugbears when they turn around and say, ‘How many sugars does [Nancy] take?’ Nancy’s sitting there. Ask her. Don’t talk over them. Involve them it. ‘Will Nancy want chips or will she want mash?’ Nancy’s sitting there. Ask Nancy.”*

[Interview\_StaffB42\_Home2\_19/12/19]

There were also positive examples of staff being patient and resourceful to ascertain residents' preferences – when simply asking the resident verbally was not sufficient,

because of their level of impairment. In those circumstances, some staff relied on information from family, or notes in the care plan. However, this information could quickly become out-of-date – particularly given what we know about people with dementia experiencing changes in preferences. Some staff found other ways to discover these preferences first-hand. A member of the kitchen team in Care Home 1 gave an example:

*“I have had a couple [of residents] that haven’t had capacity. They couldn’t speak, they couldn’t tell me what they wanted, what they didn’t. My diet notification told me they like chocolate mousse. So obviously I did try different food. In a weird sort of way, even though they can’t speak and communicate, if you watch them you can tell. If you give a child, I don’t know, say a gherkin for the first time, their face screws up and starts... So, you try someone with food and obviously if they pull a face, this, that and the other and you’re like, ‘Ooh no they don’t like that so we’ll go back to the chocolate mousse.’ And then you can try again the next day and it’s perseverance. It’s about finding what they like – and if they do like the chocolate mousse then they can still have it. It’s not a problem.”*

[Interview\_StaffA14\_Home1\_10/03/20]

So, enabling choice was not just about having a wide range of options. It was equally about taking the time to understand residents’ preferences, and then responding to them. In this way, a person-centred approach was integral to this aspect of mealtime care.

Similarly, I learned that person-centred care was important when care staff were encouraging residents to eat and drink independently. A care assistant told me about the “gentle encouragement” needed to help residents to be independent. I found that this encouragement could be enacted in various ways. Sometimes this was through physical prompts, to try to transition from direct assistance towards independence:

*After a while, and with approximately half his meal remaining, Jeff stops eating and sits quite passively. StaffA7 goes over and orientates his plate so the sandwich is in front of him. This has no discernible effect, so she picks it up and places it in his hand, giving him verbal encouragement. This works well; he eats the rest of the sandwich independently. ... StaffA11 returns to Helena, breaks off a small piece of cookie, and gently places it in her mouth. Helena seems momentarily taken aback by this, but then proceeds to eat the remainder of the cookie independently.*

[Field-notes\_dining-room\_Home1\_teatime\_12/11/19]

At other times, care staff used verbal prompts. This care assistant implied that a light-hearted, humorous tone was helpful:

*“If they start saying, ‘I can’t, I can’t...’ you’ve got to say, ‘No, now come on, you can...’ you’ve got to encourage them that way. You can’t say, ‘you can, you can...’ You’ve got to say, ‘Come on you – eeh, you can! Now come on. If your daughter comes in and sees me giving you that cup she’ll go mad with me,’ and it brings them round and they think well she’s right and it encourages them to do it themselves.”*

[Interview\_StaffB31\_Home2\_04/12/19]

It was clear to me that staff needed to make careful judgements about when, and how, to support residents. What was appropriate for one resident may have been inappropriate for another. They needed to strike the right tone in their approach, and they also need to achieve the right balance – to provide enough assistance, but not too much. Residents had different skills and capabilities – which could vary from day-to-day, or even moment-to-moment. At this mealtime, I saw carers use different approaches with the resident – Jeff – depending on the stage of the meal and the nature of the food:

*On his side-table Jeff has a small plate which contains sandwiches, potato skins with mayonnaise dip, and jacket potato with cheese. Jeff successfully eats the sandwiches independently. He sometimes pauses for long periods, and StaffA7 comes over to encourage him to continue. He needs a bit more support for other elements of the meal. StaffA8 cuts the potato skins and jacket potato into small pieces, and places the fork into Jeff’s hand. He eats several pieces of potato skin independently in this way.*

[Field-notes\_lounge\_Home1\_lunchtime 08/10/19]

During another mealtime, in the other care home, a carer explained she had varied her usual approach with this particular resident, because he was presenting somewhat differently to normal:

*StaffB3 sits down next to Percy, and directly assists him to eat the chicken stir-fry. They chat occasionally – sometimes Percy’s responses are unclear, or do not really correspond to what StaffB3 is saying. But they both seem comfortable and relaxed. StaffB3 assists at a moderate pace, allowing enough time for Percy to finish each mouthful. ... As she moves away from his table, StaffB3 says to me he normally eats independently, but is tired today; “It would go everywhere.” She leaves him to drink his tea himself, and some of it does spill out of the cup onto his apron.*

[Field-notes\_dining-room\_Home2\_teatime\_26/11/19]

It seemed that the carer’s existing knowledge of Percy, and her responsiveness in the moment to his presentation and his actions, helped her to provide an appropriate level of assistance. Although on this occasion Percy was not able to eat independently, the carer

followed his lead to moderate the pace of her assistance accordingly – waiting for him to finish each mouthful.

This kind of attention on the skills and requirements of the individual was helpful, whether residents needed significant or minimal assistance. I was told by a care assistant about the importance of individualised preparation, to ensure everything needed was in place – even for the most independent residents:

*“Make sure that those who can assist themselves, their food is in a place where they can actually reach it because apart from the breakfasts and lunchtimes when we come down to teatime and we’re winding down, I see people putting food on the table and the residents sitting there and they can’t get to it and you have to remember if the resident is right-handed, there’s no point putting it all the way over here on the left because they can’t get it.*

[Interview\_StaffA3\_Home1\_09/01/20]

It seemed to me the carer was thinking about how to set up residents for success at mealtimes. I saw this kind of approach enacted by another care assistant, who took time at the start of this meal to make sure Cathy was equipped, orientated and ready to go:

*Hayley brings over Cathy’s cup of tea and meal, and puts this on a folding table in front of her. She places a knife and fork into her hands “Here’s your knife and fork”. She describes the various components of the meal and orientates Cathy to where they are on the plate.*

[Field-notes\_lounge\_Home1\_lunchtime\_27/11/19]

In Care Home 2, a carer told me how she would check in with residents who were independent at mealtimes, as they began the meal:

*“Well the ones that – me personally, the ones who can deal with ... on their own. I would say, ‘Have you got everything that you need?’ Salt, pepper, vinegar... ‘Do you need anything cut?’ Because sometimes their meat is tough. ‘No, I’m fine.’ Right.”*

[Interview\_StaffB31\_Home2\_04/12/19]

In all these cases, carers were focused on their residents’ individual needs, in order to provide suitable tailored support. It was evident that this person-centred approach was key to encouraging independence at mealtimes. I also saw that it was important when carers were attending to the social aspects of eating and drinking. With some residents, care staff seemed to adopt a distinctly jovial tone; I noticed this in both homes:

*There are good-natured interactions between Cheryl and the residents, as Cheryl pours their tea. “How are you today?” “Well, I’m alive.” “Oh good, you’re not dead yet”. Elsa is appreciative of her cup of tea: “It’s the most important thing. That’s the first thing I do when I go downstairs – I put the kettle on”. Cheryl affectionately places her hands on Elsa’s shoulders during an exchange. She says: “You ladies are easy to please.” Elsa replies: “Don’t let it go to your head!”*

[Field-notes\_dining-room\_Home1\_breakfast\_30/10/19]

*The atmosphere is convivial. Kiera and Kathleen work well together as a team, efficiently preparing/serving the meals. There are frequent smiles and laughter, between the two staff, and also between the staff and residents. The tone between staff and residents is informal and often jokey (“There you go ladies”, “There you go madam!”). Some residents are chatting at tables, especially on Barbara’s table.*

[Field-notes\_dining-room\_Home2\_teatime\_29/10/19]

With other residents, staff took a different approach. In the following extract, the care assistant was demonstrative and tactile with a resident who was in the advanced stages of dementia:

*Olga is sleeping in an armchair in the lounge. StaffB17 crouches down beside her and gently touches her arm. Olga stirs briefly then goes back to sleep. StaffB17 leaves, and then returns with a bowl of cornflakes which she places on the folding table in front of Olga. She crouches down again, strokes Olga’s arm and says her name. Olga wakes up suddenly, sees StaffB17, and smiles. She puts her hands on her face. StaffB17 leans forward and kisses her on the head. “I’ve brought you a bit of breakfast. I’ll get you a cup of tea.” Olga begins to eat her cornflakes.*

[Field-notes\_lounge\_Home2\_breakfast\_20/11/19]

The physical contact in this interaction was notable, and felt entirely appropriate – a means of communicating, of socially interacting, where words may not have been effective. Another care assistant spoke about this, when I asked her what was important in dementia care:

*“I think it’s kind of they feel more at ease with you. They know that you’re there and they kind of warm to you. It’s like a comfort – like a touch of comfort, that ‘we’re going to look after you,’ and I think they sense that. So, I think that’s really, really important and that’s not just in personal care or if we’re going to sit them down, that’s throughout the day. These little – just holding on to – touching their shoulder or touching their hand or a hand on their hip or the waist. It’s really important, I think.”*

[Interview\_StaffA3\_Home1\_09/01/20]

The carer referred here to residents feeling at ease, and comfortable. Sometimes this happened through humour, sometimes through touch – from what I could tell, skilled carers were flexible in their use of social interaction, depending on the resident. They were also mindful of the various ways in which residents interacted socially with one another at mealtimes. From speaking to participants, and from my observations, I knew that social relations between residents were often powerful, and could impact on mealtimes either positively or negatively – as illustrated in these field-notes from Care Home 1:

*Freya chooses fishcakes; StaffB32 brings them over and says in a cheery voice “Hello! Fishcakes for you!” He asks Freya if she would like him to cut them up – she declines this offer. He then takes Barbara’s empty plate and replaces it with a bowl of strawberry cake. However, this remains untouched by Barbara. Soon StaffB31 bends down beside her to ask if she is okay. It transpires she is upset because she’s fallen out with her friend. StaffB31 is sympathetic and tries to reassure her. At Barbara’s request, she takes the pudding away. Shortly afterwards, StaffB21 helps her to leave the table and move through to the lounge. There she is reunited with her friend; all seems well again. They sit side-by-side, watching TV together and chatting.*

[Field-notes\_dining-room\_Home2\_teatime\_21/11/19]

While Barbara’s interactions here implied companionship and friendship, I learned that some mealtime interactions between residents were not so friendly. For example, a senior carer in Care Home 2 described how residents could appear territorial about where they sat in the dining room:

*“[You] can’t sit there that’s my seat.’ ‘Don’t sit there, that’s her seat.’ That’s how – it’s hard. To be honest I would hate to come onto this unit as a resident because they can be so unsociable, territorial to – especially to seats and tables ... One of my ladies has been here since 2006. So, they’re set in their ways, you know and there’s others as well been here five and six years, so it is – to them, it’s their home. So, somebody else – you coming in, it’s like somebody coming in your front door, sitting on your settee and saying, ‘Right I’m moving in here.’ How would you feel?”*

[Interview\_StaffB42\_Home2\_19/12/19]

Here, the senior carer touched on an interesting aspect of care home life. Residents found themselves living with people who may have quite different personalities, backgrounds, and interests. Moreover, new people were introduced on a regular basis, changing the social environment to a greater or lesser extent. I found that this juxtaposition of different

characters had consequences at mealtimes. A care assistant in Care Home 1 gave an example of this:

*“Ah, I would say obviously when everyone does come in the dining room and everyone’s got different behaviours or characteristics – so if, like I say, if one gets angry – then it does set other people off and then everyone’s dinner time is sort of gone off down the rail.”*

[Interview\_StaffA8\_Home1\_08/01/20]

Peer influence could adversely affect mealtimes in other ways. Another carer described a scenario in which residents left the dining table early because their friends did:

*“There’s some people... like, say I’m eating now and I get up and walk away, and if you liked me, you would leave your [meal]to be with me. So, you’ve got to say, ‘Ah no. Come on, you eat yours. She’s just going to go away – you try and eat yours!’ You’ve got to try and make that person stay. And if [they’re] doing it all the time it would be best to put them on a different table. Because you know that I’m going to get up and you know for a fact that you’re hungry, but you’re going to get up because I’ve gotten up – and it’s not fair to you.”*

[Interview\_StaffB31\_Home1\_04/12/1919]

In these conversations, and others, I heard from staff the importance of noticing and responding to the social dynamics between residents at mealtimes. Often, they were proactive about this – for instance, using their knowledge of residents for seating arrangements:

*“We do know, and we do observe, who gets on better with who – so we put them together. We have got some residents that won’t get on well with other people so we’re not going to sit them at the same table. Do you know what I mean?”*

[Interview\_StaffB25\_Home2\_05/12/19]

A family carer elaborated on this idea:

*“I think you’ve got to know where to seat people. To me, it isn’t a question of moving everybody in and just sitting them anywhere. I think you’ve got to have certain people in certain seats who get on with each other. After a while I think they get used to the people sitting with them and I think if you move – even my mam who’s obviously, I don’t think she knows who I am, but I think if you moved her to a different seat with different people I think that might affect her. I think people get used to... I suppose it’s like anybody in any walk of life. I mean, I’m getting moved tomorrow; my job. I’ll go back and I’ll be working with different people, so you’re out of your comfort zone, and I’ve got to get to know them. And I think it’s the same with these, and I think if you keep them altogether in their little pack, sort of thing, it will be happier rather than moving them round.”*

[Interview\_FamilyCarerA1\_Home1\_15/10/19]

Thus, in order to help residents enjoy the social side of mealtimes, care staff not only attended to the different characteristics and needs of individual residents – they also took into account the social interplay between groups of residents. It could be said that they used both a person-centred approach, and a people-centred approach.

Focusing on the resident as an individual also helped staff to promote adequate nutrition and hydration at mealtimes. In interviews, when describing their response to reduced intake, staff often talked about looking for underlying reasons. The implication was that reduced eating and drinking may indicate a different problem, requiring further exploration. Staff in both homes described a type of questioning, investigative way of working:

*“It’s like, well, the girls are sort of switched on, ‘Well, is there anything wrong? Do you have a pain? Are you just not hungry?’”*

[Interview\_StaffB41\_Home2\_19/12/19]

*“You try and encourage them or you try to work out why. You know, there could be a simple explanation. Maybe their dentures don’t fit properly, or anything. Just eliminate everything. Try and work it all out and see – maybe they don’t actually like what they’re asking for.”*

[Interview\_StaffB33\_Home2\_05/12/19]

*“Someone with a poor diet: I’m looking in to see what’s going on there but I don’t just look at it saying, ‘Ooh they’re not eating.’ It could be a certain type of behaviour. Something could have upset them, the dementia could have just progressed you know and I watch all the time, people change, diets change.”*

[Interview\_StaffA14\_Home1\_10/03/20]

In this way, thinking carefully and holistically about the person could give carers a valuable insight into why they were eating or drinking less than usual. A person-centred approach was similarly important when carers were actively encouraging residents to eat and drink more. I saw from mealtime observations that there was considerable challenge in knowing when to persist in this, and knowing when to withdraw. I reflected on this in field-notes from an observation involving Frida – a resident who sometimes ate very little at mealtimes. The care assistant was directly assisting Frida to eat a pudding, persisting gently as Frida showed some reluctance:

*It is a fine balance; we are in that grey area between following the resident’s lead and imposing on the resident. But in general Frida is accepting of the spoonfuls and eats well. Towards the end of the pudding, she starts to close her mouth a bit*



*more frequently. StaffA2 says “Do you not want any more? Okay.” She stops, and wipes Frida’s mouth.*

[Field-notes\_dining-room\_Home1\_teatime\_27/11/19]

My impression was that this was very skilled work, and I wondered how the carer judged whether – or how much – to persevere. But it appeared that knowing the person – their requirements, their preferences, and the approach that worked best for them – was key. I heard this voiced very clearly by a care assistant in Care Home 2, whom I spoke to at the end of a mealtime:

*I chat with Rikki, another carer who is on shift today. She tells me she always sits with residents at mealtimes. She says she waits till everyone’s finished, then gets her meal and sits down with the residents. She thinks some staff don’t persevere enough when residents say they don’t want to eat much. “They just clear the plate away.” She says it’s important to know the residents; their preferences and needs, for example some have lost their sense of smell, or taste. Some are not able to chew. She tells me about an occasion recently when a resident said she didn’t want her meal, so it was put in the bin. She says she brought the resident something softer, and the resident ate all of it.*

[Field-notes\_dining-room\_Home2\_lunchtime\_14/11/19]

Rikki’s point about not withdrawing too early if residents decline to eat or drink was echoed by a visiting professional in Care Home 1:

*“So they’ve had a couple of people here just recently who are just being absolutely adamant that they’re not gonna [have a drink] ... and I think sometimes it’s – I don’t know if it’s the staff’s perception, in that you can give somebody a cup, say to them, ‘Have a drink’, if they then say, ‘No,’ you just accept that. Well, you don’t. If somebody’s at risk of being dehydrated, or becoming clinically quite unwell because they’re not eating or drinking, then you have to take that time. And I think you have to have that structured approach, so it may be that you have to go in every hour and sit with that person. And you might have to sit for 10 minutes and encourage them to drink, and that’s not just constantly saying, ‘You need to have a drink. You need to have a drink.’ It might be that you distract them by having a conversation about something else, but encourage them to eat or drink at the same time.”*

[Interview\_VisitingProfessionalA1\_Home1\_08/10/19]

I was interested to hear the visiting professional emphasise the importance of persisting, particularly if a resident is known to be at risk of dehydration. Again, focusing on the resident and their individual circumstances could guide a carer’s actions here, in respect of how much to persevere. There is also, in the extract, advice about *how* to persevere: a

suggestion to take the pressure out of the situation, by conversing with the resident. This same suggestion was made by a care assistant in a later interview:

*“Having a conversation, actually. Having a conversation. So you’re trying to assist someone, they’re just going, ‘No.’ Maybe it’s a case of having a talk with that person. Maybe they’re getting a bit uncomfortable. Maybe just, you know, put the knife and fork, spoon down, whatever and just have a chat for a bit, and kind of reset the situation, you know. And then maybe try again once things have calmed through and again, that’s detaching, kind of step out of the room. Maybe come back a bit later.”*

[Interview\_StaffA6\_Home1\_10/12/19]

It seemed to me that the care assistant was describing a kind of ‘careful encouragement’: persevering in a way that was responsive to, and respectful of, the resident. I felt then that this pointed towards a person-centred approach as being a key to unlock the tensions I had noted in mealtime care; as described earlier, those tensions lying broadly between autonomy (the resident expressing and enacting their wishes) and care (the care home providing for the resident’s physical and psychological needs).

### **5.7 Navigating tensions via a person-centred approach**

I noticed that this principle of person-centred care could be instructive for carers in a variety of complex mealtime situations. To take the case presented earlier in this chapter, of the resident who preferred to stay in her bedroom for meals: the resident’s daughter was concerned that a preference to stay in her room at mealtimes was detrimental to her social well-being. The daughter proposed a solution which tried to take account of her characteristics, habits and history:

*“When my mam broke her hand – I don’t know if it was last year, beginning of the year – and she wouldn’t come out of the room... You know, that’s fine but then it got where she wasn’t coming out of her room at all so the social isolation was starting. And then they were saying, ‘Ah well we’ll bring her out for breakfast.’ Well my mam’s not a morning person and they should know that by now. She’s been here a year and a half so she likes to take it slow and I said, ‘Well I would prefer when mam gets up just leave her in her dressing gown and give her breakfast in her room. Encourage her to come out at lunch time when she’s more alert.’”*

Interview\_FamilyCarerB1\_Home2\_14/11/19

Knowing that the resident was “not a morning person”, and adapting care accordingly, seemed to be key to this; a way of respecting their individual preferences whilst attending to a more general idea of social well-being. Another family carer described how her

mother – whose dementia was at an advanced stage – became distressed if the dining room was loud, but not if it was quiet. She wondered whether, in these particular circumstances, it may be better if the resident’s social needs were met in a different way:

*“My thought is that on a day where [other residents are] agitated and more, say, vocal, she might do better on her own in a different room, so all she’s got to concentrate on then is the food and being able to eat. And then maybe doing a social time later with everybody. So that might be something, if it’s on one of those days where it isn’t working well in the dining room, you know to have an alternative almost?”*

[Interview\_FamilyCarerA7\_Home1\_08/10/19]

The family carer knew her mother well, and knew what would work for her. Thinking in these terms signposted a way to accommodate her needs both for adequate nutrition/hydration, and for social well-being. It seemed that a perspective of this kind could potentially help care staff to prioritise well, and make good decisions at mealtimes. This was also relevant when staff were seeking to promote independence whilst at the same time make sure residents ate enough. A care assistant in home two told me about the tailored approach they used:

*“Well the ones who can’t cut their meat, you would say, ‘Are you fine now?’ They would say ‘Well...’ and you know that they’re fine. You don’t want to start saying, ‘Well come here I’ll feed you’. You know, you read their care plans that they’re alright to eat on their own. But the ones that you know can’t eat, you’re not going to cut it up and say, ‘Look it’s cut into tiny little pieces, right you try that yourself...’ and struggle. You know for a fact they’re not going to eat it, so you put your plate-guard on the back of it, and the ones who struggle a little bit you would put the plate-guard on and that helps them a lot. But the ones that can’t eat, I wouldn’t be leaving them. I would sit with them until it’s all gone.”*

[Interview\_StaffB31\_Home2\_04/12/19]

Some residents were able to eat and drink independently, but in so doing would be at risk of spilling food or drink onto themselves, onto the table, or onto the floor. This meant that staff needed to think about how they could maintain their independence, and their dignity. I spoke to one care assistant who had firm opinions about this:

*“I don’t think somebody’s independence should be taken away because they make a bit of a mess. Like we’ve got one lady in here if you give her a big spoon she’ll make a mess but if you think ahead a little bit and give her the smaller spoon she doesn’t make quite as much mess. You don’t just automatically think, ‘oh she’s making a mess, we’ll feed her.’ I think there is – you should always look for something else.”*

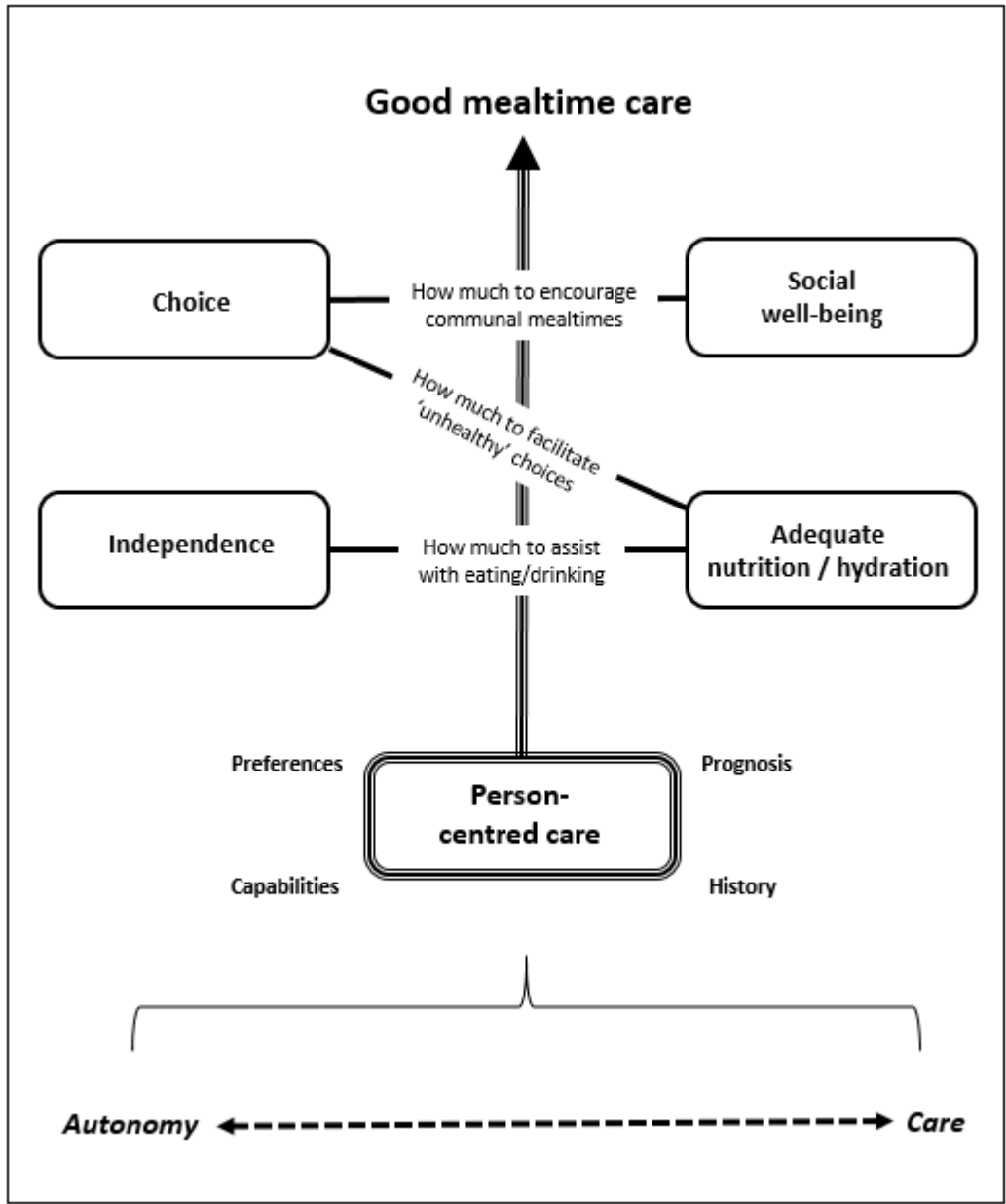
[Interview\_StaffB25\_Home2\_05/12/19]

The staff member knew the resident benefited from using a smaller spoon, and used this knowledge to defuse a tension between two important facets of care. Similarly, I saw instances in practice of how responsive care helped residents meet these differing and potentially conflicting needs; for example:

*Helena is eating well, using a combination of her fork, and her left hand. This is effective, and she eats the entire first course in this way. It means her left hand gets a bit messy; StaffA7 cleans her hand with a tissue periodically. To me, this is an example of good mealtime care; it is facilitating independence, and maintaining dignity. StaffA7 says she is happy for residents to eat with their hands – the main thing is that they eat.*

[Field-notes\_dining-room\_Home1\_breakfast\_29/11/19]

Through these kind of examples, I saw that person-centred care was important in resolving tension between autonomy and care – because it *encompassed* both autonomy and care. That is to say, when care staff took into account a resident’s preferences, capabilities and other personal factors, they often seemed able to navigate a path through tensions in mealtime care – meeting the resident’s care needs without compromising their personhood (Kitwood & Bredin, 1992). I have illustrated this in Figure 5.7 below.



**Figure 5.7: Navigating tensions via a person-centred approach**

Finally, I noticed that a person-centred approach was helpful when staff were caring for residents who preferred unhealthy foods or drinks. A carer in Care Home 1 described a resident who would only eat food if accompanied by a particular fizzy drink. The carer was aware that this resident would otherwise be unable to meet their nutritional needs. In the carer’s words, the fizzy drink was an imperfect solution – but it was, nonetheless, a solution:

*“There’s another gent who, he won’t – it was getting to the point where he wouldn’t eat without having coca cola. ... and it’s just a case of... ‘Right, there’s*

*the coca cola there and... ' But it isn't a perfect solution, it's not... but it is a solution, if he's only going to eat when he's got a drink of coke to go with it... "*

[Interview\_StaffA6\_Home1\_10/12/19]

Being person-centred here led to a pragmatic way forward. Among the staff I spoke to, there was acknowledgement that for some residents – typically those with more advanced dementia – consumption of calories was the critical factor, rather than a balanced diet. A senior carer in Care Home 2 was relaxed about staff prioritising sweet, high-calorie foods for those particular residents:

*"I mean if they put the dinner down to them and they kind of just do that with their fork and just mess it around, and we've seen that they haven't eaten, and then we know the resident: 'ah but they do like puddings and it's cake and custard. Right, give them cake and custard' and usually they'll clear that because it's nice and sweet."*

[Interview\_StaffB41\_Home2\_13/12/19]

This kind of pragmatism was grounded in person-centred care, because it was tailored to residents' needs and prognosis, and took full account of their preferences. It acknowledged what was realistic for the individual at a given time. I saw that it could enable care staff to find a way through the challenge of wanting residents to eat, but also wanting them to eat well. In so doing, I sensed it could also help defuse some of the emotional burden that staff may experience in the face of reduced eating and drinking. In the most extreme cases – where a resident's oral intake had dwindled to nothing, or almost nothing, because of the natural course of their dementia – it seemed that appropriate expectations around this were vital, to enable staff to provide the right care for residents, and for themselves. A care assistant in home one touched on this, when talking about the difficulties of encouraging residents to eat and drink:

*"I've found that in this job, it's probably one of the first things that happens before they become very ill and pass away: their food and fluids start to suffer. They literally stop eating you know? They don't want to drink anymore and that's very hard to see."*

[Interview\_StaffA3\_Home1\_09/01/20]

It was clear that caring for residents with this presentation would never be easy. Nevertheless, if there was recognition and acceptance that a resident was at an end-stage in the progression of their dementia, then carers could perhaps feel less weighed-down by an obligation to ensure they ate and drank.

## **5.8 Conclusion**

I came to the understanding that adequate nutrition and hydration – like all goals of mealtime care for residents with dementia – was not generic; not one-size-fits-all. Staff knowing the resident was fundamental to their making wise decisions about care. There were challenges inherent in balancing various priorities at mealtimes, and in navigating the tension between autonomy and care. By focusing on the person as an individual – their history, capabilities, preferences and so on – staff were better able to find a way through these challenges.

However, in reaching this conclusion I was aware that this was only a part of the picture of mealtime care. So far in my analysis, I had concentrated primarily on what happened at the level of carer-resident interactions: what happened in the moment of the mealtime, as the staff member provided direct care to the resident. I realised that there was more to mealtime care than this. In particular, I noticed from my observations and interviews that carers were constrained in what they were able to do by several contextual factors. That is to say, all carer-resident activity occurred within a complex system – the care home. This comprised many different departments, staff-groups, and other stakeholders (such as external management, family carers, and visiting professionals) who interacted in various ways. In the following chapter I elaborate on this, and its implications for mealtime care.

## **Chapter 6. Good mealtime care relies on teamwork**

### **6.1 Introduction**

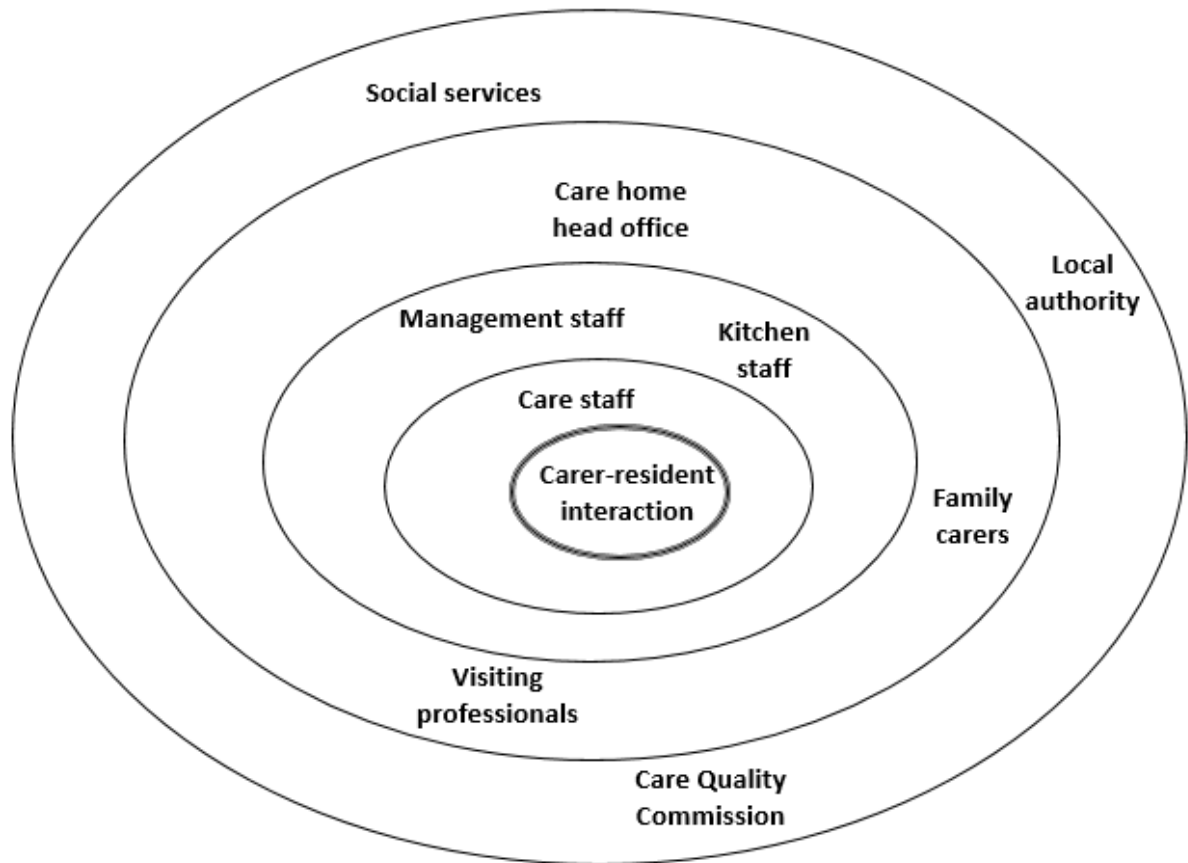
In the previous chapter I set out various priorities of mealtime care, as pursued by care home staff in their interactions with residents. I noted the tendency, at times, for these priorities to clash with one another, and I proposed that a person-centred approach can help to guide staff through the challenges that this presents. In this chapter, I explore the contextual factors at play in mealtime care. I show how these factors constrain the care that staff are able to provide, and I suggest that teamwork is integral to overcoming constraints.

### **6.2 Contextual constraints on mealtime care**

In my literature review, reported in chapter 3, I had conceptualised mealtime care as occurring within carer-resident interactions. To an extent, I took this idea into the ethnography. In observations and interviews, I focused – initially at least – on what happened between carer and resident at the mealtime; this seemed a logical place to start. As I proceeded with the ethnography, however, it became apparent that these interactions by themselves did not tell the full story of mealtime care. They were the most direct expression of that care, but they occurred within a system, a context, which influenced them – sometimes positively, sometimes negatively. That context, of course, was the care home itself.

I was already aware, from related literature, of the importance of context. For example, Moore et al. (2019) describe schools and hospitals as complex social systems, with many interacting parts and a diverse range of actors. (The authors emphasise this in relation to the success or otherwise of interventions taking place within these settings.) I quickly began to see how true this was for care homes, too. I saw that the ‘interacting parts’ here included various internal departments and staff-groups – such as kitchen staff, domestic staff, management staff, and care staff. They also included external elements – such as head office, family carers, and visiting health and social care professionals (as illustrated in Figure 6.1 below). I found that each of these could have an influence on mealtime care, in different ways and in different combinations.





**Figure 6.1: Contextual factors in mealtime care**

The role of the kitchen seemed a prime example of this. In particular, kitchen staff were tasked with producing food to certain timescales. In both homes, food trolleys were delivered by kitchen staff at regular times, and collected again approximately one hour later. I found there was a general expectation that trolleys would be loaded and ready when kitchen staff returned. I talked to a care assistant in Care Home 2 about whether there was any flexibility in this (we were talking here about lunchtimes, when the food trolley was delivered at 1pm and collected at 2pm):

JF: *“Do you mean that you have to be finished by 2pm?”*

StaffB38: *“Um, yeah. It’s not a long time at all. Especially if the trolley is late because then you’re rushing around.”*

JF: *“Yeah but I suppose I’m just thinking so what happens at 2pm really...? Would it be a problem if it just sort of dragged on after, sort of 2:30 or whatever...?”*

StaffB38: *“I think it would only be a problem for people who were in the kitchen because they’ve got to come and get the trolleys, take them back down, clean them, wash the dishes and bring them back up.”*

[Interview\_StaffB38\_Home2\_23/11/19]

The carer’s perception was that kitchen staff worked to exacting deadlines. When I spoke to a member of the kitchen team in that home, and asked them to describe their day, this perception was strongly borne out:

*“Well when breakfast is out the way obviously I start on lunch, and when lunch is out the way I start on tea – so you don’t tend to get a bit of a break really.”*

[Interview\_StaffB18\_Home2\_19/12/19]

Notwithstanding the detrimental effect on the kitchen staff themselves, it was clear this kind of tight schedule could have consequences for mealtime care. For one thing, there was the sense that a rushed mealtime was less likely to be a pleasant, sociable experience. A senior member of staff had strong views on this:

*“They [staff] forget it’s their [residents’] social time, and they can try and rush at times. You’ve probably witnessed it yourself, where plates getting taken away or a meal is not finished and desert is getting put down and that gets on my nerves. To the extent like ‘give them time!’. It’s a 12-hour shift. There’s no reason for that dining room to be emptied in 20 minutes. Let them have that bit of social time. You’ve seen in the lounges. They go in the lounges after meals, they fall asleep so there’s no social interaction unless they’re getting involved in activities... where in the dining rooms, a lot of them, especially men, stay in their rooms, so the only interaction they’re getting is at a mealtime.”*

[Interview\_StaffB42\_Home2\_19/12/19]

In addition, time constraints had the potential to affect the way carers assisted residents at mealtimes. This was exemplified during a lunchtime in Care Home 1. Lunch was late in starting; the food trolley had arrived from the kitchen 15 minutes later than scheduled, but it would be collected at the same time as normal. I watched a carer helping a resident who tended to have only light-touch assistance. For the main course, the carer cut up the food and then left the resident to eat it independently. For the pudding, however, they took a different approach:

*StaffA8 brings Gracie the pineapple upside-down cake. She tries to directly assist her to eat; Gracie looks surprised by this, turns her face away and grabs for the spoon.*

[Field-notes\_dining-room\_Home1\_lunchtime\_01/11/19]

Looking at this in context, I wondered if the carer became more hands-on in their assistance as the time neared one o'clock – compromising Gracie's independence as a result. In interviews, I heard other participants describe the challenges inherent in allowing sufficient time for residents to eat independently. A visiting professional told me about this, in relation to their personal experience with a family member living with dementia:

*“It takes absolutely ages so, for example, a bowl of sponge pudding and custard might take an hour to eat and I think that the time is essential because if she's pressurised into – well she's not eating it... It's not that she didn't want it. She will eat it. She just can't eat it quickly. The whole effort of getting something on the spoon, getting it into her mouth, chewing it, takes so much longer than it ever did before, so you've got to allow her that time.”*

[Interview\_VisitingProfessionalA1\_Home1\_08/10/19]

Evidently, time was an important resource in mealtime care. I had seen, and heard, that it could be squeezed by the operational demands of the kitchen. I also noticed it was impacted by staff numbers on the care home floors. When I asked one care assistant what they would change about mealtimes, they said:

*“We would need more staff – not just to actually assist them and not just to give the food out. We could just sit with them and just chat with them, just like how you would usually do. Just not be rushing, because obviously you can't help it when you just need to get things done. Because obviously if we speak to one resident too much we've got to remember that there is somebody else that needs assisting and might need help.”*

[Interview\_StaffA08\_Home1\_08/01/20]

I noted the frustration expressed by this carer – about care being confined to the essentials; about the potential for better care if staffing was increased. They wanted to do more, but were limited by factors outside their control. Another carer explained that even basic care was sometimes compromised by staffing levels:

*“On the middle floor there's a more hands on approach where they need more help, they need assistance. And when you do that, really you should be doing it one-to-one. You shouldn't really be trying to assist two people at the same time, because you're not giving them your full attention.”*

[Interview\_StaffA3\_Home1\_09/01/20]

A care assistant in Care Home 2 echoed this concern, when describing the challenges of providing adequate support to residents with advanced dementia:

*“Oh, it’s really hard. You’ve got to have quite a few carers so you’ll [ideally] have one carer at the table watching, whereas [instead] they’ll give them their dinner then they’ll walk away and start at the next table.”*

[Interview\_StaffB31\_Home2\_04/12/19]

I inferred from this that carers might cut corners at times: providing less assistance and supervision than they would wish to. On occasion, I saw that this could actually have positive unintended consequences; namely when it created more opportunity for independence. For example, I observed a mealtime during which the staff had seemed particularly stretched to care for the numbers of residents involved. Two residents, whom I had seen receive moderate levels of support at previous meals, were left to eat and drink independently – and, in fact they did so, without any significant problems. I reflected on this in my field-notes:

*There is limited assistance for either resident here – this may be at least partly because of staff numbers, and the need to focus on a resident who requires full assistance. Is the residents’ independence being maximised here by accident?*

[Field-notes\_lounge\_Home1\_teatime\_10/10/19]

This idea was echoed in a conversation I had with a care assistant, when I spoke to them about the way they set up residents at the beginning of a mealtime to promote independence. The carer’s comments seemed to frame this set-up process as a pragmatic response to staffing levels – necessary in the circumstances, but less preferable than one-to-one supervision:

*“It’s just the little things are sometimes the most important things to make sure – because we can’t sit with everybody.”*

[Interview\_StaffA3\_Home1\_09/01/20]

I was prompted to think that, for some residents, an assumption that they always needed high levels of support may have limited their ability or motivation to act more independently at mealtimes. However, this did not take away from the fact that reduced staffing seemed to be broadly detrimental to residents. There was acknowledgement that staff-resident ratios, even when on target, could quickly become inadequate:

*“If you’ve got three staff and somebody needs your assistance – say they need to go to the toilet or they’ve actually had an accident – then that takes at least one member of staff away from the dining room. Because that person has to be dealt with, you can’t leave a person like that. It’s not fair to the other residents and it’s not fair to them. .... You’ve got to take them away and see to them, so it takes a person away. That means there’s two left to run the dining room.”*

[Interview\_StaffB33\_Home2\_05/12/19]

Thus, staffing numbers constrained the care that was provided at mealtimes. In addition to this, I noticed that the way in which staff were allocated across the various units of a care home could potentially have an impact on care. In both homes, some staff were assigned long-term to a particular floor or unit, while others rotated and could find themselves working anywhere within the home on any given day. The prevailing view from staff in these homes was that fixed allocations were preferable. They explained that working with the same residents on a regular basis meant they got to know them better, learning their likes and dislikes, and other important information:

*“It’s much easier because I think if I go on a different floor, you’re sort of like blinded so you don’t obviously know the residents as much as what you should if you’re working with them so it does make mealtimes especially harder. ... Because you don’t know what they prefer.”*

[Interview\_StaffB38\_Home2\_23/11/19]

*“I think the main thing for me is you’ve got to know the residents that you’re dealing with. I mean some of the girls will go off onto another floor. They don’t know the resident and that resident could be a diabetic. That resident might say, ‘Oh can I have a bit of cake?’ If that member of staff doesn’t know, gives them a bit of cake then, you know...”*

[Interview\_StaffB40\_Home2\_13/12/19]

I was interested that the care assistants I spoke to tended to express a preference for working consistently on the same unit – and yet, in both homes, staff were often asked to rotate around the units, working in different areas from shift-to-shift. When I spoke to a senior member of the management team in Care Home 1, I questioned this. Their response revealed an alternative perspective:

*“I think they forget a lot of times that people can change their minds. ... A lot of the time people will say, ‘She doesn’t like that,’ and it might just be that they’ve refused it on one occasion. ... I think sometimes staff think because they’ve looked after somebody for a long time that they know what they want and they know their preferences. ... I think sometimes a fresh pair of eyes notices different things. Sometimes the staff become complacent.”*

[Interview\_StaffA15\_Home1\_22/07/20]

This seemed a valid argument, and indeed it corresponded to work by Driessen and Ibanez Martin (2020, p. 252), which contends that residents do not always have stable preferences. Staff with a fixed allocation have the advantage of long-term knowledge, but staff who are floating have the advantage of fresh perspective. It could be, therefore, that

both approaches have merit. However, the broader point I took from this was the potential for disconnect between care assistants and management. In this case, care assistants had their own instinctive or experiential idea of good practice, while senior staff may have looked at the issue in a different way. Ultimately, it was senior staff who decided on staffing allocation – and in so doing, shaped the way that care assistants went about their work.

I noticed something similar in respect of staff sitting and eating with residents. I had already seen this was a recommended mealtime care practice in the guidelines literature – as a way of modelling eating and drinking behaviour, as well as an opportunity for social interaction. In my observations, though, it was more usual for staff not to do this, and instead to wait until their breaks to eat – or to eat quickly ‘on-the-go’. In this extract, two care assistants demonstrated contrasting approaches – and I reflected on why this might be.

