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*Staying safe at home in winter: case studies of people with dementia*

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# Staying safe at home in winter: case studies of people with dementia

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## Abstract

This thesis presents the findings of a constructivist multiple case study design of six people with dementia's experience of trying to stay warm and safe at home during winter. People with dementia have been found to experience a higher rate of morbidity and mortality during the winter months (Liddell et al., 2016; ONS, 2015), though the reasons for these increased rates are unknown. This programme of research aimed to explore and understand the challenges that people with dementia have in keeping warm and safe in their own home during winter.

This study was conducted in the winter and early spring of 2014/15 between October and April, in a post-industrial Northern city of England. Semi-structured interviews with a person with dementia and relevant family caregivers form the core of the data in each case. Data from interviews was supported by observations, and temperature and humidity readings, both inside and outside of the home. Consent of people with dementia was secured through a Process Consent method (Dewing, 2007 and 2008b), which aimed to maximise the capacity of a person with dementia to consent to participation.

Through thematic and inter-case analysis an overarching thematic framework emerged of people 'Trying to stay safe in winter', though the progression of dementia and old age. Three themes describe this framework: 'Losing me', 'Hanging on', and 'Winter wellbeing'. Taken together these themes tell a narrative of people trying to stay safe in winter while trying to hang on to a sense of self, and control over their lives.

This thesis argues for greater support for people with dementia who live in their own home, without the support of family members. Such support should be ongoing from the point of diagnosis and take a person centred approach. Additionally, existing advice material for caregivers should be updated to better reflect the challenges people with dementia have staying warm and safe at home in winter.

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# Declaration

I declare that the work contained within this thesis is composed by the candidate: Benjamin David Thomas. All contributions from other researchers and authors are referenced within the work.

Benjamin Thomas

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## Chapter 1. Introduction to the thesis

Dementia is one of the greatest health and social care challenges, now and for the foreseeable future. As of 2016 in the UK, dementia became the leading cause of death for women and the third for men. This shift in mortality is due to the UK's ageing population. Most importantly, beyond its population level impact, dementia affects individuals, families and communities, each faced with a cruel and unforgiving condition, influencing all levels of society. The challenge of dementia has been growing in public and political awareness, though there is still much more work to be done.

*“One of the greatest challenges of our time is what I’d call “The Quiet Crisis”; One that steals lives and tears at the hearts of families, but that relative to its impact is hardly acknowledged.*

*We’ve got to treat this like the national crisis it is. We need an all-out fight back against this disease; one that cuts across society.”*

Former Prime Minister David Cameron

This chapter sets out the key issues that are discussed within this thesis along with a brief overview of the method. There then follows a brief contextual background to the thesis. The research question, aim, and objectives of the thesis are introduced. Finally, there is an overview of the structure of this thesis.

### 1.1 Thesis summary

This study aims to understand the challenges that people with dementia have in keeping warm and safe in their own home during winter.

This study conducted in the winter and early spring of 2014/15 between October and April, in a post-industrial Northern city of England. This study uses a constructivist multiple case study design, with a person with dementia, living in their own home, sitting at the centre of each case. The experiences of participants with dementia were elicited through interviews, observations, and temperature and humidity readings. These were supported with interviews from family

members and carers to provide a greater understanding of the story of warmth and safety in winter for each case.

This thesis sits at the intersection of the effects of dementia, living in a cold home, and ageing. To adequately explore these effects, the thesis encompasses the fields of Health and Social Care, Gerontology, Sociology, Psychology, Public Health, and Public Policy. These fields of study have been drawn upon to craft the narrative of this thesis, and to provide context and describe the experience of people with dementia of being cold at home in winter. The research is inductive and follows a constructivist view of social actors, with each person creating their own valid view of social reality. This thesis takes the position that truth is subjective and that each person's experience holds within it an important contribution to understanding a phenomenon.

The study consists of six cases, each centred on a person with dementia. Participants were recruited through a specialist mental health nurses who worked for a community-based dementia association and acted as gatekeeper for the study. A Process Consent approach (Dewing, 2007 and 2008b) was used to maximise the capacity of a person with dementia to consent to participation in the study.

## 1.2 Research question

The research question for this study is:

**What are the experiences of people with dementia keeping warm and safe in their own home during winter?**

This research question aims to support an open inductive inquiry. The research question was developed to focus on exploring the agency of person with dementia to make decisions on warmth and safety at home. The focus on safety, captured in the thesis title, was a gradual development through the field work and analysis of data. The research began from a point of trying to understand people with dementia's experience of trying to keep warm at home during winter. Literature was reviewed and data collection designed to effectively capture this

warmth experience. However, through an iterative analysis process safety and staying safe emerged as a lens to understand the experience of people with dementia keeping warm at home in winter. The structure of the thesis, described in section 1.4, reflects this change in focus. Similarly, the aim and objectives of this thesis, section 1.3, mirror the shift from a focus on warmth to include a notion of safety.

### **1.3 Aim and objectives**

The aim of the study is to understand the challenges that people with dementia have in keeping safe and warm in their own home during winter. To further explore this aim, the thesis has the following objectives:

- To elicit the experiences of people with dementia and their carers regarding winter safety and warmth in the home.
- To identify any unique challenges faced in keeping safe and warm in winter for a person with dementia.
- To describe the different challenges faced by people with dementia living within different home environments.
- To identify any strategies used to keep a person with dementia safe and warm in their home.
- To identify the input that carers have in keeping a person with dementia safe and warm in their own home.

These objectives are intended to guide the study in understanding the behaviour challenges and actions of people keeping warm and safe at home during winter.

### **1.4 Structure of the thesis**

The structure of this thesis reflects the programme of study and the candidates movement to understanding winter warmth and harm through the lens of safety.

Earlier chapters in this thesis focus on winter warmth and harm, relating to people with dementia, the analysis chapters, seven through nine, draw out wider themes related to safety and staying safe in winter. The final chapter draws together the two threads of warmth and safety in winter, from the key threads of the analysis chapters. This thesis is organised as 10 chapters:

Chapter 2 sets out the contextual background of this thesis in two threads: living with dementia and living with cold. The chapter describes the growing importance of dementia on the health and social care policy agenda. The section also highlights the effects of dementia, with a focus on the social and psychological implications of living with dementia. The second half of chapter 2 describes the effects of living in a cold environment, advice on keeping warm, and existing cold policy. The discussion focuses on older people's risk in living in a cold environment.