*Most residents in the dining room have finished their cereal now, and some have moved onto cooked breakfast. StaffB4 asks StaffB35 if she’s having some breakfast – StaffB35 says “I’ve pinched a slice of bacon”. StaffB35 and StaffB37 stand in the kitchen eating bacon sandwiches, while StaffB4 takes her cooked breakfast over to Clara and Daphne’s table and sits with them. (Note: There are different approaches here taken by the staff – StaffB4 appears comfortable with spending a few minutes to sit and have her breakfast with the residents, whereas the other staff eat quickly, standing up – do they feel a pressure to quickly resume their work?)*

[Field-notes: dining room, Home2, breakfast 05/12/19]

When I broached this subject on a different occasion with one of the carers, they implied that not all senior staff were in favour of the practice (and it was also evident from this field-note that there were practical challenges):

*As the residents are finishing their pudding, StaffB4 sits down with a portion of chicken pie, on a table with one resident. As she eats, I comment on the fact that she is doing this – she tells me “This is the only floor you’re allowed to do it.” I say I saw it happen on another unit earlier in the week. She says “Let’s put it this way – it depends which seniors are on!” She tells me it is actually quite difficult, because she will often still need to get up to assist a resident. In fact while we are talking, a nearby resident asks for another yoghurt – she stands to go to the kitchen, but StaffB35 has overheard and gets the yoghurt instead.*

[Field-notes: dining room, Home2, lunch 16/11/19]

On further exploration with participants, it seemed to me there may have been some miscommunication between senior staff and care assistants on this topic. In interviews, senior staff in the same care home expressed broad support for eating with residents. Albeit, certain caveats were mentioned, as in this extract:

*“They could sit and have it but it should be maybe just one staff or two at the most. Maybe one on each table if it was something like that and then that should be a proper sit-down meal with the residents to give a normality to the occasion. What I don’t want to see and I do see is the pickers and the ‘well I’ll have it over here’ where it’s away from everybody and that’s not part of the socialisation, the interaction, the engagement, everything that’s good about having a meal is spoilt if somebody is just going to sit away from everyone and then they don’t even know what’s going on.”*

[Interview: StaffB28, Home2, 12/12/19]

*“As long as the residents are fed. As long as they’re being seen to and as long as everything is running smooth: sit down with the residents*

[Interview: StaffB42, Home2, 19/12/19]

The implication was that eating with residents was a good thing – so long as it was done in the right way. This was echoed in comments from a family carer:

*“When I first come here, I was shocked because I was a manager and when I seen the staff walking around with their plates in their hands and eating and walking around and... I thought, ‘My God. How professional is that? Not!’ But that’s – they’ve got the permission I suppose off the manager. Now staff sitting down – separating and sitting down and eating with the residents is a different thing. That is interacting.”*

[Interview: FamilyCarerB1, Home2, 14/11/19]

It appeared there was general recognition of the value of staff sitting and eating with residents. However, I sensed that what was missing was a ‘top-down’ firm commitment to make it happen. I heard managers endorse the practice in interviews, but with reservation. I saw staff trying to enact it in observations, but in a way that felt hurried, and compromised – sometimes because of time pressures, sometimes because of uncertainty about senior colleagues’ expectations. I asked a care assistant in home one where the impetus came from to sit and eat with residents:

*“I think that’s what we’ve done, like, ourselves. I think at first quite a few people were just paranoid and thought: we work here, are we meant to eat? But then I think you just... at the end of the day, if it’s going to encourage them then you should do it.”*

[Interview\_StaffA08\_Home1\_08/01/20]

My analysis was that some staff did not feel empowered or encouraged to give care in this way – just as they were not always empowered to take adequate time over mealtime care, or to provide continuity of care. These things were, in some important respects, outside of their control; they were constrained by other factors, such as kitchen timings, staffing ratios, and management policies. I heard another pertinent example of this, when a staff member in Care Home 1 told me about their ability to respond to residents’ food and drink preferences:

*“Generally, from a company policy, if [residents] have got a certain type of preference then usually it’s the family members that would provide that preference. Because obviously that preference is outside of our menu. And then you go along the lines of – we’ve got to control everything that comes into the building so it’s got to come to the kitchen. I’ve got to label it. I’ve got to check it and things like that. ... We do try and pander to their needs, kind of thing, but as a company they don’t necessarily recommend it because it’s added cost and stuff.”*

[Interview\_StaffA14\_Home1\_10/03/20]

Thus, administrative and financial considerations, alongside other organisational constraints, impacted on the care that staff were able to provide. It was tempting to characterise frontline, direct care staff as the ‘heroes’ in this, and other departments as the ‘villains’ – with frontline staff thwarted in their endeavours to give good care by the unreasonable agendas of their backroom colleagues. However, as I thought more about what I had seen and heard, I came to understand that this characterisation was not only unhelpful; it was inaccurate. In truth, each of the various departments within the care homes was operating within necessary parameters which constrained their work. Kitchen staff had to turn meals round on time. Management staff had to meet regulatory requirements and balance the budget. These were important aspects of the running of a care home. The problem was that they had unintended consequences for mealtime care. In particular, I noted that organisational constraints made a person-centred approach more difficult. At times there was a risk of the needs of the individual becoming subservient to the needs of the organisation. I have already presented examples from the data where a resident’s need for more time to eat and drink independently – or for greater social interaction at mealtimes, or for freedom to choose the food they like – was not fully met because of organisational pressures. Most obviously, financial constraints resulted in staffing constraints which resulted in time constraints.



Through further exploration, via observations and interviews, I discerned a way that those pressures might be relieved – a way in which the organisation could better serve the individual. As outlined at the start of this chapter, care staff did not interact with residents in a vacuum – rather, they were one of many parts within an interconnected system. It became apparent to me that the strength of connection between those different parts was central to the quality of mealtime care. When they operated separately – with different aims and perspectives – care was soon compromised. When they came together – through collaboration, sharing and problem-solving – care seemed to be at its best. In this way, I saw that the system could be transformed, potentially, from something that constrained care to something that enabled it – with a crucial added ingredient that was both free, and readily available: teamwork.

### **6.3 Teamwork in mealtime care**

I saw and heard teamwork in mealtime care expressed in various ways and at various levels. Most obviously, I saw it when staff providing direct care at mealtimes worked together well. This is illustrated by the following field-notes from Care Home 1, in which two carers are helping Jeff at teatime. One was the senior carer on the unit and knew Jeff well. The other worked more often as a kitchen assistant, and was less familiar with the residents. I noticed that the senior carer shared their knowledge about Jeff, which optimised his care:

*Jeff is eating a sandwich from a plate. Abruptly, and before he has finished, he throws the plate onto the floor. StaffA12 picks it up and then fetches another sandwich on another plate. StaffA10 says he might not want it and might want pudding instead. StaffA12 takes away the sandwich and puts the bowl of ice-cream on the small table in front of him. He ignores it. Shortly afterwards, StaffA10 goes over and moves the bowl closer to him, and verbally encourages him to have some. He begins to feed himself steadily. Sometimes he gets distracted by his bib again and begins to fiddle with it. StaffA10 asks StaffA12 to get him a second pudding, as he often has two puddings.*

[Field-notes\_lounge\_Home1\_teatime\_10/10/19]

The importance of sharing knowledge – and concerns – was articulated in interviews by several care assistants; for example:

*“All the staff will just – we always work together. We’re a team. It’s no good me knowing what’s good for that resident if I don’t pass it on to everybody else because she won’t get the same care when I’m not here if that’s the case. Everybody knows and we all follow it.”*

[Interview\_StaffB33\_Home2\_05/12/19]

*“We’ll come onto the floor, and sometimes I’ll say to whoever of the girls who’s been on that floor before, I’ll say to them, ‘Who had a bad diet yesterday?’ Or, ‘Who’s not drinking so good?’ So that I can try and encourage them. As long as I know who it is then I’ll try to, you know, encourage more and just be a bit more hands on to try and make it a better day.”*

[Interview\_StaffA3\_Home1\_09/01/20]

I also heard staff describe the ways in which they co-operated at mealtimes, to ensure that they were organised more efficiently. This seemed particularly necessary when residents were dispersed in different locations at mealtimes (such as the dining room, lounge and bedrooms). Sometimes this co-ordination happened via brief discussions to allocate tasks and responsibilities; sometimes it appeared to be more instinctive. Often it was accompanied by friendly and humorous interactions.

*“It’s always best to know what everybody’s doing. I don’t know if you’ve seen it happening but we usually group together before dinner time and we’ll say, ‘Right, you do drinks. I’ll serve, you run. You do bedrooms...’ Whatever. Like that, so everybody knows what they’re doing...”*

[Interview\_StaffB33\_Home2\_05/12/19]

*“We all know where we’re going and we all have our own jobs in a way, so it runs quite smooth.”*

[Interview\_StaffB30\_Home2\_20/11/19]

*The staff on duty today seem to have a natural connection with one another; there is often singing, and laughter ... There is obvious camaraderie.*

[Field-notes\_Home2\_breakfast\_28/11/19]

This kind of close teamwork between care assistants was evident in both care homes. It seemed intuitive to me for care assistants to collaborate in this way; they spent their working days side-by-side, attending to the same tasks. It did not always happen exactly like this – in another part of my field-notes, I reflected that “I have seen care staff go about their business in quite a functional way, providing mealtime care without a great deal of interaction between them” (Field-notes\_Home2\_breakfast\_28/11/19). But my general impression from the data was that carers operated as a tight-knit unit, to the benefit of mealtime care.

Co-operation between different departments within the homes seemed more sporadic. In Care Home 2 particularly, I noted a certain lack of connection between kitchen staff and care staff. At a basic level, they were physically separate from one another. The kitchen

was in the basement, set apart from the rest of the home. I picked up this sense of separation in interviews with the kitchen staff – for example, when I asked their views on what was important in mealtime care for residents with dementia:

*“I don’t know. I don’t know because like I say, I’m not there. I don’t know what they do at mealtimes or how they do it.”*

[Interview\_StaffB19\_Home2\_02/12/19]

*“I don’t really intervene with the residents as much. I just normally see ... if there’s something I hear, I just ask the carers straight away because sometimes I don’t really feel comfortable, in a way.”*

[Interview\_StaffB20\_Home2\_02/12/19]

*“Obviously we don’t deal with the care side ... or the dementia side.”*

[Interview\_StaffB18\_Home2\_02/12/19]

The kitchen staff seemed to perceive a clear distinction between kitchen work and care work. That is certainly not to say they were not helpful, or that they did not see their work as directly beneficial to residents. For instance, a member of the team explained to me how they liaised with care staff to provide responsive care:

*“Throughout the day if anyone needs anything the carers just ring down and say ‘Have you got such and such?’ and we take it up. Or, say someone had been at hospital or something in the morning, the staff will ring down and say, ‘Can I have a cheese sandwich?’ Do you know what I mean? So they’ve always got something.”*

[Interview\_StaffB19\_Home2\_02/12/19]

My analysis was that their contribution was vitally important – but it happened within a silo. In Care Home 1, by contrast, ‘kitchen’ and ‘care’ appeared to be more cohesive. This was epitomised by a member of kitchen staff who spent time each day in the dining room, helping with the mealtime service. In their interview, it was notable that they spoke in a holistic, resident-focused way about their work:

*“I think if I had to trade being on time all day or rushing a resident, I think I would prefer to be late. I’m not going to rush them. I’ve spent nearly an hour one day upstairs, it’s just when I’ve got back to the kitchen then obviously I’ve got to push myself a little bit to catch myself up. But you can’t rush them and I don’t care how long it takes as long as they’re getting something. Yeah so it is a lot of pressure when things like that happen but obviously you don’t show that pressure because it’s important for the residents. You want them to be relaxed, you want them to sit, enjoy the food and if that takes 10 minutes, if it takes an hour, I’m not bothered.”*

[Interview\_StaffA14\_Home1\_10/03/20]

I sensed that this holistic approach, this greater connection between kitchen and care, could have a potentially powerful impact on mealtimes. I wondered if it was significant that the kitchen here was physically linked to the rest of the home, in a way that was absent in Care Home 2. In Care Home 1, it was directly adjacent to the ground-floor dining room, joined by a hatch – the kitchen staff could see and hear the residents, and the residents could see and hear the kitchen staff. I noticed that kitchen staff sometimes stood at the hatch, interacting and joking with the residents – they were at the interface, as exemplified here:

*StaffA12 is working as kitchen assistant today. From time-to-time he stands at the hatch, which is near to Daisy and Elsa's table. There are various jovial exchanges between StaffA12 and the two residents. Elsa lifts up her empty glass and waves it in his direction. He asks if she'd like a glass of whisky; she says "I would! That'll make me sit up straight!" (She does sit up straighter.) StaffA12 comes out of the kitchen: "She wouldn't refuse it you know!" He rubs her back and pours her a glass of juice. The mood is lightened, and Elsa eats a bit more of her dinner.*

[Field-notes\_dining-room\_Home2\_lunchtime\_09/10/19]

I have already cited this extract – in chapter 4 – to illustrate how staff can facilitate a sociable atmosphere at mealtimes. On further analysis, I saw it as noteworthy that this staff member was, officially, working as a kitchen assistant. In practice, their role appeared to merge seamlessly here into that of care assistant. This team approach – without obvious boundaries of role – seemed beneficial to everyone involved. The kitchen assistant was sensitive to the needs of the resident and able to respond directly; the care staff were supported in their workload; the atmosphere in the dining room was convivial and relaxed. Constraints of time and resource were, even if just in that moment, transcended.

I was also interested to explore the relationship between care assistants and senior staff – and the effect of this relationship on mealtime care. As with kitchen and care staff, I was aware of moments when the two groups were 'out of sync' with one another; I had noticed different perspectives, or even miscommunication, on issues such as staffing allocation and eating with residents. However, I also saw – and heard about – instances of senior staff and care assistants working together very effectively. This seemed to happen particularly when they faced the challenge of caring for a resident who was eating and drinking very little. My perception was that the staff groups came together strongly

around these difficult cases – with senior staff often leading the process. A member of the senior team in Care Home 2 told me about how they dealt with this:

*“It’s sometimes difficult, and maybe that’s where supervision is important, discussing about a certain client, you know, ‘Have you got problems with anybody?’ ... It’s about having that discussion and saying, ‘Look what you’re doing is fine, you’re offering different types of food, you’re doing a good job’.*

[Interview\_StaffB28\_Home2\_12/12/19]

Later in the interview, I asked them to elaborate on their interactions with the care team in these situations. They described a consultative, two-way approach:

*“Put them [the care assistants] fully in the picture of what’s going on: that we’ve reported this to a GP or we’re going down this route and we’re a little bit worried, saying we share your concerns... ‘Please monitor it carefully – we appreciate that it’s... the job your doing is really good’ and you know, value the carer and give feedback and maybe any special instructions we can give. But it’s about not making it that individual’s responsibility, but sharing the responsibility.”*

[Interview\_StaffB28\_Home2\_12/12/19]

I noted that the senior staff member spoke about valuing the contribution of their care assistant colleagues. This sentiment was echoed by another member of the senior team, when talking about the same subject:

*“They [the care assistants] are quite observant; if they don’t feel... they’ll come and say to me, ‘I don’t think he’s quite right,’ or, ‘I don’t think she’s quite right.’ They’ll keep an eye on them, and I do food and fluid charts.”*

[Interview\_StaffB41\_Home2\_19/12/19]

Good communication, with everyone playing their part, seemed key to managing these challenges. It was also evident that a collaborative way of working may have helped to reduce feelings of burden and pressure in relation to mealtime care. I had heard various staff members describe this kind of emotional response to eating and drinking difficulties (as documented in chapter 4); now I began to see how teamwork could potentially alleviate such feelings. A member of the management team in Care Home 1 expressed the importance of talking to care assistants in these moments, to provide support and encouragement:

*“Sometimes you can go to assist somebody and they won’t accept anything from you, but they’ll accept it from somebody else. And especially the newer members of staff take that personally, but it’s about supporting them and letting them know ‘it’s not just you’. And [the resident] might not accept something from you, but*

*you go back and try again, or you get somebody else to try, or you offer the resident something different.”*

[Interview\_StaffA15\_Home1\_22/07/20]

Indeed, it was not only less experienced or less senior staff who benefited from discussions like these. A member of the senior team in Care Home 2 explained how problem-solving with colleagues helped them to manage their own response to complex cases:

*“The onus isn’t on you. You’ve got a plan in place, you can write that into your care plan that maybe we need to... from a monthly weight we need to go to weekly, we need to make sure that they are getting – they’re eating everything but it’s at the expense of having meals. Let’s fully focus on what they’re eating at the moment so those are the type of things that might be discussed sort-of-thing and it just, it gives everybody in the team confidence to try and tackle it in a different way and it doesn’t mean that it’s falling upon you; ‘Oh that guy’s losing weight. I’m responsible and I’m his named nurse...’.”*

[Interview\_StaffB28\_Home2\_12/12/19]

Thus, I saw examples of a positive, mutual relationship between management and carers. In particular, I heard senior staff articulate respect and appreciation for the care assistants’ input. This tended to be in the context of tackling the challenging issue of reduced eating and drinking. My sense was there were missed opportunities, in both homes, for this kind of teamwork to be replicated in other operational areas. I wondered, for example, whether care assistants and other less senior staff could be more closely involved in decision-making about floor allocations, or about menu planning, or about sitting and eating with residents. Collaboration around reduced eating and drinking seemed to me to be good practice, which could – potentially – be applied elsewhere.

So far in my analysis, I have described the care team around the resident as consisting of care home staff. However, it was strongly evident from observations and interviews that this team actually extended beyond the boundaries of the home – to become what could be termed a “wider care team”. I noted, for example, the importance of interactions between care home staff and external health and care workers – such as GPs, dietitians, SLTs, and community nurses. In one of the previous extracts above, a care home worker talked about liaising with their GP, and in several interviews I heard care home staff refer to seeking out external support in this way. This senior staff member, for example, was able to recognise when they needed help – and they knew where to find it:

*“And then you’ve got residents where they just won’t eat at all. They’ve forgotten how to do that and that’s when we get the dietitian involvement because that’s where we’re struggling, so then we need to go and it’s about saying, ‘We are struggling, so we need support in this area.’”*

[Interview\_StaffB41\_Home2\_19/12/19]

Similarly, when I asked a care assistant about what action they took when facing challenging situations, they told me:

*“Well you’ve got to get the practitioners in, and they come and do an assessment of how you’re going to best deal with it.”*

[Interview\_StaffB31\_Home2\_04/12/19]

As I explored further the relationship between care home staff and external support, it became apparent this was not necessarily a deferential relationship, whereby responsibility for care was delegated to ‘experts’. Rather, when the relationship worked well, it seemed to be collaborative, and mutual – a joint effort between care home staff and the external team to resolve problems and dilemmas. This is illustrated by the following extracts, taken from conversations with a care assistant in Care Home 2, and a GP visiting Care Home 1:

*“SALT [Speech and Language Therapists] are good to advise and help. We tell them what we think would be best for that resident. Obviously, we’ve known [the residents] longer, what they will eat, what they won’t eat, what sort of fluid intake they’ve got...”*

[Interview\_StaffB42\_Home2\_19/12/19]

*He [the GP] says that GPs are only able to do one-off assessments, so really good information from staff makes him feel safe. He gives an example of a nurse he has worked with previously, who kept really good charts and weights. And he says he feels reassured when [this carer] gives him information about a resident.*

[Field-notes\_Home1\_19/11/19]

Both extracts highlighted to me the value of people working together as peers – with no obvious sense of hierarchy, and acknowledging the different and complementary skills and experience that each side brings to the situation. In both cases, there is a sense that the role of the care home staff in these interactions is valuable, and valued. It seemed to me that this kind of mutual respect was empowering of staff, and facilitative of good care. In the best examples, care home staff were not working in isolation, worrying about whether they were doing the right thing or fearful of giving their opinion. Instead, they

felt confident to share their knowledge and make their contribution – to the benefit of the residents.

Finally, I saw teamwork in mealtime care expressed through the involvement of family carers. To illustrate: in Care Home 1, Ian’s family visited every Saturday lunchtime. He preferred to eat in his room, and needed a lot of assistance – his family were happy to help with this:

*Various family members are present. Ian is sitting in a comfy armchair. A member of care home staff has brought the first course on a tray – vegetable soup. The family suggest that they assist, and invite me to stay during the meal. His daughter takes the soup; she is sitting slightly behind Ian on the bed. She is directly assisting him, at a suitable pace. Ian seems to enjoy the soup and eats all of it.*

[Field-notes\_resident’s-room\_Home1\_lunchtime\_21/09/19]

In this kind of way, I noted that family carers were able to complement or augment staffing at mealtimes. I asked one of the senior staff in Care Home 2 about this. They made the point that some residents may be more receptive to assistance from family – or other loved ones – than from care home staff:

*“You could have a resident, especially with dementia, where they will eat better with somebody present. They might, if they’re being assisted to feed, they might take their food better off daughter, mam, whatever...”*

[Interview\_StaffB42\_Home2\_19/12/19]

This was echoed by an external healthcare worker who was a regular visitor to Care Home 1. They suggested there were certain advantages that loved ones had, which helped them to assist in mealtime care:

*“Family have that time and that relationship with the person. ... I know today there’s somebody upstairs, a member of their family has come in to give them lunch, so I have seen it. I’ve seen it in this home before and I know families have commitments, people still work and not everybody can do that and it doesn’t have to be family. It might be an old friend or something ...”*

[Interview\_VisitingProfessionalA1\_Home1\_08/10/19]

I was interested to hear this reference to ‘time’ as playing a part here. The interviewee was highlighting the importance of this resource – often in short supply among care home staff, sometimes (though not always) more abundant among family or friends. By joining in with mealtime care, family were unofficially expanding the care team still further – beyond care home staff, and beyond external health and care workers. As such, some of



the constraints of staff shortages could, potentially, be overcome. I saw this enacted in mealtime observations – not just when family carers gave direct assistance to residents, but also when they provided them with valuable social interaction. During one lunchtime in Care Home 2, I spoke with a family carer – whose mother was called Muriel – about her role in mealtimes:

*Muriel is sitting on a nearby table, with her daughter Alison, and another family member. Alison talks to me about the atmosphere in the dining room: “They are often chatting in this dining room; it might be muddled, but at least they are chatting. They are a bit regimented about where they sit.” She also tells me about her visits to the home: “The staff have cleared it for me and [another family member] to come in at mealtimes and eat with my mum. When the residents have finished, and if there is some food left over – there usually is.” She tells me that she and [another family member] also take mum out for meals periodically, to local cafes.*

[Field-notes\_dining-room\_Home2\_lunchtime\_12/11/19]

Muriel’s daughter visited the home at several mealtimes each week, sitting and eating at the dining table with her mother and fellow residents. Her circumstances were such that she had time to do this. This seemed to me to be a relatively simple (and cost-free) way to resolve some of the challenges of finite resource in care homes. It is important to acknowledge that not all residents were as fortunate as Muriel, in the sense that their family were too far away, or too busy, to visit regularly. Indeed, some residents had no remaining family to which they were connected. In this respect, Muriel was in possession of more social capital than some of her contemporaries (Furstenburg & Kaplan, 2004). That said, her daughter was notably inclusive of other residents in her mealtime interactions, chatting quite naturally with a range of people and even providing assistance at times – as in this later extract from the field-notes:

*Ken is unhappy about his cup of tea: “The tea’s cold and strong. They just haven’t got time.” [Alison] goes over to Ken’s table and offers to make him a fresh cup. He accepts the offer, and she brings him the tea.*

[Field-notes\_dining-room\_Home2\_lunchtime\_12/11/19]

Alison was such a regular presence in the dining room that she appeared in some ways to have become an integral part of the home: almost a supernumerary team member, sharing the workload with staff. However, it was apparent that there were also complexities in family involvement. A detail in her remarks above points towards this – she is “cleared” to eat with her mother “when the residents have finished, and if there is some food left

over”. I explored these complexities with care home staff. There was a view, commonly expressed, that family involvement at mealtimes required careful management – to avoid unintended consequences:

*“I worked in a home prior to this one, and we used to have one family and on a protected mealtime it wouldn’t be just the son or the daughter just coming in, it would be a whole family. They used to virtually take up the dining room. You have also got people that won’t eat in front of strangers so that can be a hindrance as well.”*

[Interview\_StaffB25\_Home2\_05/12/19]

*“There’s some residents that perhaps would be better and eat better and have a better diet when the family members are present at a mealtime. It calms them down and makes them feel more comfortable whereas others, it could be a big distraction having their family there and draw away from the fact that it’s mealtimes, so it is still very individual and that’s the balancing act within a care home.”*

[Interview\_StaffB39\_Home2\_13/12/19]

This was the same ‘balancing act’, of recognising and meeting the needs of individual residents in a group setting, that necessarily informed all aspects of mealtime care. One care assistant I spoke to suggested a way to involve families which would not impinge on other residents – by making use of a suitable private space in the care home (such as the activities lounge):

*“We used to set up a table, and families would come in and we’d have the resident in [their] with their families. They would sit with them and sometimes it works better with family because they’re more of a familiar face and they eat better.”*

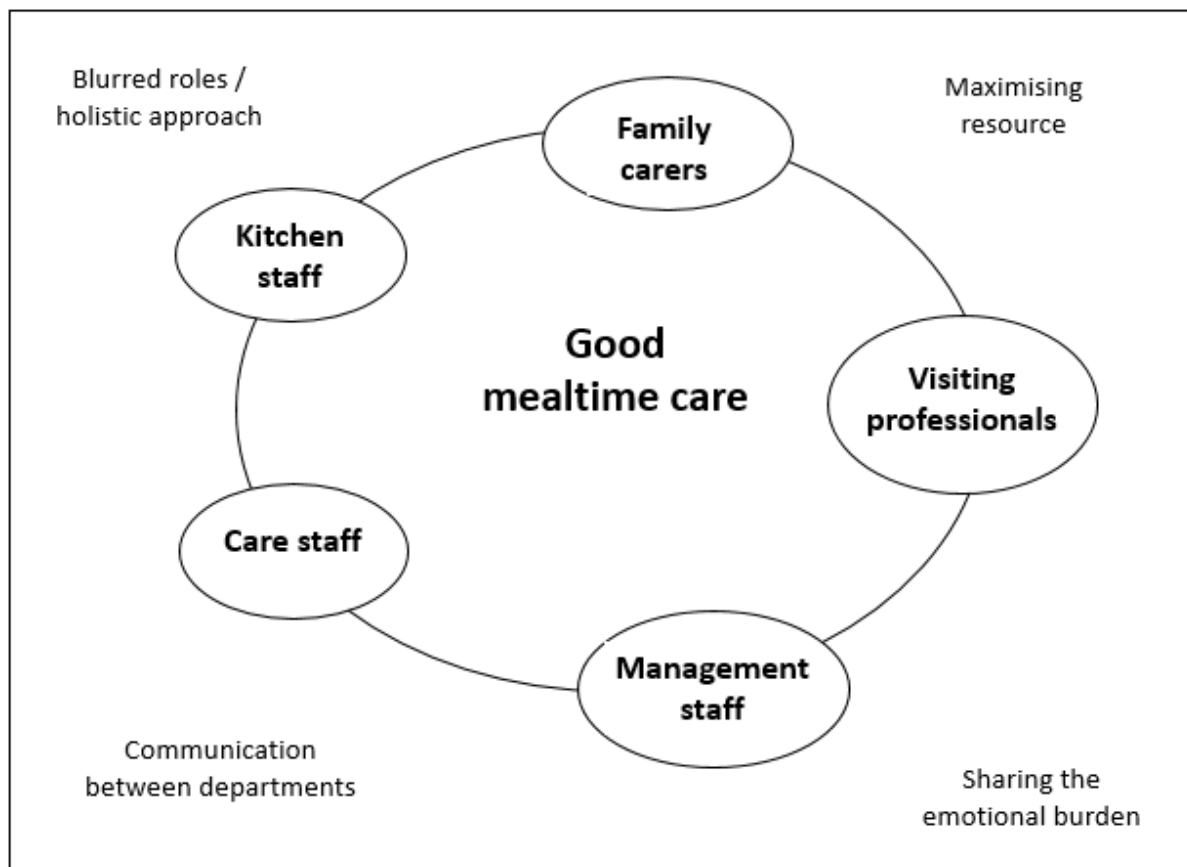
[Interview\_StaffA8\_Home1\_08/01/20]

My inference from speaking to these staff was that it was idealistic always to expect family members, care staff and residents to co-exist in the home in perfect harmony. Certainly, there were complexities to address. However, I also saw that with a careful and joined-up approach, families could become an important part of mealtimes – relieving some workload pressure from staff, and enhancing the experience for residents.

## **6.4 Conclusion**

I came to the conclusion that good mealtime care relied on an integrated approach between family, care home staff and all others who were in the ‘wider care team’ around the resident. I have represented this in Figure 6.2 below. Carer-resident interactions may

have been the most tangible expression of mealtime care, but these interactions were shaped by many other important factors. When different departments within the home worked together well – for example, the care team and the kitchen team – resource was maximised and care was enhanced. When staff and management communicated effectively, burdens were shared and problems were solved. When external healthcare professionals and care home staff collaborated as equal partners, staff were empowered and residents received appropriate specialist input. When families were carefully incorporated into mealtime care, this was to the benefit of not only their loved ones, but also – sometimes – other residents too. Mealtime care was the product of a system. For mealtime care to be at its best, the various elements of that system needed to be in tune and in sync; teamwork helped this to happen.



**Figure 6.2: Teamwork in mealtime care**

In the next chapter, I describe in detail the co-development process. I explain how evidence from the ethnographic study and the literature review was summarised for use in

a series of co-development workshops, and how the workshops resulted in a prototype mealtime care training intervention.

## **Chapter 7. Co-developing a prototype intervention**

### **7.1 Introduction**

This chapter describes the co-development work which generated a prototype intervention for mealtime care training. In the first part of the chapter, the methodology and theoretical framework underpinning this phase of the research is presented. After this, the methods are described; I explain how participants were recruited, and how the workshops were designed. Finally, the results from each workshop are reported, including decisions about content, mode of delivery and implementation which informed the prototype intervention. The prototype intervention itself is presented in Appendix X.

#### ***7.1.1 Co-development, co-production and co-design***

I use the term co-development to denote the process by which we arrived at a prototype intervention. This term is used in the intervention development literature to describe working with stakeholders to develop the content and mode of delivery of an intervention (Avery et al., 2016; Macdonald et al., 2017). It is sometimes used interchangeably with other, similar terms such as co-production (Filipe et al., 2017) and co-design (O'Brien et al., 2016; Zamenopoulos & Alexiou, 2018). While each uses specific methods, the underlying concept of working with stakeholders unites these ideas, and differences between the terms are subtle. Co-development is the term used here, because it has the most specific meaning of the three. Co-production and co-design tend to be used as broad terms to describe an overall process in which groups of people come together to influence the way that services are designed and delivered (see, for example, Department of Health and Social Care (2022), and Zamenopoulos and Alexiou, (2018)). Co-development, meanwhile, has been used to refer to the development of a tangible output within that process: an end-product, or artefact (White et al., 2021). Thus, co-development aptly describes this phase of my work, which led to a prototype manual for a mealtime care training intervention.

#### ***7.1.2 Co-development in healthcare research and intervention development***

Working closely with stakeholders is a well-established and important element of health-care research in general, and intervention development in particular (Craig et al., 2006). It is important to engage stakeholders with different roles and responsibilities – including

patients, practitioners and service managers – in the co-development of interventions (Glasgow et al., 2003). This provides valuable insights which help with real-world implementation (Buckley et al., 2018). Perspectives and understandings which may otherwise have been excluded are drawn into the decision-making processes (Williams et al., 2020). Thus, researchers or policy-makers are able to develop a more holistic understanding of a context, a problem or a solution (Oliver et al., 2019). Moreover, it has been argued there is a moral imperative for frontline health and care staff to contribute to research decision-making, because in most cases delivery of interventions involves them (Locock & Boaz, 2019).

The process brings challenges as well as benefits. Whilst diversity of perspective and experience is a valued element of this work, genuine and equal collaboration between diverse stakeholders is not always straightforward. It requires mutual understanding and respect of roles, contexts and contributions – with clear expectations from the outset (Rycroft-Malone et al., 2016). It can be time-consuming and expensive. There is a danger that it may be used by researchers in a tokenistic or superficial way, for example in the interests of securing funding.

Mindful of these benefits and challenges, I have worked with stakeholders throughout the research process described in this thesis. My advisory group – members of the public with insight and experience of the topic – have been integral to the design of the research. In addition, I was able to gather rich data from care home residents, staff, family carers and healthcare staff in the ethnography. In the co-development phase of the project, which is the focus of this chapter, I worked with a range of stakeholders in a series of workshops to produce a prototype mealtime care training intervention.

### ***7.1.3 Normalization Process Theory***

Some of the key questions I addressed with workshop participants were informed by Normalization Process Theory (NPT) (May & Finch, 2009). For example, we thought about how the mode of delivery could be designed to improve the intervention's chances of being implemented. NPT helps with understanding the dynamics of implementing, embedding, and integrating a complex intervention, by considering the intervention in relation to four core constructs: *Coherence*, *Cognitive participation*, *Collective action*, and *Reflexive monitoring*. *Coherence* refers to how people make sense of a new practice (for example, an intervention or a new way of working), so that they are able to enact it.

*Cognitive participation* describes how people build and sustain communal engagement around a new practice. *Collective action* is about the operational work that people do to enact a new practice, by interacting with others, building accountability and allocating resources. *Reflexive monitoring* relates to the way that people assess and understand how a new practice affects them and others. Whilst I did not explicitly introduce NPT and these constructs to participants, I asked them to consider issues of feasibility – such as the acceptability of the intervention to recipients. The idea of acceptability relates to various components within the NPT constructs, including *Enrolment* (which is a component of *Cognitive participation*), and *Individual appraisal* (which is a component of *Reflexive monitoring*).

## **7.2 Ethical approval for co-development work**

A favourable ethical opinion was obtained for this co-development work from the Social Care Research Ethics Committee (reference 19/IEC08/0020) in June 2019.

## **7.3 Methods for co-development work**

### ***7.3.1 Sampling and recruiting participants***

My principal objective in identifying types of participants for the workshops was to have representation from stakeholders in mealtime care. Stakeholders can be defined as “individuals, organizations or communities that have a direct interest in the process and outcomes of a project, research or policy endeavour” (Deverka et al., 2012, p. 5). I sought to assemble a group of people who had complementary experience and knowledge of the topic, and a direct interest in achieving better mealtime care for residents with dementia. Thus, I chose to approach family carers of people with dementia, care home staff, and healthcare professionals. To obtain a variety of relevant perspectives, I aimed to include different types of care home staff (for example, care assistants, who directly provided mealtime care, and managers, who made decisions which informed mealtime care), as well as different types of healthcare professionals (for example, SLTs, dietitians, and community nurses – each of these professions can have involvement in mealtime care issues for residents with dementia). In addition, I wished to have at least one participant with expertise in the field of vocational education and training. I termed this participant an educationalist. My intention was that this person would bring specialist insight into training delivery and learning styles – important so that the format of intervention could

be designed to meet recipients' needs. I describe below how I identified and recruited the participants.

For each of the stakeholders, I used bespoke channels to circulate a publicity flyer (see Appendix R). In the case of family carers, these channels were the North East Dementia Alliance (NEDA: a partnership of health, social care, voluntary and private sector organisations ([https://www.dementiaaction.org.uk/north\\_east](https://www.dementiaaction.org.uk/north_east))), and VOICE (a community of members of the public, patients and carers (<https://www.voice-global.org/>)). For care home staff, I used a regional care homes interest group. (According to my original protocol, I had intended to recruit care home staff exclusively from the care homes who had participated in my ethnographic study. I amended this, with relevant permissions, to enable recruitment of staff from any care home. The purpose of this amendment was two-fold: firstly, to allow for new and broader input into the co-development process; and secondly, to guard against the original care homes (who had already been very generous with their time-commitment to the project) feeling any pressure to participate again. This was particularly important in the context of the COVID-19 pandemic and its ongoing impact on care homes (the co-development workshops took place in Autumn 2020).) To reach healthcare professionals, I used various professional mailing lists, including the Dysphagia Discussion Group, the British Dietetic Association Older People Specialist Group, and the regional NIHR Clinical Research Network (<https://local.nihr.ac.uk/lcrn/north-east-and-north-cumbria/>).

The publicity flyer provided brief details of the study, and my contact details. When potential participants contacted me, I sent them a Participant Information Sheet and consent form (see Appendices S and T), and gave opportunity for them to ask any questions. Because of COVID-19 restrictions, the consent process was conducted remotely, using email, electronic documentation (see Appendix U), and phone calls where necessary.

Recruitment of the educationalist happened through the local NIHR Clinical Research Network, who were able to put me in contact with a learning and development professional. This person had significant (more than 15 years) experience as a learning and organisational development facilitator. This experience included designing and delivering a range of training interventions in health and social care settings. As such, I



was expectant they would be able to provide relevant advice and ideas as we developed the mode of delivery for the intervention.

As detailed in section 7.3.2 below, there was a series of three workshops. They operated in a sequential way, such that workshop two built on the results of workshop one, and workshop three built on the results of workshop two. At the same time, each workshop had its own discrete theme and objectives. In recognition of this, I adopted a flexible approach to recruitment, so participants could attend just one workshop, two workshops, or all three. My aim was to achieve a balance of both new and returning participants in workshops two and three. This was in order to seek broad diversity of experiences and perspectives, and to bring fresh voices and challenge in each workshop – whilst also generating a sense of continuity and teamwork among participants. Therefore, I used theoretical sampling to identify participants for successive workshops, considering who had already participated, what results had so far been obtained, and whether there were any gaps to be addressed in representation or knowledge. I planned to have approximately seven participants at each workshop, allowing for slightly more than this if it enabled better representation (groups of between two and fourteen participants have typically been used in research of this kind, with some literature suggesting seven as an optimal number (McMillan et al., 2016)).

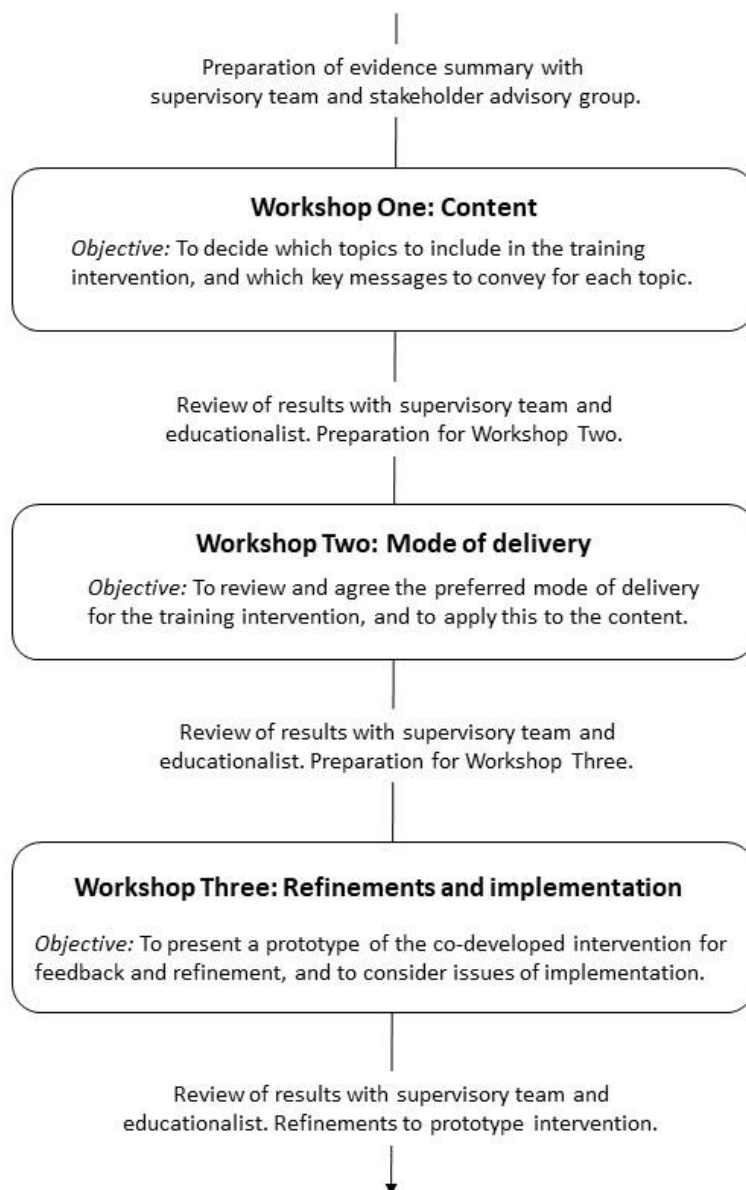
### ***7.3.2 Workshops design***

I worked with the educationalist, my supervisory team and stakeholder advisory group to design the workshops. The original plan was to run face-to-face workshops, using a university meeting room. In order to follow government guidance on social distancing, in place at the time due to the COVID-19 pandemic, this plan was amended so that the workshops took place via Zoom. In this context, I asked the educationalist to help me design the workshops – they had valuable previous experience and expertise as a facilitator, including in the facilitation of online meetings.

I wanted to ensure that participants felt comfortable taking part, and able to contribute their thoughts and ideas. To this end, I had individual contact with all participants by email or phone prior to the workshops, so that they at least felt some connection to me, even if they did not know other participants. I offered the participants a practice-run with Zoom before their first workshop, in case they were unfamiliar with the technology. I sent

out a pre-meeting note in the days leading up to a workshop (see Appendix V for an example), to brief participants and give them time to prepare.

Workshops were two-and-a-quarter hours in duration – with a short break halfway through. This was shorter than the face-to-face sessions originally planned, to allow for the increased concentration typically needed for Zoom meetings, and to guard against fatigue. There were three workshops in total, each focusing on a different aspect of the intervention: content, mode of delivery, and implementation. They were spaced approximately three-to-four weeks apart. Figure 7.1 below sets out the sequence of workshops and accompanying work.



**Figure 7.1: Sequence of co-development workshops and accompanying work**

Each workshop had the same overall structure, which was intended to build rapport and promote accessible involvement (Simons, 2012). The running-order document for workshop one is presented in Appendix W as an example. After introductions, housekeeping, and a warm-up activity, I presented relevant evidence and information, and then participants worked together to discuss key issues and make decisions about the intervention. In doing so, I adapted the co-development model set out by Moynihan et al. (2018, p. 182), whereby “concepts emerging from the evidence base were developed with the assistance of users and stakeholders’ experience and insights”. In the work done by Moynihan et al., a set of key service principles for a new food service were presented. In our workshops, we sought to agree principles for intervention content and mode of delivery – as informed by evidence from the literature review and ethnography.

The workshops were facilitated by me, with assistance from the educationalist who managed any technical difficulties and summarised some of the discussions. Thus, the educationalist performed a dual role in workshops: contributing knowledge and ideas about mode of delivery, as well as assisting me in facilitation. All workshops were audio recorded and transcribed automatically using Zoom functionality, and transcripts were subsequently checked, corrected and anonymised by me.

#### **7.4 Trustworthiness of research**

In lieu of any guidance specific to co-development work, I followed established principles on how to conduct rigorous qualitative research. After each workshop, I reviewed the transcripts and reflected on the discussions and decisions made, whilst writing reflexive notes. In this process, I aimed to scrutinise my own relationship to the research – taking into account my professional background as an SLT – in order to identify potential bias in the workshop process and outcomes (Dowling, 2006). I then met with the educationalist for a de-briefing session, in which I provided my reflections on the workshop, and my account of the decisions and agreed actions, to check this was consistent with their understanding of these. Subsequently I consulted with my supervisory team, sharing results from the workshop and explaining next steps (Whiteley, 2012). Finally, at the subsequent workshop I presented a summary of discussions and decisions from the previous workshop, to give an opportunity for participants to challenge or refine this – a process akin to member-checking (Johnson et al., 2020). It was possible to do this because there was a degree of continuity in the participants attending each

workshop. Four participants at workshop two had also attended workshop one; seven participants attending workshop three had also attended workshop two.

In the following sections, I describe in detail the preparation, activities and results specific to each workshop.

## **7.5 Workshop One: Co-developing the intervention content**

The objective of workshop one was to decide on intervention content; specifically, to decide which topics to include in the training intervention, and which key messages to convey for each topic.

### ***7.5.1 Preparing for the workshop***

In preparation for the workshop, I compared the evidence from my literature review (which explored carer-resident interactions, and synthesised guidelines recommendations) and my ethnographic study (which identified how good practice is enacted in real-world settings, and the challenges therein). I summarised the common themes and categories from these evidence sources. I noted that one of the themes from my review of guidelines recommendations – *Safety* – was absent from my ethnography findings. I included this theme in the presentation of evidence, with the caveat that it had been identified in one but not all sources of evidence.

In order to present the evidence in a way that was clear and accessible, I carefully considered the language used for terms and descriptions. I decided on the following terms: *Empowerment and respect; Facilitating independence; Social interaction; Being safe; Careful encouragement; Working as a team; Tailored care*. I wrote brief descriptions for each, seeking to encapsulate succinctly the meaning of the terms. I was intentional about using action-oriented, positive language. That is to say, I wrote the terms and descriptions from the perspective that carers *were* doing these things, not that they *should* be doing them. This was to reflect the fact that I had seen and heard about this good practice in reality – it was not a hypothetical or abstract concept – and my aim now was to communicate it to others.