Chapter 3 is a critical review of the evidence about older people's experience and approaches to keeping warm and safe at home during winter. This broad approach was used because preliminary searches of the literature indicated a lack of evidence specifically related to the winter warmth experience of people with dementia. The findings from this review will be considered in relation to their relevance to those with dementia.

Chapter 4 describes the methodological underpinnings, key considerations, and research design that informed the method of this thesis. There is a specific focus on the methodological and ethical considerations when conducting research with people with dementia. Research design choices are critically discussed. The chosen case study design is argued as an approach that fits with the research questions and study objectives, and allows for the exploration of phenomena in their natural setting.

Chapter 5 details the methods used to conduct data collection and analysis. The chapter describes how a multiple case study design was applied to the research question. A multi-methods approach is described, which focuses on qualitative data to capture the subjective experience of people with dementia. Data collection tools include: interviews with people with dementia, interviews with carers,

observations, and temperature and humidity readings inside and outside of a person's home.

Chapter 6 is the first of four chapters that communicate the findings of this programme of research. The chapter presents individual case analyses of the six cases. The analyses combine interviews from participants, their caregivers, observations, and temperature and humidity readings. The chapter provides biographical information on the participants, their support structure, and individual cases' story of winter warmth and safety.

Chapter 7, 8, and 9 describe the findings from the thematic inter-case analysis. The three chapters describe a story of people with dementia trying to stay safe during winter, in the context of declining physical and cognitive capabilities. The three chapters describe the three themes of 'Losing me', 'Hanging on', and 'Winter wellbeing'. 'Losing me' explores participants' desire to maintain their sense of self and social connections through dementia. 'Hanging on' uses a metaphor of a climber's journey up a wall to describe participants' desire for control security, as dementia limited a person's ability to be independent. The final theme, 'Winter wellbeing', portrays winter warmth as being important to participants, but this existed in a wider need for staying safe at home. These three themes, and their accompanying sub themes, highlight the complex challenges presenting people with dementia trying to keeping warm and safe at home during winter.

Chapter 10 concludes the thesis by discussing the findings of this study within the wider academic and policy context. The discussion of the findings of this thesis framed in three threads: comparing the warmth and safety experience of older people with or without dementia, how people with dementia appear to perceive risks to winter warmth or safety, and the role of social connections in keeping a person warm and safe at home. These threads are discussed in terms of their theoretical and policy implications. In addition, this chapter critically assesses the strengths and limitations of the study, highlights the studies contributions to knowledge, and details recommendations for research and practice.

## Chapter 2. Background

### 2.1 Introduction

The aim of this chapter is to provide a contextual foundation for the two key elements of the research question: those of living with dementia and living in a cold environment. The first half of the chapter provides an overview of dementia, financial and social costs, current dementia policy, and the impact of living at home with dementia. The second half describes issues related to living in cold environments, including: the effects of living in a cold home, winter mortality, and cold policy, each with a focus on older people. The chapter concludes that there appear to be aspects of dementia that places people with dementia at higher risk of winter mortality and morbidity, but the underlying reasons are unknown.

### 2.2 What is Dementia?

Dementia is an umbrella term for a group of symptoms caused by the atrophy and death of nerve cells, with varying pathology. It is a fatal and degenerative condition that requires long-term complex management (Bakker, 2003). It is a condition that while rooted in a cognitive decline presents a complex interaction of physical, cognitive, psychological, and social changes.

There are over 100 hundred forms of dementia, with Alzheimer's disease being the most associated with the condition. Short-term memory loss is the effect most associated with dementia, but the condition can affect any function of the nervous system. While there are multiple forms of dementia, they fall under two major branches; Primary Degenerative, where dementia and its symptoms are the main condition, and Secondary Degenerative, where the symptoms of dementia are caused by a separate condition, e.g. Parkinson disease. In the UK, around 60% of those diagnosed with dementia have Alzheimer's disease and 20% Vascular dementia (Prince et al., 2014). Alzheimer's disease is thought to be caused in part by the build-up of proteins at the end of nerves cells, preventing nerve signals, and neurofibrillary tangles, which pass nutrients in cell keeping it alive, breaking down (Reitz and Mayeux, 2015). Vascular dementia is associated to



conditions such as strokes leading to the death of nerve cells. It is possible however for a person to have a mixture of dementias.

Dementia and Alzheimer's disease was for the first time in 2013 identified as the main cause of mortality of women in the UK, with 31,850 deaths (ONS, 2014). This represents 12.2% of all female deaths and the third most common cause in men, with 15,021 deaths (ONS, 2014). This increase is likely due to an ageing population, where chronic and degenerative conditions are more prevalent. There has also been better recording and awareness of Dementia and Alzheimer's disease within the health care system. In recent years, there have been significant advancements in medical science's ability to identify a person's risk of Alzheimer's disease (Cruchaga, 2013) and several potential avenues for future treatment (Leinenga and Gotz, 2015; Sevigny et al., 2016). However, it remains a condition that requires long-term management through social care, at a substantial human and financial cost.

### 2.2.1 **Symptoms and effects of dementia**

The symptoms of dementia vary for each person, in part depending on the type of dementia a person has. Short-term memory loss is the symptom most commonly associated with dementia, though physiologically dementia can affect any process that nerves carry out, most commonly in the brain. Additionally, people with dementia will likely experience psychological and behavioural changes (Prince, et al., 2016).

A person with dementia can experience changes in their sensory perception resulting in difficulties with communication, changes to physical senses, changes to spatial awareness, and amnesia (both forgetting past events and difficulties creating new memories) (Galvin and Sadowsky, 2012). The sensory perceptions of a person with dementia will likely decrease as their condition progresses, with interpretation and adaption to their environment becoming increasingly difficult (Van Hoof et al., 2010). The ability of a person with dementia to achieve functional independence is reduced because of the sensory change and reduced ability to complete previously simple, daily tasks (Burge et al., 2012; Chan et al., 2015). For example, a common effect of dementia is wandering behaviour (Cipriani et

al., 2014), where memory problems and reduced spatial awareness results in a person becoming lost, reducing a person's ability to live without assistance. As the condition of a person with dementia progresses, he or she will likely become increasingly dependent on others to support them in their daily activities and physical needs (Giebel et al., 2014).