I presented a draft of terms and descriptions to my supervisory team and stakeholder advisory group. I also explained the process by which I arrived at this summary. I was mindful of making sure that the language I used was appropriate and intelligible, and

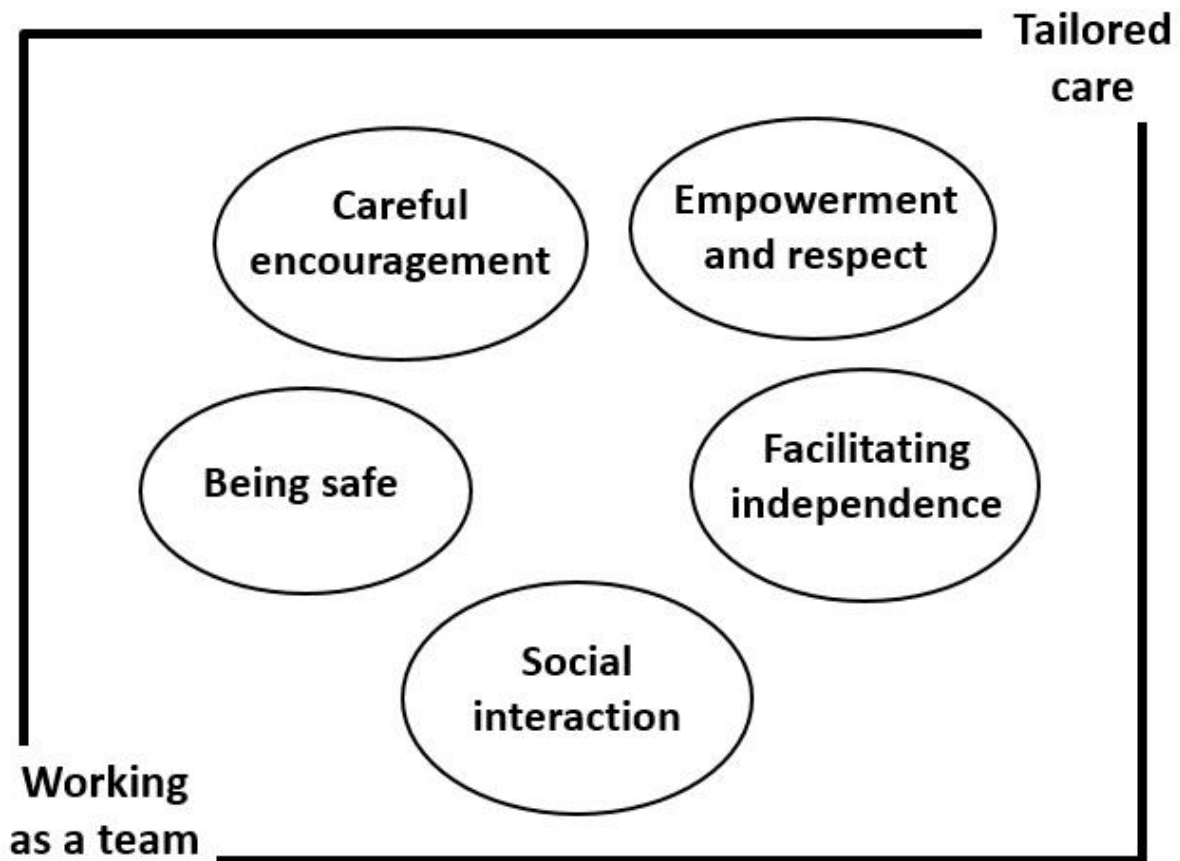
listened carefully to feedback on this (Brett et al., 2014). The finalised terms and descriptions are shown in Table 7.1 below.

<b>Term</b>	<b>Description</b>
<i>Empowerment and respect</i>	Carers enable residents to make their own decisions, where possible. They understand residents' preferences and respect their choices.
<i>Facilitating independence</i>	Carers vary the amount and the type of assistance they give at mealtimes, depending on individual need. Setting up the mealtime in the right way also promotes independence. The best kind of assistance helps residents to be as independent as possible.
<i>Social interaction</i>	Carers build relationship with residents through their social interactions with them. Interactions are tailored to the person or the situation. Staff understand the social dynamics between different residents, and encourage positive interactions between them. They join in with residents, sometimes eating with them, which helps to model eating and drinking.
<i>Being safe</i>	Carers keep residents safe at mealtimes. They check they are alert enough and in a good position to eat and drink. They make sure food and drink is a suitable temperature and consistency. They help residents eat at the right pace, with the right size of mouthfuls.
<i>Careful encouragement</i>	Carers use skill and judgement to respond to food refusal and poor oral intake. They try various techniques and consider underlying causes. They get the balance right, carefully encouraging the resident but not forcing them.
<i>Tailored care</i>	Carers focus on the person, and provide care that is tailored to the resident's needs, skills and preferences.
<i>Working as a team</i>	When carers work together, mealtimes work better. They share information about residents' preferences and needs. They work together to run mealtimes smoothly. They have fun and enjoy each other's company, in a way that is inclusive of the residents and creates a positive atmosphere.

**Table 7.1: Terms and descriptions for evidence summary in Workshop One**

I also wanted to have a visual representation of the evidence, to complement my verbal presentation at the workshops – in order to take into account different learning styles

(Mangold et al., 2018). Therefore, I created the figure shown in Figure 7.2 below. Note that *Tailored care* and *Working as a team* are located on a line encompassing all of the other terms, to indicate their overarching connection and relevance to them.



**Figure 7.2: Visual representation of evidence summary for Workshop One**

### ***7.5.2 Delivering the workshop***

In the workshop itself, I presented the summary of evidence on good mealtime care, as described above. Then I facilitated a discussion in which participants responded to this and made decisions about which topics to include in the training intervention. As a framework for the discussion, I asked participants to consider which topics were the most important. In the event that there were differences of opinion, I planned to use nominal group technique (Chapple & Murphy, 1996), which allows for agreement to be reached via anonymous voting if there are divergent viewpoints within a group.

In the second half of the workshop, participants were asked to build on the decisions already made, by considering the chosen topics in detail, and identifying for each one the

key messages to be conveyed in the training intervention. The discussion was guided by the following prompt questions:

- What new knowledge and skills would help staff here?
- What lessons can we learn from good practice?
- Why doesn't good practice always happen?
- What are the key messages we want to communicate?

### ***7.5.3 Results from the workshop***

Seven participants attended workshop one, including: a dietitian, an SLT, an educationalist, two care home assistants (from the same care home), and two family carers with experience of caring for a person with dementia. Eleven participants were invited in total; four did not respond or were unable to attend (these were three care home managers and a community nurse).

There was broad agreement from participants on the proposed topics to be included in the intervention content. All proposed topics were accepted as relevant and important for the intervention.

Key messages for each topic were identified. Participants added various ideas to the descriptions that had been provided to them in the evidence summary. These additional ideas were: for *Empowerment and respect*, an understanding of mental capacity and the best-interests process; for *Facilitating independence*, the use of adaptive and appropriate equipment, and accessible foods such as finger foods; for *Social interaction*, involving family, and capitalising on special occasions and festivals; for *Being safe*, monitoring for difficulties and changes, including kitchen staff, and clear communication with healthcare professionals; for *Careful encouragement*, referring to personalised care plans, liaising with family, and knowing when and how to engage external support.

As a result of this work, a set of principles for intervention content was documented, as shown in Table 7.2. These principles encompassed ideas that had originated from the evidence summary and had been agreed as relevant by participants, as well as new ideas generated by participants in the workshop. (Note that ideas relating to *Tailored care* and *Working as a team* are threaded through each of the other topics. In the case of *Tailored care*, examples of this are: knowing residents' preferences in *Empowerment and respect*, and providing varied assistance in *Facilitating independence*; in the case of *Working as a*

team, examples are: involving family in *Social interaction*, and engaging other professionals in *Careful encouragement*.)

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**Principles for intervention content**

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*Empowerment and respect*

- Know residents' preferences
- Provide and respect choice
- Enable decision-making
- Understand mental capacity and best-interests process

*Facilitating independence*

- Varied assistance
- Set up for success
- Adaptive equipment, e.g. plate-guards
- Appropriate crockery/cutlery, (e.g. colour, pattern, ease of use)
- Tailored food, e.g. finger foods

*Social interaction*

- Build relationship
- Tailor to the person
- Understand the social dynamics
- Facilitate resident-resident interaction
- Involve family
- Capitalise on special occasions

*Being safe*

- Monitor for difficulties/changes
- Consider alertness and positioning
- Check pacing and bolus-size
- Correct consistency and temperature
- Involve kitchen staff
- Clear communication with GP and SALT (e.g. re. thickener)

*Careful encouragement*

- Skill and judgement
  - Encourage, don't force
  - Consider underlying factors, e.g. oral health
  - Personalised care plan
  - Liaise with family
  - Know when and how to engage other professionals
- 

**Table 7.2 Principles for intervention content**

The workshop also provided important information about the perspective and potential influence of care home assistants. Whilst acknowledging that care assistants are constrained to an extent in the care they can provide (as described in chapter 6),



participants at the same time attributed to them a degree of agency and control in respect of some wider organisational factors. For example, there was consensus among participants that care assistants have interest in, and influence over, decisions about resources – like adaptive cutlery, and menu choices. This seemed to be a more nuanced view than simply considering some matters as being entirely within their remit, and others entirely outside it.

In addition, workshop participants were clear that the idea of teamwork in mealtime care extended beyond teamwork between care assistants. In my evidence presentation, I had focused on the importance of care assistants working as a team. Because of the timing of the workshop, analysis of the ethnographic data had not yet progressed to a point where my conception of the “wider care team” was fully-formed. However, on discussion of this topic with workshop participants it was agreed that teamwork should encompass the working relationships of all involved in residents’ care, including management staff, kitchen staff, family carers and healthcare professionals.

Finally, the workshop clearly demonstrated the value of assembling a range of people with different but related insight and experience, to discuss and problem-solve together. Thus, not only did it result in agreed principles for intervention content; it also helped me to think about possible approaches for mode of delivery. I was interested to know whether the cooperative process used in the workshop might be in some way suitable as a learning method in the intervention. This idea lined up to some extent with existing evidence on mode of delivery, and I pursued it further when preparing and delivering workshop two – which I describe in the next section.

## **7.6 Workshop Two: Co-developing the intervention mode of delivery**

The objective of workshop two was to review and agree the preferred mode of delivery for the training intervention, and to apply this to the content.

### ***7.6.1 Preparing for the workshop***

Before the workshop, I prepared a summary of relevant evidence to present. Just as for workshop one, the evidence came from my primary data and from existing published literature (namely, publications from the Health Education England (HEE) study *What works in dementia education and training?*, as detailed below).

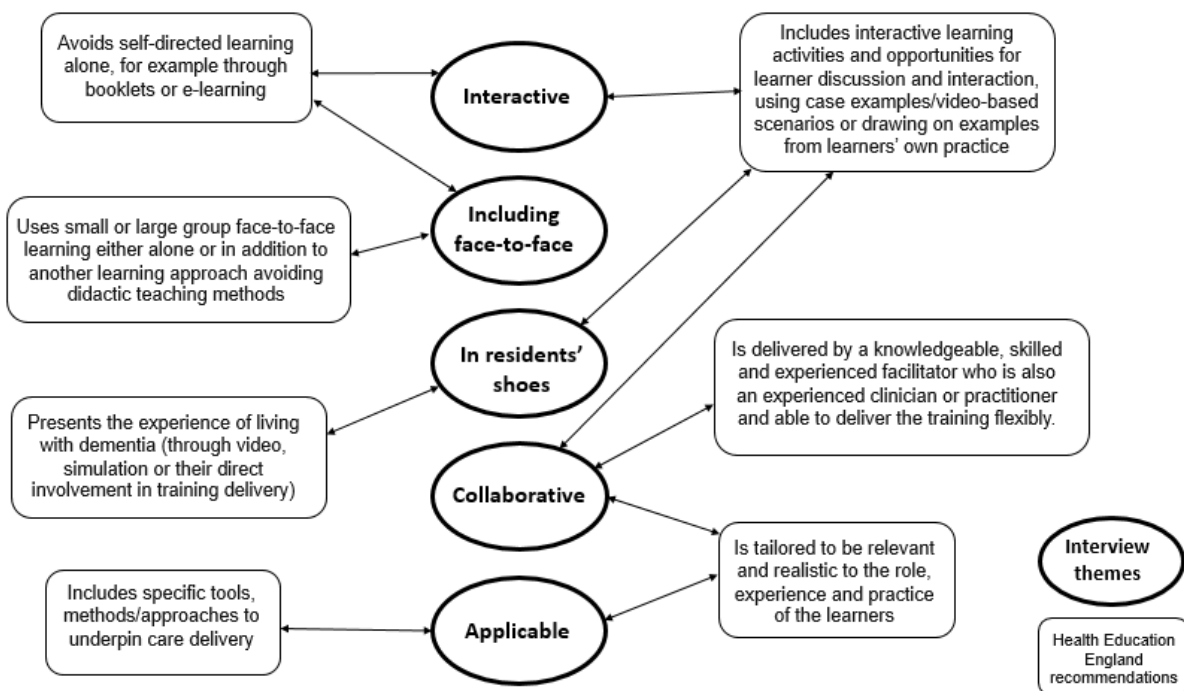
The primary data was generated during my ethnographic study. Whilst interviewing care home staff and visiting healthcare professionals, I sought their views on training delivery – in particular, asking them what would be the most helpful ways to deliver mealtime care training. I spoke to people in a variety of roles, including care assistants, kitchen staff, senior carers, nurses and managers. To analyse the data, I used thematic analysis (Braun & Clarke, 2006). Briefly: I read and re-read the interview transcripts, and systematically coded relevant features of the data. I then collated the codes into potential themes, which were reviewed and refined until a coherent pattern was formed which accurately reflected the data set. Finalised themes were named and described; these are presented and illustrated in Table 7.3 below. As previously, I was careful to use language which would be meaningful and accessible, avoiding jargon. (Note that earlier in my analysis, the theme name *On-the-job* was used instead of *Applicable*. However, this was subsequently refined because *Applicable* was considered a more accurate name to encapsulate the meaning of the theme. The theme pertains to training which enables learning to be applied in practice; it is not about learning in practice per se. (For a useful discussion on this topic, see de Rijdt et al., 2013, p. 67.)

Theme (Name, description)	Illustrative quotes
<p><b>Interactive</b> Not just didactic teaching; there may also be group discussion and a range of different exercises and activities, so that people are involved and participating in training.</p>	<p>“I always think in a care setting, training is always better received when it’s practical opposed to written or going online and doing a course.” StaffB16</p> <p>“It’s not just talking, sometimes you’re hands-on as well” StaffB20</p> <p>“I think informal teaching sessions work much better than somebody standing with a PowerPoint saying, ‘This is what you need to do...’ A lot of question and answers, I think.” VisitingProfessionalA1</p>
<p><b>Including face-to-face</b> There is value in human interaction, so that the participants are not learning alone. Face-to-face can happen online (via teleconferencing software) or in-person.</p>	<p>“Me personally, I think face-to-face training is better than doing it actually sitting down and doing it on a computer. ... It gets you more involved.” StaffB10</p> <p>“I don’t believe in eLearning. ... I don’t think it really engages many people from what I can tell. It doesn’t seem to engage me in the slightest.” StaffA15</p>
<p><b>In residents’ shoes</b> Presenting the real experience of the person with dementia. For</p>	<p>“When I’m going in, you know like at a teatime, I kind of put myself in that person sitting there.” StaffA21</p>

example, through videos, vignettes, or by simulating in some way the experience of living with dementia.	<p>“You’re going to learn because you’re going to know how it’s affected you.”<sup>StaffB18</sup></p> <p>“You need to have a little bit of insight of their world.”<sup>StaffB31</sup></p>
<p><b>Collaborative</b></p> <p>A two-way approach which acknowledges and capitalises on the experience of the participants. Not just <i>done to</i> people, but <i>done with</i> people. It is tailored to fit the setting and situation, and encourages learning through peer discussion.</p>	<p>“I’d like to know what staff make of mealtimes first.”<sup>StaffB11</sup></p> <p>“Come with any issues. So if you were doing one on feeding, what issues do [staff] have? What do they think are challenges around the lunchtime or teatime or whatever, feeding environment?” VisitingProfessionalA1</p> <p>“It has to be two-way, you can’t just come in and say ‘I want it done this way’.”<sup>StaffB31</sup></p>
<p><b>Applicable</b></p> <p>Enables participants to apply the theory they have learned. They have opportunity to take things out of the classroom and put them into practice.</p>	<p>“It’s not just the session itself, it’s about putting it into practice.”<sup>StaffB11</sup></p> <p>“You’re doing it not just talking about it.”<sup>StaffB9</sup></p> <p>“In the work setting you can relate it straightaway to what you’re doing.”<sup>StaffB39</sup></p>

**Table 7.3: Themes on training mode of delivery, from semi-structured interviews**

The other evidence used was from *What works in dementia education and training?*, a study conducted on behalf of Health Education England (HEE) which has produced several outputs relevant to my intervention (Surr et al., 2017, 2020; Surr & Gates, 2017). I mapped the recommendations from the HEE study onto the mode of delivery themes from my interview data (see Figure 7.3 below). I found that the things that local staff had said on this matter matched very closely with the national evidence. For example, the *Interactive* theme was echoed in HEE recommendations about having learning activities and opportunities for discussion and interaction. *Including face-to-face* was reflected in their advice to avoid purely self-directed learning. The theme *In residents’ shoes* corresponded to the HEE recommendations on using case examples and presenting the experience of living with dementia. *Collaborative* related to their recommendation that training should draw on examples from learners’ own practice, and should be tailored to their experience. The *Applicable* theme matched up to HEE advice about ensuring training is relevant and realistic to the role, and includes specific tools, methods and approaches to underpin care delivery.



**Figure 7.3: Mapping Health Education England recommendations onto interview themes**

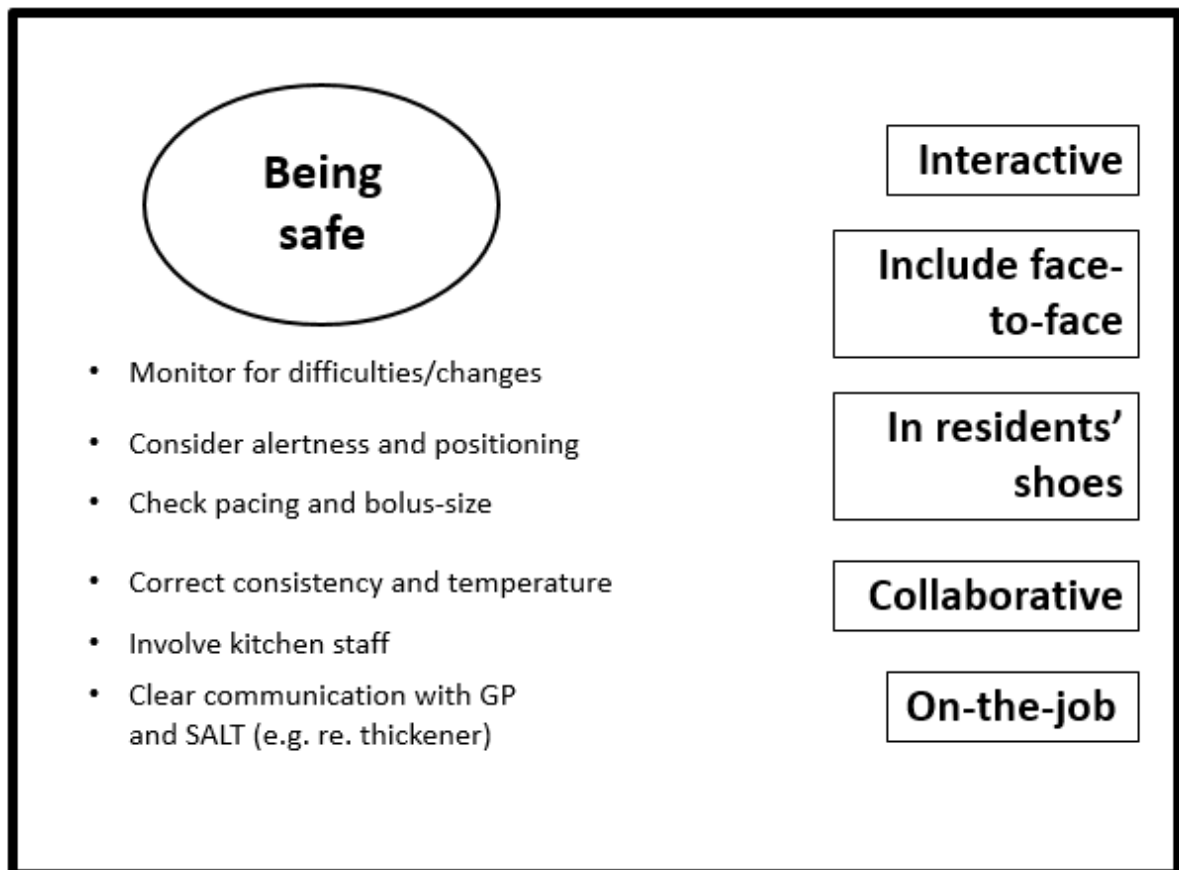
I worked with the educationalist to refine this evidence synthesis, to decide on the best way to present it, and to plan the workshop in order to arrive at useful decisions about mode of delivery. We considered issues including how much detail to provide in the evidence summary, how much time to allocate to each element of the workshop, how to organise participants into breakout rooms (if necessary), and how to capture participants' contributions.

I selected participants for the workshop following principles of theoretical sampling outlined above. In particular, I endeavoured to recruit care home managers, and community nurses, since these stakeholders had not been represented at workshop one.

### ***7.6.2 Delivering the workshop***

In the workshop itself, I presented the evidence on mode of delivery (as outlined above), being explicit about the evidence sources. Then I facilitated a discussion in which participants reflected on the evidence and responded to it. I asked them to consider how closely this aligned to their own experience, and whether there were any aspects they disagreed with or would modify, or if there was anything they would add to it. After a short comfort break, I recapped on the decisions made in the previous workshop about intervention content. Finally, participants worked together to think in detail about how to

apply the agreed delivery methods to the agreed content. I encouraged participants to provide ideas and suggestions, however embryonic they might be – emphasising that we were not expecting to produce a fully-specified training intervention by the end of the workshop. We considered each content topic in turn, using PowerPoint slides to prompt discussion. See Figure 7.4 below, by way of example.



**Figure 7.4: Example PowerPoint slide used to prompt discussion in Workshop Two**

### ***7.6.3 Results from the workshop***

Seven participants attended workshop two, including: a dietitian, an SLT, an educationalist, two care home assistants, and two family carers with experience of caring for a person with dementia (both of home also had relevant professional experience).

Thirteen participants were invited in total; six did not respond or were unable to attend (these were four care home managers, a community nurse and a family carer). The care home assistants, the dietitian and the educationalist were the same as in workshop one; the family carers and the SLT were different.

Through discussion in the workshop, a set of principles for intervention mode of delivery were agreed. These largely reflected the presented evidence, except it was decided that *Include face-to-face* could usefully be subsumed under *Interactive* – since having a face-to-face aspect to the intervention would likely help it to be interactive. In so doing, a distinction was drawn between face-to-face and in-person, to take into account the growing use of online platforms which enable live, real-time interaction (such as Zoom, Microsoft Teams, and so on). It was agreed that interactions of this kind could certainly be considered face-to-face, even though they are not in-person. Thus, the finalised principles for intervention mode of delivery were *Interactive*, *In residents' shoes*, *Collaborative*, and *Applicable* – as detailed in Table 7.4.

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**Principles for intervention mode of delivery**

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*Interactive*

- Not just didactic teaching
- Group discussion
- Exercises and activities
- Include face-to-face (on-line or in-person)

*In residents' shoes*

- Present the residents' experience
- Videos, vignettes, simulation, in-person

*Collaborative*

- Two-way approach
- Incorporating trainees' experience
- Tailored to the situation
- Involving staff in delivery of training

*Applicable*

- Applying classroom theory in practice
  - Real-world tools and methods
  - Learning from colleagues
- 

**Table 7.4: Principles for intervention mode of delivery**

In considering how to apply these principles to the intervention content, participants refined them further and articulated how they might be enacted. For example, in order to portray residents' experience as authentically as possible, it was agreed that vignettes or case studies should be based on real life (but anonymised), with potential input from residents and family. To ensure the training was directly applicable to local context, it was decided there should be opportunity for staff to discuss relevant situations from their own practice – and to address pragmatically any barriers to good mealtime care. To help learners engage positively with intervention content, there was consensus they should be

encouraged to interact with and learn from one another – and should feel comfortable in doing so (for example, not be compelled to do role-play activities).

One mode of delivery principle was particularly well-specified during the course of the workshop: *Collaborative*. Participants seemed to focus on this principle more than others, and there were many contributions which served to give it greater definition. For example, there was agreement that many aspects of the intervention content were not straightforward, but nuanced and multifaceted – and as such did not lend themselves to didactic, instructional teaching. It was acknowledged that the intervention should provide participants time and ‘a safe space’ to engage with this complexity together – and that a skilled facilitator was key to this. It was suggested that ‘training’ may not necessarily be the most appropriate term for this kind of intervention, and that ‘learning’ or ‘education’ may describe it more accurately.

Finally, participants spoke about some issues outside the scope of mode of delivery. These issues included evaluation, implementation, and organisational support. I was mindful of keeping discussions on track, but equally I recognised that thinking and talking about intervention mode of delivery can very naturally lead into these other considerations. Therefore, I did not shut down the discussions, but made a record of what was said, in order to return to the issues in workshop three.

### **7.7 Workshop Three: Presenting a prototype and considering implementation**

The objective of workshop three was to present a prototype of the co-developed intervention for feedback and refinement, and to consider issues of implementation.

#### ***7.7.1 Preparing for the workshop***

The previous workshops had provided a set of principles for intervention content and mode of delivery, as set out in Tables 7.2 and 7.4 above. In preparation for workshop three, I sought to create a prototype of the intervention based on these principles.

First, I consulted relevant literature and theory in order to better understand the idea of collaborative learning. This idea, which had emerged strongly from the previous workshops, has several expressions in the literature – notably within emancipatory practice development, action learning, and andragogy. In emancipatory practice development, practitioners collectively explore current practice, taking into account context and complexity. There is an emphasis on open, safe communication and critical

enquiry, in order to empower rather than direct practice change (Peet et al., 2019, p. 2925). Expert facilitation is an important component (Shaw, 2013). Similarly, action learning is an approach to collaborative problem-solving and learning (Lamont et al., 2010). The ability to critically think and reflect upon experience is seen as essential to learning (Wilson et al., 2003). Learning and reflection happens with the support of a group or set of colleagues working on real problems (Dewar & Sharp, 2006, p. 220). Andragogy is a theory of adult learning which proposes that adults approach learning as problem-solving (Knowles, 1977), and bring an expanding pool of experience that can be used as a resource for that learning (Cox, 2015). In this model, instructors again adopt the role of facilitator, and promote dialogue in the classroom – for instance, through group work and use of relevant scenarios (McGrath, 2009). The approach advocates that adult learning takes place in an environment which is respectful, trusting, supportive, and collaborative (Henschke, 2011). Guided by this literature and theory, and the closely corresponding workshop results, I concluded that a collaborative learning approach should be integral to the intervention. Thus I allocated the most amount of time to activities in which learners considered and discussed relevant case scenarios.

However, I was also mindful of the need for learning to be consistent and evidence-based. In other words, I wanted learners to acquire knowledge of evidence-based best practice – so that they could utilise this when sharing experiences and solving problems rooted in their own context. I was aware therefore of a possible tension between evidence-based practice and approaches such as emancipatory practice development (see Ball and Regan, 2019; Fairbrother et al., 2015). And I knew that in any group of learners there would be variation in the levels of experience, knowledge and self-direction in the group (Merriam, 2001). In response, I included in the intervention a section in which theoretical content is communicated. This was also consistent with guidance that dementia care education and training should provide knowledge-based/theoretical content alongside other learning methods (Surr et al., 2017). In doing so, I was careful to ensure that the content would be conveyed in an interactive way, for example by inviting contributions from learners. This section, and the scenarios section, were informed by the principles for intervention content agreed in previous workshops.

I carefully considered the optimal order for the theory section and the scenarios section – taking into account relevant literature on adult learning. In particular, I was mindful of the traditions of problem-based learning (in which learners begin by being presented with a

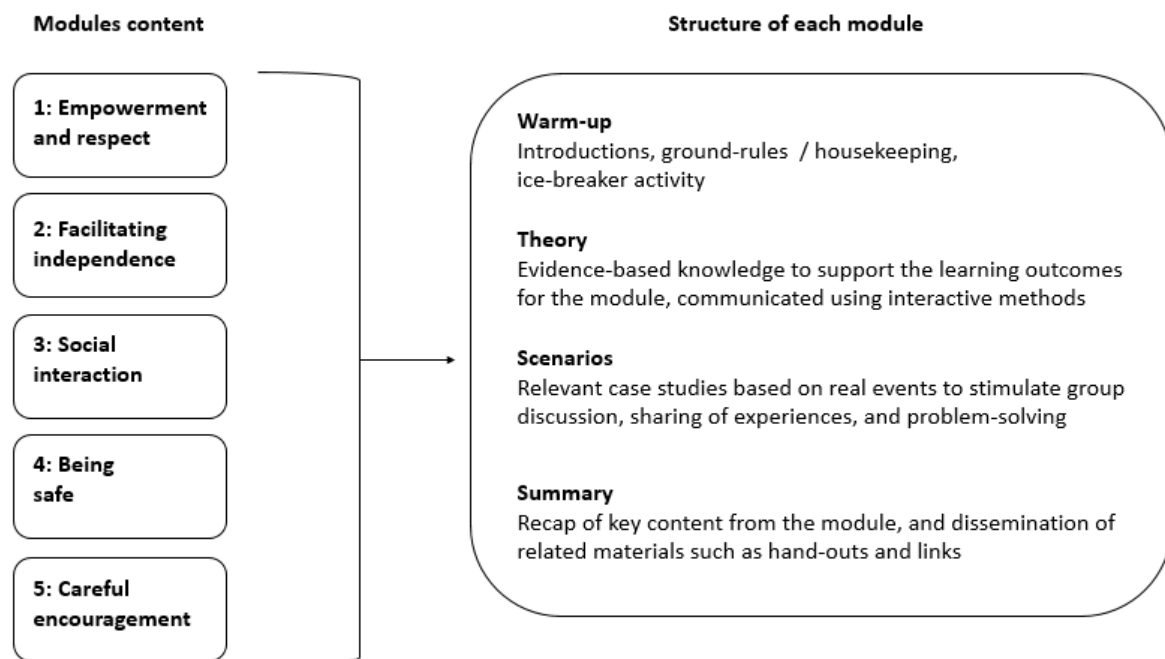


problem-situation), and subject-based learning (in which learners begin by being presented with a lecture in the subject matter to be learned) (Alavi, 2002; Margetson, 1994). I decided to place the theory section first. My rationale was that learners would then be able to apply this when thinking about and discussing the case scenarios. Facilitators would be able to refer learners back to relevant theoretical principles during these discussions, as needed. I anticipated this approach may be less demanding for the facilitator than trying to introduce theoretical knowledge after the discussions, and may make for a more uniform, standardised experience for learners. Thus, the intervention was different in some ways to problem-based learning, but there were similarities – in accordance with Wood (2003), who contends that “a small number of lectures may be desirable to introduce topics or provide an overview of difficult subject material in conjunction with the PBL scenarios” (Wood, 2003, p. 329).

To complete the outline of the intervention, I included two further elements. At the beginning, a ‘warm-up’ section. This was to comprise introductions, ground-rules and housekeeping – and, importantly, ice-breaker activities. The intention was to provide an initial opportunity for the facilitator to build rapport and credibility with the learners, and to encourage a sense of team, important to the idea of collaborative learning. At the end: a ‘summary’ section. This was a time for the facilitator to remind learners of the key learning points from both the theory section and the scenarios section. Learners would be given hand-outs covering all material from the session, and including links to relevant online resources (see Appendix X).

Thus, the structure of the prototype intervention comprised the following sections: (1) Warm-up; (2) Theory; (3) Scenarios; (4) Summary. Populating this structure with content was relatively straightforward. The content had already been organised into five discrete topics: *Empowerment and respect*, *Facilitating independence*, *Social interaction*, *Being safe*, and *Careful encouragement*. It seemed logical therefore to have five modules in the intervention – each addressing one of those topics, and each having the same four-section structure outlined above. This is illustrated in Figure 7.5 below. I determined that each module would be two hours in duration. I wanted to allow sufficient time for learning to be effective, and I was guided by evidence on optimal duration times for dementia care training sessions (Surr et al., 2017, 2018). To build flexibility into the delivery, modules could be delivered together in a block (for example, spread over two days), or separately in a series (for example. one session per week for five weeks). The two overarching

concepts with general relevance to mealtime care – *Tailored care* and *Working as a team* – were not treated as discrete modules. Rather, it was decided they would be diffused across the training as a whole. To explain: a central premise of the training was that learners would consider case scenarios, anonymised but based on reality, emphasising the diversity of residents and calling for person-centred thinking. Another central premise was that learners would work together to share experiences and solve problems, learning as a team. In these respects, tailored care and working as a team would be integral to all modules.



**Figure 7.5: Content and structure of prototype intervention**

For the purposes of presenting a prototype of the intervention at workshop three, I opted to use one topic: *Empowerment and respect*. The rationale for this was two-fold: partly in order to make best use of the available time, but also to increase the chances of workshop participants feeling able to give honest and constructive feedback (Hickey et al., 2018). I surmised that if I presented a large body of work which had clearly taken a long time for me to complete, participants may have been more reluctant to suggest significant changes. In any case, by presenting one topic I was able to demonstrate in broad terms the various key aspects of the intervention. (Subsequently, on the basis of feedback received in workshop three, I created a full prototype comprising all five topics – and then shared this with the educationalist and my supervisory team for further refinements.) Some decisions

about the prototype were made solely on practical grounds. For instance, one of the agreements from of the previous workshop was that we would use videos, vignettes, or simulation to present case scenarios and illustrate resident experience. Because of time and resource constraints, written vignettes were used. Finally, I liaised with the educationalist to refine the prototype and finalise the content and running order of the workshop.

When selecting participants for this workshop, I adopted a strategy of ‘over-booking’. That is to say, I chose to invite more participants than was needed. This was because, in organising the previous workshops, I had found potential participants had sometimes dropped out at short-notice, due to busy and unpredictable schedules (for example one participant cancelled because of an unexpected CQC inspection). As a result, some participant-types had been under-represented in these workshops, or not represented at all. Given this, I was keen that this did not happen in the final workshop (and particularly to ensure representation from senior care home staff, and community nursing staff). Therefore, I invited relatively large numbers to attend – sixteen people in total – in the expectation that some, but not all, would have to drop out.

### ***7.7.2 Delivering the workshop***

In the workshop itself, I recapped on previous decisions made about intervention content and mode of delivery (as summarised in Table 7.2 above). I then presented a prototype intervention – which comprised a facilitator’s manual in the form of a Word document, and accompanying PowerPoint slides for the ‘theory’ section – and invited verbal feedback from participants. After a comfort break, we spent the second half of the workshop considering some specific issues which had either arisen from the feedback, or were otherwise pertinent to implementation of the intervention. Some of this work built on points which had been raised in previous workshops.

Firstly, we discussed the facilitator, in other words: the person (or people) who would deliver the intervention. Prompt questions were used, including:

- Who could be a facilitator?
- What would be the criteria for a facilitator?
- How much direction would a facilitator need?

Secondly, we discussed acceptability of the intervention – exploring whether it could be changed to improve its chances of being implemented. Again, we used prompt questions to do this. These questions were informed by various Normalization Process Theory (NPT) constructs (May & Finch, 2009), as indicated below:

- What is more likely to make this training happen? (Relevant NPT constructs: *Coherence; Cognitive participation; Collective action*)
- What would make it easier to run the training? (Relevant NPT constructs: *Cognitive participation; Collective action*)
- What do you think about the duration of the training? (Relevant NPT constructs: *Collective action*)

Finally, we discussed impact of the intervention on practice; thinking about what would happen after the training, and how the learning might become embedded. Prompt questions and relevant NPT constructs are listed below:

- What would make the intervention more likely to change practice? (Relevant NPT constructs: *Coherence; Reflexive monitoring*)
- How would we know it had changed practice? (Relevant NPT constructs: *Reflexive monitoring*)
- What kind of organisational support would be needed? (Relevant NPT constructs: *Cognitive participation; Collective action*)

### **7.7.3 Results from the workshop**

Fourteen participants attended this workshop, including: a dietitian, two SLTs, an educationalist, a care home manager, a care home regional manager, a care home senior carer, two care home deputy managers, two community nurses, and three family carers with experience of caring for a person with dementia. One participant – a care home deputy manager – was unable to get her microphone to work, so they contributed to the workshop using the chat function. I had a telephone conversation with them afterwards to capture any points they had been unable to make earlier.

There were twice as many participants in this workshop compared with the others, because of my ‘over-booking’ strategy – in the event, almost all invitees attended. As in workshop two, some of the participants were new (specifically, the care home staff and the community nurses); the others had attended previously. Again, the balance of

continuity and fresh perspective was helpful. There was a sense of rapport and familiarity in the group, because some participants knew each other from previous workshops. Equally, new participants were able to bring challenge and new ideas to the process.

Participants gave useful feedback on the prototype intervention, with respect to both content and mode of delivery. They said there was appropriate balance between covering key points and allowing room for creativity. They cautioned against ‘information-overload’, recommending that materials remain succinct and streamlined. At the same time, they suggested supplementary materials be considered, for example posters and prompt-sheets for use in dining rooms, as well as signposting to relevant external resources. They advised an emphasis on mealtime content in the theory section, to differentiate it from other, more generic training – and that the section be sufficiently interactive to keep learners engaged. They agreed that the case scenarios (shown in Appendix X) were relevant and thought-provoking, and would likely capitalise on learners’ previous experiences – considering them to be an important aspect of the mode of delivery, with appropriate prominence in the intervention. They recommended that the scenarios should include cases of advanced-stage dementia and end-of-life care.

The characteristics and criteria for the intervention facilitator were discussed at length, and a person-specification was sketched out. There was agreement that this person did not necessarily need to be a healthcare professional, but did need to have adequate knowledge and experience of the subject matter. They would also need interpersonal skills to build rapport, and a high level of facilitation skills. One of their key tasks would be to maximise contributions from learners, whilst keeping on track and covering core content. It was acknowledged that a facilitator already known to learners may be quick to build rapport and elicit meaningful contributions, but equally that a skilled facilitator without that existing connection would also be able to do this. These kind of skills and attributes for facilitators of collaborative learning are emphasised in the literature (Hmelo-Silver & Barrows, 2006; Salinitri et al., 2015; Tsimane & Downing, 2020).

Outcomes for the intervention were considered in detail. It was agreed there were several types of outcome. Important immediate outcomes were increased staff knowledge, skill and confidence. These could potentially be measured via a combination of quantitative and qualitative methods (such as knowledge-assessment, and interviews). Improved mealtime care was also an outcome of interest; observation, video and audit were

proposed as possible instruments for measuring this. Residents' quality of life was considered to be a significant longer-term outcome. There was less certainty about the relevance, in this context, of resident outcomes such as weight and nutritional intake, or their connection to quality of life. Each of these outcomes can be mapped on to Kirkpatrick's levels of evaluation (Kirkpatrick, 1998). Staff knowledge pertains to Level Two (Learning), improved care maps to Level Three (Behaviour), and resident outcomes relate to Level Four (Results).

Participants gave advice on how to increase the intervention's acceptability to care home staff and managers, so that it would be more likely to be implemented. Duration of training was thought to be an important factor. The predominant view from care home staff was that the proposed duration (ten hours in total) was ambitious, and possibly unrealistic – that managers may find it difficult to release staff for this length of time.

Flexibility in approach was suggested; for example, having standalone modules which care homes could select on-demand, or a mix of e-learning and in-person content. But there was also caution about weakening the intervention by making significant modifications. Flexibility about venue was seen as helpful, with potential benefits to hosting the intervention either in care homes, or in other venues. Overall, endorsement from senior care home management was agreed as critical to the chances of implementation.

Finally: there were a number of points made in the workshop which were valuable in relation to later stages of intervention evaluation and implementation. For example, there was advice about how the intervention might be rolled-out on a regional or national scale. A train-the-trainer model was advocated, with appropriate ownership, accreditation and recruitment. This approach has been successfully trialled for other training interventions in care homes. Lee and Scott (2009) reported effective use of a train-the-trainer package to cascade teaching on the Malnutrition Universal Screening Tool across care homes in a UK region, while Mayrhofer et al. (2016) found that a train-the-trainer programme of education on end-of-life care had good outcomes – particularly in care homes with organisational stability. It was also suggested the intervention could be connected to existing competency frameworks, such as the Care Certificate (Skills for Care, 2022). Other competency frameworks have been developed for use specifically in dementia care (Tsaroucha et al., 2013), and in care homes (Thompson et al., 2018). These points were

welcomed. I knew they would be helpful in planning for larger-scale evaluation and implementation in the future, to ensure the intervention was scalable, transferable and sustainable.

### 7.8 Refining the prototype

After the workshop, I discussed its findings with my supervisory team, and with the educationalist. There was agreement on the importance of maintaining appropriate scope for this prototype of the intervention. To help with this, I referred to an appropriate framework: the Training Intervention Components (TIC) taxonomy (Perryman, 2014). This divides training into three phases: pre-training, training delivery, and post-training (see Table 7.5 below).

Phase	Groupings
Pre-training	Pre-training planning/preparation Incentives to attend training
Training delivery	Content Training methods Characteristics of the training provider/facilitator Characteristics of the recipients Length/duration Characteristics of the setting
Post-training	Evaluation Skills transfer techniques Leadership

**Table 7.5: Overview of Training Intervention Components taxonomy (Adapted from Perryman, 2014)**

All three phases of this taxonomy were relevant to the co-development process, and clearly of interest to workshop participants. For example, the first phase in the taxonomy – pre-training – includes consideration of barriers to implementation, and tailoring content to be relevant to practice. The third phase – post-training – includes evaluation, managerial support, and helping learners transfer skills into practice (see also Illing et al., 2018; Surr et al., 2020). These elements have informed the development of the prototype intervention, and can inform a future feasibility study. (For example, a feasibility study may include evaluation of the intervention, both by measuring recipients’ knowledge, skill and confidence, and by collecting qualitative data on recipients’ experience of the intervention and their perception of its impact on their practice.)

However, the output of the co-development work – the prototype intervention – relates most closely to the second phase: training delivery. It consists of a manual (see Appendix X) and accompanying slides (see Appendix Y for a sample slide) to enable delivery of the training by a facilitator. As such, to use Perryman’s terminology, its focus is on content and training methods (or mode of delivery) – but it also considers characteristics of the training provider/facilitator, characteristics of the recipients, length/duration, and characteristics of the setting (or venue). While many aspects of the prototype intervention were resolved during the course of the workshops, some were ambiguous and required further decision-making. An example was duration of the intervention. It was argued by some workshop participants that the proposed duration of two hours per module, and ten hours in total, was incompatible with care home pressures and workloads. It was argued by others that shortening the duration risked diluting the intervention’s effectiveness. I turned to available evidence and theory to help resolve this dilemma. Surr et al. (2017, 2018), in their review of all published evidence about training and education in dementia for the health and social care workforce, proposed that dementia care education and training was optimally at least eight hours in total duration, with individual sessions of half a day or longer more likely to significantly change learner attitudes. Equally, Normalization Process Theory promotes that interventions should be acceptable to the recipients (for example, care home staff), and to those responsible for adopting it (for example, care home management). This would be influenced by whether it could be easily integrated into existing work, and whether there were sufficient resources available to support it (May & Finch, 2009). Taking all of this into account, I modified the duration so that it was eight hours in total (not 10). Each module was now 75 minutes (with the exception of the first module, which was extended to 90 minutes to allow more time for introductions and house-keeping). The modules could be delivered altogether in one day, or in two half-day sessions. I was mindful that any specifications, including duration, could be tested and refined further through a later feasibility study.

There were also different opinions expressed by workshop participants about whether training sessions should be attended by staff all from the same care home, or staff from more than one care home. Advantages and disadvantages of both approaches were put forward. For example, if staff were all from the same home, they would already be familiar with one another and would perhaps find it easier to share and problem-solve with reference to their local context. Conversely, if staff were from more than one home,



they may bring new perspectives and ideas – constructively challenging existing practice, and avoiding groupthink (Janis, 1982). In addition, it may be more realistic for several care homes to release smaller numbers of staff to attend training, than for one home to release a large staff group. I did not find any definitive evidence to direct this decision one way or the other, so opted to provide flexibility, allowing for either approach to be adopted.

## 7.9 Conclusion

In this chapter, I have described how I worked closely with relevant stakeholders to generate a prototype intervention for mealtime care training. Through a co-development process, which was informed by evidence from extant literature and from my ethnographic study, we were able to specify key features for the prototype. The prototype itself – comprising a facilitator’s manual and supplementary materials – is presented in Appendix X. I summarise the key features below:

- The content comprises five modules: *Empowerment and respect; Facilitating independence; Social interaction; Being safe; Careful encouragement*. Two concepts with general relevance to mealtime care – *Tailored care* and *Working as a team* – are integrated into each of these modules.
- Each module is delivered in four sections. *Warm-up* is a time for the facilitator to make introductions, agree ground-rules, explain housekeeping, and set the tone for collaborative learning. *Theory* provides evidence-based knowledge to support the learning outcomes for the module, communicated using interactive methods. *Scenarios* uses relevant case studies based on real events to stimulate group discussion, sharing of experiences, and problem-solving. *Summary* gives opportunity for the facilitator to recap the key content from the module, and to disseminate related materials such as hand-outs and links.
- The facilitator is recommended to be someone with adequate knowledge and experience of the topics addressed by the intervention. This may be, for example, an SLT, a dietitian, a care home manager, or a senior carer, (Note that this is not an exhaustive list and is provided for illustration.) The facilitator should have strong interpersonal skills so that they can build rapport and trust with learners, to elicit rich contributions and discussions. They also need good chairing skills, in order to ensure all core content is covered.

- The recipients are all those in a care home setting who have involvement in mealtime care. This may include (but not be limited to) care assistants, senior carers, management staff, nurses, kitchen staff, and domestic staff. Recipients may be all from the same care home, or from several different care homes.
- Each module lasts for 75 minutes (with the exception of the first module, which is 90 minutes to allow sufficient time for introductions and house-keeping). The modules can be delivered altogether in one day. In this configuration, it is suggested that three modules are delivered in the morning, and two are delivered in the afternoon. If 10- minute breaks are taken between each module – and an hour for lunch – the total duration of the training day is eight hours. Alternatively, the modules can be delivered in two half-day sessions spread across different days – with three modules delivered on one half-day, and two modules delivered on another.
- The venue may be a room may be within a care home – for example, a dedicated training room, or a meeting room, or another sufficiently large room in the home which is not otherwise in use. It may also be within a different location, such as a community centre, or local authority building, or NHS building.

In the next chapter, I discuss the work presented in this thesis. I identify new knowledge, consider strengths and limitations, and highlight implications for research, practice and policy.