The ability to communicate effectively is a common adverse effect of cognitive degeneration in dementia. A person with dementia might have an increasing difficulty in using and understanding language effectively, leading to a person no longer being able to express their needs or wishes. Perhaps more significantly a person may struggle to effectively express who they are to those around them, and loved ones may struggle to identify with the person they have known (Killock and Allan, 2001; Kitwood, 1997; Sabat and Harre, 1992). This has implications to how a person with dementia can maintain and create social bonds, with the emotional and physical support these can bring.

Psychological and behavioural changes might also occur in the progression of a person's dementia. These behavioural changes can initially be very subtle, with only close family and friends being aware (Draper, 2013). Behavioural changes can take many forms: loss of inhibition, aggression, depression, anxiety, obsession, and a regression to previous behaviour, such as from childhood (Bakker 2003). While some form of behavioural change is likely in all forms dementia, frontal lobe dementia is associated with large changes in behaviour, such as loss of inhibition. Some behavioural changes and conditions, such as depression, can be managed through drugs and therapy. However, as a person's condition progresses these behavioural changes can become more pronounced and increasingly difficult to manage. As a secondary effect of dementia, studies have found those with dementia are at increased chance of social isolation and loneliness, along with wider mental and physical health risks (Gilmour, Gibson, and Campbell, 2003; Kane and Cook, 2013, Fratiglioni et al., 2000; Miranda-Castillo, Woods and Orrell, 2010).

### 2.2.2 Treatment and management of dementia

There is no cure for Alzheimer's disease or vascular dementia. Treatment is directed towards drugs that can alleviate symptoms of dementia or slow down the progression of the condition. In the UK, the National Institute for Clinical Excellence recommend drugs be used to slow down the progression of symptoms in the early to mid-stages of Alzheimer's disease (NICE, 2016a). The progression of vascular dementia, similarly, can be managed through stroke controlling medication. Therapies are being developed to reduce the causal factors related to Alzheimer's disease (Leinenga and Gotz, 2015; Sevigny et al., 2016). These therapies are currently in the early trial stages. Even with the success of such treatments some forms of dementia, e.g. Secondary Degenerative, seem likely to remain an issue for the foreseeable future.

Due to the lack of curative medical treatments, the management of dementia has been focused on maintaining the wellbeing and independence of people with dementia for as long possible (NICE, 2013). This can include the management of symptoms, creating a social care plan, making adaptations to homes, cognitive behavioural therapy, and psychosocial interventions. The focus of dementia care on wellbeing and independence has coincided with the development of person-centred care, which emerged from the work of Kitwood and Bredin (1992) and Kitwood (1997) as an approach to tailoring a person's care to their interests, personality, abilities, and needs. Person-centred care has since been adopted as a central principle in the UK for health and social care treatment and management of dementia (NICE, 2016b).

As with any long-term health condition, there are advantages of early diagnosis in dementia management; a push for greater early diagnosis has become a foundation of UK dementia policy (Great Britain, Department of Health, 2009). Early diagnosis allows people with dementia to plan ahead while retaining the capacity to make informed decisions about their care (Prince, Bryce and Ferri, 2011), empowering people through the progression of their condition. As a person's dementia and cognitive decline progresses, management shifts to maintaining functional capabilities, such as the ability to self-care (Gitlin et al., 2005; Graff et al., 2006; Lam, et al., 2009). As a person's dementia moves

towards its end stages, management and treatment moves to continuous assistance with basic activities of daily life and finally palliative care (Reisberg and Franssen, 1999). The management of dementia through these stages is complicated further by the age-related nature of the condition. People with dementia are likely to have other long-term health conditions (Prince et al., 2016), making the treatment of dementia more complex, and dementia makes the management of other conditions more challenging.

### 2.2.3 Prevalence of dementia

Age is the most important risk factor for dementia. Beyond the age of 65, a person's chance of developing dementia increases rapidly (Parkin and Baker, 2016; Prince et al., 2014) beyond 95 a person has an estimated one in three chance of contracting dementia (Matthews et al., 2013).

Assessing how many people have dementia is difficult due to the challenges of diagnosis and the difficulty of accurately assessing dementia rates within certain populations, e.g. ethnic minorities (Husaini et al., 2003; Prince et al., 2014). The Dementia UK report 2014 (Prince et al., 2014) report a prevalence rate for over 65s with dementia of 7.1%, in the UK. When added to the estimated 42,320 people in the UK with early onset dementia (pre-65), Prince et al.'s prevalence rate results in an estimated 850,000 people with dementia in the UK. The Department of Health, with the use of a different prevalence measure from the second Cognitive Function Age study (Matthews et al., 2013; Parkin and Baker, 2016), reports a lower rate of prevalence of dementia for over 65s of 6.4%, resulting in an estimated 800,000 people with dementia in the UK. The two prevalence measures differ particularly for those aged over 90. The difference between these two commonly used measures illustrates the difficulty in establishing an accurate prevalence rate for dementia, subsequently affecting the effective planning for future health care provision. Table 2-1 shows a comparison of age related prevalence estimates from the two studies.

**Table 2-1 Comparison of estimates for prevalence % of late onset dementia from key studies**

|                       | Age (years) |       |       |       |       |       |       |      |                      |
|-----------------------|-------------|-------|-------|-------|-------|-------|-------|------|----------------------|
|                       | 60–64       | 65–69 | 70–74 | 75–79 | 80–84 | 85–89 | 90–94 | 95+  | Age standardised 65+ |
| Prince et al., 2014   | 0.9         | 1.7   | 3.0   | 6.0   | 11.1  | 18.3  | 29.9  | 41.1 | 7.1                  |
| Matthews et al., 2013 | -           | 1.5   | 2.7   | 5.7   | 10.0  | 16.1  | 30.1  | 30.1 | 6.4                  |

Table 2-1 highlights the age-related nature of dementia. At 65-69 a person has around a 1-in-75 chance of having dementia, by 95 this has risen to around a 1-in-3 chance. Life expectancy in the UK has been rising for several decades, due to improvements in the public's health; this is a trend that is expected to continue (Bennett et al., 2015). By 2030 it is estimated that the life expectancy will be 85.7 years for men and 87.6 for women (Bennett et al., 2015). With this ageing population, the number of people with dementia is expected to dramatically increase. If there is no change in the prevalence rates for dementia, Prince et al. (2014) forecast that by 2025 there will be 1,142,677 people with dementia in the UK and 2,092,945 by 2051.

#### 2.2.4 What are the costs?

The financial and social cost of dementia is difficult to determine. In 2010 it was estimated that the NHS spent £1.3bn on those identified as having dementia (NHS Confederation, 2010). This calculation represents only a portion of the full financial burden of dementia to the UK economy. Prince et al. (2014) estimated the total cost of dementia to UK society in 2014 to be £26.3bn, with £4.3 billion on healthcare costs. Social care was estimated to cost the UK £10.3 billion annually, with £4.5 billion spent on publicly-funded and £5.8 billion spent on privately-funded social care. However, the largest cost burden is estimated to be £11.6 billion of unpaid care. In total, this equates to an average cost of £32,250 per person with dementia, with an ageing population the financial and social

burden of dementia is set to increase. These figures show, the disproportionate burden placed on unpaid carer costs and privately funded social care, together around 75% of the cost to UK society.

The needs of those with dementia place a disproportionate burden on the NHS and social care services. In 2009, the Alzheimer's Society identified that one quarter of hospital beds were being used by people over 65 with dementia at any one time (Alzheimer's Society, 2009), while 40% of people over 65 in hospital are living with dementia (Care Quality Commission, 2014). Once admitted people with dementia are more likely to stay for longer and more likely to die whilst in hospital (Young et al., 2011). These longer stays in hospital are in part due to a more complicated and time consuming discharge process into social or community care (Care Quality Commission, 2014; Young et al., 2011). In 2013, the Care Quality Commission reported that in 78 out of 151 of Primary Care Trusts (now Foundation Trusts) people with dementia were significantly more likely to attend hospital with an avoidable condition like urinary infections, dehydration and pressure sores. The majority of the 400,000 older people living in care homes have dementia or a similar cognitive impairment (Care Quality Commission, 2014). Taken together, these figures illustrate the large financial, time, and care pressures created by dementia on the UK's health and social care system.

### **2.3 Informal carer role**

Informal or family carers are often the main support for people with dementia (Broadaty and Donkin, 2009; Lethin et al., 2016). As previously mentioned it is estimated the unpaid carer 'costs' consist of more than 50% of the annual UK cost of dementia, at £11.6bn (Prince et al., 2014). Informal care can encompass a wide range of roles, such as assistance with activities of daily living, care management, supporting independence, psychological support, and surveillance (Broadaty and Donkin, 2009; Wimo et al., 2002). Wimo et al.'s (2002) study in with informal caregivers in Sweden found that around 50% of an informal carer's time is spent on surveillance of a person with dementia, looking for needs and

risks. As Berry, Apesoa-Varano and Gomez (2015) point out family caregivers have a nuanced understanding of a person with dementia's needs, which a non-family member would struggle to replicate. This understanding of a loved ones' needs has been suggested to have a strong impact on a person with dementia's ability to hold on to their identity (Keady and Nolan, 2003; Hellstrom, Nolan, and Lundh, 2005).

In the later stages of dementia, informal carers can be providing 24-hour care and support (Andrieu et al., 2005). This high intensity of care required in the later stages of dementia, can generate a high degree of burden and stress for caregivers (Burns and Rabins, 2000; Eters, Goodall and Harrison, 2008; Papastavrou, 2007). For spousal caregivers, sustaining 'couplehood' is a difficult process, given the burden of care and difficulty identifying with a partner in the way they once had (Hellstrom, Nolan, and Lundh, 2005 and 2007).

## **2.4 Modelling dementia**

This section presents two different models of dementia, a biomedical model and a person-centred model. These two models illustrate two distinctly different ways of viewing dementia, its symptoms, and treatment.

### **2.4.1 Biomedical model**

The biomedical model has dominated western approaches to management and treatment of dementia and ageing (Estes and Binney, 1989). This has led to the process of medicalization of dementia (Bond, 1992; Bond et al., 2002; Kitwood, 1997; Lyman, 1989), a term in the discipline of the sociology of health and illness where behavioural symptoms become defined as medical problems. This process resulted in the power of treatment of dementia being held in the hands of medical experts, limiting the role of social care interventions and support in the management of dementia. There has been limited success in the application of medical curative treatments to dementia. This has allowed for alternative views of dementia to emerge, critical of a purely medicalized approach and in favour of psychosocial and cultural aspects of dementia (Bond, 1992; Bond et al., 2002; Downs, 2000; Kitwood, 1997; Lois, Seman and Stansell, 1997; Lyman, 1989;

Pratt and Wilkinson, 2003). Lyman (1989) went as far as to suggest that the biomedicalization of dementia has the potential to cause a form of social death before physical death, by failing to recognise and tackle the socially destructive effects of dementia.

#### 2.4.2 Personhood model

Those critical of a biomedical approach to understanding and treatment of dementia have suggested that viewing dementia through a psychosocial lens enables greater understanding of the condition along with the experiences and needs of people with dementia (Kitwood, 1997; Lois, Seman and Stansell, 1997; Pratt and Wilkinson, 2003). In this way, these approaches draw upon a social constructionist tradition of thought, linked to a person-centred view of people of dementia. A dialectical approach was argued for by Kitwood (1997), against the deterministic approach of the biomedical model. Kitwood argued that dementia does not emerge solely because of neurodegeneration but also from psychosocial interactions. In short, changes to social engagement and a person's perception changes of who they are, i.e. their personhood. Kitwood's (1997, p.8) described personhood as:

*"A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust."*

In this view, the most damaging aspects of dementia are not necessarily the physical effects, but rather the psychosocial changes to how a person and others view them.

Kitwood and Bredin (1992) highlighted the Western tradition of equating individuality with personhood, whereby a person who is able to be and act independently is viewed as having greater worth. However, such a view does not capture the social element of people. As infants, we are individuals that form a sense of self and build a notion of agency through interactions with others, and thus personhood is bestowed upon us. Through most of our lives this view of ourselves is frozen but not fixed; there is fragility to our sense of self, which changes to social environment can affect. For example, in dementia for those entering institutionalised care there is likely to be a dramatic change in their social



environment, such as altering how a person with dementia views themselves, their agency, and their standing within social groups. This type of social change for a person with dementia, along with perhaps an altered personality, could alter how they view themselves and how others view them.

Kitwood's (1997) model of personhood draws upon symbolic interactionism and social psychology to argue for two kinds of self. Adapted Self arises from the interaction of high socialization and performance of given roles. Experiential Self arises out of being in the presence of others in a context of equality, mutual respect and attention. Experiential Self can be maintained in a person with dementia under the right conditions through to the moment of death, through a person's severe memory loss, or confusion, etc. If the sense of self can be maintained, they have a chance of retaining their dignity, some enhanced independence, a greater sense of fulfilment, and a gratification of being understood (Sabat & Harre, 1992). This social constructionist approach to self within dementia is predicated on the cooperation of individuals.