## **Chapter 8. Discussion**

### **8.1 Introduction**

In this chapter I discuss the work presented in this thesis. I refer to the key findings in relation to good practice in mealtime care for people with dementia living in care homes, and the development of a staff training intervention on this topic. I also consider the strengths and limitations of my work, and highlight implications for research, policy and practice.

### **8.2 Aims and summary of thesis**

The overall aim of this thesis was to develop an evidence-based staff training intervention to improve mealtime care for people with dementia in care homes. There were three phases to the work; each of these had individual aims, which contributed to the overall aim.

The first phase was a literature review. This comprised a systematic review of research studies, and a scoping review of guidelines. The aim of the systematic review was to synthesise evidence from research studies on mealtime care for people with dementia living in care homes, in order to identify important categories of carer-resident interaction. The aim of the scoping review was to synthesise recommendations from guidelines on the topic of mealtime care for people with dementia living in care homes.

The second phase was an ethnographic study. This comprised observations and interviews in two care homes in northeast England. The aim of this study was to critically examine current practice in mealtime care, and to identify good practice.

The third phase was a process of co-development work. This process comprised a series of workshops, and associated activity before and after the workshops (including preparation of evidence summaries, consultation of stakeholder advisory group, and review of workshop results with my supervisory team). The aim of this process was to produce a prototype mealtime care training intervention, informed by evidence from the literature review and the ethnographic study.

In summary, this research has resulted in evidence-based content and mode of delivery for a training intervention to improve mealtime care for people with dementia living in care homes. The design of the prototype intervention reflects my thesis: Good mealtime

care promotes choice, independence, social well-being, safety, and adequate nutrition and remainder of the chapter I will explore this thesis in more depth.

### 8.3 Key findings

#### **Novel contributions**

Before discussing key findings in detail, I summarise here the novel contributions in my thesis:

1. I have found that priorities in mealtime care for residents with dementia, such as providing choice, facilitating independence, attending to social well-being and promoting adequate nutrition/hydration, are sometimes in tension with one another.
2. I have found that mealtime care operates within a complex system which can both constrain and enable care. The degree of connectedness between care staff, kitchen staff, management, external health and care professionals, and family members is an important determinant of good mealtime care.
3. I have found that a person-centred approach helps to resolve tensions between competing priorities in mealtime care. By focusing on the person as an individual – their history, capabilities, preferences and prognosis – staff are better able to navigate through to the right priority at the right time.
4. I have found that teamwork is key in overcoming contextual constraints, tackling dilemmas and uncertainty, and reducing the emotional burden associated with mealtime care for residents with dementia.
5. I have found that collaborative learning is a potentially useful approach in care home training interventions. This is because it acknowledges local context; capitalises on the experience of all participants (including care assistants); encourages learning through peer discussion; and provides a forum for strengthening team relationships.
6. These findings have contributed to the development of a training intervention to improve mealtime care for care home residents with dementia. As a Speech and Language Therapist, I have co-developed this intervention in partnership with relevant stakeholders and informed by multiple-methods evidence. To my knowledge, this is the first such intervention development research on this topic.

Earlier in this thesis – for the purposes of eligibility criteria in my systematic review – I set out the following definition of mealtime care: “Interactions occurring between care staff and people with dementia at mealtimes, which may promote safe, adequate and/or enjoyable oral intake, and which may occur within a care home” (Faraday et al., 2021). My rationale was that these interactions have the potential to be targeted through the training of care home staff, because these staff are on the ‘front-line’ in providing care. Thus, I excluded at that stage other potentially modifiable factors such as menu design and staffing ratios.

The above definition proposes that care is both an action (as performed by the carer) and an outcome (as experienced by the cared-for – in this case, the care home resident). For example: where there is good mealtime care, the carer acts in a way that is empowering, and the resident experiences empowerment. The definition also presupposes broad categories of outcome: safety, adequacy and enjoyment. These were informed by national care standards (Skills for Care, 2015), and to some extent by my own professional experience and prior knowledge. They were subsequently refined, developed and augmented by the literature review, the ethnographic study and the co-development work.

The literature review in chapter 3 – encompassing both peer-reviewed papers and published guidelines – identified that good mealtime care promotes empowerment, independence, social connection, safety, and adequate nutrition and hydration (with particular reference to those residents who would otherwise experience reduced nutrition and hydration). The ethnographic study described in chapters 4 to 6 corroborated and augmented these findings – as I saw and heard mealtime care enacted and described in practice. Significantly, I noted also that care was enhanced by a person-centred approach, and by teamwork. In the co-development process reported in chapter 7, findings were presented to – and sense-checked by – stakeholders. This served to underscore the notion that teamwork in mealtime care is about a ‘wider care team’ comprising management staff, kitchen staff, family carers and healthcare professionals, and to add important perspective on the degree of control and influence that care assistants may have in providing mealtime care. I discuss the key findings below, and show how they advance previous understanding of the topic.

### ***8.3.1 Priorities in mealtime care***

I will explore in turn each of the priorities in mealtime care for residents with dementia identified by my research. Through good mealtime care, residents are empowered to make *choices* about what to eat, where to eat, and when to eat. Making such choices means residents have some agency in the care home (Daly et al., 2018). This is important because agency may be otherwise elusive for them, whether because of impaired cognition and/or communication (Welford et al., 2012) , or because of the organisational constraints of the care home setting (see, for example, Reimer and Keller (2009), who stated that “when much of the care that is provided to older adults in nursing homes is prescribed, every opportunity to make decisions that are meaningful, such as what and how one eats, need to be provided to promote satisfaction and quality of life” (p. 335)). I found that care staff’s proactivity and skill was crucial in enabling choice-making. Their role included understanding and facilitating residents’ wishes. The importance of the care staff’s role is underlined in research by Wu et al. (2018), who emphasised the value of “supporting identity” in residents; a process they describe as “accepting and acknowledging a resident for who they are today, while working to understand their life story that includes significant events, roles, and important relationships. Who they are will impact how they experience mealtimes” (p. 3). This idea is particularly pertinent for residents with dementia, for whom cognitive-communication difficulties may lead to risk of exclusion from decision-making in daily care (Smebye et al., 2012). It is key that these (and all) residents are supported to make their own decisions. Moreover, although it is helpful that staff have knowledge of residents’ previously-expressed preferences, it is also important that staff are alert to possible changes in preference – and do not assume that preferences remain the same forever. See, for example, Driessen and Ibanez Martin (2020, p. 252) :

Care workers know about singular, and relatively stable tastes and habits. This knowledge has often been accumulated over years of caring for the same residents (and takes some time to be built when new residents are admitted to the [care home]). What has been found out in many previous encounters is trusted to be true for present encounters. Because it relies on a certain degree of stability, the individual is enacted as continuous – stretching from past into present.

Like choice, physical *independence* at mealtimes contributes to a sense of autonomy and can positively affect quality of life (2019). Du Toit et al. (2019) emphasised the importance of collaborative dementia care which “will support residents to continue to participate and engage in meaningful occupation (p. 349)”. The authors encouraged carers to form an ‘interdependence’ with residents – which they characterise as ‘doing with’ rather than ‘doing to’ – in order to help residents engage more in daily routine activities. They also gave an example relevant to mealtime care, which they termed “bridging” (p. 350): helping the resident to use a hand-held object, to promote a shared feeling of participation. I saw this kind of collaborative assistance a number of times during mealtime observations.

The contrast between ‘doing with’ and ‘doing to’ residents is perhaps reflected in the terminology which is sometimes used in relation to mealtime care. In particular, ‘feeding’ is a term that has been commonly used in the literature, to mean direct assistance with eating, or mealtime support. For example, it features in the name of a well-established tool for assessment of mealtime difficulties in dementia care – The Edinburgh Feeding Evaluation in Dementia scale (Watson, 1994). It is a term still prominent today, and in fact was used on many occasions by participants in my ethnographic study and the co-development workshops – participants who spoke lucidly and passionately about the importance of facilitating residents’ independence. To my knowledge, there is limited existing research on the topic of terminology in mealtime care – future research might consider how terminology interacts with this kind of care. Suffice to say that the term ‘feeding’ does not seem especially conducive to the idea of collaborative care and a shared feeling of participation. Indeed, it can be construed as a term that infantilizes people with dementia (Jongsma & Schweda, 2018), since it is more commonly used in the context of care for young children and babies.

As part of this discussion, it is worth reflecting on the meaning of ‘empowerment’. I have used this word frequently in my thesis, to describe interactions which promote residents’ autonomy and independence. But we should consider in more detail the meaning of the word, particularly in the context of people with dementia living in care homes. A dictionary definition of empowerment is “the act of giving somebody more control over their own life or the situation they are in” (Oxford University Press, 2023). More specifically, in a recent study by McConnell et al. (2019) the authors co-produced with

people living with dementia a definition of empowerment as follows: “a confidence building process whereby people with dementia are respected, have a voice and are heard, are involved in making decisions about their lives and have the opportunity to create change through access to appropriate resources” (p. 2). Building on this work, van Corven et al. (2021) explored the concept of empowerment with people living with dementia and their carers, in settings including care homes. They identified challenges in achieving empowerment in the care home setting, such as difficulty maintaining a sense of identity within group dynamics, difficulty maintaining control over the environment, and difficulty having unusual choices respected. Interestingly, they also suggested that people with dementia in a care home may have the same feelings of choice and control as people with dementia living at home, even if the type of choice and level of control they experience is different. Even if this is true, empowerment in a care home is different to empowerment elsewhere, because of the parameters of the context, and the role of care staff. Some authors have described this with reference to the citizenship model. Baldwin and Greason (2016), for example, call for “citizenship-alliances” between residents in long-term care facilities and dementia care staff, through shared participation and engagement in everyday activities. This means envisaging long-term care as a community of citizens, with a reformulation of roles and responsibilities arising from the current division between staff and residents. Of note, the authors illustrate this idea with the example of a resident serving afternoon tea to her fellow residents – thus making a meaningful contribution and becoming part of the care team. In summary, empowerment for this population and in this setting is complex, but that does not mean it should not be pursued.

As well as empowering residents to make choices, good mealtime care also considers the *social* aspects of eating and drinking. Greater social engagement is associated with better quality of life for people with dementia. According to Martyr et al. (2018), quality of life may be improved by supporting relationships and social engagement. Quinn et al. (2022) found that people with dementia strongly connected the idea of ‘living well’ to having positive relationships and social contact with others. In care homes, staff play a fundamental role in this. Morgan–Brown et al. (2019, p. 402) noted: “people with dementia in residential care depend upon the stimulation of staff for engagement”. During mealtime observations I saw that the nature of social engagement could look different for different people. Paudel et al. (2019, p. 1) acknowledge that staff–resident interaction



may vary from “a brief smile” to a “one-on-one conversation”, depending on various resident and caregiver factors – including but not limited to the resident’s underlying cognitive impairment. One possible mechanism by which staff may facilitate social interaction, and which may benefit multiple different residents, regardless of their degree of cognitive impairment, is the act of sitting down and eating with residents. Abbot et al. (2017) associated this with residents expressing more positive affect during meals. I have acknowledged in chapter 6 that this is a complex subject, with evident barriers in practice (both perceived and real). In their study of care home staff’s perspectives on how to engage staff in eating, Lieu et al. (2020, p. 2100) noted that a state policy prohibited staff from sitting and eating with residents during mealtimes, and thus staff may have missed opportunities to engage and interact with residents at mealtimes as part of a shared social event. The ethnographic study pointed to family involvement as a way to overcome constraints of time and resource. In addition, during the co-development work it was suggested that special occasions such as birthdays, Christmas and other festivals can be a useful conduit for this; a natural time for people to come together to eat, drink and enjoy one another’s company (Watkins et al., 2017).

On the face of it, promoting *adequate nutrition and hydration* is perhaps the most intuitive aspect of good mealtime care. Mealtimes are, after all, largely about eating and drinking. However, it is worth examining in more detail what is meant by adequate nutrition – particularly in respect of people with dementia. For example, findings from the ethnographic study indicated that for residents with advanced dementia, the calorific content of a meal may take precedence over its nutritional balance. The suggestion was that for these residents, this was the right approach to healthy eating. This idea is also seen in some literature and guidelines, which (for instance) may recommend capitalising on a preference for sweet food or drink (Barchester Healthcare, 2016; Health and Social Care Northern Ireland, 2015; Lopez & Molony, 2018) or maximising calories in food portions (Murphy & Aryal, 2020). Other literature emphasises the importance of a nutrient-dense diet which is adequate in energy (Sossen et al., 2020). Their study is relevant to the care of all older people in residential care, not just people with dementia. People with dementia, however, are widely considered to be at greater risk of undernutrition, because of problems such as dysphagia, wandering, and resistance to care (Murphy et al., 2017).

Finally, good mealtime care attends to residents' *safety*. Interestingly, this concept was not strongly prevalent in my observation or interview data – but it featured in several published guidelines on mealtime care for residents with dementia (Health and Social Care Northern Ireland, 2015, p. 7; Irish Nutrition and Dietetic Institute, 2016, p. 6; VOICES, 1998, p. 45), and was endorsed in the co-development workshops. This apparent discrepancy was rather surprising, but as stated in chapter 3, it is possible that mealtime safety was prominent in the guidelines due to authorship. Safety from choking on food, or from aspiration of fluids, is a professional concern of SLTs. Several of the published guidelines in my literature review were authored by SLTs, and so they may have placed a particular emphasis on mealtime safety. In any case, I took the view that a theme coming from a review of published guidelines should not be quickly discarded. Review evidence is generally considered to be of high value in hierarchies of evidence (Evans, 2003; Shaneyfelt, 2016). I resolved, then, to include the idea of safety in the summary of evidence which I presented at the co-development workshops – but in so doing, to be transparent about the fact that it came from one but not all evidence sources. In the event, it was decided in the workshops that safety was a valid and important priority in mealtime care for people with dementia, and that it should be included in the training content.

Of note, each of these priorities in mealtime care can be related in some way to the work of Tom Kitwood, and in particular to the psychological needs he defined in respect of people with dementia. Kitwood sought to develop a social-psychological theory of dementia care (Kitwood, 1997; Kitwood & Bredin, 1992). He used the term 'personhood' to emphasise the need to acknowledge each person's uniqueness, and "the likelihood that there will be great differences in their experience" (Kitwood, 1997, p. 14). For Kitwood, the promotion of personhood was to be the defining aim of dementia care, and an understanding of someone's personality and life history was essential to that process (Mitchell & Agnelli, 2015). Moreover, he proposed a set of psychological needs experienced by people with dementia, those being: comfort (the feeling of trust that comes from others); attachment (security and finding familiarity in unusual places); inclusion (being involved in the lives of others), occupation (being involved in the processes of normal life); and identity (that which distinguishes a person from others and makes them unique) (Kitwood, 1997).

Some of Kitwood's ideas, such as personhood, have been referenced previously in mealtime care literature (Hung & Chaudhury, 2011; Leah, 2019). In my research findings, I noticed that the priorities in mealtime care dovetailed closely with Kitwood's psychological needs in particular. When care staff properly facilitate choice at mealtimes, they enable residents to have meaningful control in a way that promotes their identity (Kitwood & Bredin, 1992). When care staff encourage independence in eating and drinking – drawing out residents' abilities and skills, so they can complete actions for themselves – they enhance residents' sense of occupation (Brooker & Surr, 2018, p. 90). When care staff promote social interaction at mealtimes, enabling residents to flourish through relationship and by feeling part of a group, they support their need for attachment and inclusion (Kitwood, 1997). When care staff provide adequate nutrition and hydration for residents, and keep them safe from harm by guarding against aspiration and choking episodes, they attend not only to resident's physical needs, but also to their psychological need for comfort. (Clissett et al. (2013, p. 1496) define 'comfort' as follows: “[Comfort is] about the provision of tenderness, closeness and soothing and is provided through physical touch, comforting words and gestures. Comfort also includes physical comfort with one's body and a pleasant environment”.)

Thus, the priorities of mealtime care for residents with dementia identified here are, in themselves, broadly uncontroversial and well-supported by extant literature. However, in the complex and multifaceted setting of a care home, it is not always straightforward for staff to pursue these priorities. My literature review had collated and synthesised existing knowledge about ideal mealtime care; my ethnographic study identified the challenges of enacting mealtime care in practice, and explored how staff overcame those challenges.

### ***8.3.2 Challenges in mealtime care***

Through my ethnography, I found that the priorities of mealtime care were often in tension with one another. For example, carers wanted to enable residents to choose where to have their meals, but also wanted them to experience social well-being by eating in communal areas. Some staff spoke of giving residents opportunity to eat alone if that was their preference; others mentioned trying to persuade residents to come out of their rooms at mealtimes. Carers wanted to maximise residents' independence at mealtimes, but also wanted to assist them to eat and drink adequate amounts. I heard staff describe the importance of encouraging independence, but I also saw staff stepping in to provide direct

assistance when residents took a long time to eat. Carers wanted to give residents freedom to choose foods they enjoyed, but also wanted them to have a healthy diet. Sometimes staff emphasised that the care home was ‘the residents’ home’, and as such a place where they should have freedom to eat and drink whatever they choose; on other occasions, staff acted to prevent residents from having food which was considered bad for their health. Each of these examples illustrates a broader tension between autonomy and care, which can be difficult for care home staff to navigate (Wasson et al., 2001; Willemse et al., 2015).

This tension was epitomised when residents declined to have food or drink. Residents’ actions here were sometimes labelled in a negative way, and indeed terms like ‘refusal’ and ‘resistance’ are used widely in care homes, as well as in research literature and published guidelines. This may particularly happen with people living with dementia, some of whom – because of cognitive impairment – have “greater difficulty communicating their needs with caregivers and may not understand or recognize the purpose of the care interactions with staff” (Paudel et al., 2019, p. 1). The implication of terms like ‘refusal’ and ‘resistance’ is that, rather than expressing autonomy, the resident actions are contrary and unhelpful, going against the benevolent actions of the carer. This fits with a narrative of paternalism, a historical feature of health and social care (Fernández-Ballesteros et al., 2019), whereby the doctor/carers ‘knows best’ and therefore makes decisions on behalf of the patient/resident.

My findings indicated that care home staff were in many instances aware they were walking a difficult line between autonomy of residents, and care for residents. Even with this insight, they tended to come down on the more paternalistic side of the line – as exemplified in this quote from the ethnography, in chapter 4:

*“Of course it would be lovely in an ideal world for everybody to have all of that independence and be able to do the things they want to do but you’ve seen yourself, it can be quite hectic in that kitchen at a mealtime and all it takes is a member of staff to turn around too quickly and we’ve got a resident scalded and for me, that wouldn’t be something I would be comfortable with. So it’s not about taking away their rights as such or anything like that, but protecting them and trying to make the best decision to make sure these kinds of things don’t happen.”*

[Interview\_StaffB39\_Home2\_05/12/19]

In addition to tensions between the various priorities of mealtime care, I noted challenges arising from the complex nature of the care home setting. Mealtime care operates within a complex system which can both constrain and enable good care. Moore et al. (2019) argued

that schools and hospitals are complex ecological systems, whose functioning is shaped by interactions among a diverse range of ever-changing actors (p. 25). Care homes can be added to that list (Peryer et al., 2022), and my research provides a new and rich understanding of the way this complexity influences mealtimes.

For example, I found there was, at times, a disconnect between kitchen staff and care staff which negatively impacted mealtime care. Both teams, of course, played key roles in the process of providing meals to residents. Kitchen staff prepared and cooked the food, and delivered it to dining rooms; care staff plated-up the food, served it to residents and assisted them with eating and drinking as needed. Difficulties arose because they operated to different timescales. In the kitchen, the need to cater on a large scale meant there was an impetus to turn around mealtimes promptly and efficiently. In the dining room, however, residents needed time and space to enjoy their meals, to eat and drink as independently as possible, and to finish as much of their meals as possible. The extent to which each department understood the pressures and motivations affecting their counterparts was seemingly variable; on a typical day, kitchen staff and care staff might connect briefly when the food trolley was delivered to and collected from the dining room, but could otherwise be quite separate.

Similarly, I saw that care assistants and managerial staff were sometimes at odds with one another. Differing views were expressed about what was helpful or important in mealtime care. These views were not necessarily incompatible; nor was it the case that one camp was 'right' and the other 'wrong'. Rather, care assistants and managers typically had somewhat different perspectives: on the one hand, a day-to-day, direct experience of providing mealtime care; on the other, a broader overview of issues relating to mealtime care. There was potential here for a joined-up and balanced approach, with staff working together to share ideas and maximise the mealtime experience. However, there was also potential for miscommunication, misunderstandings, and compromised practice at mealtimes. To give an example: both care assistants and managers recognised the value of staff sitting and eating with residents, but it did not regularly happen in practice. I heard care assistants say that they felt it was discouraged by some senior staff, whereas I heard managers say they endorsed it provided there was sufficient resource (that is, staffing) for it to happen well. What seemed to be missing here was a constructive conversation between the two parties, to problem-solve and make this idea a routine reality.

There are other important actors within the complex system of the care home, such as visiting health and social care professionals, and family carers. In particular, family carers are a significant component of care home life. This was strongly underlined during the height of the COVID-19 pandemic, when lockdown rules meant family carer visits were severely curtailed and, for a time, prohibited. The impact on residents and families of these restrictions is only beginning to be understood (Giebel et al., 2022; Kemp, 2021). My ethnographic fieldwork was conducted before the lockdown, and I saw and heard many positive examples of family visitors interacting at mealtimes with their loved ones and with other residents (see chapter 6). It was also evident that family involvement could be complicated, and even problematic; in extreme cases, diminishing the mealtime experience for other residents or perhaps highlighting that some residents do not receive family visits. This was a complex dynamic which required careful management.

In addition, there are financial constraints on mealtime care which need to be acknowledged. Care homes, like any business, must operate within a budget. This influences staffing levels, which in turn may influence the quality of mealtime care (Liu et al., 2020). For example, there may be insufficient staff to ensure residents receive appropriate assistance with eating and drinking, or to give adequate opportunities for social interaction during the mealtime. The budget also influences menu-planning, with cost of ingredients an important factor in what is provided at mealtimes (Dinsdale & Egan, 2017). Indeed, in some cases menu-planning is centralised. For example, in Care Home 1, menu-planning was a function which took place in head office, and from there the menus were disseminated to homes across the chain. There may be efficiencies in this model, but it does not account for local preferences, and may have the effect of disempowering local staff – in particular, the chef and kitchen staff. The chef in Care Home 1 was a very proactive and resourceful individual, who expressed some frustration at being constrained in this way.

### ***8.3.3 Solutions in mealtime care***

Just as I found in my ethnography challenges to the enactment of good mealtime care, so I also found possible solutions to these challenges. These solutions were tested and refined with stakeholders in the co-development process (described in detail in chapter 7), and then framed in such a way that they could be incorporated into a staff training intervention (presented in Appendix X).

Firstly, a person-centred approach is essential in mealtime care. Clearly, person-centredness is a well-known concept in health and social care. In the context of dementia, Kitwood referred to person-centred approaches to distinguish these from approaches that emphasise the medical and behavioural management of dementia (Kitwood, 1988), and to bring together ideas and ways of working that emphasise communication and relationships (Kitwood, 1997). Person-centred care is now considered integral to all aspects of dementia care (NICE, 2018). If the person is viewed holistically, and as an individual, care can be provided which meets their needs and priorities. My findings reinforce the importance of this at mealtimes.

The concept of tailoring care to the resident featured prominently in my literature review, but at that stage I did not distinguish it from other concepts like empowering the resident and socially connecting to the resident. Subsequently, through the ethnography, I discovered it *is* conceptually different – it is a higher-order, over-arching idea which serves to facilitate and enhance those other concepts. I saw it as a touchpoint to help staff navigate the competing demands of mealtime care. For example, staff in Care Home 2 faced the challenge of supporting the social well-being of a resident who often chose to eat in her own room. The proposed solution was to encourage communal dining at selective mealtimes in the later part of the day – because the resident was known to be more alert at these times. To give another example, staff in Care Home 1 described a scenario in which a resident was eating and drinking very little. They emphasised the importance of discovering more about the resident: investigating for changes in mood, or health, or preference, in order to find an explanation for their behaviour and to treat the cause. Thus, my findings support work by Konno et al. (2014), who noted a recent change in the way that care staff respond to so-called “resistance-to-care behaviours” in respect of activities of daily living (such as bathing, dressing – or eating and drinking):

In the past decade, the interpretation of resistance-to-care behaviours has changed from being considered symptoms of dysfunctional cognitive status to being considered meaningful behaviour requiring validation of unmet needs (Ayalon et al., 2006, Spira & Edelstein, 2006). This shift has been facilitated by the person-centred care approach (Kitwood, 1997), which sees the personhood of individuals with dementia in all aspects of care. (p. 2168)

In the specific context of mealtimes, person-centred care means that reduced nutrition and hydration is interpreted and managed more holistically, in a way that emphasises the person as a unique individual – as in the previous example from Care Home 1. This application of the principles of Kitwood’s person-centred dementia care to mealtimes is advocated in research undertaken in the hospital setting (Leah, 2019), and my findings show that it is relevant in care homes too.

Mealtimes provide a good opportunity for the enactment of person-centred care. Each resident has their own preferences and capabilities which can and should guide the way that staff care for them at mealtimes. This happened in the care homes I visited – to an extent. Staff tried to be responsive to residents’ preferences about what to eat, where to eat and when to eat. There were examples of staff tailoring support and interaction depending on residents’ individual skills and characteristics. But there were also situations in which residents’ wishes were compromised, or discounted altogether – particularly when those wishes were perceived to be unwise. Clearly there is more that can be done to operationalise person-centred care at mealtimes. Edvardsson et al. (2008) made some relevant suggestions on this, in the broader context of dementia care. They pointed to the importance of incorporating biographical knowledge of the person with into their care, because “accounts of a person's previous life, routines, and occupation can provide interpretative cues for their present behaviour, needs, and wishes that inform their care” (pp. 363-4). They also prioritised quality of relationship between carer and person with dementia above the completion of tasks – acknowledging that this requires organisational adaptation and flexibility. More recently, Mohr et al. (2021) called for an examination of culture in long-term care, and in particular, whether this is changing to better promote person-centred care for people with dementia. In addition, they recommended more detailed description of what it is that constitutes ‘person-centred’ in an intervention (such as assessment of preferences and needs, or facilitation of relationship).

Significantly, however, I found that person-centred care is not a panacea for the challenges of mealtime care. It does not, by itself, provide all the answers for care home staff who are seeking to provide the best possible care for residents. It does not always make it obvious to the carer what to do in a given situation. Nor does it necessarily help carers to overcome contextual constraints on mealtime care. Even with recourse to person-centred care, there remain complexities at mealtimes, and barriers to optimal care. It is essential, therefore,



that care home staff follow a second guiding principle in their implementation of mealtime care – that is the principle of teamwork.

My findings show that teamwork is a crucial mechanism for overcoming organisational constraints, tackling dilemmas and uncertainty, and reducing the emotional burden arising from mealtime care for residents with dementia. Effective teamwork is already known to be an important component of long-term care in general, and dementia care in particular. To illustrate: Etherton-Beer et al. (2013) found that teamwork was consistently recognised as a potential positive influence on staff and resident outcomes, in their study of organisational culture in older people’s care facilities. Gordon et al. (2018), in their evaluation of healthcare delivery in care homes, noted that relational working between NHS and care home staff generated a sense of common purpose and mitigated the effects of staff turnover. Gilster et al. (2018), who reviewed practice principles for quality dementia care, highlighted the importance of communication, teamwork, and interdepartmental/interdisciplinary collaboration. In the context of mealtimes, the value of teamwork has been identified by Shune and Linville (2019), who proposed the creation of interdisciplinary teams to oversee mealtime care – which they termed ‘dining teams’:

Rather than partitioning out the elements of dining by discipline as is the current model of care (e.g., dietitian focuses on nutrition, speech language pathologist focuses on swallowing, nursing assistant focuses on feeding), a dining team could address goals that are more globally meaningful. This approach would allow for a more streamlined process (e.g., communication, training), create more of a sense of community, and ultimately focus attention on the overall dining experience. In turn, this could help to de-medicalize the mealtime and improve quality of life. The development and implementation of such an interdisciplinary approach should be prioritized in future research. (p. 152)

My findings complement this understanding of teamwork, but they also take it further – because they indicate that the mealtime care team should not be limited to health and social care staff. Rather, everyone who is involved in the life of a resident – inside and outside the care home – may come together at different times and in different combinations to improve mealtimes for that person. Interactions between care assistants and residents are at the heart of mealtime care, but they are supported by a network of other interactions which can involve care assistants, kitchen staff, management, visiting

healthcare professionals, and, importantly, family members. I have termed these people the 'wider care team'.

Of course, early notions of the concept of care for older people centred on unpaid, informal care by family members within the family home. (Indeed, in many countries it continues to be the case that older people typically live with their families in multi-generational households (Shaji, 2009).) Although residential institutions for older people have been in existence in the UK and other countries in one form or another for centuries, historically these were reserved for people without any family to care for them (Chance, 2008; Nagaratnam & Nagaratnam, 2019). Clearly this is no longer the case, and today family members often, to varying degrees, play a part in the care of loved ones who live in care homes (Gaugler, 2005). However, the relationship between family members and care home staff has been found to be complicated and, at times, problematic. For example, some family members have described feeling ignored, excluded and even threatened by care homes staff (Baumbusch & Phinney, 2014), whilst conflict with family members has been seen to increase burnout and dissatisfaction in care home staff (Abrahamson et al., 2009).

Certainly, I found complexities inherent in family involvement at mealtimes. For one thing, not all residents have family members, or family members who visit them. As such, greater family involvement may be beneficial for some residents but not others. My findings suggest this is mitigated to some extent by family members who are a positive presence and resource in the care home, inclusive of and attentive to other residents. There is also a question about the extent to which family, care home staff and others within the wider care team would share the same values and objectives in respect of mealtime care. Thus, there is still some work to be done to ensure that family carers are able to contribute appropriately to care home life in general, and mealtime care in particular. This contribution must take into account the capabilities and resources of family carers, the best way to integrate this with the work of care home and other staff, and – foremost – the needs and preferences of the residents. However, when family members are a recognised and incorporated part of the team at mealtimes, organisational constraints (such as reduced staffing) are tackled and care is enhanced – with the residents experiencing such benefits as suitable assistance with eating and drinking, and richer social interaction.

I also saw that teamwork can help defuse the emotional burden associated with mealtime care, and in particular with reduced eating and drinking (Featherstone et al., 2019; Hopkins, 2004). Staff in both care homes described vividly the difficulties inherent in caring for residents who are eating less than usual (see chapter 5). Moreover, they talked about instances where tailoring their approach to the resident did not seem to significantly change the situation, or to relieve the pressure they felt about it – for example:

*“Staff can take it personally. They take it as a problem and then of course what doesn’t help and exaggerates everything is the fact that families are, ‘Well, are you trying her with that? Are you trying him with this and that and the other?’ ‘We’ve got beans, he likes beans,’ and they’ll try and it might work once so they think that was the answer, that staff aren’t doing their job and so you can get suddenly a melt-down of confidence and then – it feels pressured and, ‘We must get him to eat!’”*

[Interview\_StaffB28\_Home2\_12/12/19]

Notably, the member of staff quoted in the above extract went on in their interview to emphasise the importance of collaborating with colleagues when facing challenges of this kind. They spoke about “not making it that individual’s responsibility, but sharing the responsibility”, and “discussing about a certain client, you know, ‘Have you got problems with anybody?’ ... It’s about having that discussion”. Discussing challenging issues was seen as an important means of support. This was evident to a degree in both care homes I visited, with staff describing and valuing supportive conversations with peers and other members of the wider care team. Interestingly, this kind of open communication was valued not only by care assistants, but also by more senior staff. In these moments, the hierarchical nature of the care home workforce was briefly transcended – and I saw care assistants making important and recognised contributions to the well-being of residents and the culture of the home. This points to another finding of the thesis, about the reach and remit of the care assistant in mealtime care, which I discuss in the next section.

#### ***8.3.4 The influence of the care assistant***

My understanding of the role of the care assistant in mealtime care has evolved during the course of this research. At the outset, I conceptualised interactions between care assistants and residents as being fundamental to mealtime care – and framed my literature review in these terms. From the ethnography, I learned that these interactions – whilst still central to mealtime care – are shaped and constrained by the context in which they occur; by organisational factors inherent in care homes. Subsequently I came to see that care

assistants are not passive in this process; they are not without control or power. Rather, they have the potential to influence the wider context, as well as to be influenced by it. This idea was reinforced in the co-development work that proceeded from the ethnographic study.

Care assistants have important insights into mealtime care; they are the closest to it of everyone involved in the life of a care home resident, experiencing at first-hand the successes and challenges of mealtimes. Where there is good practice, this insight is prized and utilised by senior care home staff and visiting healthcare professionals, and care assistants are enabled to play a role in higher-level decisions about mealtime care. This may include, for example, providing information about nutritional intake for the GP or dietitian to formulate a plan of action, or contributing suggestions about adapted cutlery or modified diet. There is scope for this to go further, with care assistants potentially bringing about significant cultural and systemic changes – such as in respect of allocation of staffing within the home, or attitudes towards sitting and eating with residents. However, this requires enlightened leadership from the management team. The work of Kadri et al. (2018, p. 10), who found that managers do not always appreciate carers' values and expertise – seeing them rather as “instruments for operationalising care routines” – suggests there remains progress to be made here. As a counterpoint to this, Du Toit et al. (2019) invoked servant leadership, and the idea that person-centred management results in person-centred care:

This approach is grounded in the belief that care staff members treated by the organization in a person-centered way will reciprocate by serving residents through person-centered practice. ... Servant leadership is therefore proposed to substitute authoritarian leadership styles enhancing the knowledge level of care staff regarding person-centered care, and empowering them to take initiative and be creative in their practices. (p. 350)

Similarly, Caspar et al. (2020), who studied the social organisation of care delivery in care homes, came to this conclusion:

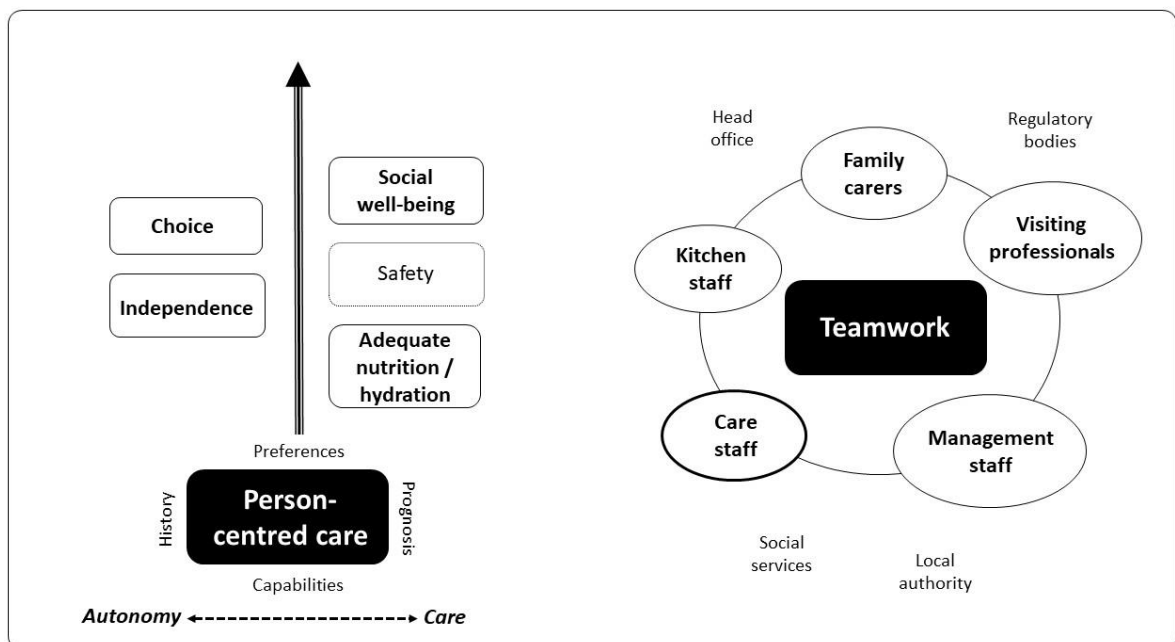
For leaders in these settings, we suggest that there are several questions to ponder: How do we arrive at decisions about care – collaboratively or unilaterally? Are our traditional care hierarchies serving us, or our residents, well? Are we truly respecting and acknowledging RCAs [resident care aides] as the ‘eyes and ears’ of

care? How can we create workplaces that are more connected and collegial? Is there a better way? (p. 26)

These authors' findings relate to general care in care homes. My work has shown that these principles are pertinent for mealtime care. If care assistants are consulted and involved in more aspects of mealtime care, not just in the immediate mealtime interactions, they may be empowered and care may be improved. Thus, good mealtime care is not about directing care assistants to provide care in a way that is deemed optimal by others (such as SLTs, dietitians, care home managers, or academics). Rather, it is about collaborating with care assistants to arrive at optimal mealtime care. These ideas of collaboration and consultation were important to my understanding of mealtime care. As such they significantly informed my prototype intervention, which I present in Appendix X.

### 8.3.5 A model of mealtime care for people with dementia living in care homes

Figure 8.1 below depicts a model of mealtime care for people with dementia living in care homes. Thus, it builds on figures presented earlier in the thesis (in chapters 5, 6 and 7) and derives from the key findings of this study.



**Figure 8.1: A model of mealtime care for people with dementia living in care homes**

In summary, the tenets of the model are as follows. There are various priorities in

mealtime care for residents living with dementia. They include choice, independence, social well-being, safety, and adequate nutrition and hydration. These priorities are sometimes in tension with one another. An example is the tension between empowering a resident to choose what they want to eat and drink, but also ensuring they have a healthy diet. Such examples point towards a more general tension between autonomy (the resident expressing and enacting their wishes) and care (the care home providing for the resident's physical and psychological needs). A person-centred approach helps to resolve these tensions. By focusing on the person as an individual – their history, capabilities, preferences and prognosis – staff are better able to navigate through to the right priority at the right time. Challenges remain because mealtime care operates within a complex system – the care home – which has the potential to both constrain and enable care. In particular, connection between departments within the home – and to agencies outside it, such as health and care professionals, and family members – is an important determinant of good mealtime care for residents living with dementia. As such, teamwork is key in overcoming constraints and enabling good mealtime care. By way of example: when care staff and kitchen staff work together well, resource is maximised and care is enhanced. When staff, management, and external health and care professionals collaborate as equal partners, staff are empowered, burdens are shared and problems are solved. When families are carefully incorporated into mealtime care, this can benefit not only their loved ones, but other residents too. Care home staff, in particular, are crucial and influential members of this team, and mealtime care is most obviously manifest in their interactions with residents.

This model builds on previous work in the field of mealtime care for residents with dementia. It confirms the importance of a person-centred approach (see also Driessen & Ibáñez Martín, 2020; Murphy et al., 2017; Nell et al., 2016; Palese et al., 2018). It develops this idea by showing that person-centred care enables carers to find a way through the competing priorities that arise at mealtimes. In addition, my findings in relation to teamwork complement and augment the existing literature on this topic. Effective teamwork is a recognised feature of good dementia care and good long-term care (Etherton-Beer et al., 2013; Gilster et al., 2018; Gordon et al., 2018). I found that teamwork has a specific role in mitigating the constraints of time and resource that can otherwise hinder care, and has a positive effect on the system in which mealtime care operates, in a way that enhances care. I also found that the team is most powerful when it

is wide-ranging and inclusive – comprising care home staff, families and external agencies – and when the contribution of care assistants is properly recognised. In addition, teamwork helps to reduce the emotional burden associated with caring for people with dementia at mealtimes. This notion is briefly explored in previous studies (Douglas et al., 2020; Pasman et al., 2003). My work develops this by proposing a tangible mechanism for team-building, through the collaborative learning approach in the training intervention.

It is important to note that the optimal care proposed in this model was not always evident in the care homes I visited. As discussed earlier in this chapter, enactment of person-centred care at mealtimes was variable. For example, care staff did not consistently respond to residents' wishes about where to have their meals. There were also times when more could have been done to find out residents' food preferences. Similarly, there was an absence of teamwork in some of the situations I observed or heard about. I noted a disconnect between care staff and kitchen staff, miscommunication between management and carers, and some wasted opportunities to include family carers as part of the wider care team. This dissonance, between what ought to happen and what does happen, helped to further shape the development of the prototype training intervention – as described in the following section.

#### **8.4 How the key findings informed the prototype intervention**

The key findings described above contributed directly to the overall aim of this research, by informing the development of a prototype mealtime care training intervention.

Intervention development was led by me, a practising SLT. It was informed by multiple-methods evidence, and conducted in close collaboration with a range of relevant stakeholders. To my knowledge this is the first such intervention development research on the topic of mealtime care for care home residents with dementia.

The priorities of mealtime care identified in my research are clearly reflected in the five modules which make up the intervention content (as outlined in chapter 7):

Empowerment and respect; Facilitating independence; Social interaction; Being safe; Careful encouragement. The mode of delivery of the intervention, in turn, emphasises the guiding principles of person-centred care and teamwork that I found to be central to good mealtime care. For example, the case scenarios, which are anonymised cases based on real situations from the ethnography, flag up the diverse and individual nature of people

living with dementia, and require attendees to use a person-centred approach when addressing the problems highlighted in the cases. In respect of teamwork, it became apparent to me that presenting this concept as a piece of knowledge to be acquired (akin to, for example, learning about the Mental Capacity Act) would not be the most effective method. Rather, I sought to build in the notion of teamwork as integral to the delivery of the intervention – so that attendees would grow closer as a team, and learn together as a team; a process of collaborative learning. This approach was endorsed by findings from my interviews with care home staff, which identified the value of mutual learning – acknowledging and capitalising on the experience of participants, and encouraging learning through peer discussion. It was also consistent with evidence from extant literature on education and workforce development in dementia care, with a body of work by Surr et al. supporting the idea of learning through discussion and drawing on examples from learners' own practice (Surr et al., 2017, 2020; Surr & Gates, 2017). In this way, my intervention builds on ideas expressed in the LOCK framework, described in Mills et al. (2018). This is a framework for problem-solving and quality improvement in care homes; the acronym stands for Look for the bright spots, Observe, Collaborate in huddles, Keep it bite-sized. The framework is intended to capitalise on the strong team-relationships in care homes. My intervention provides a forum for strengthening those relationships further.

In addition to this, I wanted the intervention to utilise staff's existing knowledge and skills in an empowering way. My findings indicated that care home staff, not least care assistants, had valuable insights and understanding about mealtime care. For this reason, I referred to emancipatory practice development (EPD), a methodology which considers local practitioners to be in a unique position to examine and develop practice change (McCormack et al., 2014). Practitioners are encouraged to critically reflect on current practice in an open and safe way, with a view to being freed from aspects of established practice which are unsatisfying, oppressive and not in accordance with their values (Habermas, 1987). Thus, EPD has its theoretical roots in critical social science. Its goal is to empower rather than direct practice change (Peet et al., 2019). In my intervention, through group discussion and problem-solving, all attendees have an opportunity to contribute to the development of good mealtime care practice within their particular setting – informed by evidence, but in a way that is responsive to local circumstances.



This has led me to some difficulties with terminology; specifically, use of the terms ‘training’ and ‘learning’. In conceiving, designing, conducting and reporting this research, I have consistently used the former term to describe the endpoint: a training intervention. However, in moving closer to that endpoint, I have begun to think of this instead as a learning intervention. ‘Training’ is often defined from the perspective of the one doing the training (the trainer, rather than the trainee). ‘Learning’ can only be defined from the perspective of the one doing the learning (the learner). Therefore, ‘learning intervention’ now seems the more appropriate descriptor for an intervention which seeks to respect and utilise the experiences, insights and contributions of learners in this way.

With this focus on collaborative learning rather than didactic training, the intervention mode of delivery is similar to, but distinct from, Problem-Based Learning (PBL). In PBL, students work cooperatively in groups to seek solutions to real-life problems (Seibert, 2021). It is a somewhat different approach because, as might be inferred from the name, the problems provide the starting-point for the learning. Boud and Feletti (1997, p. 15) describe this as “confronting students with problems from practice which provide a stimulus for learning”. As detailed in chapter 7, in my intervention a theory section precedes the case scenarios (the problems for discussion). This enables learners to apply theoretical knowledge when thinking about and discussing the case scenarios, and facilitators to be able to signpost learners back to relevant theoretical principles during these discussions, if necessary. As such, it is intended to address a potential shortcoming of collaborative learning approaches – that the content is insufficiently evidence-based. In their overview of EPD, Fairbrother et al. (2015, p. 2) describe this as “a common criticism ... that [EPD] promotes context-specific (rather than absolutist) implementation well, but the science around what it implements is lacking”.

## **8.5 Strengths of the research**

There are various aspects of this work which strengthen its findings. I discuss each of these below.

### **8.5.1 PPI**

The research was designed and conducted in close consultation with members of the public, carers of people living with dementia, and relevant health and care professionals, as outlined in chapter 2. In summary, PPI was integral to the research design process and precipitated several refinements to my protocol which were important and beneficial. This

was in areas including: how to engage and recruit care homes; how to design and phrase patient information forms; how to conduct mealtime observations; how to facilitate equal participation in co-development workshops; and how to ensure expert input on vocational education and training.