A person-centred approach has altered the provision and conceptualization of care (Baldwin and Capstick, 2007). The process of supporting personhood through dementia has risen in prominence in health and social care policy (Great Britain 2005; NICE, 2016b). However, this approach has been criticised because the application of an individualistic personhood approach in dementia care in practice is extremely difficult in terms of time and cost (Dewing, 2008a; Higgs and Gilleard, 2015). Higgs and Gileard (2015) argue that personhood is too ambiguous a concept to be helpful in dementia care provision; attention should be focused on maximising existing capacities. A person-centred approach to care has also been criticised for being too myopic and not encompassing the role informal and professional carers play in supporting a person with dementia and the accompanying interdependence that forms from caring relationships (Keady and Nolan, 2003; Nolan et al, 2004). These critiques have particular relevance to the operationalization of dementia care provision.

## 2.5 Dementia policy

Dementia was recognised as a health and social care policy priority in the UK in 2009 with the launch of 'Living Well with Dementia: A National dementia strategy' (Great Britain, 2009). The strategy aimed to improve dementia services across three key areas of firstly awareness, secondly earlier diagnosis and intervention, and thirdly provision of a higher quality of care. The third aim was supported in the 2009 strategy with the objectives of:

1. Access to care, support and advice soon after diagnosis;
2. Development of community and peer support networks;
3. Greater support for carers, with the implementation of the carers' strategy.

An increased rate and earlier diagnosis of dementia is a central strand of UK dementia policy. An earlier diagnosis empowers people with dementia and their families to adjust to the condition earlier and put in place plans. Earlier diagnosis also allows clinical service providers to plan more effectively for the future, leading to increases in patient wellness and potential cost savings (Banerjee and Wittenberg, 2009). Another major strand of the current UK policy is the support for people with dementia to continue to live in the community and care homes for as long possible (Great Britain, Department of Health, 2009). This includes the objectives of improving community support, developing structured peer support, supporting family carers, facilitating access to services, and exploring tailoring housing support for people with dementia.

The 2009 Dementia Strategy was criticised from the outset for the lack of resources committed to its implementation (Hilton, 2010). There have also been concerns that the strategy has raised expectations from users without the resources for front line staff to meet these expectations (Greaves and Jolley, 2010).

The 2009 Dementia Strategy remains the most substantive policy document in the UK for dementia. The strategy was supported by two policy papers from the former Prime Minister David Cameron in 2012 (Great Britain, 2012) and 2015 (Great Britain, 2015). These two Prime Ministerial policy papers supported the

Dementia Strategy, developed under the previous Labour government, with the 2012 document supporting the introduction of Dementia friendly communities and in 2015 setting ambitious targets of Britain becoming a world leader in Dementia care and research by 2020. In support of the 2020 ambitions, a Dementia Discovery Fund was established in 2015 to fund dementia research, with £130 million of investment in 2016, and the establishment of a £150 million pound multi centre Dementia Research Institute (Parkin and Baker, 2016).

These policies are not a starting point but are part of a continuum of policy initiatives in health and social care that have given a greater focus to the needs of people with dementia. They also represent a shift towards a person-centred approach to support and care of people with dementia. The Mental Capacity Act (Great Britain, 2005) redefined the way those with impaired cognitive functions should be engaged within health and social care. This legislation enshrined a legal right that those with dementia must be enabled to exercise their extant and remaining decision-making capacity in their health and social care. Additionally, the Mental Capacity Act has encouraged researchers to increase engagement with people with dementia within the research process, particularly on the process of consent (Dewing, 2008b; McKeown et al., 2010).

## **2.6 Dementia, ageing and living at home**

There is increased emphasis in health and social care policy towards supporting people with dementia living at home. The national dementia strategy's (Great Britain, 2009) objective 10 calls for targeted housing support for people with dementia, to support their independence. This theme has continued into the Dementia quality standards (NICE, 2013, p.43) so that people with dementia can "maintain and develop their involvement in and contribution to their community".

If managed appropriately, an older person living in their own home and community can experience strong psychosocial benefits, such as maintaining support networks (Sixsmith and Sixsmith, 2008; Stewart et al., 2014). However, living at home presents challenges to older people such as maintaining their physical environment, increased social isolation and managing loss in physical

capacity (Fausset et al., 2011; Nicholson et al., 2013; Rolls, et al., 2010; Sixsmith and Sixsmith, 2008). These are challenges faced by older people with dementia while trying to manage the physical, social and behavioural aspects of their condition. Supporting people with dementia living at home, along with the general old age population, is therefore recognised in health and social care policy. This can be seen in the Dementia quality standards (NICE, 2013), which states that people with dementia should be able to "maintain and develop their involvement in and contribution to their community".

It is estimated that one third of people with dementia live alone (Gilmour, Gibson, and Campbell, 2003). While it is possible that those living alone may have access to appropriate care and support, the progressive nature of dementia makes maintaining appropriate levels of care potentially challenging. For people with dementia, living alone have been shown to be exposed to challenges that those living with others were more able to manage (Evans, Price and Meyer, 2016; Gilmour, Gibson, and Campbell, 2003; Miranda-Castillo, Woods and Orrell, 2010). Research with people with dementia and carers has highlighted people living alone struggling with money management, personal hygiene, coping with technology, cooking, and poor nutrition (Evans, Price and Meyer, 2016; Gilmour, Gibson, and Campbell, 2003). In a comparison of people with dementia living alone or with someone else, Miranda-Castillo, Woods and Orrell (2010) identified that those living alone were at increased risk for unmet social, environmental, psychological and medical needs. They identify that, social connections for those living alone were difficult to maintain; the maintenance of these social connections being particularly important to the care and wellbeing of a person with dementia (Kane and Cook, 2013).

Social isolation appears to be associated to the development of dementia (Bennett et al., 2006; Fratiglioni et al., 2000). Tracking a dementia population of 1203 people in Sweden for an average of three years, Fratiglioni et al. (2000) found that those judged to have poor or limited social networks were 60% more likely to develop dementia. Bennett et al. (2006) tracked the cognitive decline of 89 people with Alzheimer's disease and found that larger social networks reduced levels of cognitive decline.

Those living alone with dementia appear to be a particularly vulnerable group to personal and home safety challenges, in comparison to older people and those with dementia living with family. At present, this is an under-researched area (Evans, Price and Meyer, 2016) and there is a need for greater understanding of the experiences of those living alone if health and social care systems are to better support people with dementia living in their own homes.

## **2.7 Cold**

This section outlines some of the health and wellbeing effects of living in a cold environment, with a focus on older people. There is also a discussion of the UK's cold weather policy to manage cold and winter related harm for older people. It will be described that living in a cold home presents risks to people's physical and mental health. The UK has a relatively high level of winter mortality and morbidity compared to other European countries, including countries that experience significantly lower temperatures. Older people, along with the young and those with long-term health conditions, are particularly at risk during cold weather (Healy, 2003; Marmot, 2011). This is reflected in the UK's policy response (Katiyo, Dorey and Bone, 2016).

### **2.7.1 Effects of living in a cold environment**

Living in a cold home has been associated with a range of negative health effects and conditions. Cold indoor temperatures have been shown to affect a person's risk of cardiovascular and respiratory conditions along with suppressing a person's immune system (Healy, 2003). The effects of living in a cold environment also have negative impacts on quality of life, social engagement, and mental health (Liddell and Morris, 2010). These effects are heightened for the old, the young, and those with pre-existing medical conditions particularly at risk (Marmot, 2011).

Cardiovascular risk is seen to increase with long-term exposure to lower temperatures, with studies initially finding an increased risk starting at 18°C (Shiue and Shiue, 2014; Wookey et al., 2014). Living in a 'cold' environment raises blood pressure by causing a narrowing of the arteries, and increases in

blood viscosity (Lloyd et al., 2008; WHO, 1985; Wookey et al., 2014). Further, raised fibrinogen levels, due to respiratory infections, can increase the risk of heart attacks, during winter (Marmot, 2011).

Breathing cold air affects the regular protective functions of the respiratory tract, causing issues such as bronchoconstriction, mucus production, and reduced mucus clearance (Marmot, 2011). GP consultations for respiratory tract infections have been observed to increase by 19% for every one degree drop in mean temperature below five degrees Celsius (Hajat, Kovats and Lachowycz, 2007). For people with an already suppressed immune system, due to frailty or long-term health conditions, the risk of infection is further increased during cold weather.

Older people are more likely to be affected by cold conditions due to low body fat percentage, sedentary life style, medication use and chronic conditions, including heart conditions, circulatory disease, and diabetes (Marmot, 2011). Living in a cold environment has been found to exacerbate the symptoms of Arthritis and so increasing a person's risk of falls (Department of Health, 2007). Additionally, icy and snowy conditions increase the risk of falls outside of the home, with such incidences leading to higher rates of hip fractures, hospital stays, and decreased independence (Department of Health, 2007).

Living in cold and damp homes has been associated with an increased risk of mental health problems such as anxiety and depression (Marmot, 2011). An evaluation study of a warm home initiative found that living in a warmer home could alleviate borderline anxiety and depression, in the short to medium term (Green and Gilbertson, 2008). It has been suggested that the joint impact of ill health and financial worry may take a toll on mental health (Marmot, 2011). There is limited evidence on the effect of living in a cold home on the mental health of an older person. However, there is some indication that the situation may contribute to social isolation (DoECCa, 2015). This association is suggested to be due to a reluctance to invite family or friends into a cold home (Katiyo, Dorey and Bone, 2015). This social isolation may further exacerbate mental health problems that have been associated with living in cold homes.

### 2.7.2 Excess winter mortality and morbidity

Mortality and morbidity rates for the elderly and those with pre-existing medical conditions are higher in winter. The standard measure for an increase in winter mortality is called excess winter mortality (EWM) index, sometimes referred to as excess winter death index (EWDi). The EWM index compares the number of deaths between the coldest four months of the year (December to March) to the warmest months (April to November). The EWM index represents the percentage difference in mortality. The Office of National Statistics (ONS) calculates the index as:

$$\text{EWM index (\%)} = \frac{(\text{Winter deaths} - (0.5 \times \text{Non winter deaths})) \times 100}{(0.5 \times \text{Non winter deaths})}$$

There has been a general downward trend in EWM index since the 1950s (Figure 2-1). In the winter of 204/15, 43,900 excess winter deaths were recorded in England and Wales (ONS, 2015). This is the highest figure for 13 years and represents a 250% increase on the record low figure of 17,460 deaths in 2013/14. Around 40% of total excess winter deaths are attributed to cardiovascular disease and 33% to respiratory disease (Katiyo, Dorey and Bone, 2016). Fluctuation in excess winter death numbers is not uncommon; with the 2014/15 high numbers being attributed to a particularly bad flu season. There are, however, segments of society in the UK and certain health conditions increase susceptibility to hold related harm in winter.

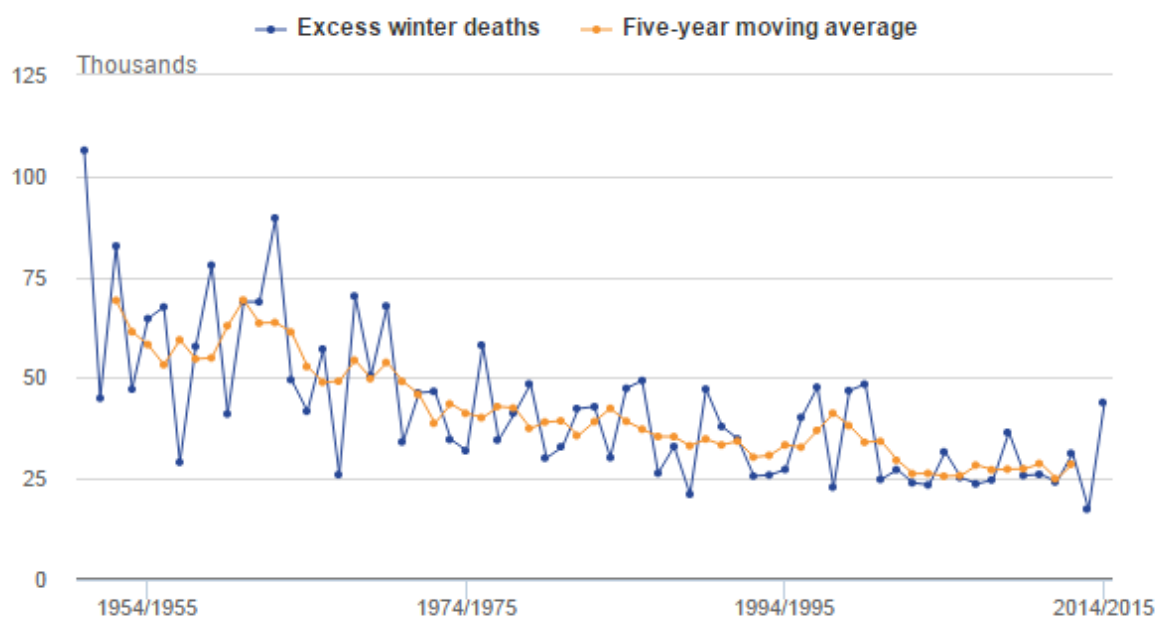


Figure 2-1 Excess winter mortality index in the UK since the 1950s (ONS, 2015)