### ***8.5.2 Multiple evidence sources***

In developing the prototype intervention, which is the primary output of this research, I have used multiple evidence sources. This has ensured a rich and comprehensive evidence-base for the intervention. My literature review comprised a systematic review of peer-reviewed research publications, and a scoping review of grey literature, in the form of published guidelines. The inclusion of grey literature in reviews is recommended in the Cochrane Handbook for Systematic Reviews of Interventions (Higgins et al., 2019), and in the Institute of Medicine Standards for Systematic Review (Morton et al., 2011). In addition to systematically searching on-line sources, other key resources were consulted to locate other literature, including professional mailing lists and topic experts. The ethnographic study allowed for exploration of culture, perspectives and practices the care home setting, and generated rich and detailed accounts of carer-resident interactions. This is consistent with Medical Research Council (MRC) complex interventions guidance, which advises that existing evidence is supplemented by new primary research (Craig et al., 2006). In particular, observations enabled the collection of rich and directly observed data, thus adding value to the retrospective accounts from participant interviews which may provide idealised accounts of events. As described in chapter 7, I carefully compared this evidence from various sources, summarising common themes and categories. I then presented it at the co-development workshops in such a way so that it was clear, accessible, and visual.

### ***8.5.3 Use of Constructivist Grounded Theory***

Existing theories may provide a certain amount of relevant information to aid intervention development – but they are likely to be general in nature, and therefore may not correspond exactly to the intervention under development, or be more difficult to apply than expected (O’Cathain, Croot, Duncan, et al., 2019). Moreover, it has been argued that a tendency to privilege off-the-shelf theories leads to inappropriate use of theory, or reliance on theory which is at an individual level rather than a systems level (Moore & Evans, 2017). In the case of my intervention, I had access to some useful existing theories

about, for example, dementia care (Kitwood, 1997; Kitwood & Bredin, 1992), and embedding interventions into practice (May & Finch, 2009). However, I did not find any theories which were specific to mealtime care for care home residents living with dementia. Therefore, I took the opportunity to use Constructivist Grounded Theory methodology to generate theoretical insights into this subject, articulated in detail in chapters 5 and 6. As such, an iterative and non-linear approach was taken to data collection and analysis. The combination of methods for data collection – observation, informal conversations, and semi-structured interviews – served to provide a detailed picture of mealtime care (both usual care and good practice) with far greater depth and understanding than would have been achieved by relying on only one method of data collection. Spending time in each care home concurrently allowed for ongoing comparison between them. Using the constant comparative method, data analysis began as data were being collected. Thus, I was able to adjust the data collection process as and when it appeared that additional concepts and relationships required exploration.

#### ***8.5.4 Co-development with stakeholders***

I worked closely with stakeholders during the co-development workshops. I was mindful of the importance of engaging stakeholders with different roles and responsibilities – including family carers, care assistants, care home managers, community nurses, SLTs, and dietitians. I spent time and care identifying and recruiting participants for the workshops, using a flexible approach so participants could attend just one workshop, two workshops, or all three. My aim was to achieve a balance of both new and returning participants in later workshops. This ensured broad diversity of experiences and perspectives, and brought fresh voices and challenge in each workshop – whilst also generating a sense of continuity and teamwork among participants. The contribution of the educationalist was important because of their expertise in the field of vocational education and training. They brought specialist insight into training delivery and learning styles. Stakeholders also contributed valuable ideas to help with planning ahead to implementation of the intervention, considering issues of acceptability and evaluation, and how learning might become embedded. To prompt these discussions, I used questions informed by NPT constructs (May & Finch, 2009).

### **8.5.5 Positionality**

My professional background as an SLT specialising in the care of older people has been beneficial to the research process in various ways. Through my clinical role, I already had valuable experience of working into care homes and interacting with residents, staff and family. This meant I was quickly able to build rapport during my orientation period in the care homes, and during data collection – helping participants to feel at ease during conversations and interviews, and eliciting rich data as a result. I was also used to observing carer-resident interactions at mealtimes, from a clinical perspective, and in that sense well-positioned to collect data via observation. At the same time, I was very aware that the observations I conducted for this research were different in nature and purpose from any I had done before. I have taken care to acknowledge and reflect on my professional knowledge and experience as an SLT, in making the transition from clinician to researcher. This has been important to maintain perspective and minimise professional bias. During the period of data collection I wrote reflexive notes, scrutinising my research decisions and interpretations so that they are transparent and accountable (Davies et al., 2004; Watt, 2015). I also regularly discussed the data with my supervisory team, to explain the thinking and decision-making behind my analysis.

### **8.6 Limitations of the research**

As well as strengths, there were several challenges inherent in conducting this research which limit its findings. I consider these below.

#### ***8.6.1 Reconciling constructivist grounded theory, the conventions of PhD research, and the objectives of intervention development***

In carrying out this work, I was attempting to do a number of things at once. These included completing a constructivist grounded theory study, fulfilling the requirements of a PhD degree, and developing a prototype intervention. These objectives were clearly aligned, but in some respects they were also separate and even – at times – in tension with one another. For example: I conducted a literature review prior to the ethnography. This is usual in PhD studies, and had the practical advantage of allowing me to make progress with one phase of my project (the literature review) whilst awaiting ethical approval for another (the ethnography). Early proponents of grounded theory would contend that this order of working carries a risk: namely, that the knowledge the researcher acquires through their literature review may adversely influence the theory they go on to develop.

In particular, Glaser and Strauss (1967) advocated a *tabula rasa* approach, whereby the researcher enters the field with no preconceived ideas or established understanding of relevant literature. However, I took the view that this approach was unrealistic. For one thing, I was carrying out the research precisely because of my pre-existing clinical interest and experience in the topic. For another, I had of necessity familiarised myself with relevant literature prior to beginning the research, in order to develop a funding bid. Therefore, in following the approach of Charmaz (2006), I acknowledge that my previous experience and knowledge played a part in constructing this novel theory. I have reflected on this throughout the research process. In particular, during the ethnography I was careful to consider ways in which knowledge I had acquired from relevant literature may potentially interact with and inform data collection and analysis in the ethnography. I endeavoured to approach this work “with a mind that is sufficiently open so as to allow new, perhaps contradictory, findings to emerge from the raw data” (Dunne, 2011, p. 117). In so doing, I took the stance expressed by Urquart (2007, p. 351): “There is no reason why a researcher cannot be self aware and be able to appreciate other theories without imposing them on the data. Once these data have been analysed to form an emergent theory, it is helpful to test the emergent theory against extant literature and theory”. I hope that I was (at least partly) successful in this. There are some similarities between the findings of my literature review and the findings of my ethnographic study. Whether this is because the literature review unduly influenced the ethnography, or because the ethnography corroborated and strengthened the findings of the literature review, is probably difficult to discern with certainty.

In addition, the juxtaposition of intervention development methodology with constructivist grounded theory felt uncomfortable at times. For example – constructivist grounded theory would propose that a theory continues to develop in an ongoing way – beyond the point of data collection and analysis, during and after the writing-up process (Charmaz, 2006). Intervention development, however (and, for that matter, the completion of a PhD), requires timescales and end-points. As such, the theory may develop and iterate beyond the completion of tangible outputs such as a prototype intervention. In the case of this intervention, for instance, at the time that I presented evidence at the co-development workshops, analysis of the ethnographic data had not yet progressed to a point where my conception of the ‘wider care team’ was fully-formed. However, on discussion of this topic with workshop participants it was agreed that

teamwork should encompass the working relationships of all involved in residents' care, including management staff, kitchen staff, family carers and healthcare professionals.

### ***8.6.2 Presupposing the intervention-type***

I made a decision at the outset of my research to presuppose that the type of intervention would be a training intervention. This was based on recommendations from research literature (see, for example, Liu et al. (2015) and Bunn et al. (2016), and guidance from relevant professional bodies (Enderby et al., 2013; RCSLT, 2014). The decision was helpful in that it gave direction and momentum to the research, but it has perhaps meant that other intervention-types have not been fully considered – such as other behaviour-change interventions (Michie et al., 2015). These may have included, for example, feedback and monitoring, goal setting, and restructuring the physical environment. It is possible that the application of behaviour change methodology in this work would have pointed to alternative relevant approaches. In addition, a greater reference to frameworks of training evaluation criteria – such as Kirkpatrick's four level model (*reaction, learning, behaviour, and results*) (Kirkpatrick, 1998) – may have allowed me to understand better whether my intervention is aiming to change behaviour or increase knowledge.

### ***8.6.3 Sampling and recruitment***

In most respects, my approach to sampling and recruitment seemed to be successful in meeting the stated objectives. For example, I intended to investigate mealtime care in care home settings that differed in certain aspects, to see if those differences had any impact on care. In particular, my objective was to have variety in size (number of beds) and ownership (national/regional/local). The care homes I recruited to the ethnographic study were different in those ways. However, in other ways they were similar. They were both located in socially-deprived urban areas, for example. (The third care home which agreed to take part was in a suburban area with less social deprivation, but I was unable to conduct fieldwork there due to the onset of COVID-19 lockdown measures.)

Additionally, the care homes each had a rating of 'Good' in their most recent Care Quality Commission (CQC) reports. My rationale for this was that I sought to identify good mealtime care in the study, but it could be argued that having a greater range of quality ratings across the homes would have made my findings more generalizable.

On gaining access to the care homes, I managed to recruit participants from a variety of roles and professions, including care assistants, senior staff, healthcare professionals and

family members. Amongst the residents, however, there was a certain group which was under-represented – those with advanced-stage dementia. Recruiting within this group proved to be challenging in some ways. These residents almost invariably lacked capacity to consent to participation, and therefore consultee opinion was required; although a relevant consultee was usually identified, in many cases they did not respond to contact. In addition, these residents were often in more compromised health than those whose dementia was less advanced. Understandably, the care home staff who helped with recruitment did not tend to approach residents who were unwell, likely feeling that this was not in their best interests. Indeed, one of the exclusion criteria in my protocol was “residents will be excluded if, in the judgement of senior care home staff, it would be inappropriate to approach them (e.g. residents who are at the end of life, and for whom there would be unjustifiable risk of upset/distress/inconvenience to them and/or their families)”. Thus, for good reasons, there were relatively few residents in the study whose dementia was very advanced. My findings should be interpreted in light of this, and future studies must consider carefully how to be more inclusive of this population.

Similarly, people with dementia were not recruited to participate in the co-development workshops. I took the decision instead to recruit family carers of people with dementia – on the basis that it may have been difficult for people with dementia to take part in the workshops. By involving family carers, I intended that they would provide relevant insight into the experience of caring for a person with dementia at mealtimes, and would be able to represent and advocate for their loved ones to an extent. On reflection, it may have been preferable to also hear directly the voices of people with dementia in the workshops (and not just in the ethnography). There were certain other potential participant-types not recruited to the workshops who would likely have made a valuable contribution to the discussions, for example occupational therapists. Moreover, some participant-types who I did actively seek out proved to be somewhat difficult to recruit. Community nurses and care home managers were in this category, and I learned from experience that intentionally over-booking these participants was a useful strategy to ensure adequate representation. With hindsight, I could perhaps have employed this strategy from the outset. Overall, the number of workshop participants was relatively small, and so validating findings with a wider group of stakeholders subsequently may have been a beneficial extra step.

#### ***8.6.4 Decision-making in the workshops, and the problem of ‘groupthink’***

Thinking specifically about the methods employed in the workshops: I had intended initially to use Nominal Group Technique (NGT) (Chapple & Murphy, 1996), in the event that there were differences of opinion. This approach allows for agreement to be reached via anonymous voting if there are divergent viewpoints within a group. In the event, I did not use this. This may be because there were genuinely few if any divergent viewpoints in the workshops, but an alternative explanation is that the workshops became closer in style to focus groups. On reflection, it would have been beneficial to have a tighter structure, with greater emphasis on hearing all views equitably and making accountable decisions based on these – which is what NGT would have enabled. Through discussion in the workshops, we did arrive at a set of decisions to inform the prototype intervention – but a more robust process may have reduced the risk of bias and in particular the problem of ‘groupthink’. Hoddinott (2015) describes the problem thus:

Groupthink is where cognitively homogeneous groups have strong allegiances, tend not to voice dissent, rationalise away counterarguments and are confident in their plans. Groupthink can result in premature conceptual closure, the collection and reporting of confirming data only and for “assumption habits” or blind spots to be unrecognised. ... It can be argued, therefore, that methods which tend towards consensus (e.g. focus groups; Delphi techniques) are only appropriate when finalising an intervention specification. (p. 2)

The objective of my workshops was to develop an intervention specification, rather than simply finalise one, and therefore in Hoddinott’s view “methods which tend towards consensus” were less appropriate here.

#### **8.7 Implications of findings for future research, policy and practice**

My work points to a number of possible directions for future research. I plan next to conduct a study to explore the feasibility and acceptability of the prototype training intervention. I plan to do this in approximately three local care homes, to obtain data on the amenability of the intervention to embed in everyday practice. The care homes would be chosen for diversity in regards to various characteristics including size, and organisational structure. The prototype training intervention would be provided to a purposive sample of care home staff in each of the care homes. Semi-structured, in-depth interviews with approximately 20 participants would be conducted at intervention



completion, in order to obtain participants' views on various aspects of the intervention and its feasibility, including: expectations of the training intervention; their experience of the intervention (for example, in regards to its usefulness); any suggestions for improvement; any impacts on their practice. Participants would reflect on their experiences using broad, open-ended questions. Data from the semi-structured interviews would be supplemented by my own reflections on the process and practicality of implementing and evaluating the training, through use of a reflexive diary.

The feasibility study would also collect data on recruitment, by way of the number of learners agreeing to take part. Other factors to be considered would be: cost and funding of training; time taken to train; time taken to do the work that the training promotes; attendance rate; compliance with training; intervention fidelity. The feasibility study would help to inform the sample required for a future pilot randomised controlled trial (RCT). In addition, a pre- and post-intervention skills/knowledge assessment may be developed for use with learners. This assessment would be circulated to interview participants. The purpose would be to test the assessment for its feasibility and acceptability in preparation for the future pilot RCT, in addition to providing information about retention rate (in terms of the number of staff completing the skills assessment at each time point). As such, the feasibility study would reduce uncertainty about the acceptability of the intervention and its outcome measures. Feasibility would be decided based on pre-defined parameters for the criteria described above. The future pilot RCT would also measure patient outcomes such as incidence of aspiration pneumonia, nutritional outcomes, and quality of life outcomes, as well and other outcomes such as staff wellbeing.

Future research may also consider various issues in relation to how best to implement and evaluate the intervention, including: how to roll-out the intervention more widely (e.g. via a train-the-trainer approach); whether and how to connect the intervention to an existing competency framework (such as the Care Certificate, or a National Vocational Qualification (NVQ)); whether evaluation should target the individual and/or the care home; how best to provide follow-up / on-going support.

Finally, future research should consider the impact of COVID-19 – both on mealtime care for residents with dementia, and on training interventions. The ethnographic fieldwork reported in this thesis took place before the pandemic. It therefore does not examine how

factors such as social distancing, personal protective equipment (PPE), visiting restrictions and increased staffing pressures may have affected mealtime care in care homes. Future studies could explore, for example, whether the introduction of essential caregiver status in the UK (Bailey et al., 2022) was beneficial to mealtime care, and whether this has had lasting impact (although the designation itself has since been withdrawn). In addition, research is needed to understand the way in which the pandemic has normalised the use of online meetings and online training, and how this may change expectations and practice around training delivery for care home staff.

Implications for policy and practice should be caveated by the fact that the prototype intervention is yet to be tested for feasibility, acceptability or effectiveness. Nevertheless, the research findings provide valuable principles to inform both policy and practice in mealtime care for residents living with dementia. Policy in this area should take account of the complex system in which mealtime care operates, and the fact that it is best delivered in a collaborative way. In particular, it is important that all those involved in the provision of mealtime care are consulted and have a voice in the development and refinement of policy on this topic. This may include – but not be limited to – residents, care assistants, kitchen staff, care home management, external health and care professionals, and family members. A tangible outworking of this would be better inclusion of each of these groups on relevant committees and panels, for example those that contribute to mealtime care guidelines.

In respect of practice, my research findings indicate that care homes should consider the following priorities when providing mealtime care for residents with dementia:

- *Choice*. Empower residents to choose, by knowing residents' preferences, enabling and respecting decision-making, and understanding mental capacity and the best-interests process.
- *Independence*. Provide appropriate levels of assistance, such as 'set-up' help for residents at the start of a mealtime, use of adaptive equipment (such as plate-guards), suitable crockery/cutlery (considering, for example, colour, pattern, ease of use), and tailored food (including finger foods).
- *Social well-being*. Facilitate positive relationships, by tailoring social interaction to the person, understanding social dynamics between residents, facilitating

resident-resident interaction, involving family at mealtimes, and capitalising on special occasions.

- *Safety.* Monitor residents for mealtime difficulties and changes in their presentation, considering factors such as alertness and positioning, checking pacing and bolus-size, ensuring food and drink is of the correct consistency and temperature, involving kitchen staff in this process, and communicating clearly with other agencies such as the GP and SLT (for example, in regards to use of thickened drinks).
- *Adequate nutrition and hydration.* Carefully encourage eating and drinking without being forceful, considering underlying factors such as oral health, referring to residents' personalised care plans, liaising with family members where possible, and knowing when and how to engage other professionals.

In addition to this, mealtime care should be person-centred. This is always important, but is particularly informative where there is apparent conflict between two or more of the priorities described above. Focusing on the person as an individual – their history, capabilities, preferences and prognosis – can help to identify the right approach in a complex or uncertain situation. In practice, this may include staff having ready access to comprehensive and up-to-date information about residents, and ensuring that relevant knowledge and insights about residents is communicated well.

Following on from this, mealtime care practice should do more to foster joined-up working between all those involved in the resident's care. A starting-point for this is better understanding and mutual appreciation of one another's roles – and overt acknowledgement of their contribution to the care of residents. Importantly, this applies to those outside the care home as well as within it. My findings suggest that a blurring of this boundary to facilitate a 'wider care team' will lead to better, more cohesive care. In particular, including family members in a more explicit way may help them feel they are part of this team. Therefore, structures and initiatives that promote greater connection within and beyond the home should be encouraged. This might take the shape of a regular forum for discussing mealtime care, or inclusion of all of the wider care team in training events. There will be inevitable complexities to manage here: team-members will bring different perspectives and backgrounds; some will have formal responsibility for the resident's care, others will not. Nevertheless, coming together means that challenges in mealtime care can be faced in partnership. By sharing insights, knowledge and

experience, a problem which seemed intractable can sometimes be overcome. This can happen at multiple levels, for example: two care assistants discussing how best to care for a resident; a family member sharing information about their loved one's food and drink preferences; carers liaising with kitchen staff so that a meal is prepared in the right way; a GP problem-solving with care assistants and nursing staff.

## **8.8 Conclusion**

This thesis contributes to the field through the co-development of a new prototype intervention to improve mealtime care for people with dementia in care homes. The intervention is informed by new knowledge about good practice in mealtime care for this population, and about contextual constraints on practice. This knowledge was generated through a literature review (comprising a systematic review of research studies, and a scoping review of guidelines), and an ethnographic study in two care homes in northeast England. Evidence from these sources was used by stakeholders in a series of co-development workshops to produce the prototype intervention presented in Appendix X. The content and mode of delivery of the intervention reflect the key findings of the thesis. Good mealtime care for residents with dementia promotes choice, independence, social well-being, safety, and adequate nutrition and hydration. A person-centred approach helps carers to find the right balance between these priorities. Teamwork is instrumental in overcoming the contextual constraints inherent within the complex care home setting, so that the best possible care is provided.

Future work should address the gaps that continue to exist between good practice and current practice. My forthcoming feasibility study will contribute to this by testing the prototype training intervention in local care homes, in preparation for a pilot RCT – as outlined above. Ongoing work is also needed to understand how best to operationalise person-centred care and teamwork in the care home setting. If mealtime care for residents with dementia is to be truly person-centred, the resident's voice must be heard – in day-to-day practice, in policy, and in research into this topic. In particular, concerted efforts should be made to facilitate this where the resident has cognitive or communication difficulties which may otherwise make it difficult. (For example, in my future study I will work closely with experts by experience in the planning and design of the research, via group or one-to-one meetings depending on preference.) In addition, if genuine teamwork is to characterise mealtime care, it is essential that everyone involved – not least care

assistants – is enabled to play their part, with an emphasis on mutual respect and joined-up working. In this thesis I have proposed that collaborative learning is a potential mechanism for this. In future work I will examine whether it leads to more collaborative care and better mealtimes.

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- Young, J. M., & Unger, D. (2016). Covert Administration of Medication to Persons with Dementia: Exploring Ethical Dimensions. *The Journal of Clinical Ethics*, 27(4).
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## Appendix A. Systematic review of research studies – MEDLINE search strategy

1. exp DEMENTIA/
2. "COGNITION DISORDERS"/ OR "COGNITIVE DYSFUNCTION"/
3. (dement\*).ti,ab
4. (Alzheimer\*).ti,ab
5. (1 OR 2 OR 3 OR 4)
6. DEGLUTITION/
7. "DEGLUTITION DISORDERS"/
8. exp EATING/
9. exp MEALS/
10. FOOD/
11. (eat\*).ti,ab
12. (drink\*).ti,ab
13. (meal\*).ti,ab
14. (swallow\*).ti,ab
15. (dysphagi\*).ti,ab
16. (feed\*).ti,ab
17. (food\*).ti,ab
18. (6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17)
19. (carer\*).ti,ab
20. (caring).ti,ab
21. CAREGIVERS/
22. "PATIENT CARE"/ OR "CUSTODIAL CARE"/ OR "LONG-TERM CARE"/  
OR "NURSING CARE"/
23. NURSES/
24. "NURSES' AIDES"/
25. "NURSING STAFF"/
26. (nurs\*).ti,ab
27. exp "RESIDENTIAL FACILITIES"/
28. ("care home\*).ti,ab
29. ("care worker\*).ti,ab
30. (caregiver\*).ti,ab
31. ("long-term care" OR "long term care").ti,ab
32. (19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR  
30 OR 32)
33. (5 AND 18 AND 33)

## Appendix B. Systematic review of research studies – Full-text articles excluded, with reasons for exclusion

Article	Reason for exclusion
Akerlund, B., & Norberg, A. (1985). An ethical analysis of double bind conflicts as experienced by care workers feeding severely demented patients. <i>International Journal of Nursing Studies</i> , 22, 207–216.	Not all participants in care homes
Altus, D. (2002). Using Family-Style Meals to Increase Participation and Communication in Persons with Dementia. <i>Journal of Gerontological Nursing</i> , 28(9), 47-53.	Outside direct control of care staff
Amella, E. J. & Batchelor-Aselage, M. B. (2014). Facilitating ADLs by caregivers of persons with dementia: the C3P model. <i>Occupational Therapy in Health Care</i> , 28(1), 51-61.	Not a primary study
Amella, E. J. & Lawrence, J. F. (2008). Eating and Feeding Issues in Older Adults with Dementia: Part I: Assessment. <i>Annals of Long-Term Care</i> , 16(3).	Not all participants in care homes
Amella, E. J. & Lawrence, J. F. (2008). Eating and Feeding Issues in Older Adults with Dementia: Part II: Interventions. <i>Annals of Long-Term Care</i> , 16(4).	Not all participants in care homes
Aparanji, K. P. & Dharmarajan, T.S. (2010). Pause Before a PEG: A Feeding Tube May Not Be Necessary in Every Candidate!, <i>Journal of the American Medical Directors Association</i> , 11(6), 453-456.	Outside direct control of care staff
Athlin, E. & Norberg, A. (1987). Interaction between the severely demented patient and his caregiver during feeding. A theoretical model. <i>Scandinavian Journal of Caring Sciences</i> , 1(3-4), 117–123.	Focus is assessment not care
Athlin, E. & Norberg A. (1987). Caregivers' attitudes to and interpretations of the behaviour of severely demented patients during feeding in a patient assignment care system. <i>International Journal of Nursing Studies</i> , 24(2), 145–153.	Outside direct control of care staff
Athlin, E., Norberg, A., & Asplund, K. (1990). Caregivers' perceptions and interpretations of severely demented patients during feeding in a task assignment system. <i>Scandinavian Journal of Caring Sciences</i> , 4(4), 147–156.	Not all participants in care homes
Athlin E. & Norberg A. (1998) Interaction between patients with severe dementia and their caregivers during feeding in a task-assignment versus a patient-assignment care system. <i>European Nurse</i> , 3, 215–227.	Study reported in another article
Athlin, E., Norberg, A., Asplund, K. and Jansson, L. (1989). Feeding Problems in Severely Demented Patients Seen from Task and Relationship Aspects. <i>Scandinavian Journal of Caring Sciences</i> , 3(3), 113-121.	Focus is assessment not care
Austbø Holteng, L., Frøiland, C., Corbett, A., & Testad, I. (2017). Care staff perspective on use of texture modified food in care home residents with dysphagia and dementia. <i>Annals Of Palliative Medicine</i> , 6(4), 310-318.	Outside direct control of care staff
Bäckström, Å., Norberg, A., & Norberg, B. (1987). Feeding difficulties in long-stay patients at nursing homes. Caregiver turnover and caregivers' assessments of duration and difficulty of assisted feeding and amount of food received by the patient. <i>International Journal of Nursing Studies</i> 24(1), 69–76.	Focus is assessment not care

Ball, L., Jansen, S., Desbrow, B., Morgan, K., Moyle, W., & Hughes, R. (2015). Experiences and nutrition support strategies in dementia care: Lessons from family carers. <i>Nutrition &amp; Dietetics</i> , 72(1), 22– 29.	Not all participants in care homes
Barnes S., Wasielewska C., Raiswell C., & Drummond B. (2013). Exploring the mealtime experience in residential care settings for older people: an observational study. <i>Health and Social Care in the Community</i> 21(4), 442–450.	Population focus is not people with dementia
Batchelor-Murphy, M., Amella, E. J., Zapka, J., Mueller, M., & Beck, C. (2015). Feasibility of a web-based dementia feeding skills training program for nursing home staff. <i>Geriatric Nursing</i> , 36(3), 212–218.	Outside direct control of care staff
Baur, V., & Abma, T. (2012). ‘The Taste Buddies’: Participation and empowerment in a residential home for older people. <i>Ageing and Society</i> , 32(6), 1055-1078.	Population focus is not people with dementia
Bautmans, I.; Demarteau, J., Cruts, B., Lemper, J-C., & Mets, T. (2008). Dysphagia in elderly nursing home residents with severe cognitive impairment. <i>Journal of Rehabilitation Medicine</i> , 40(9), 755-760.	Outside direct control of care staff
Beattie, E. R. A., Algase, D. L., & Song, J. (2004) Special Section—Behavioral symptoms of dementia: their measurement and intervention. Keeping wandering nursing home residents at the table: improving food intake using a behavioral communication intervention, <i>Aging &amp; Mental Health</i> , 8(2), 109-116.	Outside direct control of care staff
Beattie, E., O’Reilly, M., Strange, E., Franklin, S., & Isenring, E. (2014). How much do residential aged care staff members know about the nutritional needs of residents? <i>International Journal of Older People Nursing</i> , 9(1), 54–64.	Outside direct control of care staff
Beel-Bates, C., Stephenson, P.L., Nochera, C.L., & Rogers, J.F. (2012). Caregiver-resident interaction with Barnard's feeding scale. <i>Research in Gerontological Nursing</i> , 5(4), 284-293.	Focus is assessment not care
Benati, G., Coppola, D., & Delvecchio, S. (2009). Staff training effect on the management of patients with dysphagia and dementia in a nursing home. <i>Nutritional Therapy &amp; Metabolism</i> , 27(2), 95-99.	Outside direct control of care staff
Berkhout, A. M. M., Cools, H. J. M., & Van Houwelingen, H. C. (1998). The relationship between difficulties in feeding oneself and loss of weight in nursing-home patients with dementia. <i>Age and Ageing</i> , 27(5), 637–641	Focus is assessment not care
Calkins, M. P. (2007). Exploring options along the safety-autonomy continuum. <i>Alzheimers Care Quarterly</i> , 8(3), 206.	Focus is not mealtime care activities
Caspar, S., Davis, E., Berg, K., Slaughter, S., Keller, H., & Kellett, P. (2020). Stakeholder Engagement in Practice Change: Enabling Person-Centred Mealtime Experiences in Residential Care Homes. <i>Canadian Journal on Aging / La Revue Canadienne Du Vieillessement</i> , 1-15.	Outside direct control of care staff
Chang, C.-C., & Lin, L-C. (2005). Effects of a feeding skills training programme on nursing assistants and dementia patients. <i>Journal of Clinical Nursing</i> , 14, 1185–1192.	Outside direct control of care staff
Chang, C.-C., Wykle, M. L., & Madigan, E. A. (2006). The effect of a feeding skills training program for nursing assistants who feed dementia patients in Taiwanese nursing homes. <i>Geriatric Nursing</i> , 27(4), 229–237.	Outside direct control of care staff

Chang, F.-Y., Huang, H.-C., Lin, K.-C., & Lin, L.-C. (2010). The effect of a music programme during lunchtime on the problem behaviour of the older residents with dementia at an institution in Taiwan. <i>Journal of Clinical Nursing, 19</i> , 939–948.	Outside direct control of care staff
Chang, E., Brownhill, S., Bidewell, J., Johnson, A., & Ratnayake, S. (2015). Focus on feeding! Evaluation of a framework for maximizing mealtime in aged care facilities. <i>International Journal of Nursing Practice, 21</i> , 269–277.	Population focus is not people with dementia
Charras, K., & Fremontier, M. (2010). Sharing meals with institutionalized people with dementia: A natural experiment. <i>Journal of Gerontological Social Work, 53</i> (5), 436–448.	Outside direct control of care staff
Chaudhury, H., Hung, L., Rust, T., & Wu, S. (2017). Do physical environmental changes make a difference? Supporting person-centered care at mealtimes in nursing homes. <i>Dementia, 16</i> (7), 878–896.	Population focus is not people with dementia
Chen, L. L., Li, H., Lin, R., Zheng, J. H., Wei, Y. P., Li, J., . . . Chen, H. Y. (2016). Effects of a feeding intervention in patients with Alzheimer’s disease and dysphagia. <i>Journal of Clinical Nursing, 25</i> (5-6), 699–707.	Outside direct control of care staff
Chiang, C. K., & Hwu, Y. J. (2018). Feeding experiences of nursing aides for residents with dysphagia. <i>Geriatric Nursing, 39</i> (4), 436-442.	Population focus is not people with dementia
Chouinard, J., Lavigne, E. & Villeneuve, C. (1998). Weight Loss, Dysphagia, and Outcome in Advanced Dementia. <i>Dysphagia, 13</i> , 151–155.	Focus is not mealtime care activities
Cleary, S. (2009). Using environmental interventions to facilitate eating and swallowing in residents with dementia. <i>Canadian Nursing Home, 20</i> (2), 5-12.	Outside direct control of care staff
Cleary, S., Hopper, T., Forseth, M., & Van Soest, D. Using routine seating plans to improve mealtimes for residents with dementia. <i>Canadian Nursing Home, 19</i> (3), 4-10.	Outside direct control of care staff
Cluskey, M., & Kim, Y. K. (2001). Use and perceived effectiveness of strategies for enhancing food and nutrient intakes among elderly persons in long-term care. <i>Journal of the American Dietetic Association, 101</i> (1), 111-114.	Population focus is not people with dementia
Cohen, D., Post, S. G., Lo, A., Lombardo, R., & Pfeffer, B. (2020). “Music & Memory” and improved swallowing in advanced dementia. <i>Dementia, 19</i> (2), 195–204.	Outside direct control of care staff
Corcoran, M. A., & Gitlin, L. N. (1996). Managing Dementia at Home: The Role of Home Environmental Modifications. <i>Topics in Geriatric Rehabilitation, 12</i> (2), 63-69.	Not all participants in care homes
Crack, J., & Crack, G. (2007). Promoting quality care for older people in meal management: whose responsibility is it? <i>Australian Journal of Advanced Nursing, 25</i> (1), 85-89.	Population focus is not people with dementia
Davies, N., Mathew, R., Wilcock, J., Manthorpe, J., Sampson, E. L., Lamahewa, K., & Iliffe, S. (2016). A co-design process developing heuristics for practitioners providing end of life care for people with dementia. <i>BMC Palliative Care, 15</i> (1), 68.	Outside direct control of care staff

Denney, A. (1997). Quiet music. An intervention for mealtime agitation? <i>Journal of Gerontological Nursing</i> , 23(7), 16-23.	Outside direct control of care staff
Desai, J., Winter, A., Young, K.W.H., & Greenwood, C.E. (2007). Changes in type of foodservice and dining room environment preferentially benefit institutionalized seniors with low body mass indexes. <i>Journal of the American Dietetic Association</i> , 107(5), 808-814.	Population focus is not people with dementia
Durkin, D. W., Shotwell, M. S., & Simmons, S. F. (2014). The Impact of Family Visitation on Feeding Assistance Quality in Nursing Homes. <i>Journal of Applied Gerontology</i> , 33(5), 586–602.	Outside direct control of care staff
Durnbaugh, T., Haley, B., & Roberts, S. (1996). Assessing problem feeding behaviors in mid-stage Alzheimer's disease. <i>Geriatric Nursing</i> , 17(2), 63-67.	Focus is assessment not care
European Society for Clinical Nutrition and Metabolism (ESPEN). (2015). ESPEN guidelines on nutrition in dementia. <i>Clinical nutrition</i> , 34(6), 1052-1073.	Not a primary study
Genoe, M., Keller, H., Martin, L., Dupuis, S., Reimer, H., Cassolato, C., & Edward, G. (2012). Adjusting to Mealtime Change within the Context of Dementia. <i>Canadian Journal on Aging / La Revue Canadienne Du Vieillissement</i> , 31(2), 173-194.	Not all participants in care homes
Gilmore-Bykovskiy, A. L. (2015). Caregiver person-centeredness and behavioral symptoms during mealtime interactions: development and feasibility of a coding scheme. <i>Geriatric nursing</i> , 36(2 Suppl), S10–S15.	Focus is assessment not care
Gilmore-Bykovskiy, A. L., & Rogus-Pulia, N. (2018). Temporal associations between caregiving approach, behavioral symptoms and observable indicators of aspiration in nursing home residents with dementia. <i>The Journal of Nutrition Health and Aging</i> , 22(3), 400-406.	Not a primary study
Goddaer, J., & Abraham, I.L. (1994). Effects of relaxing music on agitation during meals among nursing home residents with severe cognitive impairment. <i>Archives of Psychiatric Nursing</i> , 8(3), 150-158.	Outside direct control of care staff
Hammar, L. M., Swall, A., & Meranius, M. S. (2016). Ethical aspects of caregivers' experience with persons with dementia at mealtimes. <i>Nursing Ethics</i> , 23(6), 624–635.	Focus is not mealtime care activities
Hanssen, I., & Kuven, B. M. (2016). Moments of joy and delight: The meaning of traditional food in dementia care. <i>Journal of Clinical Nursing</i> , 25, 866– 874.	Outside direct control of care staff
Harnett, T., & Jönson, H. (2017). Shaping nursing home mealtimes. <i>Ageing and Society</i> , 37(4), 823-844.	Population focus is not people with dementia
Hicks-Moore, S. L. (2005). Relaxing music at mealtimes in nursing homes: effects on agitated patients with dementia. <i>Journal of Gerontological Nursing</i> , 31(12), 26–32.	Outside direct control of care staff
Ho, S.-Y., Lai, H.-L., Jeng, S.-Y., Tang, C.-W., Sung, H.-C., & Chen, P.-W. (2011). The Effects of Researcher-Composed Music at Mealtime on Agitation in Nursing Home Residents With Dementia. <i>Archives of Psychiatric Nursing</i> , 25(6), e49-e55.	Outside direct control of care staff



Holdoway, A., & Smith, A. (2020). Meeting nutritional need and managing patients with dysphagia. <i>Journal of Community Nursing</i> , 34(2).	Population focus is not people with dementia
Holm, B., & Soderhamn, O. (2003). Factors associated with nutritional status in a group of people in an early stage of dementia. <i>Clinical Nutrition</i> , 22(4), 385-389.	Not all participants in care homes
Hsiao, H. C., Chao, H. C., & Wang J. J. (2013). Features of problematic eating behaviors among community-dwelling older adults with dementia: family caregivers' experience. <i>Geriatric Nursing</i> , 34(5), 361-365.	Not all participants in care homes
Hung, L., Chaudhury, H., & Rust, T. (2016). The Effect of Dining Room Physical Environmental Renovations on Person-Centered Care Practice and Residents' Dining Experiences in Long-Term Care Facilities. <i>Journal of Applied Gerontology</i> , 35(12), 1279–1301.	Population focus is not people with dementia
Hyden, L. C. (2014). Cutting Brussels sprouts: Collaboration involving people with dementia. <i>Journal of Aging Studies</i> , 29, 115–23.	Not all participants in care homes
Jansson, L., & Norberg, A. (1992). Ethical reasoning Among Registered Nurses Experienced in Dementia Care. Interviews Concerning the Feeding of Severely Demented Patients. <i>Scandinavian Journal of Caring Sciences</i> , 6(4), 219– 27.	Focus is not mealtime care activities
Jean, L. A. (1997). " Finger food menu" restores independence in dining. <i>Health care food &amp; nutrition focus</i> , 14(1), 4-6.	Not peer-reviewed (missed on title/abstract screening)
Jensen, L. H., Rekve, K. H., Ulstein, I., & Skovdahl, K. (2016). Promoting independence at mealtimes for older persons with severe dementia. <i>International Practice Development Journal</i> , 6(2), 1-13.	Not all participants in care homes
Jimoh, O. F., Brown, T. J., Bunn, D., & Hooper, L. (2019). Beverage intake and drinking patterns—clues to support older people living in long-term care to drink well: DRIE and FISE studies. <i>Nutrients</i> , 11(2), 447.	Population focus is not people with dementia
Johansson, L., Wijk, H., & Christensson, L. (2017). Improving nutritional status of older persons with dementia using a national preventive care program. <i>Journal of Nutrition, health &amp; aging</i> , 21, 292–298.	Not all participants in care homes
Johansson, L., Björklund, A., Sidenvall, B., & Christensson, L. (2017). Staff views on how to improve mealtimes for elderly people with dementia living at home. <i>Dementia</i> , 16(7), 835–852.	Not all participants in care homes
Jones, J. A., Brown E. J., & Ladislav, V. (2000). Target outcomes for long-term oral health care in dementia: a Delphi approach. <i>Journal of Public Health Dentistry</i> , 60(4), 330–333.	Outside direct control of care staff
Kayser-Jones J, Schell E. S., Porter C., Barbaccia J. C., & Shaw H. (1999). Factors contributing to dehydration in nursing homes: Inadequate staffing and lack of professional supervision. <i>Journal of the American Geriatrics Society</i> , 47(10), 1187–1194.	Outside direct control of care staff
Keller, H.H., Gibbs-Ward, A., Randall-Simpson, J., Bocock, M.-A., & Dimou, E. (2006). Meal rounds: An essential aspect of quality nutrition services in long-term care. <i>Journal of the American Medical Directors Association</i> , 7(1), 40-45.	Outside direct control of care staff

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Liu, W., Jao, Y. L., & Williams, K. (2017). The association of eating performance and environmental stimulation among older adults with dementia in nursing homes: A secondary analysis. <i>International journal of nursing studies</i> , 71, 70-79.	Not a primary study
Lopez, R. P., & Amella, E. J. (2011). Time travel: The lived experience of providing feeding assistance to a family member with dementia. <i>Research in gerontological nursing</i> , 4(2), 127-134.	Not all participants in care homes
Lou, M. F., Dai, Y. T., Huang, G. S., & Yu, P. J. (2007). Nutritional status and health outcomes for older people with dementia living in institutions. <i>Journal of advanced nursing</i> , 60(5), 470-477.	Focus is not mealtime care activities
Mamhidir, A. G., Karlsson, I., Norberg, A., & Mona, K. (2007). Weight increase in patients with dementia, and alteration in meal routines and meal environment after integrity promoting care. <i>Journal of clinical nursing</i> , 16(5), 987-996.	Outside direct control of care staff
Mann, K., Lengyel, C. O., Slaughter, S. E., Carrier, N., & Keller, H. (2019). Resident and Staff Mealtime Actions and Energy Intake of Long-Term Care Residents With Cognitive Impairment: Analysis of the Making the Most of Mealtimes Study. <i>Journal of Gerontological Nursing</i> , 45(8), 32-42.	Not a primary study
Manthorpe, J., Watson, R., & Stimpson, A. (2003). Cooking up a problem in the kitchen Changes in cooking, food preparation and eating habits may give rise to concern among relatives of people with dementia. <i>Journal of Dementia Care</i> , 11(5), 16-18.	Not all participants in care homes
Marsden, J. P., Meehan, R. A., & Calkins, M. P. (2001). Therapeutic kitchens for residents with dementia. <i>American Journal of Alzheimer's Disease &amp; Other Dementias</i> , 16(5), 303-311.	Outside direct control of care staff
Martinsen, B., & Norlyk, A. (2012). Caregivers' lived experience of assisted feeding. <i>Journal of clinical nursing</i> , 21(19pt20), 2966-2974.	Population focus is not people with dementia
McDaniel, J. H., Hunt, A., Hackes, B., & Pope, J. F. (2001). Impact of dining room environment on nutritional intake of Alzheimer's residents: A case study. <i>American Journal of Alzheimer's Disease &amp; Other Dementias</i> , 16(5), 297-302	Outside direct control of care staff
Milte, R., Shulver, W., Killington, M., Bradley, C., Miller, M., & Crotty, M. (2017). Struggling to maintain individuality—describing the experience of food in nursing homes for people with dementia. <i>Archives of Gerontology and Geriatrics</i> , 72, 52-58.	Not all participants in care homes
Milte, R., Ratcliffe, J., Chen, G., Miller, M., & Crotty, M. (2018). Taste, choice and timing: Investigating resident and carer preferences for meals in aged care homes. <i>Nursing &amp; health sciences</i> , 20(1), 116-124.	Population focus is not people with dementia

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- Nolan, B. A., & Mathews, R. M. (2004). Facilitating resident information seeking regarding meals in a special care unit: an environmental design intervention. *Journal of Gerontological nursing, 30(10)*, 12-16. Outside direct control of care staff
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Pezzana, A., Cereda, E., Avagnina, P., Malfi, G., Paiola, E., Frighi, Z., ... & Amerio, M. L. (2015). Nutritional care needs in elderly residents of long-term care institutions: Potential implications for policies. <i>The journal of nutrition, health &amp; aging</i> , 19(9), 947-954.	Focus is not mealtime care activities
Porter, C., Schell, E. S., Kayser-Jones, J., & Paul, S. M. (1999). Dynamics of nutrition care among nursing home residents who are eating poorly. <i>Journal of the American Dietetic Association</i> , 99(11), 1444-1446.	Outside direct control of care staff
Pouyet, V., Giboreau, A., Benattar, L., & Cuvelier, G. (2014). Attractiveness and consumption of finger foods in elderly Alzheimer's disease patients. <i>Food quality and preference</i> , 34, 62-69.	Outside direct control of care staff
Pouyet, V., Cuvelier, G., Benattar, L., & Giboreau, A. (2015). Influence of flavour enhancement on food liking and consumption in older adults with poor, moderate or high cognitive status. <i>Food Quality and Preference</i> , 44, 119-129.	Outside direct control of care staff
Ragneskog, H., Kihlgren, M., Karlsson, I., & Norberg, A. (1996). Dinner music for demented patients: analysis of video-recorded observations. <i>Clinical Nursing Research</i> , 5(3), 262-277.	Outside direct control of care staff
Ragneskog, H., Bråne, G., Karlsson, I., & Kihlgren, M. (1996). Influence of dinner music on food intake and symptoms common in dementia. <i>Scandinavian journal of caring sciences</i> , 10(1), 11-17.	Outside direct control of care staff
Richeson, N. E., & Neill, D. J. (2004). Therapeutic recreation music intervention to decrease mealtime agitation and increase food intake in older adults with dementia. <i>American Journal of Recreation Therapy</i> , 3(1), 37-41.	Outside direct control of care staff
Rivière, S., Gillette-Guyonnet, S., Nourhashemi, F., & Vellas, B. (1999). Nutrition and Alzheimer's disease. <i>Nutrition reviews</i> , 57(12), 363-367.	Not all participants in care homes
Roberts, S., & Durnbaugh, T. (2002). Enhancing nutrition and eating skills in long-term care. <i>Alzheimer's Care Today</i> , 3(4), 316-329.	Focus is not mealtime care activities
Roberts, E. (2011). Six for lunch: A dining option for residents with dementia in a special care unit. <i>Journal of Housing for the Elderly</i> , 25(4), 352-379.	Outside direct control of care staff
Salva, A., Coll-Planas, L., Bruce, S., De Groot, L., Andrieu, S., Abellan, G., & Vellas, B. (2009). Nutritional assessment of residents in long-term care facilities (LTCFs): recommendations of the task force on nutrition and ageing of the IAGG European region and the IANA. <i>The Journal of Nutrition, Health and Aging</i> , 13(6), 475-483.	Population focus is not people with dementia
Scott, D. (1999). Communication and swallowing training for care home staff. <i>Nursing And Residential Care</i> , 1(6), 318-321.	Population focus is not people with dementia
Shatenstein, B., Ska, B., & Ferland, G. (2001). Employee reactions to the introduction of a bulk food distribution system in a nursing home. <i>Canadian Journal of Dietetic Practice and Research</i> , 62(1), 18.	Outside direct control of care staff
Silva, P., Kergoat, M. J., & Shatenstein, B. (2013). Challenges in managing the diet of older adults with early-stage Alzheimer dementia: a caregiver perspective. <i>The journal of nutrition, health &amp; aging</i> , 17(2), 142-147.	Not all participants in care homes

Simmons, S. F., Lam, H. Y., Rao, G., & Schnelle, J. F. (2003). Family members' preferences for nutrition interventions to improve nursing home residents' oral food and fluid intake. <i>Journal of the American Geriatrics Society</i> , 51(1), 69-74.	Outside direct control of care staff
Simmons, S. F., Coelho, C. S., Sandler, A., & Schnelle, J. F. (2018). A quality improvement system to manage feeding assistance care in assisted-living. <i>Journal of the American Medical Directors Association</i> , 19(3), 262-269.	Outside direct control of care staff
Slaughter, S. E., Morrison-Koehler, J. M., Chaudhury, H., Lengyel, C. O., Carrier, N., & Keller, H. H. (2020). The association of eating challenges with energy intake is moderated by the mealtime environment in residential care homes. <i>International Psychogeriatrics</i> , 1-11.	Focus is not mealtime care activities
Steele, C. M., Rivera, T., Bernick, L., & Mortensen, L. (2007). Insights regarding mealtime assistance for individuals in long-term care: lessons from a time of crisis. <i>Topics in Geriatric Rehabilitation</i> , 23(4), 319-329.	Population focus is not people with dementia
Stockdell, R., & Amella, E. J. (2008). How to Try This: The Edinburgh Feeding Evaluation in Dementia Scale. <i>American Journal of Nursing</i> , 108(8), 46.	Not all participants in care homes
Suominen, M. H., Kivisto, S. M., & Pitkala, K. H. (2007). The effects of nutrition education on professionals' practice and on the nutrition of aged residents in dementia wards. <i>European journal of clinical nutrition</i> , 61(10), 1226-1232.	Focus is not mealtime care activities
Tarzian, A. (2019). Foregoing Spoon Feeding in End-Stage Dementia. <i>The American Journal of Bioethics: AJOB</i> , 19(1), 88-89.	Not a primary study
Thomas, D. W., & Smith, M. (2009). The effect of music on caloric consumption among nursing home residents with Dementia of the Alzheimer's type. <i>Activities, Adaptation &amp; Aging</i> , 33(1), 1-16.	Outside direct control of care staff
Törmä, J., Winblad, U., Saletti, A., & Cederholm, T. (2018). The effects of nutritional guideline implementation on nursing home staff performance: A controlled trial. <i>Scandinavian journal of caring sciences</i> , 32(2), 622-633.	Population focus is not people with dementia
van Hoof, J., Verbeek, H., Janssen, B. M., Eijkelenboom, A., Molony, S. L., Felix, E., ... & Wouters, E. J. M. (2016). A three perspective study of the sense of home of nursing home residents: the views of residents, care professionals and relatives. <i>BMC Geriatrics</i> , 16(1), 169.	Population focus is not people with dementia
Van Ort, S., & Phillips, L. R. (1995). Nursing interventions to promote functional feeding. <i>Journal of gerontological nursing</i> , 21(10), 6-9.	Population focus is not people with dementia
Watson, R., & Deary, I. (1996). Is there a relationship between feeding difficulty and nursing intervention in elderly people with dementia? <i>Journal of Research in Nursing</i> , 1(1), 44-54.	Focus is not mealtime care activities
Watson, R., & Deary, I. J. (1997). A longitudinal study of feeding difficulty and nursing intervention in elderly patients with dementia. <i>Journal of Advanced Nursing</i> , 26(1), 25-32.	Focus is not mealtime care activities

Watson, R. (1994). Measuring feeding difficulty in patients with dementia: replication and validation of the EdFED Scale# 1. *Journal of Advanced Nursing*, 19(5), 850-855. Focus is assessment not care

Wong, F., Keller, H. H., Schindel Martin, L., & Sutherland, O. (2015). A recipe for mealtime resilience for families living with dementia. *Scandinavian journal of caring sciences*, 29(3), 486-494. Not all participants in care homes

Young, K. W., Binns, M. A., & Greenwood, C. E. (2001). Meal delivery practices do not meet needs of Alzheimer patients with increased cognitive and behavioral difficulties in a long-term care facility. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 56(10), M656-M661. Outside direct control of care staff

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### Appendix C. Systematic review of research studies – Study characteristics

Study	Setting, sample	Design, methods	Intervention / Exposure / Phenomenon of interest
<i>Quantitative studies</i>			
Suski & Nielsen (1989)	<i>Setting:</i> Long-term care facility (n=1), USA. <i>Sample:</i> Residents with Alzheimer’s disease (n=19).	<i>Design:</i> Quantitative: Cross-sectional. <i>Methods:</i> Food intake recorded for study group on 3 consecutive days at all meals. Factors that could affect optimal intake, i.e., the time of day and types of food and assistance, were recorded and evaluated.	<i>Exposure:</i> Time of day; type of food; type of assistance.
Coyne & Hoskins (1997)	<i>Setting:</i> Dementia unit in skilled nursing facility (n=1), USA. <i>Sample:</i> Residents with dementia (n=24).	<i>Design:</i> Quantitative: Randomized controlled trial. <i>Methods:</i> Experimental group received intervention; control group received usual care. Level of eating independence (LEI) measured at 3 daily meals across 3 time-points (1 pre-test, 2 post-test).	<i>Intervention:</i> Directed verbal prompt and positive reinforcement. Prompts for solid food: “Pick up the [name of utensil]”; “Put the food on the [name of utensil]”; “Move the food to your mouth”; “Put the food in your mouth”; “Chew the food”; “Swallow the food”. Positive reinforcement: “Correct”; “That’s right”; “Good”.
Amella (1999)	<i>Setting:</i> Nursing home (n=1), USA. <i>Sample:</i> Residents with dementia (n=53); Nursing staff (n=53).	<i>Design:</i> Quantitative: Cross-sectional. <i>Methods:</i> Observations of resident/staff dyads at mealtimes. Interaction, food/fluid intake, and time to complete meal measured. Carer empathy/power measured via questionnaire post-meals.	<i>Exposure:</i> Interaction between resident and carer; carer empathy; carer perceived power.
Engström & Hammar (2012)	<i>Setting:</i> Municipal nursing home (n=1), Sweden. <i>Sample:</i> Residents with severe dementia (n=2).	<i>Design:</i> Quantitative: Quasi-experimental. <i>Methods:</i> Each resident video-observed at mealtimes once per week over 5	<i>Intervention:</i> Carers instructed to hum sing-along songs, children’s songs, and popular songs from the early part of the 20th century.