The UK has one of the highest rates of excess winter deaths in Europe, significantly higher than countries that experience colder winters (Fowler, et al., 2014; Healy, 2003; Laake and Sverre, 1996). This pattern of warmer countries having higher rates of excess winter death is attributed to the poorer standard of housing and lower levels of winter preparedness in these countries, rather than outdoor temperatures (Healy, 2003; Laake & Sverre, 1996; Marmot, 2011). Socioeconomic factors are not necessarily determinants for increased chances of excess winter death. This lack of correlation has been attributed to factors such as income needed to heat a home not following a clear relationship with deprivation (Burholt and Windle, 2006; Wilkinson et al., 2004). In the UK, those families who are most deprived often live in social housing, which commonly has better energy efficiency than privately owned housing stock (Marmot, 2011). Therefore, this issue cuts across socio economic groups in the UK.

The breakdown of EWM index by age and gender (Figure 2-2 and Figure 2-3) shows a clear correlation between age and susceptibility to death in winter. The EWM index for men and women shows that the 85 and over group have a roughly



three times greater chance of mortality during winter than those under 65. This illustrates the high risk older people's health is placed in during winter.

**Males**

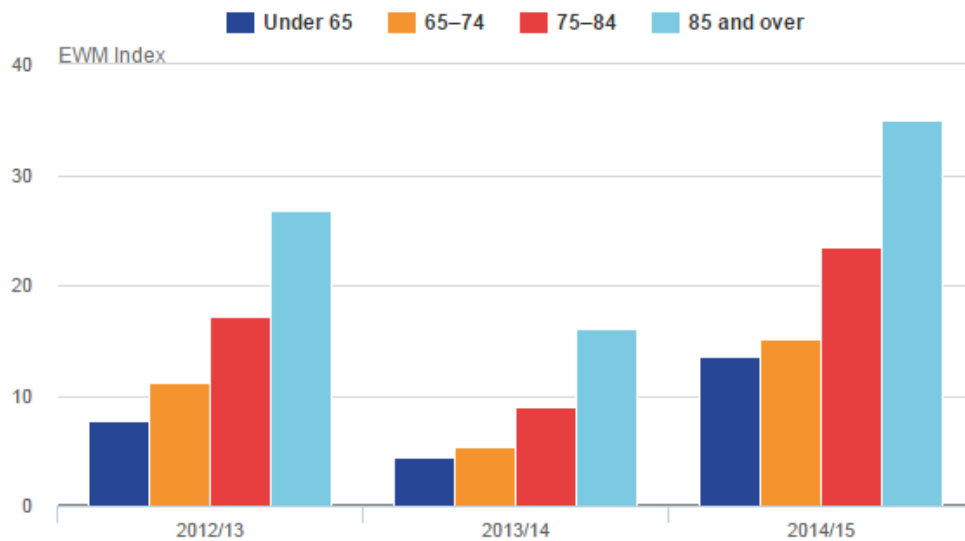


Figure 2-2 Excess winter mortality index in the UK for men (ONS, 2015)

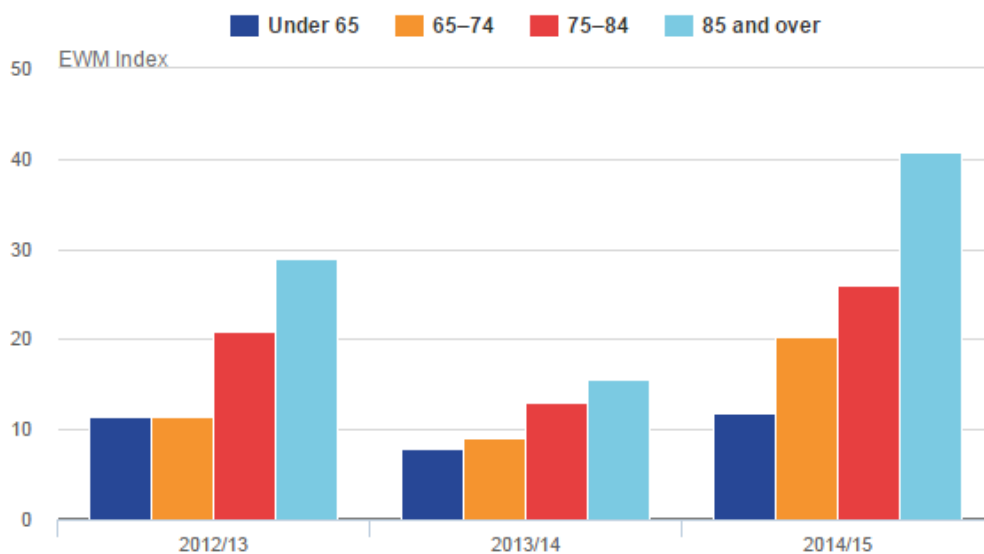


Figure 2-3 Excess winter mortality index in the UK for women (ONS, 2015)

Living in a cold home has been found to have a negative effect on morbidity and mortality for all ages, with over 65s being particularly at risk (Marmot, 2011, Rudge and Gilchrist, 2005; Wilkinson et al., 2004). Marmot (2011) estimated that 21.5% of all excess winter deaths can be attributed to the coldest quarter of

housing in the UK. This equates to excess winter deaths in the coldest quarter of homes being around three times greater than those in the warmest quarter of homes.