Batchelor-Murphy et al. (2017)	<p><i>Setting:</i> Nursing homes (n=11), USA.  <i>Sample:</i> Residents with dementia (n=30).</p>	<p>consecutive weeks. Weeks 1 and 2: usual care. Weeks 3 and 4: Intervention. Week 5: usual care. Eating behaviour and food intake measured at baseline (x2), intervention (x2), and return to baseline condition (x1).  <i>Design:</i> Quantitative: Randomized cross-over study (within-subjects).  <i>Methods:</i> Residents received the three interventions in different sequences over 6 consecutive meals. Time providing eating assistance, meal intake, eating behaviours measured.</p>	<p><i>Intervention:</i> Three techniques for eating assistance: direct hand; over hand; and under hand. These were defined as follows: direct hand – carer holds utensil, no active involvement from resident; over hand – care puts hand over resident’s hand to assist them; under-hand – care holds utensil and places hand under resident’s hand.</p>
<p><i>Qualitative studies</i>  Van Ort &amp; Phillips (1992)</p>	<p><i>Setting:</i> Special dementia-care unit of long-term care facility (n=1), USA.  <i>Sample:</i> Residents (n=10); Nursing assistants, Licensed practical nurses, Registered nurses (n=11).</p>	<p><i>Design:</i> Qualitative.  <i>Methods:</i> Data collection focused on mealtime interactions between carers and residents in the dayroom. Data were videotaped, allowing detailed systematic observation of events. Open coding was used to devise categories of behaviour.</p>	<p><i>Phenomenon of interest:</i> Nursing activities, resident behaviours and interactions during mealtimes</p>
Kayser-Jones & Schell (1997a)	<p><i>Setting:</i> Nursing homes (n=2), USA.  <i>Sample:</i> Resident with dementia (n=1); Nursing staff (n=not stated).</p>	<p><i>Design:</i> Qualitative.  <i>Methods:</i> Participant observations, interviews. Event analysis.</p>	<p><i>Phenomenon of interest:</i> Mealtime experience of cognitively impaired resident in nursing home.</p>
Kayser-Jones & Schell (1997b)	<p><i>Setting:</i> Special care unit for dementia patients (n=1), USA.</p>	<p><i>Design:</i> Qualitative.  <i>Methods:</i> Participant observations, in-depth interviews. Event analysis.</p>	<p><i>Phenomenon of interest:</i> Effect of staffing on the mealtime experience of residents.</p>

Pierson (1999)	<p><i>Sample:</i> Residents (n=100); Nursing staff (n=50); Physicians (n=36); Family members (n=50).</p> <p><i>Setting:</i> Long-term care facility (n=1), USA.</p> <p><i>Sample:</i> Nursing assistants (n=not stated).</p>	<p><i>Design:</i> Qualitative.</p> <p><i>Methods:</i> Participant observation of 12 mealtimes across 3 dining areas. Review of residents' daily food records. Analysis proceeded concurrently with data collection.</p>	<p><i>Phenomenon of interest:</i> The self-organizing activities and unspoken knowledge of nursing assistants employed in assisting residents with dementia to eat.</p>
De Bellis et al. (2003)	<p><i>Setting:</i> Residential care facility (n=1), Australia. <i>Sample:</i> Residents with dementia (n=24); Nursing and personal care staff (n=not stated).</p>	<p><i>Design:</i> Qualitative*.</p> <p><i>Methods:</i> Non-participant observation of each resident and the person assisting with eating and drinking, for one mealtime. Qualitative analysis and extrapolation of themes or issues.</p>	<p><i>Phenomenon of interest:</i> Issues associated with oral intake of food and fluids from perspective of the resident and/or carer.</p>
Pasman et al. (2003)	<p><i>Setting:</i> Nursing homes (n=2), The Netherlands.</p> <p><i>Sample:</i> Residents (n=60); Nurses (n=46).</p>	<p><i>Design:</i> Qualitative.</p> <p><i>Methods:</i> Participant observation, formal interviews, access to medical records. Constant comparison analysis.</p>	<p><i>Phenomenon of interest:</i> The nature of the problems faced by nurses when assisting nursing home patients with severe dementia at mealtimes, and how they deal with these problems.</p>
Gibbs-Ward & Keller (2005)	<p><i>Setting:</i> Special care units, long-term care facilities (n=2), Canada.</p> <p><i>Sample:</i> Residents (n=20); Health care aides (n=18); Registered Nurse (n=1); Registered Practical Nurses (n=4); Registered Dieticians (n=8).</p>	<p><i>Design:</i> Qualitative.</p> <p><i>Methods:</i> Observations of 9 meals during 3 to 4 non-consecutive days, using meal observation form. Semi-structured interviews with key informants; questions informed by observations. Constant comparison analysis.</p>	<p><i>Phenomenon of interest:</i> Mealtime care for people with dementia in long-term care facilities.</p>
Chang & Roberts (2008)	<p><i>Setting:</i> Nursing home (n=1), Taiwan.</p> <p><i>Sample:</i> Residents with dementia (n=48); Nursing assistants (n=31).</p>	<p><i>Design:</i> Qualitative**.</p> <p><i>Methods:</i> Observations of mealtimes. Interviews with nursing assistants on</p>	<p><i>Phenomena of interest:</i> Eating difficulties; eating assistance strategies; interactions during eating assistance; mealtime environment.</p>

Hung & Chaudhury (2011)	<p><i>Setting:</i> Long-term care facilities (n=2), Canada.</p> <p><i>Sample:</i> Residents with dementia (n=20); Care aides (n=4); Nurses (n=2); Dieticians (n=2).</p>	<p>strategies used to address eating difficulties. Content analysis.</p> <p><i>Design:</i> Qualitative.</p> <p><i>Methods:</i> Participant observations, conversational interviews with residents, focus groups with care home staff, review of documents. Integrated deductive–inductive approach to data analysis.</p>	<p><i>Phenomenon of interest:</i> Mealtime care for people with dementia in long-term care facilities.</p>
Nell et al. (2016)	<p><i>Setting:</i> Specialised Dementia Care Units (n=2), New Zealand.</p> <p><i>Sample:</i> Staff caregivers (n=11)</p>	<p><i>Design:</i> Qualitative.</p> <p><i>Methods:</i> Semi-structured interviews. General inductive five-step approach to analysis.</p>	<p><i>Phenomenon of interest:</i> Perceptions of staff caregivers regarding factors affecting optimal nutrition/ hydration.</p>
Murphy et al. (2017)	<p><i>Setting:</i> Neutral venue (n=1), UK</p> <p><i>Sample:</i> Care staff (n=30); Family carers (n=8); Dietitians (n=3); Speech and Language Therapists (n=9).</p>	<p><i>Design:</i> Qualitative:</p> <p><i>Methods:</i> Semi-structured interviews, focus groups. Thematic analysis.</p>	<p><i>Phenomenon of interest:</i> Complex nutritional problems associated with eating and drinking for people with dementia.</p>
Palese et al. (2018)	<p><i>Setting:</i> Nursing homes (n=13). Italy.</p> <p><i>Sample:</i> Care staff (n=54).</p>	<p><i>Design:</i> Qualitative:</p> <p><i>Methods:</i> Observations of mealtimes, focus groups. Qualitative content analysis.</p>	<p><i>Phenomenon of interest:</i> Perceived effectiveness of interventions to maintain eating independence among older people with dementia who live in nursing homes.</p>
Driessen & Ibáñez Martín (2020)	<p><i>Setting:</i> Residential care homes (n=3). The Netherlands.</p> <p><i>Sample:</i> Residents (n=100 approx.); Care professionals (n=60 approx.).</p>	<p><i>Design:</i> Qualitative:</p> <p><i>Methods:</i> Participant observation, informal conversations, interviews. Method of analysis not stated.</p>	<p><i>Phenomenon of interest:</i> How carers attend to differences in providing mealtime care.</p>

**Appendix D. Systematic review of research studies – Study quality – Quantitative studies**

<b>Critical appraisal question</b>	<b>Study</b>	
<b><i>Analytical cross sectional studies</i></b>	Suski & Nielsen (1989)	Amella (1999)
Were the criteria for inclusion in the sample clearly defined?	Y	Y
Were the study subjects and the setting described in detail?	Y	Y
Was the exposure measured in a valid and reliable way?	N/A	Y
Were objective, standard criteria used for measurement of the condition?	U	Y
Were confounding factors identified?	Y	N
Were strategies to deal with confounding factors stated?	U	Y
Were the outcomes measured in a valid and reliable way?	N	Y
Was appropriate statistical analysis used?	Y	Y
<b><i>Quasi-experimental studies</i></b>	Engström & Hammar (2012)	
Is it clear in the study what is the ‘cause’ and what is the ‘effect’ (i.e. there is no confusion about which variable comes first)?	Y	
Were the participants included in any comparisons similar?	Y	
Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Y	
Was there a control group?	N	
Were there multiple measurements of the outcome both pre and post the intervention/exposure?	Y	
Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	N	
Were the outcomes of participants included in any comparisons measured in the same way?	Y	
Were outcomes measured in a reliable way?	Y	
Was appropriate statistical analysis used?	N	
<b><i>Randomized Controlled Trials</i></b>	Coyne and Hoskins (1997)	Batchelor-Murphy et al. (2017)
Was true randomization used for assignment of participants to treatment groups?	Y	U
Was allocation to treatment groups concealed?	Y	N/A

Were treatment groups similar at the baseline?	N	N/A
Were participants blind to treatment assignment?	U	N/A
Were those delivering treatment blind to treatment assignment?	N/A	N/A
Were outcomes assessors blind to treatment assignment?	Y	N/A
Were treatment groups treated identically other than the intervention of interest?	Y	Y
Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Y	Y
Were participants analyzed in the groups to which they were randomized?	Y	Y
Were outcomes measured in the same way for treatment groups?	Y	Y
Were outcomes measured in a reliable way?	Y	Y
Was appropriate statistical analysis used?	Y	Y
Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	U	Y

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Questions are from the Joanna Briggs Institute Critical Appraisal Tools. Y=Yes, N=No, U=Unclear, N/A=Not applicable.

**Appendix E. Systematic review of research studies – Study quality – Qualitative studies**

<b>Critical appraisal question</b>	<b>Study</b>												
	Van Ort & Phillips (1992)	Kayser-Jones & Schell (1997a)	Kayser-Jones & Schell (1997b)	Pierson (1999)	De Bellis et al. (2003)	Pasman et al. (2003)	Gibbs-Ward & Keller (2005)	Chang & Roberts (2008)	Hung & Chaudhury (2011)	Nell et al. (2016)	Murphy et al. (2017)	Palese et al. (2018)	Driessen & Ibáñez Martín (2020)
Is there congruity between the stated philosophical perspective and the research methodology?	Y	U	U	Y	Y	N	Y	U	Y	U	U	N	U
Is there congruity between the research methodology and the research question or objectives?	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	Y	U	Y
Is there congruity between the research methodology and the methods used to collect data?	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	Y	N	Y
Is there congruity between the research methodology and the representation and analysis of data?	Y	Y	U	Y	Y	Y	Y	U	Y	Y	Y	N	U
Is there congruity between the research methodology and the interpretation of results?	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	Y	N	U
Is there a statement locating the researcher culturally or theoretically?	Y	Y	Y	Y	Y	Y	Y	U	Y	Y	Y	N	Y
Is the influence of the researcher on the research, and vice-versa, addressed?	U	N	Y	U	N	U	Y	N	N	N	U	Y	N
Are participants, and their voices, adequately represented?	U	N	N	U	N	Y	Y	N	Y	N	U	Y	U
Is the research ethical according to current criteria or, for recent studies, is there	N	Y	U	Y	N	Y	Y	N	N	Y	Y	Y	Y

evidence of ethical approval by an appropriate body?													
Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	N	N	N	Y	N	Y	Y	Y	Y	Y	Y	Y	U

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Questions are from the Joanna Briggs Institute Critical Appraisal Tools. Y=Yes, N=No, U=Unclear, N/A=Not applicable.

## Appendix F. Systematic review of research studies – Study findings

Study	Findings
<i>Quantitative studies</i>	
Suski & Nielsen (1989)	Four major factors emerged that promoted optimal intake: using skilful techniques to assist eating, selecting appropriate food consistency, providing adequate time in which to assist eating, and capitalizing on the midday meal when cognitive abilities were at their peak.
Coyne & Hoskins (1997)	Significant difference between experimental and control groups for both solid and liquid food on task performance. For solid food: Experimental group grand mean = 16.6; Control group grand mean = 13.1, $F(1,22) = 7.78$ , $p = 0.011$ . Significant interaction when comparing pre-test to first and second post tests, $t = 2.38$ , $p = 0.026$ . For liquid food: Experimental group grand mean = 13.8; Control group grand mean = 11.4, $F(1,22) = 8.90$ , $p = 0.007$ . Significant interaction when comparing pre-test to first and second post-tests, $t = 2.52$ , $p = 0.019$ .
Amella (1999)	Quality of reciprocal relationship between resident and carer significantly and positively related to proportion of food consumed ( $R^2 = .40$ ; $F_{6,46} = 5.13$ ; $P = .0004$ ). Willingness of carer to let another control their behaviour positively correlated to proportion of food consumed ( $r = .29$ ; $P = .024$ ).
Engström & Hammar (2012)	Inconclusive results. First resident: negative eating behaviours (as measured by Edinburgh Feeding Evaluation in Dementia (EdFED) scale) decreased during the humming and increased during the follow-up (Baseline#1 = 14, Baseline#2 = 14, Intervention#1 = 6, Intervention#2 = 11, Follow-up = 16). Second resident: negative eating behaviour scores from baseline observations were higher than those recorded during the intervention sessions (Baseline#1 = 8, Baseline#2 = 16, Intervention#1 = 9, Intervention#2 = 6, Follow-up = 5).
Batchelor-Murphy et al. (2017)	Under hand eating assistance technique reduced eating behaviours and promoted meal intake at same level as direct hand, while requiring no additional time to implement. Eating assistance technique had a significant effect on eating behaviours as measured by EdFED total scores per meal ( $P = .025$ ). The mean total score per meal for OH (8.3, SD 1.8) was significantly higher relative to DH (8.0, SD 1.8, $P = .041$ , Cohen $d = 0.17$ , small effect) and UH (7.7, SD 1.8), $P = .001$ , Cohen $d = 0.33$ , medium effect). Eating assistance technique had a significant effect on percent meal intake per meal based on tray weight ( $P = .023$ ), with the mean percent meal intake significantly higher for DH (67%, SD 15.2) and UH (65%, SD 15.0) when compared to OH (59.9%, SD 15.1) $P < .001$ and $.001$ , respectively). Findings suggest that use of each eating assistance technique should be considered within context of the residents' functional ability, energy



level, and individual preferences, any of which may vary on a day-to-day, meal-to-meal basis.

### *Qualitative studies*

Van Ort & Phillips (1992)

Three categories were identified which were associated with the resident's acceptance or rejection of food. These were: behaviours that elicit functional eating; behaviours that sustain functional eating; behaviours that extinguish functional eating. Although preliminary analysis yielded initial categories, mutually exclusive categories were difficult to distinguish. Relationships between identified cues and specific behaviours are being examined in further analysis.

Kayser-Jones & Schell (1997a)

Ineffective mealtime strategies: Labelling resident and lack of assistance and supervision at mealtime; Providing total eating assistance and mixing food together. Effective mealtime strategies: Encouraging independence while providing supervision and assistance; Creating a social mealtime environment and simplifying the process of eating.

Kayser-Jones & Schell (1997b)

The aesthetic and social dimensions of mealtimes were neglected. Residents did not receive the necessary assistance. Residents were fed forcefully.

Pierson (1999)

Providing eating assistance to residents was something that nursing assistants did out of their own understanding of the situation. Nursing assistants were constantly assessing the situation and reacting accordingly. They had to know how to read and respond to nonverbal cues.

De Bellis et al. (2003)

Main themes: Approach and attitude of staff; Commitment to dementia care; Supervision and support; Role models; Family, visitors and volunteers Major determining factors in mealtime outcomes included carer having: 1. Knowledge of dementia; 2. Commitment to the relationship with the resident; 3. The ability to interact with the person in an appropriate way maintaining and restoring dignity; and taking 4. That extra step in the care process.

Pasman et al. (2003)

Nurses used techniques to improve food intake, e.g. moving a patient to a less distracting environment, and softly touching the patient's lips with a napkin to stimulate the swallowing reflex. Nurses discussed for each individual patient the right approach to maximize food intake. Nurses had different interpretations of the aversive behaviour of different patients.

Gibbs-Ward & Keller (2005)

Three themes identified: Each mealtime is a process embedded within the larger context of the care home environment; Residents are central to the mealtime process through their actions; Internal and external influences affect residents' actions at mealtimes

Chang & Roberts (2008)	Nursing assistants used limited strategies to deal with eating difficulty, and many did not use strategies that were effective especially when the residents refused food. Residents' personal tastes were not considered. Nursing assistants did not communicate with residents to verify eating and food preferences or whether residents had enough to eat.
Hung & Chaudhury (2011)	Nine themes proposed in relation to personhood in dining experiences: Outpacing/relaxed pace; Withholding/holding; Disrespect/respect; Invalidation/validation; Distancing/connecting; Disempowerment/empowerment; Ignoring/inclusion. The themes speak to the importance of moving away from the task-based care approaches to allow paying more careful attention to the psychosocial needs of residents.
Nell et al. (2016)	Two main themes: It's about the individual (factors relating to the individual's appetite (and subsequent desire for food), personal food preferences and ability to manage the eating process); It's about the environment (factors relating to the dining environment (e.g. background music), social interactions and assistance provided by others).
Murphy et al. (2017)	One overarching theme identified: Person-centred nutritional care. Six sub-themes: Availability of food and drinks; Tools, resources and equipment; Relationship to others when eating and drinking; Participation in activities; Consistency of care; Provision of information.
Palese et al. (2018)	The promotion and maintenance of eating independence for as long as possible is ensured by a set of interventions targeting three levels: (a) environmental, by 'Ritualising the mealtime experience by creating a controlled stimulated environment'; (b) social, by 'Structuring effective mealtime social interactions'; and (c) individual, by 'Individualising eating assistance'.
Driessen & Ibáñez Martín (2020)	Three "repertoires of difference" presented: Providing choice (in this repertoire what is valued is being able to choose for oneself, in order to be able to eat what one feels like having in a specific moment); Knowing residents (here, care workers know about singular, and relatively stable tastes and habits); Catering to identities (Care workers do this by temporarily suspending their knowledge about a resident's preferences, habits and the like. In other words, they temporarily stop knowing, and tap into what is emergent in order to 'know anew').

## Appendix G. Systematic review of research studies – Thematic categories of carer-resident interaction

Thematic category	Description	Relevant findings
Social connection	Interactions which build relationship and social connection	<p><i>Creating a social mealtime environment and simplifying the process of eating</i> (Kayser-Jones &amp; Schell, 1997a, p. 36)</p> <p><i>The aesthetic and social dimensions of mealtimes were neglected</i> (Kayser-Jones &amp; Schell, 1997b, p. 69)</p> <p><i>The quality of the reciprocal relationship was significantly and positively related to the proportion of food consumed</i> (Amella, 1999, p. 883)</p> <p><i>Withholding/holding</i> (Hung &amp; Chaudhury, 2011, p. 6)</p> <p><i>Distancing/connecting</i> (Hung &amp; Chaudhury, 2011, p. 9)</p> <p><i>Ignoring/inclusion</i> (Hung &amp; Chaudhury, 2011, p. 10)</p> <p><i>Structuring effective social interactions ensuring mealtime as a pleasant social experience</i> (Palese et al., 2019, p. 5)</p>
Tailored care	Interactions which are tailored to the individual	<p><i>Providing adequate time in which to feed</i> (Suski &amp; Nielsen, 1989, p. 1770)</p> <p><i>Labelling resident and lack of assistance and supervision at mealtime</i> (Kayser-Jones &amp; Schell, 1997a, p. 35)</p> <p><i>Residents did not receive the necessary assistance</i> (Kayser-Jones &amp; Schell, 1997b, p. 70)</p> <p><i>Approach and attitude of staff</i> (De Bellis, 2003, p. 7)</p> <p><i>Outpacing/relaxed pace</i> (Hung &amp; Chaudhury, 2011, pp. 5, 6)</p> <p><i>Invalidation/validation</i> (Hung &amp; Chaudhury, 2011, pp. 8, 9)</p> <p><i>Person-centred nutritional care</i> (Murphy et al., 2017, p. 4)</p> <p><i>Findings suggest that the use of each handfeeding technique should be considered within context of the residents' functional ability, energy level, and individual preferences</i> (Batchelor-Murphy et al., 2017, p. e92)</p> <p><i>It's about the individual</i> (Nell et al., 2016, p. E2)</p> <p><i>Individualised eating assistance</i> (Palese et al., 2018, p. 6)</p> <p><i>Knowing residents</i> (Driessen &amp; Ibáñez Martín, 2020, p. 252)</p> <p><i>Catering to identities</i> (Driessen &amp; Ibáñez Martín, 2020, p. 254)</p>

Empowering the resident	Interactions which promote autonomy and independence	<p><i>Totally feeding the resident and mixing food together</i> (Kayser-Jones &amp; Schell, 1997a, pp. 35)</p> <p><i>Encouraging independence while providing supervision and assistance</i> (Kayser-Jones &amp; Schell, 1997a, pp. 36, 37)</p> <p><i>Wanted Control, the willingness to let another control one's behavior, was positively correlated to the criterion [the proportion of food consumed]</i> (Amella, 1999, p. 883)</p> <p><i>Disrespect/respect</i> (Hung &amp; Chaudhury, 2011, pp. 7, 8)</p> <p><i>Disempowerment/empowerment</i> (Hung &amp; Chaudhury, 2011, pp. 9, 10)</p> <p><i>Providing choice</i> (Driessen &amp; Ibáñez Martín, 2020, p. 250)</p>
Responding to food refusal	Interactions which carefully and skilfully address the challenge of food refusal	<p><i>Using skilful feeding techniques</i> (Suski &amp; Nielsen, 1989, p. 1770)</p> <p><i>Residents were fed forcefully</i> (Kayser-Jones &amp; Schell, 1997b, p. 70)</p> <p><i>Tricks and techniques</i> (Pasman, 2003, p. 307)</p> <p><i>To stop or to continue feeding</i> (Pasman, 2003, p. 307)</p>

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### Appendix H. Scoping review of guidelines – Guidelines characteristics

<b>Name of organisation</b>	<b>Type of organisation</b>	<b>Title of guidelines</b>	<b>Date of publication</b>	<b>Country</b>	<b>Author(s)</b>	<b>Field(s) of expertise</b>
Alzheimer's Association	Charity / non-profit	Dementia Care Practice: Recommendations for Assisted Living Residences and Nursing Homes	2006	USA	Not stated	Dementia care and support
Barchester Healthcare	Care homes provider	Nutrition for older people	2016	UK	Not stated	Care homes sector
Bournemouth University	Higher Education Institute	Eating and Drinking Well with Dementia: A Guide for Care Staff	2018	UK	Murphy et al.	Nutrition and Dietetics
Voluntary Organisations Involved in Caring in the Elderly Sector (VOICES)	Expert working group	Eating well for older people with dementia	1998	UK	Dillon Roberts, et al.	Geriatrics, Psychiatry, Dietetics, Speech and Language Therapy, Social Care
Health and Social Care Northern Ireland	Public body	Eating, drinking and swallowing: A guide for carers of people living with a dementia	2015	UK	Tomany, E.	Speech and Language Therapy
Irish Hospice Foundation	Charity / non-profit	Management of Hydration and Nutrition	2016	Ireland	Hartigan et al.	Nursing, Speech and Language Therapy, Social care, Elderly care, Dementia
Irish Nutrition and Dietetics Institute	Professional body	Nutrition and Dementia	2016	Ireland	Not stated	Nutrition and Dietetics, Dementia
European Society for Clinical Nutrition and Metabolism (ESPEN)	Expert working group	ESPEN guidelines on nutrition in dementia	2015	International	Volkert et al.	Clinical nutrition and metabolism
Social Care Institute for Excellence	Charity / non-profit	Dementia Gateway: Eating Well	2013	UK	Not stated	Social care, Improvement

## Appendix I. Scoping review of guidelines – Guidelines recommendations

Name of organisation	Recommendations
Alzheimer’s Association	<p>Residents often require assistance to maximise their ability to eat and drink.</p> <p>Encouraging residents to function independently can help prevent learned dependency.</p> <p>If assessment shows that a resident can eat independently, but does so slowly, the resident can eat at his or her own pace, perhaps with verbal reminders to eat/drink.</p> <p>Example: For those residents who manage better if they face fewer choices, serving one food item at a time is preferable.</p> <p>Example: If residents need hand feeding, guide the resident’s hand using the “hand-over-hand” technique.</p> <p>It is ideal for staff to sit, make eye contact and speak with residents when assisting with meals.</p>
Barchester Healthcare	<p>If people do not eat their main meal, don’t hold back their dessert - they may prefer the taste of it.</p> <p>Explaining what the food is and ensuring they are wearing the right glasses can help.</p> <p>Make sure they are relaxed and do not feel the need to hurry their food. If possible, let them choose where they want to eat.</p> <p>Offering encouragement and gentle reminders about the food on their plate can also prove effective.</p>
Bournemouth University	<p>Encourage independence, e.g. at breakfast serve toast in a toast rack with butter and marmalade in small dishes for residents to serve themselves.</p> <p>Offer choice of meals at point of delivery visually on the plate to help decision making. Allow 10 seconds for someone to make a decision.</p> <p>Use picture cards to help identify foods on menus.</p> <p>Set a table to eat to provide visual cues that it is a meal time.</p> <p>Give constant prompting and encouragement.</p> <p>Put hand over hand and help person to eat as dementia advances.</p> <p>Ensure tables and chairs are positioned so individuals can see those they are sitting with.</p> <p>Allow sufficient time for food and drink to be enjoyed.</p> <p>Provide positive encouragement to increase food and fluid intake.</p> <p>Provide assistance where required – open packets, discreetly cut up food, pour drinks.</p> <p>Support people to eat and drink where required.</p> <p>Staff eating with residents can build up trust and enable ‘copycat’ behaviours by the person imitating staff.</p> <p>Support and enable people to choose where they would like to sit. Negotiation may be needed to prevent conflicting personalities sitting together – but never move people against their wishes.</p> <p>Some residents may choose to eat alone in their own room and this choice must be respected.</p> <p>If a resident shows signs of anxiety at mealtimes, try to find out why by talking to family and friends about past experiences.</p>

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Voluntary Organisations  
Involved in Caring in  
the Elderly Sector  
(VOICES)

Observe the signs that bring on anxiety, e.g. if eating in the dining room causes anxiety then consider why – do they need to be accompanied into the room, face in a certain direction, eat elsewhere or eat on their own?

Do not talk over residents' heads when they are eating.

Before assisting with eating and drinking, try to have the person's attention.

Make eye contact and ensure the person is able to see what is about to happen.

Try to be calm and unhurried to show that you are focusing attention – moving quickly or showing agitation may cause confusion.

Provide reassurance – if appropriate, hold the person's hand to help focus on what is being said.

Staff should make sure they relate to their residents and patients at mealtimes. Direct contact with older people with dementia is important, particularly when staff are helping individuals to eat.

Staff should be trained in how to help older people with dementia to eat. This training should include helping individuals to retain their ability to eat independently for as long as possible, and assisting those who can no longer eat independently.

Where staff are helping older people with dementia to eat, it is important that they are treated with dignity and respect. It is useful for staff to have experienced the process of being helped to eat themselves, in order to understand how best to help people in their care.

Those who are able to eat independently, even if this is by hand only, should be encouraged to do so to maximise independence and dignity (Narrative)

In order for people to be treated appropriately by staff, a programme of care is required which is person-oriented rather than task-oriented. Care staff need to know as much as possible about each individual - finding out about their past history, life and experiences and about their current condition (Narrative).

While it is essential that those who can fully or partly eat independently are encouraged and enabled to do so, those who need help with eating must be treated sensitively. The perspective of helping people to eat rather than "feeding" them is essential (Narrative).

Verbal prompting during eating to "Open your mouth", "Chew", or "Swallow" has been suggested as particularly helpful. If direct verbal prompting fails to work, touching food against the person's lips gives a non-verbal cue to open the lips (Narrative).

If someone cannot initiate voluntary movement it is better to give indirect encouragement to eat, for example saying "This meal looks tasty" (Narrative).

Other practical suggestions include ensuring that residents or patients have an empty bladder before they start eating, and that their glasses or dentures are accessible and well-fitting (Narrative).

The same person should stay with the resident or patient throughout the meal.

Make sure the person has his or her glasses, dentures and/or hearing aid in place.

Make sure the person is sitting in an upright position.

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The carer should sit at eye level or slightly below, and either immediately in front of or slightly to one side of the person who needs help.

Give small mouthfuls but enough for the person to feel the food in his or her mouth.

Give adequate time for the person to swallow each mouthful before continuing.

Assist but never force.

Maintain eye contact with the person who needs help. Do not talk to someone else while offering food.

Use verbal prompts: talk clearly about the food you are offering (especially if it is pureed), and use a gentle but firm tone.

Discourage the person from talking with food in their mouth because of the risk of choking.

Dealing with food refusal: It is important to explore the possible reasons for food refusal ... The importance of knowing the person well, keeping a record of each person's food preferences, and being aware of dietary and religious requirements can provide insights into food refusal.

Dealing with food refusal: There may be a physical problem: for example the person may have a sore mouth, or thrush in the mouth. These problems should be dealt with promptly.

Dealing with food refusal: Older people with dementia may refuse food because of their dementia - meaning that they do not recognise that it is time to eat or cannot make appropriate voluntary movements to open the mouth or because they are unable to communicate that they do not wish to eat. In these circumstances the interpretation of the person's behaviour by the carer is particularly important and the commitment of staff to build relationships at mealtimes is fundamental.

Dealing with food refusal: Residents or patients who will not take food from staff will sometimes take it from their loved ones. This can allow the relative to play an integral part in the provision of care.

Dealing with food refusal: A carer's ability to interpret an individual's behaviour over time by establishing a consistent care plan can make a particularly positive contribution to successful eating.

Dealing with food refusal: Touch is an important way for staff to attract and focus a person's attention on eating. Holding hands, giving reassuring touches and singing softly have been found to help overcome resistance to eating.

Dealing with food refusal: Depression causes loss of appetite and lack of desire to eat and can be treated with anti-depressants. Paranoia can respond well to treatment and should be recognised and treated promptly.

Dealing with food refusal: Some people may refuse food because they believe they cannot pay for it. If residents cannot be reassured that they do not need to pay, it may be worth trying a meal ticket system.

Ensure the person is sitting as upright as possible to encourage them to be alert

Direct the person's attention to the food

Put the cutlery or cup in their hand (if needed) or guide them to take the first mouthful

If necessary, feed the first mouthful and then try to encourage them to feed themselves

Give reminders to swallow each mouthful as needed

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Use gentle physical prompts, like putting the cutlery or cup back in the person's hands

If they leave the table gently guide them back and prompt them to continue.

If they forget that they have already eaten or are concerned about where the next meal is coming from, reassure the person and provide them with a snack if appropriate.

If the person is unable to feed themselves with your guidance, as a last resort consider feeding them part or all of the meal.

Cut food up before presenting it

Only give the person the cutlery required

Put the cutlery or cup directly into the person's hand.

Use gentle verbal encouragement, for example "Oh this smells lovely".

Use gentle physical prompts, for example place your hand over the person's hand to guide their food or drink to their mouth.

Many people will still be able to hold a cup after the ability to use a fork or spoon has been lost, and this should be encouraged.

If person forgets to swallow: Alternate temperature and taste within a meal, for example sweet and savoury food or hot and very cold foods or fluids.

If person forgets to swallow: Offer sips of ice cold drink prior to a meal or in between mouthfuls.

If person forgets to swallow: Give verbal prompts to swallow.

If person forgets to swallow: Try placing an empty spoon in the mouth between mouthfuls to help stimulate a swallow.

If food remains in the mouth at the end of a meal: Check mouth after each meal and encourage or provide regular teeth brushing or denture cleaning

If food remains in the mouth at the end of a meal: The person should remain upright for a short time.

If food remains in the mouth at the end of a meal: If food remains in the mouth despite these attempts to encourage a swallow, you should safely attempt to remove it.

If the person refuses food or drink: Encourage the person to try the first mouthful to get a taste.

If the person refuses food or drink: Use prompts, for example "that's nice".

If the person opens their mouth to a cup more readily than to a spoon, try a few mouthfuls of fluid first, then move on to the spoon.

If the person refuses food or drink: Encourage the person to feed themselves as much as possible, even if this is messy.

If the person refuses food or drink: Experiment with different tastes and textures. People with dementia often have a preference for sweet foods; sweeten meals by adding sugar, maple syrup, or ketchup.

If the person is over filling their mouth with food: Cut all food into small pieces before presenting it.

If the person is over filling their mouth with food: Encourage the person to take small mouthfuls and eat at a slower rate.

If the person is over filling their mouth with food: Use smaller items of cutlery, like a teaspoon or dessert fork.

If the person is over filling their mouth with food: Encourage the person to put their cutlery down and chew or swallow.

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If the person is over filling their mouth with food: A gentle hand on the arm with a verbal prompt may help, such as “take your time”

If the person is over filling their mouth with food: Offer a soft, moist diet.

If the person is over filling their mouth with food: Offer smaller servings at one time.

If the person is over filling their mouth with food: Reheat food if necessary if the person is taking a while to eat their food.

General advice: Feed only when alert enough to swallow safely.

General advice: Be as relaxed and flexible as possible when sitting down to assist a person with a dementia to eat and drink.

General advice: Create a calm environment and use a calm approach; avoid rushing the person.

General advice: Avoid interruptions and distractions.

General advice: Give encouragement, tell the person about their food.

General advice: Sit facing the person, or slightly to their side so that you can make eye contact.

General advice: Place the food where the person can see it.

General advice: Presentation is important – make the food look attractive to eat even if it is pureed.

General advice: Encourage all attempts to feed themselves no matter how messy.

General advice: Assist where necessary but do not force.

General advice: Give prompts to chew and swallow.

General advice: Watch closely and wait for each swallow. Only give another mouthful when they have swallowed.

Always [follow] the individualised advice given by a Speech & Language Therapist.

The person should be awake and fully alert for all oral intake.

The person should ideally be seated 90° upright, in midline position, as much as possible.

Try to minimise distractions to help the person concentrate on their meal. Turn off the television or radio.

Tell the person what is happening, and what food/drink the person is having. (‘Hello Mary, it’s breakfast time. Let’s try some of your porridge’).

If feeding the person, give small sips/spoonfuls/bites, one at a time.

Never try to force-feed a person who is refusing oral intake.

Check that the person has swallowed before giving the next sip/spoonful/bite.

Stop feeding if the person becomes drowsy, slower to swallow or short of breath.

Always check the person’s oral cavity for residue after eating.

Perform oral hygiene after all intake to minimise the risk of aspirating bacteria in oral secretions.

Ensure the person remains upright for a minimum of 30 minutes after oral intake, to decrease the risk of reflux and potential aspiration of same.

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Irish Nutrition and  
Dietetics Institute

Make sure the person is ready to eat: glasses on, hearing aids on, dentures are clean, fit well and in place.  
Ensure the person is comfortable, does not need the toilet and is sitting in a good position before a mealtime.  
Meals should be relaxed and unhurried. Try not to become stressed at mealtimes if difficulties arise. Stress can be sensed. If you seem to be in a hurry a person with dementia will be aware of this and may not eat as much. Try to keep food visible or it may be forgotten and left uneaten.  
Avoid talking to other people as the person maybe distracted by this.  
Avoid the full table setting of a knife, fork and spoon. Only put out what is needed.  
If the person prefers to use a spoon, just put out a spoon. Cutting out choices at mealtimes can help to reduce distress or frustration.  
A person with dementia may eat better in company, as they may copy others and this can help to prompt memory.  
Talk about the smell and taste of the different foods you are offering, so that the person can identify what they are eating.  
Encourage the person to eat independently where possible, even if it is only one bite per meal. Do not comment on the way the person is eating as this could be upsetting.  
Prompt the person to eat by placing cutlery or a cup in their hand if they have forgotten what to do at mealtimes.  
Keep a good level of eye contact if the person with dementia is holding eye contact and it doesn't appear to be causing distress.  
As the dementia progresses it may be necessary to help the person at mealtimes. Always treat the person with dignity. Never treat them like a child  
Use an apron if necessary to protect clothes  
Ask if the food is too hot or cold, and tell the person which food or drink you are serving with each bite or sip of fluid.  
Allow the person plenty of time for eating. A person may not be finished, even if they have stopped eating  
Watch food temperatures. The person may not be able to tell if a food or drink is too hot.  
If the person appears agitated wait until they become calm before offering food and drink.  
Naming foods and drinks as you offer them can help trigger memories which in turn may help with the recognition of food items and improve food intake.  
Offer drinks after the meal instead of at the same time or offer small amounts during the meal and a full drink after the meal.  
Continue to eat sitting up in a chair at a table for as long as person is able.  
With progressing disease and decreasing ability to remember to eat, to recognize food and eat independently, personal support and help during meals becomes necessary.  
Food intake has then to be supervised, encouraged and supported by adequate nursing actions.  
These interventions should on the one hand compensate for existing deficits and on the other promote independence as far as possible at the same time.

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European Society for  
Clinical Nutrition and  
Metabolism (ESPEN)

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Social Care Institute for Excellence	Assistance should be provided according to individual needs and resources in a manner that is safe and preserves the dignity of the affected person. Paying special attention to helping people with dementia at mealtimes in an unhurried way, especially those in the advanced stages of dementia, can make mealtimes a pleasant experience.
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## Appendix J. Scoping review of guidelines – Synthesis of recommendations

Theme	Sub-theme	Examples
Independence	Set up for independence	Place the food where the person can see it (Health and Social Care (HSC), 2015)
	Keep things simple	Only put out what is needed (Irish Nutrition and Dietetics Institute (INDI), 2016)
	Use prompts	Gentle reminders about the food on their plate (Barchester Healthcare, 2016)
	Provide graded support	Support people to eat and drink where required (Bournemouth University, 2018)
	Prioritise independence	Encourage the person to feed themselves as much as possible, even if this is messy (Health and Social Care (HSC), 2015)
Oral intake	Address underlying factors	There may be a physical problem ... these problems should be dealt with promptly (Caroline Walker Trust (CWT), 1998)
	Encourage, don't force	Never try to force-feed a person who is refusing oral intake (Irish Hospice Foundation, 2016)
	Use sensory stimulation	If person forgets to swallow: Offer sips of ice cold drink prior to a meal or in between mouthfuls (HSC, 2015)
	Remember the accessories	Make sure the person has his or her glasses, dentures and/or hearing aid in place (CWT, 1998)
	Describe the meal	Talk about the smell and taste of the different foods you are offering, so that the person can identify what they are eating (INDI, 2016)
Respect	Pay attention	Do not talk to someone else while offering food (CWT, 1998)
	Maintain dignity	Use an apron if necessary to protect clothes (INDI, 2016)
	Respect choice	Some residents may choose to eat alone in their own room and this choice must be respected (Bournemouth University, 2018)
Safety	Alertness	The person should be awake and fully alert for all oral intake (Irish Hospice Foundation, 2016)
	Positioning	Make sure the person is sitting in an upright position (CWT, 1998)
	Temperature	Watch food temperatures. The person may not be able to tell if a food or drink is too hot (INDI, 2016)
	Bolus size	Encourage the person to take small mouthfuls (HSC, 2015)
	Pacing	If feeding the person, give small sips/spoonfuls/bites, one at a time ((Irish Hospice Foundation, 2016)
Atmosphere	Keep calm	Create a calm environment and use a calm approach (HSC, 2015)

	Allow enough time Avoid distractions	Allow sufficient time for food and drink to be enjoyed (Bournemouth University, 2018) Try to minimise distractions to help the person concentrate on their meal. Turn off the television or radio (Irish Hospice Foundation, 2016)
Social well-being	Connect with the resident	It is ideal for staff to sit, make eye contact and speak with residents when assisting with meals (Alzheimer's Association, 2006)
	Model eating and drinking	Staff eating with residents can build up trust and enable 'copycat' behaviours by the person imitating staff (Bournemouth University, 2018)
	Facilitate interaction	Ensure tables and chairs are positioned so individuals can see those they are sitting with (Bournemouth University, 2018)

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## Appendix K. Comparing the reviews – Synthesis matrix

<b>Study findings</b>	<b>Guidelines recommendations</b>
<p><b><i>Social connection</i></b> Interactions which build relationship and social connection</p>	<p><b><i>Social well-being</i></b> Connect with the resident Model eating and drinking Facilitate interaction</p>
<p><b><i>Tailored care</i></b> Interactions which are tailored to the individual</p>	
<p><b><i>Empowering the resident</i></b> Interactions which promote autonomy and independence</p>	<p><b><i>Respect</i></b> Pay attention Maintain dignity Respect choice</p> <p><b><i>Independence</i></b> Set up for independence Keep things simple Use prompts Provide graded support Prioritise independence</p>
<p><b><i>Responding to food refusal</i></b> Interactions which carefully and skilfully address the challenge of food refusal</p>	<p><b><i>Oral intake</i></b> Address underlying factors Encourage, don't force Use sensory stimulation Remember the accessories Describe the meal</p> <p><b><i>Atmosphere</i></b> Keep calm Allow enough time Avoid distractions</p> <p><b><i>Safety</i></b> Alertness Positioning Temperature Bolus size Pacing</p>

## Appendix L. REC Favourable Opinion



**Health Research  
Authority**

**Social Care REC**

Ground Floor  
Skipton  
House  
80 London  
Road  
London SE1  
6LH

05 June 2019

Mr James Faraday  
NIHR Clinical Doctoral Research Fellow  
The Newcastle upon Tyne Hospitals NHS Foundation  
Trust Level 2, Newcastle Biomedical Research Building  
Campus for Ageing and Vitality  
Newcastle upon Tyne  
NE4 5PL

Dear Mr Faraday

**Study title:** Improving mealtime care for people with dementia – a training intervention for care home staff  
**REC reference:** 19/IEC08/0020  
**Protocol number:** 08727  
**IRAS project ID:** 249922

Thank you for your letter of 31 May 2019, responding to the Committee's request for further information on the above research.

The further information has been considered on behalf of the Committee by the Vice-Chair. We plan to publish your research summary wording for the above study on the

HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net) outlining the reasons for your request.

### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting



documentation as revised, subject to the conditions specified below. **Mental Capacity Act 2005**

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

### **Conditions of the favourable opinion**

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

**You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.**

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees). There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

**If a sponsor wishes to request a deferral for study registration within the required**

timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

### Ethical review of research sites

#### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Newcastle University ethical approval email]	01	21 June 2018
Copies of advertisement materials for research participants [Ethnographic fieldwork]	02	13 December 2018
Copies of advertisement materials for research participants [Co-development workshops]	02	13 December 2018
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only) [Indemnity for design of research]	01	01 August 2018
GP/consultant information sheets or letters [GP letter]	01	17 December 2018
Interview schedules or topic guides for participants [Family carers]	03	13 December 2018
Interview schedules or topic guides for participants [Care home staff]	03	13 December 2018
Interview schedules or topic guides for participants [health and social care professionals]	03	13 December 2018
IRAS Application Form [IRAS_Form_11032019]		11 March 2019
Letter from funder [NIHR research contract]	04	28 August 2018
<i>Document</i>	<i>Version</i>	<i>Date</i>
Letters of invitation to participant [Care homes]	03	13 December 2018
Letters of invitation to participant [Personal consultees]	03	13 December 2018
Letters of invitation to participant [Nominated consultee]	01	06 March 2019
Other [Response to requested information from REC]	01	10 May 2019
Other [Adult Safeguarding Procedural Flowchart]	01	28 November 2018
Other [Response to requested information from REC]	02	31 May 2019
Other [Adult Safeguarding Procedural Flowchart]	02	31 May 2019
Participant consent form [Care home staff - Observations]	04	21 February 2019
Participant consent form [Care home staff - Interviews]	04	21 February 2019
Participant consent form [Visiting professionals - Observations]	03	21 February 2019
Participant consent form [Visiting professionals - Interviews]	03	21 February 2019

Participant consent form [Co-development workshops]	04	21 February 2019
Participant consent form [Residents]	04	30 April 2019
Participant consent form [Agreement of personal consultee]	05	30 April 2019
Participant consent form [Agreement - Nominated consultees]	05	30 April 2019
Participant information sheet (PIS) [Summary sheet - Residents]	02	13 December 2018
Participant information sheet (PIS) [Family carers]	06	01 March 2019
Participant information sheet (PIS) [Care home staff]	05	01 March 2019
Participant information sheet (PIS) [Visiting professionals]	04	01 March 2019
Participant information sheet (PIS) [Residents]	07	30 April 2019
Participant information sheet (PIS) [Workshops]	06	09 May 2019
Referee's report or other scientific critique report [NIHR review summary]	01	24 January 2018
Research protocol or project proposal	07	31 May 2019
Summary CV for Chief Investigator (CI) [James Faraday]	1	01 March 2019
Summary CV for supervisor (student research) [Catherine Exley]		25 February 2019
Summary CV for supervisor (student research) [Clare Abley]		01 December 2018
Summary CV for supervisor (student research) [Joanne Patterson]	01	03 March 2019
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Consent flowcharts - Ethnographic fieldwork]	04	06 March 2019

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: <https://www.hra.nhs.uk/planning-and->

[improving- research/learning/](#)

**19/IEC08/0020**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely


pp. Michael Higgs, Approvals Specialist

**Susan Harrison**  
**Vice-Chair**

Email: [nrescommittee.social-care@nhs.net](mailto:nrescommittee.social-care@nhs.net)

*Enclosures:* "After ethical review – guidance for researchers"  
*Copy to:* Mr Aaron Jackson, Newcastle Joint Research Office

## Appendix M. Letter to care home managers

The Newcastle upon Tyne Hospitals   
NHS Trust



James Faraday  
NIHR Clinical Doctoral Research Fellow  
Level 2, Newcastle Biomedical Research Building  
Campus for Ageing and Vitality  
Newcastle upon Tyne NE4 5PL  
[j.faraday@newcastle.ac.uk](mailto:j.faraday@newcastle.ac.uk)  
0191 208 2444

21<sup>st</sup> June 2019

XXXXXX  
XXXXXX  
XXXXXX  
XXXXXX  
XXXXXX

Dear xxxxx,

### **IMPROVING MEALTIMES FOR PEOPLE WITH DEMENTIA – a research study**

I am a researcher at Newcastle University. I am writing to tell you about a research study we are planning in the local area. The study is about mealtimes in care homes. I would like to invite your care home to participate in this study.

#### **Why is the study happening?**

We want to gather the views of different people who are involved in mealtimes for people with dementia in care homes. This could include the person themselves and their family, as well as care home staff, and other health professionals. We also want to observe some mealtimes in care homes, to explore what is important in providing care at mealtimes. We aim to carry out this research in several care homes in the local area. The information gathered will be used to design a training programme, to help care home staff provide the best possible care for people with dementia at mealtimes.

#### **Why is this care home being invited to take part?**

This care home is being invited to take part because it has been rated as good by the Care Quality Commission, and is registered to provide dementia care. The staff

have experience of caring for people with dementia at mealtimes, and it is important that we learn from what they do and hear their views about what it this is like and what works well in everyday life in the care home.

**What are the advantages of taking part in the study?**

If your care home takes part of this study, this will help us to understand what is important in providing mealtime care for people with dementia. In turn, this will help us to design a training course for care home staff, to improve the mealtime experience. You and your staff may also have the opportunity to express your opinions, feelings and ideas. Often people find this is helpful.

**Are there any disadvantages to taking part?**

The research will involve discussing experiences of mealtimes for people with dementia. For some people this may feel upsetting. The research will be conducted sensitively, and appropriate support will be given if needed. The work of caring for the residents is your top priority, and every attempt will be made to ensure the study minimises unnecessary disruption.

**What happens now?**

I will phone you in approximately five days, to ask if you would like to meet to discuss the study in more detail, and ask questions about it. If you would prefer to contact me, my contact details are at the top of this letter.

Thank you very much for your time.

Yours sincerely,

James Faraday  
NIHR Clinical Doctoral Research Fellow

## Appendix N. Summary sheet for residents

# Improving mealtimes for people with dementia

## Summary sheet for residents



My name is James Faraday. I am a researcher based at Newcastle University.

I would like to invite you to take part in a research study.

The aim of the study is to improve the way people with dementia experience mealtimes in care homes.

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As part of this study, I will be spending some time in your care home, to find out what is important in providing care at mealtimes.

This means I will watch what happens at mealtimes. If you take part in the study, I will observe how some meals are presented to you, and how the staff interact with you.



If possible, I will also chat with you from time to time, to find out your opinions and ideas about mealtimes.

---

You do not have to take part, if you don't want to. But if you would like to find out more about the study, you are very welcome to meet me. Just let the care home manager know.

I will explain more about the study, and give you some more written information. You can ask any questions. You could then decide whether you want to take part.

## Appendix O. Participant Information Sheet for residents

### IMPROVING MEALTIMES FOR PEOPLE WITH DEMENTIA

#### Participant Information Sheet – Residents

My name is James Faraday. I am a researcher based at Newcastle University. I would like to invite you to take part in a research study. The study is about mealtimes in care homes. The study will be written up as part of my PhD thesis. I am inviting you to take part because you have personal experience of mealtimes in care homes. I am keen to understand mealtimes from all relevant perspectives – including residents. However, you do not have to take part if you don't want to. Your care will not be affected in any way if you decide not to take part.

#### Why is the study happening?

Mealtimes are important occasions. They are important for our health, and also for our quality of life. Some people with dementia find mealtimes difficult. They might need more care and support at mealtimes, compared with before. This can be especially the case in care homes. It is important that care home staff have the right training to provide good care at mealtimes.

In this study, I will go into some care homes in the north east of England, to see what happens at mealtimes and talk to people who are involved. I will spend a lot of time in the care homes. This will mainly be in the dining room at breakfast, lunch or teatime. It may be in people's rooms if they prefer to eat there, and are happy for me to be there.

I will be looking at how the staff care for people at mealtimes, and how people enjoy their meals. The aim is to find out how to help the staff make mealtimes a really good experience for people with dementia.

#### What will happen if I take part?

If you decide to take part, this means you will be one of the residents that I observe from time to time, when you are having something to eat or drink. I will be sitting somewhere in the same room as you. I might sit nearby, or if you prefer, I will sit further away. I will be mainly looking at how the staff are interacting with you; what they are doing, and what they are saying. I will write down what I see. If possible, I might also have a chat with you about mealtimes, to find out your opinions and ideas.

I will come to the care home several times over several weeks, and will be there in total for about 20 hours. This will be spread out over about 3 months, possibly less. You will be one of



several residents taking part in the study, so I will only be observing you, or chatting with you, from time to time.

### **What will happen afterwards?**

I will gather together all the information I have collected from the care homes. I will look at this information thoroughly, and share it with my university supervisors, to make sense of it.

After this, I will have meetings with a group of people who have relevant experience. For example, family members of care home residents, care home staff, nurses, and speech therapists. They will help to design a training course for care home staff, to make mealtimes better. They will use the information collected from the care homes for this. Then I will test out the training course in some different care homes to see if it will work.

The study will be written up as part of a PhD thesis. Some results from the study might be published in research journals, and presented at conferences. This might include some of the things I observed, or some of the things you said in conversation with me. However, you would not be named or otherwise identified in any documents, publications or presentations.

The main findings of the study will also be presented to patient/carer forums, health and social care professionals, and other relevant organisations.

### **What are the advantages of taking part in the study?**

By taking part in the study, you will help to provide a clearer understanding of what happens at mealtimes in care homes. This will help with designing a training course for care home staff, to improve mealtimes. If this is successful, this may lead to people with dementia receiving better care at mealtimes in the future – in your care home, and other care homes. I cannot say for certain that this will definitely happen, but it is a possibility.

You may also have the opportunity to express your opinions, feelings and ideas, if we have a chat about mealtimes. Often people find this a helpful thing to do.

### **Are there any disadvantages to taking part?**

You might find it unusual that I am in the care home, observing you have some food or drink. You might feel worried or surprised that I am observing you, and wonder why I am doing it. To try to ensure this does not happen, I will make sure that I regularly explain why I am there, and what I am doing. I will explain why the study is happening – it is to help with designing a training course for staff, to improve mealtimes. I will explain that I am mainly looking at how the staff are helping you. For example, what the staff are doing, and what they are saying. If you become distressed or upset while I am observing a mealtime, I will ask if you would prefer me to stop the observation, and will respect your wishes. You can say at any time if you would prefer not to be in the study.

You might find it distressing to have conversations with me about mealtimes, if this topic is upsetting for you in any way. To try to ensure this does not happen, before I start having a conversation with you, I will ask you if that is okay. If you say no, I will respect your wishes. If you say yes, I will do my best to make sure that their questions are friendly, and not upsetting. If you become distressed or upset while I am having a conversation with you, I will ask if you would prefer to stop the conversation, and will respect your wishes. You can say at any time if you would prefer not to be in the study.

### **What happens to the information that is collected?**

The Newcastle upon Tyne Hospitals NHS Foundation Trust is the sponsor for this study based in England. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The Newcastle upon Tyne Hospitals NHS Foundation Trust will keep identifiable information about you for 5 years after the study has finished.

All electronic identifiable information will be stored on a secure network drive accessible only to members of the research team via password protected computers within the IT system of the Newcastle upon Tyne Hospitals NHS Foundation Trust. Paper study documents will be stored in a locked filing cabinet within the research office at Newcastle University Institute of Health and Society, by agreement with the Newcastle upon Tyne Hospitals NHS Foundation Trust. The research office can only be accessed with permission.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information at <https://microsites.ncl.ac.uk/njro/>.

### What else is important to know?

- I have asked members of the public for their advice about how to do the study well. This includes carers of people with dementia, and care home staff. I will continue to meet with members of the public, with relevant experience, several times during the study. This will help to make sure the study is safe for people to take part in.
- If you decide at any time you do not want to take part in the study, you just need to tell me or the care home manager. You do not need to give a reason. I will completely respect your decision. I will remove you from the study straightaway. I may use previously collected data, however I will not collect any further data about you.
- If anything happened during the study which you were not happy about, please tell me or the care home manager about it. Or if you prefer, you could tell my academic supervisor. This is Professor Catherine Exley, M3.050, 3rd Floor, William Leech Building, Newcastle University, Newcastle upon Tyne, NE2 4HH, [catherine.exley@ncl.ac.uk](mailto:catherine.exley@ncl.ac.uk), 0191 2085487. If you prefer to raise your concerns with someone not involved in the study, or would like to make a formal complaint, you can contact the Patient Advice and Liaison Service (PALS). This service is confidential and can be contacted on Freephone 0800 0320202 / [northoftynepals@nhct.nhs.uk](mailto:northoftynepals@nhct.nhs.uk). It may be helpful to speak to a friend or relative as well.
- There are certain extreme circumstances under which I would break confidentiality. This would only take place if I felt your safety or the safety of other people was at risk. I would only reveal the information necessary to prevent harm. I would tell you what action I planned to take and why.
- The study is sponsored by The Newcastle upon Tyne Hospitals NHS Foundation Trust. It is part of a PhD which is being undertaken at Newcastle University. The National Institute of Health Research has reviewed the study and has approved it for funding. The grant number is ICA-CDRF-2017-03-060. The study has also been passed by the appropriate Research Ethics Committee. I can give you more details about this if you wish.

### What happens now?

If you are interested in taking part, I will answer any questions you have. You will also have opportunity to discuss this with family and friends if you wish. I will give you enough time to make up your mind. You can then decide to take part, or decide not to. I will completely respect your decision.

**If you decide to take part, you will be asked to sign a Consent Form.**

If you would like to contact me at any time, you are welcome to approach me in the care home. If I am not there, you can contact me on 0191 208 2444 or [j.faraday@newcastle.ac.uk](mailto:j.faraday@newcastle.ac.uk).

**Appendix P. Consent form for residents**

**IMPROVING MEALTIMES FOR PEOPLE WITH DEMENTIA**

**Consent Form – Residents**

***Observations***

Centre Number: _____	Participant identification number: _____
Study Number: _____	

	Please initial
I have read and understand the information sheet dated _____ (version _____ ) for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, and without my care or legal rights being affected.	
I understand that personal information about me will be collected by the researcher, and may be looked at by individuals from regulatory authorities or from the NHS Trust, to ensure the research is conducted properly.	
I understand that research information collected during the study may be looked at by members of the researcher’s supervisory team from Newcastle University, and may be used to support other research in the future. I understand it may be shared with other researchers, and may be used for publication. I understand that in each of these cases, information which identifies me will be removed.	
I understand that if I withdraw from the study, no further information will be collected about me, but previously collected information may be used in the study.	

Name of participant	Date	Signature
Name of researcher	Date	Signature
Consent form-Residents-v04-2019Apr29		IRAS ID 249922

## Appendix Q. Example of field-note

### Mealtime observation

Tues 12/11/19 1:00-1:50pm

#### **First floor south dining room (Early onset)**

4 participating residents – Clara, Daphne, Keith, Muriel

2 participating staff – Margot, Nadine

1 participating family carer - Alison

There are eleven residents present, sitting on four tables. Old-fashioned music is audible from a DVD playing in the lounge; some residents had been watching this prior to coming into the dining room for lunch.

There is a convivial atmosphere on my table, where Clara, Daphne, and one other (non-participating) resident are sitting. They are frequently chatting away, joking, and commenting on events.

At the next table, Keith requests salt for his meal. Joanne shakes some over his plate. Clara and Daphne notice this, and comment that “They won’t give him it” in case he puts too much on. Later in the meal Ken requests salt again twice. The staff don’t provide it, but say it’s on its way.

Towards the end of the meal, Clara points out to Daphne: “Who hasn’t eaten much today?!” Daphne responds: “I’m just not hungry; I’ve not got any appetite.”

In discussion about mealtimes, they both agree that the staff are “lovely”

Muriel is sitting on a nearby table, with her daughter Alison, and another family member. Alison talks to me about the atmosphere in the dining room: “They are often chatting in this dining room; it might be muddled, but at least they are chatting. They are a bit regimented about where they sit.” She also tells me about her visits to the home: “The staff have cleared it for me and [another family member] to come in at mealtimes and eat with my mum. When the residents have finished, and if there is some food left over – there usually is.” She tells me that she and [another family member] also take mum out for meals periodically, to local cafes.

Alison goes into the kitchen to make her mum a cup of coffee. Later, Muriel complains of a sore stomach. Staff bring a bottle of antacid, and Alison gives Muriel a spoonful.

Back on my table, Clara and Daphne are discussing Keith again: “That’s the gobby one – he doesn’t like anything on the table.” Ken is unhappy about his cup of tea: “The tea’s cold and strong. They just haven’t got time.” Alison goes over to Ken’s table and offers to make him a fresh cup. He accepts the offer, and she brings him the tea. There is a problem with this one too, so he goes into the kitchen to make his own. Alison and Margot both monitor this, and then Margot encourages him to leave the kitchen.

Margot brings cake and custard for the Clara and Daphne, which they are very happy about. “I’ll get fat, I’m not bothered.”

## Appendix R. Example of interview topic guide

### IMPROVING MEALTIMES FOR PEOPLE WITH DEMENTIA

#### Interview topic guide – Care home staff

This document is a guide to the principal themes and issues to be covered. Questions may be modified and followed up in more detail as appropriate.

##### **Introduction/background; practicalities**

- Housekeeping; expected finish time
- Assure confidentiality
- Check permission to use audio recorder
- Mobiles off
- No right or wrong answers; views and experiences are what matters

##### **Warm-up questions**

- Could you tell me a bit about your role in the care home?
- What do you do in a typical day's work?
- How long have you worked here?

##### **Exploratory questions**

- In your experience, what is important when caring for someone with dementia?
- How do you find mealtimes in the care home?
- What is the experience of people with dementia at mealtimes?

##### **Key subject areas**

- What helps mealtimes to be a really good experience for someone with dementia?
- What, if anything, gets in the way of residents with dementia having a good experience at mealtimes?
- If you could make any changes to the way mealtimes are at the moment, what would you change?
- What training have you had about supporting people with dementia mealtimes? Can you remember what you found helpful/unhelpful about it?
- What kind of training would you find useful on this topic? What kind of areas should it cover?
- What would be the best way to deliver the training, do you think?

##### **Reflection and summary; thanks and finish**

## Improving mealtimes for people with dementia

**Would you like to help design staff training?**



My name is James Faraday. I am a researcher based at Newcastle University. I am currently doing a research project about mealtimes in care homes. Part of this project will involve designing staff training to improve mealtimes. **I am looking for people to help with this.**

---

I will be organising a series of workshops. These will take place via tele-conferencing software, e.g. Zoom.

I would like to invite people with a broad range of relevant skills and experience to take part in the workshops, so that we can work together to design the training. This will make it more likely that the training is effective.

In the workshops, we will look at current evidence on this topic. We will decide what content to have in the training, and how to deliver the training. To take part in the workshops, I am looking for:

- **care home staff and managers**
- **family or friends of people with dementia**
- **healthcare professionals**
- **people who work in education/training**

Everyone who takes part can be reimbursed for their time at an appropriate hourly rate.

---

If you are interested in taking part and would like to find out more, please let me know. My contact details are [j.faraday@newcastle.ac.uk](mailto:j.faraday@newcastle.ac.uk) or 07751730701.

## Appendix T. Participant Information Sheet for co-development workshops

### IMPROVING MEALTIMES FOR PEOPLE WITH DEMENTIA

#### Participant Information Sheet

##### *Workshops*

My name is James Faraday. I am a researcher based at Newcastle University. I would like to invite you to take part in a research study. The study is about mealtimes in care homes.

For this study I will be organising a series of workshops to design a training programme. The training programme is intended to help care home staff provide the best possible care for people with dementia at mealtimes. I want to invite people with a broad range of relevant skills and experience to participate in the workshops, so that we can work together to design the training programme. This will make it more likely that the training is effective.

You do not have to take part, if you do not want to. The rest of this leaflet will give you more information about the workshops, so you can decide if you want to take part.

#### **Why is the study happening?**

Mealtimes are important occasions. They are important for our health, and also for our quality of life. Some people with dementia find mealtimes difficult. They might need more care and support at mealtimes, compared with before. It is important that care home staff have the right training to provide the right care at mealtimes, so that mealtimes are a positive experience for residents and staff.



### **What will happen if I take part?**

If you decide to take part, you will participate in a series of workshops. The workshops will take place using tele-conferencing software, not face-to-face (unless there is a significant change in the status of the COVID-19 pandemic). We plan to have approximately 3 to 5 workshops, with each being approximately 2 to 4 hours in length, depending on the format. We would invite you to attend all the workshops, but would understand if this was not possible.

The people taking part in the workshops will be: family or friends of people with dementia; care home staff and managers; healthcare professionals; people who work in education/training. You will be reimbursed for your time.

Before the workshops take place, I will have looked at existing evidence about the mealtime care provided to people with dementia in care homes, and about current training provision on this topic. I will also have spent time in three local care homes, observing mealtimes and talking with those involved, to explore what works well and what doesn't. I will gather together all the evidence from this work, and summarize it so we can refer to it in the workshops.

The workshops will have a structured approach to make it easy for people to contribute their views and ideas. Workshop participants will discuss and decide on different aspects of the training programme, including what topics and content to have in the training, and how to deliver the training. We may audio-record and transcribe some or all of the discussions, so that we are able to capture the key points. You will not be identified in any report or publication.

### **What will happen afterwards?**

Once the training programme has been designed, I will test it out in various care homes to make sure it will work. We then plan to do further research which will result in it being rolled out more widely.

The study will be written up as part of a PhD thesis. Some results from the study might be published in research journals, and presented at conferences. You would not be named or otherwise identified in any of the documents, publications or presentations.

The main findings of the study will also be presented to patient/carer forums, health and social care professionals, and other relevant organisations.

### **What are the advantages of taking part in the study?**

Taking part in the study means that you will be helping us to design a training course for care home staff, to improve mealtimes. If this is successful, then we hope that this will lead to people with dementia receiving better care at mealtimes in the future.

### **Are there any risks to taking part?**

There are no known risks to taking part in this study.

### **What happens to the information that is collected?**

The Newcastle upon Tyne Hospitals NHS Foundation Trust is the sponsor for this study based in England. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The Newcastle upon Tyne Hospitals NHS Foundation Trust will keep identifiable information about you for 5 years after the study has finished.

All electronic identifiable information will be stored on a secure network drive accessible only to members of the research team via password protected computers within the IT system of the Newcastle upon Tyne Hospitals NHS Foundation Trust. Paper study documents will be stored in a locked filing cabinet within the research office at Newcastle University Institute of Health and Society, by agreement with the Newcastle upon Tyne Hospitals NHS Foundation Trust. The research office can only be accessed with permission.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information at <https://microsites.ncl.ac.uk/njro/>.

### **What else do I need to know?**

- I have asked members of the public for their advice about how to do the study well. This includes carers of people with dementia, and care home staff. I will continue to meet with members of the public, with relevant experience, several times during the study. This will help to make sure that the study is safe for people to take part in.
- If you decide at any time you do not want to take part in the study, you just need to tell me or the care home manager. You do not need to give a reason. I will completely respect your decision. I will remove you from the study straightaway. I may use previously collected data, however I will not collect any further data about you.
- If anything happened during the study which you were not happy about, please tell me or the care home manager about it. Or if you prefer, you could tell my academic supervisor. This is Professor Catherine Exley, M3.050, 3rd Floor, William Leech Building, Newcastle University, Newcastle upon Tyne, NE2 4HH, [catherine.exley@ncl.ac.uk](mailto:catherine.exley@ncl.ac.uk), 0191 2085487. If you prefer to raise your concerns with someone not involved in the study, or would like to make a formal complaint, you can contact the Patient Advice and Liaison Service (PALS). This service is confidential and can be contacted on Freephone 0800 0320202 / [northoftynepals@nhct.nhs.uk](mailto:northoftynepals@nhct.nhs.uk). It may be helpful to speak to a friend or relative as well.
- There are certain extreme circumstances under which I would break confidentiality. This would only take place if I felt your safety or the safety of other people was at risk. I would only reveal the information necessary to prevent harm. I would tell you what action I planned to take and why.

The study is sponsored by The Newcastle upon Tyne Hospitals NHS Foundation Trust. It is part of a PhD which is being undertaken at Newcastle University. The National Institute of Health Research has reviewed the study and has approved it for funding. The grant number is ICA-CDRF-2017-03-060. The study has also been passed by the appropriate Research Ethics Committee. I can give you more details about this if you wish.

### **What happens now?**

If you are interested in taking part, I will answer any questions you have. I can do this over the phone, or using tele-conferencing software. You will have opportunity to discuss this with family and friends if you wish. I will give you enough time to make up your mind. You can decide to take part, or decide not to. I will completely respect your decision. If you decide to take part, this will be documented on a Consent Form.

My contact details are: James Faraday, [j.faraday@newcastle.ac.uk](mailto:j.faraday@newcastle.ac.uk), 07751730701.

**Appendix U. Consent form for co-development workshops**

**IMPROVING MEALTIMES FOR PEOPLE WITH DEMENTIA**

**Consent Form**

***Workshops***

Centre Number: _____	Patient identification number: _____
Study Number: _____	

	<b>Please initial</b>
I have read and understand the information sheet dated _____ (version _____ ) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
I understand that personal information about me will be collected by the researcher, and may be looked at by individuals from regulatory authorities or from the NHS Trust, to ensure the research is conducted properly.	
I understand that research information collected during the study may be looked at by members of the researcher’s supervisory team from Newcastle University, and may be used to support other research in the future. I understand it may be shared with other researchers, and may be used for publication. I understand that in each of these cases, information which identifies me will be removed.	
I understand that if I withdraw from the study, no further information will be collected about me, but previously collected information may be used in the study.	
I agree to take part in workshops in the above study.	

Name of participant	Date	Signature
Name of researcher	Date	Signature



## Appendix W. Example of running order document for co-development workshops

### Workshop 1 – “Content”

#### Objectives:

1. Decide which topics to include in training
2. Decide key messages to convey for each topic

On-line meeting room opens for chatting / breaking the ice / testing software		1:45pm
<b>Introductions / house-keeping</b>		<b>2:00pm</b>
Welcome ,introductions, house-keeping	James welcomes the group and asks everyone to introduce themselves (say where they are calling from and why interested in this topic.) Explains house-keeping	2:00pm
Background and objectives	James briefly gives background to project, objectives for workshops overall, and specific agenda objectives for this workshop (may use PPT for this)	2:10pm
<b>Starter question</b>		<b>2:20pm</b>
What is an ideal mealtime?	Whole group discussion; xxx to scribe and summarise	2:20pm
<b>Looking at the evidence</b>		<b>2:40pm</b>
Explaining the evidence	James briefly explains sources of evidence (systematic review, guidelines and ethnography)	2:40pm
Presenting the evidence: What is important in mealtime interactions?	James presents the evidence from research literature, guidelines and ethnography	2:45pm
Reflecting on the evidence and deciding on topics to include	Whole group discussion	2:55pm
Note: The section above may take longer than scheduled, in which case time allocated for “Deciding on key messages” below will be reduced accordingly.		
Comfort break		3:10pm
<b>Deciding on key messages</b>		<b>3:15pm</b>
Drilling down towards the key messages we want to convey for each topic	Two breakout rooms, each group taking two different topics and having a nominated chair and scribe <ul style="list-style-type: none"> <li>• What new knowledge and skills would help staff here?</li> <li>• What lessons can we learn from good practice?</li> </ul>	3:15pm

	<ul style="list-style-type: none"> <li>• Why doesn't good practice always happen?</li> <li>• What are the key messages we want to communicate?</li> </ul> <p>Groups come back together and provide feedback</p>	
--	---	--

<b>Summary and next steps</b>		<b>4:00pm</b>
Summary of decisions made	James and xxxx summarise the workshop and key decisions made	4:00pm
Details of next steps	James briefly explains plan for remaining workshops	4:10pm
Close	Thanks and close	<b>4:15pm</b>

# Improving mealtimes for people with dementia



## Facilitator manual

Prototype v2



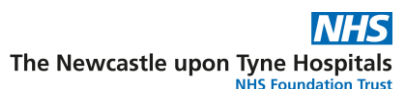
## Acknowledgements

James Faraday (Clinical Doctoral Research Fellow, ICA-CDRF-2017-03-060) is funded by Health Education England (HEE) / NIHR for this research project. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR, NHS or the UK Department of Health and Social Care.

This project was supported by the NIHR Clinical Research Network North East and North Cumbria, and sponsored by the Newcastle upon Tyne Hospitals NHS Foundation Trust. The PhD was hosted by Newcastle University.

We are very grateful to the many different people who have contributed to the project, including family carers, health and social care staff, academics, educationalists, and people living with dementia. It would not have been possible without you.

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# Introduction

## **Why is this training important?**

Mealtimes are important to our health and quality of life. Some people living with dementia need support at mealtimes, particularly in care homes. So it is essential that carers have the skills and knowledge needed to provide good mealtime care. These training materials are designed to help care home staff increase their skills, knowledge and confidence in this area.

## **How does the training work?**

The training is designed for face-to-face delivery to a group of learners. Unlike e-learning, where a learner may access training individually, the facilitator and the group of learners will work through the materials together. This is because much of the learning is expected to happen through group discussion. The training can happen with everyone physically present in the same room, or it can happen online using software like Zoom or Microsoft Teams

The materials consist of this Facilitator manual, and accompanying PowerPoint slides. The manual is for the facilitator to use as they guide the learners through the training. The manual makes it clear when the PowerPoint slides are needed. The training is intended to complement, but not replace, existing mandatory training. It touches on subjects which may be covered in more detail by other training received by care home staff. There is signposting in the manual to external resources which may be of interest.

## **Who is the training for?**

The training is for anyone working in a care home who has a role in mealtime care for people living with dementia. For example: care assistants, senior carers, management staff, nurses, kitchen staff, and domestic staff. In fact, the training may be beneficial to anyone working in the care home. The training can be delivered to staff all from the same care home, or to staff from several different care homes.

## **Who delivers the training?**

The person delivering the training does not need specific professional qualifications, but it is important they have substantial knowledge and experience of the content. This may be, for example, speech and language therapists, dieticians, care home managers, senior carers, nurses – or others with insight into mealtime care for people living with dementia. They should have strong interpersonal skills to build rapport and trust with learners – to help people engage and contribute. They also need good time-management and chairing skills, to make sure that all the key content is covered.

## Where can the training take place?

The training should take place in a room with adequate space and facilities, which is quiet and free from interruptions. This might be in a care home – for example, a dedicated training room, or a meeting room, or another room in the home which is big enough, and is not otherwise in use. Or it might be in a different venue – for example, a community centre, or local authority building, or NHS building.

## How long does the training last?

There are five modules in the training: *Empowerment and respect*, *Facilitating independence*, *Social interaction*, *Being safe*, and *Careful encouragement*. Each module lasts 75 minutes (except for the first module, which is 90 minutes to allow sufficient time for introductions and house-keeping). The modules can be delivered altogether in one day, or in two half-day sessions spread across different days. The diagram below shows two options for delivery, with suggested times for breaks and lunch. (The half-day sessions can be split differently if preferred, so that two modules are in the first half-day and three modules are in the second half-day.)

### One full-day session

**Empowerment and respect** (90 mins)

Break (10 mins)

**Facilitating independence** (75 mins)

Break (10 mins)

**Social Interaction** (75 mins)

Lunch (60 mins)

**Being safe** (75 mins)

Break (10 mins)

**Careful encouragement** (75 mins)

### Two half-day sessions

**Empowerment and respect** (90 mins)

Break (10 mins)

**Facilitating independence** (75 mins)

Break (10 mins)

**Social Interaction** (75 mins)

First half-day

**Being safe** (75 mins)

Break (10 mins)

**Careful encouragement** (75 mins)

Second half-day

# The five modules

## **Empowerment and respect**

This module is about knowing residents' preferences, offering choice (and respecting choices that are made), and enabling residents to make their own decisions where possible. It's also about understanding the Mental Capacity Act, and best interests decision-making.

## **Facilitating independence**

This module is about varying the amount and the type of assistance at mealtimes, depending on individual need. It's about setting up the mealtime in the right way to promote independence, thinking about things like adaptive equipment, appropriate crockery and cutlery, and tailored food (like finger-food).

## **Social interaction**

This module is about building relationship with residents through social interaction. Interactions are tailored to the person or the situation. It's also about understanding the social dynamics between different residents, and encouraging positive interactions between them. It's about involving others (like family members) where possible, and capitalising on special occasions like birthdays and Christmas.

## **Being safe**

This module is about monitoring residents for any difficulties or changes with eating and drinking. It's also about being aware of things like alertness, positioning, pacing and size of mouthfuls. And it's about making sure food and drink is the right consistency and a suitable temperature. Lots of people have a role in this, for example not just care assistants but also kitchen staff. Clear communication with other professionals, like GPs and Speech and Language Therapists, is also key.

## **Careful encouragement**

This module is about using skill and judgement to respond to food refusal and poor oral intake. It's about encouraging the resident without forcing them, considering underlying causes, and using the care plan. It's also about liaising with family where possible, and knowing how and when to engage other healthcare professionals (for example dieticians, speech and language therapists, and GPs).

# How each module is structured

## 1. Warm-up

25 mins for first module; 10 mins for other modules

This is a time for introductions, ground-rules and housekeeping. It is also an opportunity to build rapport and credibility with the learners, and to encourage a sense of “team”. Much of the learning is intended to take place through group discussion. For this reason, it is important that learners feel they are in a safe space in which they can share and solve problems together. **Note:** More time is allocated for this section in the first module, so that introductions and ground-rules can be properly covered.

## 2. Theory

15 mins

Here, you will introduce theoretical and evidence-based knowledge. This is delivered using PowerPoint slides. However, please try to make this interactive where possible. For example: inviting contributions from learners will recognise their prior knowledge of the topic. Please ensure all content is covered, and be careful to manage any inaccurate or off-topic contributions sensitively and clearly.

## 3. Scenarios

40 mins

In this part of the module, learners are given written case scenarios which are relevant and realistic. The case scenarios contain examples of good practice in mealtime care, and also things that could have been done differently. After presenting each scenario, you will facilitate a group discussion. This gives learners opportunity to reflect on and discuss what happened in the case scenarios. Ask learners to consider what went well in the scenarios, and what did not. For each case scenario, you will have a list of key points which you can refer to if needed. Please ensure these points are covered in the discussion. Learners may find it helpful to relate the scenarios to relevant situations from their own context, if they wish to. There may be “grey areas” in the discussion, without clear answers. Encourage the group to problem-solve together. Refer back to any relevant theoretical principles from earlier in the module, to aid this process.

## 4. Summary

10 mins

Finally, you will summarise the learning from the module. This is a chance to remind learners of the key learning points from both the theory and the scenarios. You will provide hand-outs which cover all material from the module, and which include links to relevant on-line resources.

# Module 1: *Empowerment and respect*

## Warm-up

25 mins

### Introduction

10 mins

Introduce yourself to the learners. Talk briefly about your background, so that learners know about the experience / expertise you bring. Explain relevant housekeeping, e.g. timings of session; fire alarm procedures etc.

Introduce this first module. Explain that we will be talking about *Empowerment and respect* at mealtimes. Give an example, ideally from your own experience, which illustrates the importance of preferences being respected, and of being involved in decision-making.

### Ice-breaker

5 mins

Organise learners into pairs or small groups. Ask them to share with each other either (1) a time when they felt respected and involved in decision-making, or (2) a time when this was not the case.

### Learning outcomes

5 min

State the learning outcomes for the module:

- Know how to find out about residents' mealtime preferences
- Understand how to maximise residents' choice around mealtimes
- Be aware of the Mental Capacity Act, and know how to find out more about it
- Understand what best interests decision-making is

### Ground-rules

5 mins

Invite learners to suggest ground-rules for the session. Write these on a flip-chart or whiteboard. If needed, use examples as a prompt:

- This is a safe space for discussion
- We allow people time to speak
- We respect others' opinions
- There is no such thing as a silly question

Talk through the slides on *Empowerment and respect* in the presentation. These are slides 3 – 15. There is a script in the Notes box for each slide. The script is also reproduced below for convenience. It is provided as a guide; it is not essential to use it verbatim but please ensure you cover all content within the allotted time.

**Slide 3** For the next few minutes we're going to develop our knowledge and understanding of empowerment and respect at mealtimes.

**Slide 4** The Alzheimer's Society has some helpful advice on this. They say it's important we understand a person with dementia's history, lifestyle, culture and preferences, including likes, dislikes, hobbies and interests.

**Slide 5** They say that having choice and control over care and support can help people with dementia to live well.

**Slide 6** And they say that people with dementia should be supported in making their own decisions about care and day-to-day life, for as long as possible.

**Slide 7** We're going to think about understanding residents' preferences, offering choice, and enabling decision-making.

**Slide 8 – Activity [max. 5 mins]** Let's think first of all about how we can understand someone's preferences around eating and drinking. There are several different ways we might do this, depending on the situation. Can you think of some? **[Use flip-chart or whiteboard to scribe people's suggestions]**

**Slide 9** Here are some examples of different ways we could find out about people's mealtime preferences. We can get to know the person. We can make use of their care plan. We can talk to our colleagues. We can work with the person's family or significant others to find out more about them. And we also need to keep on the look-out for any changes to preferences – they don't always stay the same. **[Check these against the suggestions given, and note any different suggestions]**

**Slide 10** Now we're going to think about the importance of choice at mealtimes.

**Slide 11 – Activity [max. 5 mins]** When we talk about having a range of options at mealtimes, we probably think first of all about having different options on the menu. But there are other choices that residents may wish to



make around mealtimes. Can you think of some examples? **[Use flip-chart or whiteboard to scribe people's suggestions]**

**Slide 12** Here are some examples of different ways that residents can make a choice at mealtimes. They can make choices about what to eat. They can also make choices about where to eat – they may wish to eat in their bedroom, or in the lounge, or in the dining room. They can make choices about when to eat – they may wish to eat at the set meal times, or at some other time. They can make choices about how to eat – for example they may wish to use a knife and fork, or a spoon, or their hands. They may also wish to make a choice about things like background music at mealtimes. **[Check these against the suggestions given, and note any different suggestions]**

Some people with cognitive or communication difficulties may find it more difficult to express their choices. We can support them by offering visual choices (like bringing them different foods to choose from), asking yes/no questions, and keeping our language simple (if appropriate).

When residents make requests (for example for certain foods, or to eat at certain times), it is good to accommodate these if at all possible.

**Slide 13** Finally we will think about decision-making, and in particular the Mental Capacity Act and best-interests decisions.

**Slide 14** The Mental Capacity Act came into law in 2005. Here are some of the key messages of the Act:

- Assume a person has the capacity to make a decision themselves, unless it's proved otherwise
- Wherever possible, help people to make their own decisions
- Don't treat a person as lacking the capacity to make a decision just because they make an unwise decision

It's important you have an understanding of this, not just in relation to mealtime care but all aspects of care. Talk to your manager if you are unsure, or feel you need further training.

**Slide 15** If a person is considered not to have capacity to make a certain decision, then that decision should be made in their best interests. The resulting treatment or care should restrict the person's basic rights and freedoms as little as possible.

It is important to understand the process for making best interests decisions. Again, talk to your manager if you are unsure, or feel you need further training.

## Scenarios

40 mins

### Scenario 1 - Tony

10 mins



Tony is in the dining room, waiting for lunch to begin. He has recently moved to the home from an extra care setting. He has moderate dementia, and some communication difficulties. His family have passed on information about his mealtime preferences, and so have his previous care team. As the carers begin to serve lunch, they discuss what he might prefer. They've looked in Tony's care plan – it says he doesn't like chicken, but he does like beef. Thankfully roast beef is one of the choices today, so they serve it to Tony.

### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- It's important to find out residents' mealtime preferences.
- We can get useful information from family, previous care teams, and the care plan.
- We should always try to enable a resident to express their preference. Preferences can change, and information from family and care plans can go out of date. We can support residents with communication difficulties to express their preferences.



Ethel is sitting in her bedroom watching a film. A carer comes in and says cheerfully “Come on Ethel, it’s lunchtime, shall I take you through to the dining room? All your friends are in there!” Ethel says “Not today thanks, I think I’ll just have it in my room”. The carer smiles. “No problem Ethel, I’ll go and get your lunch for you.”

### **Questions**

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you’ve experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### **Key points**

- It is good for residents to have a number of options to choose from, for example options for where to eat their meal.
- We may feel that it’s preferable for someone to have their meal with other people, instead of on their own. And certainly mealtimes can be an important time of social interaction, which can improve well-being. But some residents may prefer to eat on their own (either regularly or from time-to-time).
- We might consider other ways to help Ethel experience social interaction.

### Scenario 3 - Joyce

10 mins



Joyce is sitting at the dining table. It's teatime. A carer comes to the table: "It's lamb hotpot or fish today Joyce". Joyce asks for a jam sandwich instead. The carer says "You had that yesterday Joyce – and the day before. Wouldn't you prefer a proper meal today? Tell you what, I'll bring you the lamb hotpot to try. I know you like a nice bit of lamb!"

#### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

#### Key points

- Some residents might have strong preferences for certain foods, and might request to eat the same or similar foods on a regular basis.
- In general it is good to be responsive to resident's requests, and to accommodate them if possible.
- If Joyce frequently chooses jam sandwiches, we may feel concerned that she is not having a healthy, balanced diet. We would need to consider the situation as a whole. For example, what are her nutritional needs at this time? Does she have any relevant health conditions, such as diabetes?
- If we are uncertain, we could ask for advice from a Dietician.

10 mins

## Scenario 4 - Billy



Billy is having his breakfast – a big bowl of porridge. He looks agitated, and calls one of the carers over. He asks for the salt. “You know I love to have salt on my porridge!” The carer says the salt is in the kitchen, and they’ll go and get it soon. Billy is exasperated. “You say that every time, but I never get any salt! What is going on here?” Billy had a stroke last year. The carers are concerned that salt is bad for him, so they tend not to give it to him.

### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you’ve experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- Sometimes residents may make a decision which is unwise.
- If the resident has capacity to make that decision, they are entitled to make it. It’s important they are well-supported in this (e.g. have the relevant information).
- If the resident does not have capacity to make that decision, the decision should be made in their best interests.
- In Billy’s case, if he does not have capacity to make an informed decision about having salt on every meal, a best interests decision should be made. This will take into account all relevant factors, including Billy’s wishes, preferences and values.

## Summary

10 mins

1. Reiterate the key learning points from the module
  - Understand preferences
  - Offer choice
  - Enable decision-making
2. Provide hand-outs for the module (see end of manual)
  - Presentation slides from the Theory section, with notes
  - Scenarios, with key points included
  - Any links / signposts to relevant and credible resources
3. Encourage learners to share how this learning might change their practice
4. Take any final questions

## Module 2: *Facilitating independence*

<b>Warm-up</b>	<b>10 mins</b>
<b>Introduction</b>	<b>3 mins</b>
Introduce this module. Explain that we will be talking about <i>Facilitating independence</i> at mealtimes. Give an example, ideally from your own experience, which illustrates the importance of helping people to be independent.	
<b>Ice-breaker</b>	<b>5 mins</b>
Organise learners into pairs or small groups. Ask them to share with each other either (1) a time when they felt independent, or (2) a time when they were given too much help with something – or not enough.	
<b>Learning outcomes</b>	<b>2 min</b>
State the learning outcomes for the module:	
<ul style="list-style-type: none"><li>• Judge how to provide different mealtime support in different circumstances</li><li>• Know how to set up residents to be as independent as possible at mealtimes</li><li>• Be able to balance residents' independence at mealtimes with other priorities</li></ul>	

Talk through the slides on *Facilitating independence* in the presentation. These are slides 16 – 25. There is a script in the Notes box for each slide. The script is also reproduced below for convenience. It is provided as a guide; it is not essential to use it verbatim but please ensure you cover all content within the allotted time.

**Slide 16** For the next few minutes we're going to develop our knowledge and understanding of *Facilitating independence* at mealtimes.

**Slide 17** The Alzheimer's Society recommends that people with dementia are supported by family, friends and carers to do things for themselves wherever possible. This is because it helps people to feel dignified and confident – instead of helpless or worthless.

**Slide 18** They also say that carers might, in some situations, need to balance the person's independence against other concerns, such as any safety concerns and the desire to support the person to stay safe and well.

**Slide 19** In this module we're going to think about to vary the amount and type of support provided, how to set up residents to be as independent as possible, and how to manage other priorities which might sometimes feel they are conflicting with residents' independence.

**Slide 20 – Activity [max. 5 mins]** Let's think first of all about different types of support or assistance we can give to a resident with dementia during the mealtime. So just to start things off with a couple of examples: we could give no support at all; or we could directly assist the resident throughout the meal, by holding the fork or spoon, and taking it to their mouth for every mouthful. These are at two ends of a spectrum – what other ways are there to assist? **[Use flip-chart or whiteboard to scribe people's suggestions]**

**Slide 21** Here are some examples of different ways we might provide assistance. **[Check these against the suggestions given, and note any different suggestions]**

There are different amounts of assistance here. Sometimes "light-touch" support is appropriate; sometimes more significant assistance is called for. It could depend on the person's skills, or fatigue, or just how they are feeling on the day. We use our judgement, and what we and our colleagues know about the person, to make these decisions.

**Slide 22 – Activity [max. 5 mins]** Now we're going to think about how to set up residents to be as independent as possible at mealtimes. There are some



important things to consider when setting up the meal, to give residents the best possible chance of being independent – or as independent as possible. To give a really simple example: making sure the plate is in the right place on the table for them to be able to reach it easily. What other things can help, when it comes to setting up the resident to be independent? **[Use flip-chart or whiteboard to scribe people’s suggestions]**

**Slide 23** Here are some things we can do to set up the resident for independence. **[Check these against the suggestions given, and note any different suggestions]**

**Slide 24** Sometimes there are other things that can make promoting independence complicated – and it can be hard to know the best thing to do.

For example, we want to make sure residents have enough food and drink. The question “What is enough?” can also be complicated – and we cover it in more detail in Module 5: *Careful encouragement*. But sometimes residents might need help to have enough food or drink.

We also want to make sure residents have choice. Sometimes, residents might need help to have a type of food that they prefer. For example, a resident may prefer to have soup instead of a sandwich – even though they would be able to eat the sandwich independently, but not the soup.

We want to help residents maintain dignity. Sometimes residents might need help so that they can have a meal without becoming distressed about spilling food onto their clothes, for example.

**Slide 25** These things will need careful judgement, and there may not be “one size fits all” rules about what to do in a particular situation. But there are principles which can guide our actions. Here are some to consider, taken from various guidance on mealtime care for people with dementia.

Firstly: allow sufficient time for food and drink to be enjoyed. Some residents can eat and drink independently without any problem – but it is a slow process. Care staff and kitchen staff may need to work closely together to ensure that residents have enough time for their meal.

Secondly: assistance should be provided according to individual needs and resources in a manner that is safe and preserves the dignity of the affected person. So there may be situations where providing assistance helps a resident to be safe, or to maintain their dignity, or simply to enjoy their meal better. We

think carefully about how to do this. For example, maintaining dignity may mean discretely helping the resident to manage spills whilst still eating independently.

Finally, the perspective of helping people to eat rather than “feeding” them is essential. We are talking about words here, but sometimes words are important. If we think about other times we might use the word “feed” – for example “feed the cat”, “feed the baby” – we can see that it’s better to think instead in terms of “helping a person to eat”.

## Scenarios

40 mins

### Scenario 1 - Lily

10 mins



Lily comes into the dining room and sits in her usual place. The carers have made sure she has her glasses on and hearing aid in. Yesterday she used a plate-guard, and this helped her to eat independently. Today there is no plate-guard; it is being used elsewhere. She finishes most of her main course without assistance, except the peas and sweetcorn which she finds difficult to scoop up with her fork. A carer sits down next to her and gently assists her to eat the remainder of the meal. Lily smiles and thanks the carer.

### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

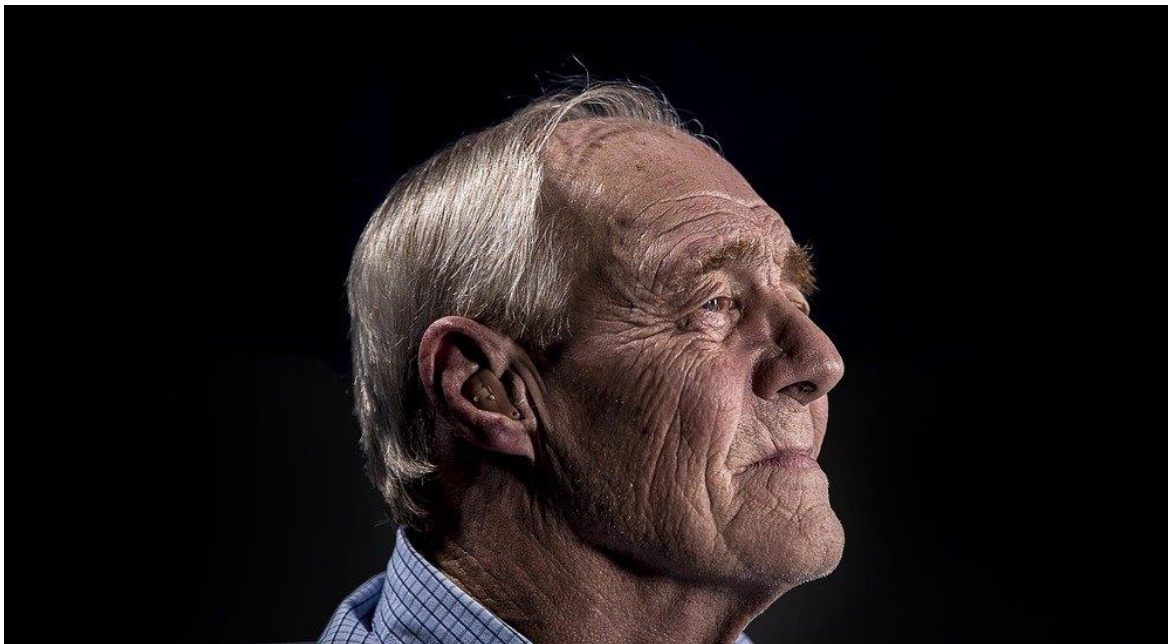
Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- We can equip residents to eat and drink as independently as possible, by making sure that everything they need is in place.
- If there is equipment that a resident finds helpful, we should try to have it available.
- Although there may be times when direct assistance is appropriate and beneficial, it is good to look for a solution that maximises independence if possible.

10 mins

## Scenario 2 - Tom



Tom is having supper – cheese sandwiches. He’s been on a day-trip to the coast today – he is feeling quite tired. The staff know Tom well. They know that he can eat independently a lot of the time – but when he’s not at his best, he does benefit from some help. A carer has noticed that Tom’s been sitting passively since he sat down at the table. She uses encouraging words to orientate him to the meal, but he remains passive. She places the sandwich in his hand and prompts him to eat – but he keeps a hold of the sandwich. Then she breaks off a small piece and places it gently into his mouth, explaining what she is doing. He chews and swallows it, and then eats the rest of the sandwich himself.

### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you’ve experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- Knowing the resident well helps us to make judgements about when to assist.
- There are different types and amounts of assistance we can offer, depending on the situation – here the carer incrementally increases the support she provides.
- Sometimes, direct assistance may prompt someone to eat independently.

**10 mins**

### Scenario 3 - Betty



Betty has finished her main course: steak and chips. She enjoys eating independently, but is quite slow – and the lunch hour is almost up. A carer brings her pudding, which is lemon mousse in a tall sundae-type glass. A colleague notices and says “Betty prefers to eat pudding from a bowl – she finds it easier to manage”. So the mousse is transferred into a bowl, and Betty makes a start, gradually eating the mousse. Then the trolley arrives back from the kitchen, for loading with empty plates. A carer sits next to Betty, and in a kind voice says “Shall I give you a hand Betty?” She helps her eat at a quicker pace; Betty finishes the mousse and the bowl goes onto the trolley.

#### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you’ve experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

#### Key points

- Colleagues are a good source of advice on how residents manage well at mealtimes.
- It is good for residents to eat independently if possible – even if it might be quicker to give assistance.
- If you feel that there are time pressures at mealtimes, talking about this as a team may help to find solutions that work for everyone and put the residents’ care first.

**10 mins**

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## Scenario 4 - Albert



Albert is in his room having lunch – fish and chips. He’s picking up bits of fish with his hands to eat it. He’s eating steadily and not having any swallowing difficulties. His fingers are getting quite messy, and he’s spilt some fish on the floor. A carer pops in to see how he’s getting on. “Hello Albert, I wonder if you’d be better off using your knife and fork for that? It’s a bit messy using your fingers.” The carer puts the knife and fork into Albert’s hands. Albert tries for a few minutes with the knife and fork, but finds it difficult. Progress is slow and he goes back to picking up the fish. The carer says “Not to worry Albert, it does look easier with your hands. Let’s not worry about a bit of mess!”

### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you’ve experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- Some residents might eat in a way we might consider unconventional, or messy. But that way might be a preferable way for them, and enable them to be independent.
- We should consider whether or not Albert feels distressed about the mess.

## Summary

10 mins

1. Reiterate the key learning points from the module
  - Provide different mealtime support in different circumstances
  - Set up residents to be as independent as possible at mealtimes
  - Balance residents' independence at mealtimes with other priorities
2. Provide hand-outs for the module (see end of manual)
  - Presentation slides from the Theory section, with notes
  - Scenarios, with key points included
  - Any links / signposts to relevant and credible resources
3. Encourage learners to share how this learning might change their practice
4. Take any final questions

## Module 3: *Social interaction*

<b>Warm-up</b>	<b>10 mins</b>
<b>Introduction</b>	<b>3 mins</b>
Introduce this module. Explain that we will be talking about <i>Social interaction</i> at mealtimes. Give an example, ideally from your own experience, which illustrates the importance of social interaction.	
<b>Ice-breaker</b>	<b>5 mins</b>
Organise learners into pairs or small groups. Ask them to share with each other either (1) a time when they really felt included in a social situation, or (2) a time when they felt left out.	
<b>Learning outcomes</b>	<b>2 min</b>
State the learning outcomes for the module:	
<ul style="list-style-type: none"><li>• Understand how social interactions at mealtimes help us build relationship with residents</li><li>• Understand how interactions between residents can impact on mealtimes</li><li>• Know how to create a social atmosphere at mealtimes</li></ul>	



Talk through the slides on *Social interaction* in the presentation. These are slides 26 – 39. There is a script in the Notes box for each slide. The script is also reproduced below for convenience. It is provided as a guide; it is not essential to use it verbatim but please ensure you cover all content within the allotted time.

**Slide 26** In this module we're going to develop our knowledge and understanding of *Social interaction* at mealtimes.

**Slide 27** NICE guidance on dementia care emphasises the importance of relationships and interactions with others ... and their potential for promoting well-being.

**Slide 28** The Alzheimer's Society says it's important there are opportunities for people with dementia to have conversations and relationships with other people.

**Slide 29** And the Centre for Applied Dementia Studies says that people with dementia should, if possible, be brought into the social world, so that they feel they are part of the group, and are welcomed and accepted.

Mealtimes provide an important and natural opportunity for all these things to happen.

**Slide 30** In this module we're going to think about building relationship with residents, about understanding interactions between residents, and about creating a social atmosphere at mealtimes.

**Slide 31-36 – Activity [max. 5 mins]** First we'll think about building relationship with residents, through our social interactions. This helps us provide better care, and can improve residents' well-being.

Our social interactions with residents will look different depending on the person – depending on, for example, their cognitive skills and personality. But it is possible – and important – to build relationship with all residents through our interactions.

There are lots of different social interactions that can take place at a mealtime. Here are some examples. For each one, tell me how you might feel if you were the resident. You can pick one of the feelings in the boxes if you like, or you might think of something different.

**[Click through the all six slides, inviting and acknowledging people's suggestions]**

**Slide 37 – Activity [max. 5 mins]** Next we'll think about how residents interact with, and get on with, other residents. Understanding interactions between residents is important in mealtime care. Interactions and relationships are often very positive. Mealtimes are occasions when we can see good friendships between residents, residents providing peer support for each other, and looking out for each other at mealtimes – for example, making sure their tablemate has got the food they wanted, or asking for assistance on their behalf.

But we also see challenges; there can be difficulties between residents at mealtimes that have a negative effect on them and others. What are some of the potential challenges?

**[Use flip-chart or whiteboard or whiteboard to scribe people's suggestions]**

**Slide 38** Here are some potential challenges that can arise from resident interactions during mealtimes.

**[List these and check against the suggestions given]**

Just like with any group of people, sometimes strong friendships can become cliques, so that others feel left out. For those who are left out, this may have a negative impact on their mealtime experience. We can also see arguments or disagreements during the mealtime – these may be long-standing, or seemingly have come out-of-the-blue. Either way, it can adversely affect the participants, and those around them – disrupting the atmosphere of the mealtime. Sometimes, a dining room may contain residents with quite a wide variety of cognitive and communication skills. This can lead to frustrations, particularly for more verbally communicative residents who may be seeking social conversation at mealtimes. And we sometimes see peer influence occurring between residents, which can negatively affect the mealtime. For example – a resident may leave the table before finishing their meal, because their friend has left.

So how can we manage situations like this?

By knowing the residents, and understanding how they relate to one another, we can anticipate difficult situations. We should always work with residents to find the best solutions. A simple solution to some difficulties may be for certain residents to sit together, and certain residents to sit apart – but we should involve and negotiate with the residents in this process. Finally, we can set the tone ourselves, by creating a positive social atmosphere at mealtimes – we're going to focus on that next.

**Slide 39** A positive social atmosphere improves the mealtime experience. We can be intentional about creating that social atmosphere. Here are some ideas that might help:

We can think about the environment. Some things are difficult to change - like the size of rooms or the physical structure of the care home. But some things we can change, and we can make the most of those. For example – changing the layout of dining room furniture might make socialising easier. Or playing residents' choice of music at mealtimes might create a better atmosphere than having the radio on.

We can involve family in mealtimes, when this is possible. Good interactions between family members and their loved ones can significantly contribute to a positive social atmosphere. We need to be sensitive to the needs of all residents in the dining room when this happens. But at its best, family involvement can be beneficial for the social well-being not just of the residents whose family members are present, but for others as well.

And we can make the most of special occasions. Celebrating birthdays, anniversaries, festivals and so on – with party food, appropriate decorations, and, again, family involvement where possible - is a really natural way to promote a social atmosphere at mealtimes. These are also great opportunities to sit down with residents and share in the mealtime with them. This can be a good thing to do at any mealtime – but special occasions could be a place to start.

**Scenario 1 - Jeanie****10 mins**

It's breakfast time. Jeanie is asleep in her favourite armchair in the lounge. Jeanie has advanced dementia and does not use verbal communication. A carer walks across, crouches down beside her and gently touches her arm. Jeanie stirs briefly then goes back to sleep. The carer leaves, then comes back with a bowl of cereal which she puts on the small table in front of Jeanie. She crouches down again, strokes Jeanie's arm and says her name. Jeanie wakes up, smiles, and puts her hand on the carer's face. The carer leans forward and kisses her on the forehead. "I've brought your breakfast Jeanie. I'll get you a cup of tea."

**Questions**

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

**Key points**

- Mealtimes provide a natural opportunity for us to interact with residents.
- Sometimes, physical touch is an appropriate and important way to interact.
- Social interactions of any kind can promote residents' well-being.

## Scenario 2 – Clara and Mabel

10 mins



Two carers come into the dining room to begin the lunch service. They work well together, and are smiling and chatting as they go about their work. It is obvious they have a good rapport with residents too, as they join in with some good-natured banter with residents Clara and Mabel. Clara and Mabel often enjoy having a laugh and a joke with the carers. On the next table, four gentleman are sitting quietly as they wait for their meals. They don't seem to notice the jokes that are going backward and forward between the carers and the ladies, and don't react to them.

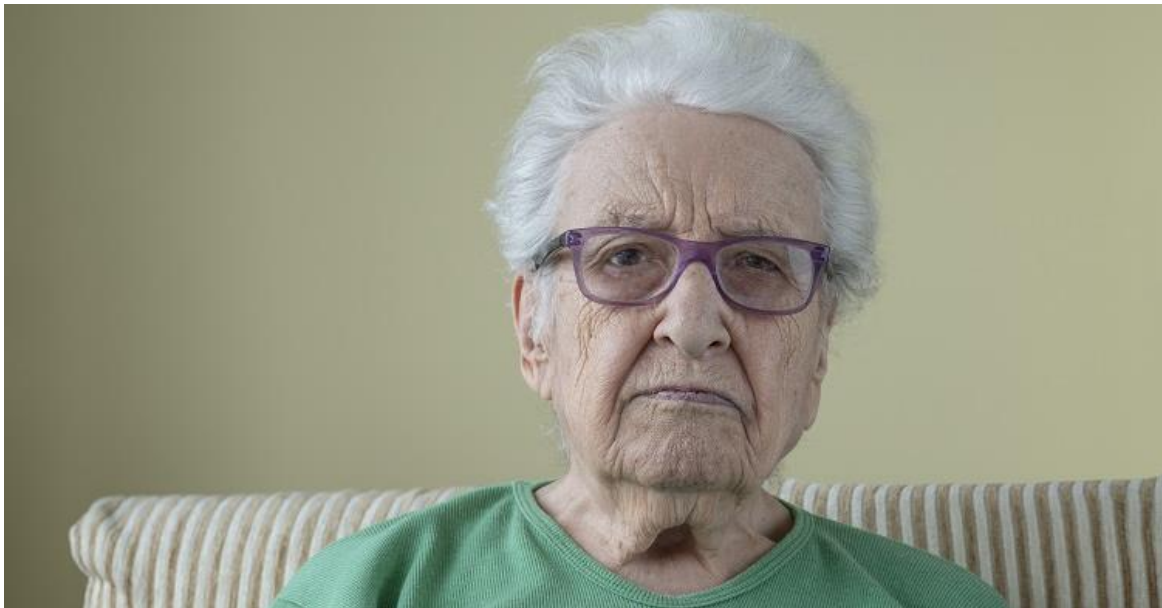
### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- A fun and upbeat atmosphere in the dining room can have a really positive effect on residents, and help to build rapport.
- Different residents will respond to this differently.
- It's important that residents don't feel left out; a different approach to social interaction may be helpful with some residents.



Maggie tells a carer she doesn't want to come to the dining room today – she says there's another resident in there who she doesn't get on with. The other resident has a forceful personality and can be quite loud at mealtimes, sometimes expressing opinions that Maggie and others do not share. The carer talks to the other resident and arranges for her to move through to the lounge, so that Maggie can come into the dining room.

### **Questions**

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### **Key points**

- All residents are unique, with different personalities, different levels of cognitive impairment, different interests, and different life stories.
- Some residents will become firm friends; others may not get on together so well.
- We can make use of our knowledge of residents to try to reduce potential opportunities for tension and disagreements – for example, by thinking carefully about seating arrangements.
- It's important to try to do this in collaboration and discussion with all residents involved – rather than imposing a solution that they may not have chosen.



It's Harry's 90th birthday. The carers have put a lot of thought into making it a really special occasion. Harry's family – children and grandchildren – have come in to join in with a special birthday lunch. Several staff are sitting at the tables with residents, enjoying the party meal. There is a festive atmosphere. The dining room is quite full, and a couple of residents have stayed in their rooms because they find it too noisy.

### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- Special occasions provide an obvious opportunity to create a very positive atmosphere in the dining room.
- Family involvement at mealtimes can be beneficial for their loved ones, and sometimes for other residents too.
- Sitting down and eating with residents, where it is possible, is a good time for social interaction between carers and residents
- It is important to be mindful of the needs and wishes of all residents in these situations, and to find a way to accommodate these.

## Summary

10 mins

1. Reiterate the key learning points from the module
  - Social interactions at mealtimes help us build relationship with residents; different approaches may be needed with different residents
  - Interactions between residents can impact on mealtimes
  - A positive social atmosphere improves the mealtime experience
2. Provide hand-outs for the module (see end of manual)
  - Presentation slides from the Theory section, with notes
  - Scenarios, with key points included
  - Any links / signposts to relevant and credible resources
3. Encourage learners to share how this learning might change their practice
4. Take any final questions



## Module 4: *Being safe*

### Warm-up

10 mins

#### Introduction

3 mins

Introduce this module. Explain that we will be talking about *Being safe* at mealtimes. Give an example, ideally from your own experience, of something that helps you to feel safe.

#### Ice-breaker

5 mins

Organise learners into pairs or small groups. Ask them to talk about things in their day-to-day life that help them to feel safe.

#### Learning outcomes

2 min

State the learning outcomes for the module:

- Know safe mealtime strategies applicable to all residents
- Know how to monitor for signs of swallowing difficulty
- Understand the importance of working with others to prioritise safety at mealtimes
- Understand the importance of knowing IDDSI names for food and drink consistencies

Talk through the slides on *Being safe* in the presentation. These are slides 40 – 52. There is a script in the Notes box for each slide. The script is also reproduced below for convenience. It is provided as a guide; it is not essential to use it verbatim but please ensure you cover all content within the allotted time.

**Slide 40** For the next few minutes we're going to develop our knowledge and understanding of *Being safe* at mealtimes.

**Slide 41** The Alzheimer's Society says that as dementia progresses, swallowing difficulties (called dysphagia) become more common, although they will vary from person to person.

**Slide 42** The Royal College of Speech and Language Therapists says that dysphagia can result in chest infections; choking; weight loss; malnutrition, and dehydration.

**Slide 43** However - the Social Care Institute for Excellence says that says that if we can identify and act on signs of chewing and swallowing difficulties we can help to reduce the risk of malnutrition.

**Slide 44** And a report published by the Alzheimer's Association says that simple strategies involving hands-on care by well-trained staff ... can prevent infection and manage feeding problems.

**Slide 45** In this module we're going to think about safe mealtime strategies we can use with all residents, how we monitor for signs of difficulty, how we work with others (both inside and outside the home) to prioritise safety, and how we provide the right consistencies of food and drink.

**Slide 46 – Activity [max. 5 mins]** So first of all, let's consider what we can do to keep things as safe as possible, for all of our residents. (We'll go on to think about responding to and managing identified swallowing difficulties.)

Please can you tell me some of the things we do to keep things safe? I'll start with an example: we make sure the resident is alert when they are eating and drinking.

**[Use flip-chart or whiteboard or whiteboard to scribe people's suggestions]**

**Slide 47** Here are some of the things we would consider when thinking about mealtime safety for any of our residents.

**[List these and check against the suggestions given]**

We make sure the person is alert enough to eat and drink – if they are drowsy, they are at greater risk of food or drink going down the wrong way. We make sure they are sitting as upright as possible – the best posture for eating and drinking is sitting in a chair, with back straight and feet flat on floor. If the person is unable to come out of bed, we use pillows/cushions and profile the bed so they are sitting as close to upright as possible. And the person should remain upright for about 20-30 minutes after the meal. We ensure that residents have good oral hygiene. Poor oral hygiene can increase the risk of infection, so we check that residents' mouths are clean before, during and after the meal. We check the food is the right temperature; not too hot, not too cold. Whether we are directly assisting the person, or monitoring them, we make sure that the pace of eating and drinking is appropriate – a suitable pace for that person. We keep an eye on the size of the mouthfuls the person is taking; we are mindful that if the pace is too fast, or the mouthfuls are too big, for some people this may lead to increased risk of choking. And reducing distractions at mealtimes may help the person to focus, and to eat and drink more safely.

These are good principles to keep in mind for all residents. But we may have increased concerns about some residents, either because they have a known history of dysphagia, or because we have started noticing some swallowing difficulties.

**Slide 48 – Activity [max. 5 mins]** So next we will think about how we monitor residents for signs and symptoms of difficulty. What are we looking out for, to check they are managing safely? What might we notice that suggests they are having swallowing difficulties?

I'll give you an example – maybe the most obvious one. We might notice coughing when eating or drinking. That would be a cause for concern, because coughing can be a sign that food or drink is going down the wrong way. This is known as aspiration, which means that food or drink is going into the wind-pipe (the trachea) instead of the food-pipe (the oesophagus) – so that it might end up in the lungs instead of the stomach, and might result in a chest infection.

What else might we notice that would be of concern?

**[Use flip-chart or whiteboard or whiteboard to scribe people's suggestions]**

**Slide 49** Here are some of things we might look out for and notice, that can suggest swallowing difficulties.

**[List these and check against the suggestions given.]**

We've already mentioned coughing. Some other things that can suggest food or drink is going down the wrong way are throat-clearing, a wet, 'gurgly'-sounding voice, changes in breathing after swallowing (like shortness of breath), and changes in face colour. The most alarming sign of aspiration is choking, which is what happens when food goes down the wrong way and gets stuck in the airway. Immediate action is needed. In your handouts there is a link to NHS advice on what to do if someone is choking, but if you are unsure please talk to your manager about training on this within your organisation.

Here are some other signs to look for which may suggest various kinds of swallowing problems. If someone feels a sensation of food "sticking" after swallowing, it may be that their swallow isn't strong enough to squeeze all the food down. Drooling can indicate the person is swallowing their saliva less frequently than normal. If food or drink spills from the mouth, it may be they do not have good oral control when preparing to swallow. In fact, this may also lead to bits of food staying in the mouth after swallowing, because the person hasn't managed to chew it all up or move it to the back of the mouth for swallowing. Difficulties with chewing can also mean someone takes a long time to finish their meal. Finally, a couple of more long-term symptoms of swallowing difficulty. People may experience chest infections, as we have already mentioned. Or they may experience weight loss.

If you would like to find out more about signs and symptoms of swallowing difficulty, there are some excellent resources freely available online. For example, the Dysphagia Guide, which is a learning resource from Health Education England, designed to support knowledge and understanding of the management of dysphagia. There is a link to this resource in your handouts.

**Slide 50** If we notice swallowing difficulties, it's important that we work with others to manage this.

Firstly, we share what we have noticed with colleagues. This helps to build a bigger picture of any difficulties the person may be displaying. We may have noticed some difficulties at one mealtime; our colleagues may have noticed the same or different difficulties at another. By pooling our knowledge of what we have seen, we understand better what is happening.

Secondly, we work out together what action to take. We talk to senior colleagues (such as nurses, senior carers, and managers), and decisions are made about how to address the problem. It may be that what we've observed points towards a simple solution; a general strategy that can be implemented

straightaway. For example – maybe we just need to help the person avoid distractions at mealtimes, or enable them to be in a more upright position when eating and drinking, or support them to eat at a slower pace.

Or it may be that there are more significant difficulties, which are not quickly resolved by implementing or reinforcing our general strategies for safer mealtimes. In this case, we involve the wider care team. In particular, we can make a referral to Speech and Language Therapy (sometimes known as the SALT team). This is the profession whose role is to provide assessment and management for swallowing difficulties. To find out more about the referral process, talk to your manager or contact your local Speech and Language Therapy team. If you are unsure about whether to refer a particular resident, talk the case through first with the GP or a Speech and Language Therapist.

**Slide 51** When a resident is assessed by the Speech and Language Therapist, they will provide various recommendations to help the resident eat and drink safely. Some of these recommendations may involve strategies from the list of ‘safe strategies for all’ we looked at earlier – but perhaps tailored to meet the individual needs of the resident. Often, the recommendations will include providing specific consistencies of food and drink. So we’ll spend some time now focusing on the different consistencies available.

Softer food consistencies may be recommended for a person who has problems with chewing, and finds harder textures too difficult to manage. Thickened drinks may be recommended for a person whose swallow is slow or uncoordinated, so that thinner drinks move too fast and go down the wrong way. The exact consistencies are recommended following careful SALT team assessment. In recent years, a new international system has been introduced to standardise the names used for different consistencies. The system is called IDDSI, which stands for International Dysphagia Diet Standardisation Initiative.

**Slide 52** This chart shows all the different IDDSI consistencies. Starting at the bottom, the drinks consistencies range from thin up to extremely thick. And starting at the top, the food consistencies range from regular (which means any kind of food) down to liquidised. If a resident has been recommended by Speech and Language Therapy to have a certain consistency of food or drink, they will use these IDDSI names to specify the consistency. It’s really important then that everyone in the home has a good understanding of these consistencies – including care staff, and kitchen staff – so that the right consistencies are given to residents.

If you would like to find out more, there is a link to the IDDSI website in your handouts. And do talk to your manager about further training which may be

available, for example from your local Speech and Language Therapists or Dieticians. The manufacturer of your thickening agent may also offer training.

**Scenario 1 - Wilbur****10 mins**

Wilbur has advanced dementia and needs assistance with eating and drinking. At breakfast today he is feeling tired, and is leaning to one side in his chair. The carer helps him to sit in a more upright position. Soon he starts to lean over again, and the carer asks a colleague to find some cushions. Between them they help Wilbur into a position which is upright, stable and comfortable. After eating some of his breakfast, Wilbur becomes more tired and is almost asleep. The carers feel he is too drowsy to eat and drink, and decide they will offer him something later when he's more awake.

**Questions**

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

**Key points**

- It's important to sit as upright as possible when eating and drinking, to help with chewing and swallowing food – some residents will benefit from support to do this.
- If a resident is too drowsy, eating and drinking will be unsafe.
- When we carefully monitor a resident, we can make a judgement about whether they are alert enough to eat and drink. If unsure, we can talk to a colleague – but it is prudent to wait until a time when the resident is more alert.



Glenys generally enjoys mealtimes, and staff have not seen any swallowing difficulties previously. Yesterday a carer noticed Glenys coughed several times when drinking her tea. She mentioned it to a colleague, who has noticed it happening today too. Both carers made sure that safe mealtime strategies applicable to all residents were in place – for example, they made sure Glenys was sitting in an upright position, and alert enough to eat and drink. But this didn't seem to help. Glenys seems well in herself. The carers discuss with the nurse, and a decision is made to refer Glenys to Speech and Language Therapy.

### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- If we notice signs of swallowing difficulty, we should always share this with colleagues, to build up a bigger picture and decide jointly what to do.
- If a resident shows signs of swallowing difficulty – particularly if this seems to be more than just a “one-off” occurrence, and all the usual safe mealtime strategies are in place – refer to Speech and Language Therapy (SLT) for a swallowing assessment.
- If unsure about whether to refer, you could discuss with the GP or SLT first.
- After making the referral, follow your local procedures to manage the situation while awaiting assessment – again, you could seek further advice from the GP or SLT.





Charles has developed swallowing problems recently, and had a swallow assessment from the Speech and Language Therapist. They have recommended he has level 1 thickened fluids (slightly thick), and level 6 soft and bite-sized diet. The carers and kitchen staff are confident and knowledgeable about modified food and drink, because they've recently had training on IDDSI consistencies. They work with Charles to think of a wide range of suitable meals he enjoys.

### **Questions**

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### **Key points**

- It's important for everyone working in the home to have a good understanding of the IDDSI food and drink consistencies – these may be recommended as safe consistencies for some residents. You may wish to arrange specific training on this.
- We should aim to provide a range of appetising and enjoyable food at the recommended consistencies, and taking into account residents' preferences.



Ruth has just returned to the home following an admission to hospital. Whilst in hospital, Ruth presented with some swallowing problems and was seen by the Speech and Language Therapist. She was recommended to have level 2 thickened fluids (mildly thick). No tubs of thickening agent were sent with her when she was transferred home from the hospital. The carers discuss this by phone with their local SALT team. The SALT team check that the prescription request has been sent to the GP, and advise using naturally thick drinks of the same consistency in the meantime, if no thickening agent is available. The carers are able to use the IDDSI flow test to make sure the consistency is right.

### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- Smooth and effective care relies on good joined-up working between several organisations, for example the hospital, the GP, the SALT team and the care home.
- If you need assistance or advice when something unexpected happens, contact the wider care team – whether that be the SALT team or one of the other organisations.
- A simple flow test can be done to check fluids consistency – details are on the IDDSI website.

1. Reiterate the key learning points from the module
  - There are safe mealtime strategies relevant to all residents
  - It's important we know how to look out for the typical signs of swallowing difficulty
  - Prioritising safety at mealtimes means working with others – including all our colleagues in the care home, and the wider care team such as Speech and Language Therapists
  - Everyone should be familiar with the IDDSI food and drink consistencies
2. Provide hand-outs for the module (see end of manual)
  - Presentation slides from the Theory section, with notes
  - Scenarios, with key points included
  - Any links / signposts to relevant and credible resources
3. Encourage learners to share how this learning might change their practice
4. Take any final questions

## Module 5: *Careful encouragement*

### Warm-up

10 mins

#### Introduction

3 mins

Introduce this module. Explain that we will be talking about *Careful encouragement* at mealtimes. Give an example, ideally from your own experience, of when you have received helpful encouragement.

#### Ice-breaker

5 mins

Organise learners into pairs or small groups. Ask them to share with each other a time when they have felt encouraged by someone.

#### Learning outcomes

2 min

State the learning outcomes for the module:

- Understand how to explore underlying causes of reduced oral intake
- Know strategies that can be used to encourage oral intake
- Understand the importance of supporting one another through the challenges of providing mealtime care

Talk through the slides on *Careful encouragement* in the presentation. These are slides 53 – 63. There is a script in the Notes box for each slide. The script is also reproduced below for convenience. It is provided as a guide; it is not essential to use it verbatim but please ensure you cover all content within the allotted time.

**Slide 53** Now we're going to develop our knowledge and understanding of providing careful encouragement at mealtimes.

**Slide 54** The Caroline Walker Trust says that food refusal is a common difficulty among older people with moderate to severe dementia.

**Slide 55** It emphasises that it is important to explore possible reasons for food refusal.

**Slide 56** The Ageing and Dementia Research Centre says we can provide positive encouragement to increase food and fluid intake.

**Slide 57** The Social Care Institute for Excellence recommends that we assist where necessary, but do not force.

**Slide 58** In this final module we'll consider how we try to work out the reasons for poor oral intake – and look for solutions. We'll look at how we carefully encourage residents to eat and drink, without forcing them. And we'll think about how we support one another in this work.

**Slide 59 – Activity [max. 5 mins]** If someone has reduced oral intake compared with normal, there may well be a particular reason or reasons for this. Let's have a think about some possible reasons why someone is eating less than normal. I'll start us off – one reason could be they have a sore mouth. Can you think of some more?

**[Use flip-chart or whiteboard or whiteboard to scribe people's suggestions]**

**Slide 60** Here are some possible reasons why someone is eating less than normal.

**[List these and check against the suggestions given.]**

For each of these, there will be action we can take to manage or resolve the issue – sometimes quick and easy, sometimes more involved – but understanding the problem is an important start.

And remember, when we're trying to understand underlying reasons, we can look for help from others. Family members will often have insight into what is

going on. We may need to consult healthcare professionals to investigate further – and to properly understand the individual nutritional needs of the resident. And always refer to the resident’s personal care plan – there may be some valuable clues in there.

**Slide 61 – Activity [max. 5 mins]** Sometimes, there may be no obvious reason why someone has reduced oral intake; no obvious problem to solve – and all that is needed is careful encouragement. There are several strategies that we use to encourage people at mealtimes; some of them may be verbal, some physical. One example is describing the meal positively to the resident – the appearance, smell, taste and so on. Can you tell me some others?

**[Use flip-chart or whiteboard or whiteboard to scribe people’s suggestions]**

**Slide 62** Here are some strategies we can use to encourage oral intake.

**[List these and check against the suggestions given.]**

We can use encouraging words to prompt the person to eat and drink; we can use appropriate touch, like a gentle hand on the shoulder as we walk past; we can place cutlery, or the cup, or the food itself into the person’s hand; we can try different food which we know the person really likes; we can sit with the person, chat with them, and maybe eat with them; we can take a little-and-often approach; we can describe the meal positively to engage the person’s senses; similarly we can touch food to the person’s lips. And we can involve family in the mealtime – sometimes the person may respond best to encouragement or assistance from a loved one. But finally, we must take care not to become forceful in our approach. Careful judgement is needed to know when is the right time to stop; when is the right time to leave it for that meal; when is the right time to try again later.

**Slide 63** Finally – it’s important to acknowledge that caring for people with dementia at mealtimes can be challenging. Let’s look at a couple of quotes from the Caroline Walker Trust. They say that caring for older people with dementia is a demanding job which can be particularly stressful in the later stages of dementia. Many staff find that helping people with dementia eat is a very challenging task. They also say that carers need support, and staff need to support each other through peer group support sessions or specialist help and support.

We need to support one another to cope with these challenges. Evidence shows the importance of regular support and supervision for staff, and an open, sharing

culture in which staff feel safe to talk about concerns and dilemmas. We must always remember we are working together, not alone.

**Scenario 1 - Fred****10 mins**

Fred has moderate dementia and limited verbal communication. He normally has a good appetite, but for the past week or so he has been off his food. He's only picking at meals and pushing his plate away after a few mouthfuls – even his favourite dishes. Several carers have noticed this, and they discuss it with the nurse and other members of the team. Later that day, a carer spends some time with Fred, using strategies to support his communication. Fred is able to tell the carer he has a sore tooth, and an urgent dental appointment is made.

**Questions**

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

**Key points**

- There may be a specific reason for reduced oral intake compared with normal.
- The resident themselves may be able to tell us why they are eating less. If they have communication difficulties, we may need to use strategies to support them in this.
- We can also investigate through discussion with colleagues, family and the wider care team.





Miriam has come to the care home recently from another part of the region. She has advanced dementia, and is nursed in bed. For several months she has eaten only small amounts at mealtimes. Carers have had a comprehensive handover from Miriam's previous care home, and try various strategies to encourage oral intake – with mixed success. Miriam's daughter lives nearby and is able to visit regularly. When she comes in, she brings Miriam's favourite snacks and treats. Miriam seems to respond best when her daughter helps her to eat.

### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- People in advanced stages of dementia will often eat less than they used to.
- Strategies to encourage oral intake may work sometimes, but not always.
- Some people may prefer foods 'little-and-often', and snacks or a small range of foods. To obtain advice about a specific resident, you could ask a Dietician.
- The presence or support of family or loved ones can really help with oral intake.



Jim is sitting in the dining room. Lunchtime has been in progress for about 15 minutes, and so far he has not eaten any of the main course. Often he will eat independently, but sometimes he does benefit from assistance. A carer sits down with Jim and tries to directly assist him to eat, holding the spoon and touching it carefully to his lips – while gently explaining what he is doing. Jim keeps his mouth closed. The carer chats to Jim for a bit, tries again a couple of times, and then says “Don’t worry Jim – let’s leave it for now and we can try again later”.

### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you’ve experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- There is a range of strategies that can be used to encourage oral intake, up to and including direct assistance. It may have been beneficial to try other strategies first, such as describing the meal, using encouraging words, placing cutlery into hands.
- We use our judgement to decide when it’s appropriate to stop and try again later.
- If Jim continues to eat or drink less than he would normally, we should explore any underlying reasons that might explain this.

## Scenario 4 - June

10 mins



June is 85. She has advanced dementia and is nearing the end of her life. For the past couple of weeks she has eaten very little; mainly just a few spoonfuls of chocolate pudding and sips of tea, at times when she is more alert. She shows signs of enjoying this, but is often sleepy. The carers know June well, and have been very sad to see her condition deteriorate. Senior staff provide time and space for sharing and discussion. They reassure their colleagues that this pattern of oral intake is common at the very end stages of dementia, and that the best possible care has been provided for June.

### Questions

- What went well?
- Is there anything you would have done differently?
- Is there anything you are unsure about?
- Can you think of any similar scenarios you've experienced?

Explore any grey areas in more depth. Encourage learners to problem-solve together. Scribe key points onto the flip-chart or whiteboard.

### Key points

- In the end stages of dementia, the person's oral intake tends to decrease slowly over time. The body adjusts to this slowing down process and the reduced intake.
- This can be a difficult and emotional time for care staff as well as family.
- Support and supervision, and an open, sharing culture in the home is important – so that staff are able to talk about concerns and feelings if they want to.

## Summary

10 mins

1. Reiterate the key learning points from the module
  - Explore underlying causes of reduced oral intake
  - Use strategies to appropriately encourage oral intake
  - Support one another through the challenges of providing mealtime care
2. Provide hand-outs for the module (see end of manual)
  - Presentation slides from the Theory section, with notes
  - Scenarios, with key points included
  - Any links / signposts to relevant and credible resources
3. Encourage learners to share how this learning might change their practice
4. Take any final questions

# Improving mealtimes for people with dementia

## Module 1: Empowerment and respect

### Understanding preferences

- Get to know the person
- Use care plan
- Communicate with colleagues
- Work with family and others
- Look out for changes

### Offering choice

- Provide a range of options around mealtimes
- Give support to make choices
- Be responsive to requests

### Enabling decision-making

- Understand the Mental Capacity Act (MCA) 2005
- Understand the process for best interests decisions

### Useful links

<https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/>

<https://www.nice.org.uk/guidance/qs194>

# Improving mealtimes for people with dementia

## **Module 2: Facilitating independence**

### **Varying assistance**

- Verbal encouragement
- Describing the meal positively – appearance, smell, taste etc.
- Placing cutlery or cup into hands
- Hand-over-hand assistance
- Direct assistance for first mouthful, then encouragement

### **Setting up for success**

- Cutting up food
- Opening packets, cartons etc., pouring drinks
- Only providing cutlery for each course
- Using plate-guards
- Using adaptive cutlery
- Putting cutlery or finger food into hands
- Dentures, glasses, hearing aids etc.

### **Managing other priorities**

- Eating and drinking enough
- Having a choice of foods
- Maintaining dignity

### **Useful links**

<https://cwt.org.uk/>

<https://www.alzheimers.org.uk/get-support/help-dementia-care/understanding-supporting-person-dementia-practical-impact>

# Improving mealtimes for people with dementia

## Module 3: Social interaction

### **Building relationship**

- We build relationship through social interaction
- This helps us provide better care, and can improve residents' well-being
- Interactions may look different depending on the person

### **Understanding interactions between residents**

- Get to know the residents
- Work with residents to find solutions
- Set the tone by creating a positive social atmosphere

### **Creating a social atmosphere**

- Think about the environment
- Involve family if possible
- Make the most of special occasions

## **Useful links**

<https://www.alzheimers.org.uk/about-dementia/treatments/person-centred-care>

<https://reflectionsgreenwich.com/2017/03/25/the-flower-of-emotional-needs/>

<https://www.bradford.ac.uk/dementia/>

# Improving mealtimes for people with dementia

## Module 4: Being safe

### Safe mealtime strategies for all

- Alert enough to eat and drink
- Sitting as upright as possible
- Good oral hygiene
- Temperature of food and drink
- Pace of eating and drinking
- Size of mouthfuls
- Reducing distractions

### Monitoring for difficulty

- Coughing / throat-clearing
- A wet, 'gurgly' voice
- Change in breathing
- Change in face colour
- Choking
- Food 'sticking' after swallowing
- Food/drink spilling from mouth
- Food staying in the mouth after swallowing
- Taking long time to finish meal
- Repeated chest infections
- Weight loss

### Working with others

- Sharing with colleagues to build a bigger picture
- Working out together what action to take
- Involving Speech and Language Therapy as needed

### The right consistencies

- Consistencies specified by Speech and Language Therapist, using IDDSI terminology
- Softer foods for people who have problems chewing; thickened drinks for people whose swallow is slow or uncoordinated

## Useful links

<https://www.e-lfh.org.uk/programmes/dysphagiaguide/>

<https://www.nhs.uk/common-health-questions/accidents-first-aid-and-treatments/what-should-i-do-if-someone-is-choking/>

<https://www.alzheimers.org.uk/get-support/daily-living/eating-drinking>

<https://iddsi.org/>



# Improving mealtimes for people with dementia

## Module 5: Careful encouragement

### Problem-solving

- Sore mouth, e.g. oral thrush
- Constipated or need the toilet
- Unwell
- Depression / low mood, or anxiety
- Concerned about paying for meals
- Relational difficulties

### Encouraging without forcing

- Prompting with encouraging words
- Gentle use of touch
- Placing cutlery, cup or food into hands
- Trying different food
- Sitting with the person
- Chatting to the person
- Eating with the person
- Little-and-often
- Snacks
- Describing the meal positively – appearance, smell, taste etc.
- Touching food against the person's lips
- Involving family in the mealtime
- Trying again later

### Supporting one another

- Support and supervision available for staff
- An open, sharing culture so staff can talk about concerns and feelings if they want to

### Useful links

<https://www.bournemouth.ac.uk/research/projects/optimising-food-nutritional-care-people-dementia>

<https://www.scie.org.uk/dementia/living-with-dementia/eating-well>

## Appendix Y. Sample from Prototype intervention slides

**Empowerment and respect**

### Understanding preferences

- Get to know the person
- Use care plan
- Communicate with colleagues
- Work with family and others
- Look out for changes

*Care plan*

Here are some examples of different ways we could find out about people’s mealtime preferences. We can get to know the person. We can make use of their care plan. We can talk to our colleagues. We can work with the person’s family or significant others to find out more about them. And we also need to keep on the look-out for any changes to preferences – they don’t always stay the same.

[Check these against the suggestions given.]