For people with dementia there is evidence to suggest that they experience a higher rate of winter mortality than those without the condition (Liddell et al., 2016; ONS, 2015). Since 2009 the ONS has only been reporting that there is an increased winter mortality rate for people with 'Alzheimer's disease and other related dementias'. The ONS (2015) winter mortality report shows Alzheimer's disease and other related dementias have the second highest association to winter mortality, after respiratory conditions. Liddell et al. (2016) further examined dementia's impact on UK winter mortality over the last 22 years, reporting that people with dementia had on average a 33% increased chance of dying during winter compared to summer months. The reason or reasons for this higher rate of winter mortality amongst people with dementia is unknown.

## 2.8 Cold advice

Though there is clear evidence that living in a cold home has a negative health effect for older and vulnerable people, the evidence base for safe living temperatures is recognised as less clear. Jevons et al.'s 2016 systematic review of appropriate indoor temperatures highlights the limited available evidence on minimum temperature thresholds for homes. The current recommendations stem from a WHO (1985) report that recommended temperatures between 18°C to 24°C for appropriately clothed sedentary people, with an air movement speed of less than 0.2m/s, a relative humidity of 50% and a mean radiant temperature within 2°C of air temperature. However, although it is unclear how these recommendations were derived by the WHO working group, they remain the base for home temperature advice. The report's recommendations have informed major research and policy in the field including: the Hills review (2012), the Marmot report (2011) and the Cold Weather Plan (Katiyo, Dorey and Bone, 2015; Wookey et al., 2014).

Public advice on safe temperatures is aimed at those who are perceived to be the most vulnerable to cold conditions, the old, young, and those with particular pre-existing health conditions. Advice for keeping warm in winter is provided by the Department of Health (NHS choices), the cold weather plan (Katiyo, Dorey and Bone, 2016), and charities. The advice from these sources is similar, recommending room temperatures between 18°C - 21°C. For over 65s they are recommended to maintain daytime living areas to at least 21°C (Age UK). The cold weather plan further advises that vulnerable people should be prepared for the effects of cold weather with flu vaccination, dressing appropriately, staying active, watching and responding to weather reports and maintaining a good diet.

## 2.9 Cold policy

This section will highlight policies aimed at tackling cold related harm for older people in the UK. The UK government's policy on cold weather has several strands: Fuel Poverty Strategy, Cold Weather Plan, Cold Weather Payments, Winter Fuel allowance, and a series of household energy efficiency policies. These policy strands, though all working within the cold and warmth policy sphere, recognise that older people are at greater risk of harm from cold weather.

The National Fuel Poverty Strategy (DECC, 2015) has the aim of reducing the number of households and individuals in fuel poverty. Fuel poverty is a measure of the percentage of income a household needs to spend to keep warm, with older people identified as being at increased risk of harmful effects of fuel poverty. In the current definition of fuel poverty, a household is considered to be fuel poor if they spend more than the UK median on energy bill and that such expenditure pushes them below the poverty line (Hills, 2012). The fuel poverty strategy informs government agencies in approaches and policy design to tackle fuel poverty and fuel poverty related harm. The Fuel Poverty strategy has been criticised for not achieving its stated aim of eliminating fuel poverty amongst vulnerable people by 2010 and within all the UK by 2016 and not targeting limited resources effectively (Kidson and Norris, 2014).

Older people have been found to be more likely to be in fuel poverty, due to requiring more heating use to reach a comfortable level of warmth (Burholt and Windle, 2006). To assist, two payments schemes are targeted at the UK older population: Winter Fuel Payments and Cold Weather Payments. The Winter Fuel Payments, sometimes known as winter fuel allowance, are an annual winter payment of £100-£300 paid to any person, 65 or older. The Cold Weather Payment scheme is an additional payment of £25 for each seven consecutive days of lower than zero degree Celsius temperatures, for anyone already receiving winter fuel allowance. The aim of these two schemes is to alleviate some of the financial burden for older people and to encourage them to use their heating more during cold periods.

The Cold Weather Plan, in its 5<sup>th</sup> iteration (Katiyo, Dorey and Bone, 2016), forms the backbone of England and Wales preparedness for cold weather. It is informed by the NICE recommendations targeting excess winter deaths, illness and the health risks associated with cold homes (NICE, 2016). Together these policy documents focus on identifying and targeting resources on those deemed to be vulnerable to cold and winter related harm. The Cold Weather Plan is a framework designed to provide guidance to agencies on providing protection against the harmful effects of cold weather, at the population level. It aims to *"prevent the major avoidable effects on health during periods of cold weather"* (Katiyo, Dorey and Bone, 2016, p.6). To do this, it contains a series of recommendations for; NHS, local authorities, social care, public agencies, professionals working with people at risk, individuals, local communities and voluntary groups. The Cold Weather Plan strongly recommends that winter preparedness should be considered a core task for Health and Wellbeing boards, in conjunction with other agencies, with the aim to reduce the prevalence of excess winter deaths and the burden on the health and social care system. However, the Cold Weather Plan is not accompanied with specific funding; it relies on local government and agencies allocating resources to implement its recommendations.

The plan identifies lung illnesses, influenza, heart attack and strokes as those health concerns that are associated with greatest risk of harm during cold weather. Mental ill-health is primarily identified as an effect of rather than a risk factor for cold-related harm. There is only a brief reference to dementia which simply makes the point that there may be cold related risk associated with having a reduced ability to self-care. (Katiyo, Dorey and Bone, 2016, p.47)

## 2.10 Chapter summary

This chapter has provided a contextual understanding of the areas of dementia and cold that are relevant to and exploration of the research question. Dementia has been described in this chapter as a condition with large impacts on individuals, their families, and health and social care systems. The UK and global aging populations are resulting in a growing number of people with dementia, which will place a growing pressure on health and social care resources. There is a push to support older people and those with dementia to live in the community for as long as possible, with the dual benefits of improving people's wellbeing and reducing the pressure on the health and social care system.

This chapter has also highlighted the health and wellbeing impacts of winter and living in cold environments for older people. Older people are at greater risk of cold-related harm, due to the physical changes of old age, and require more heating to be comfortably warm. The excess winter death rate illustrates this, with those over 85 at around a three times higher likelihood of dying during winter compared to those under 65. The excess winter death statistics for the UK also suggest that people with dementia are at increased risk of dying during winter periods, though the underlying reason for this has not been investigated.

At present the UK's existing cold weather policy (Katiyo, Dorey and Bone, 2016) makes little reference to people with dementia at being at risk of harm during cold weather. Mental ill-health is more framed as an effect of living in a cold home, rather than as a risk factor to cold or winter related harm. Notably cognitive difficulties, such as those related to dementia, are not identified in existing cold

weather policy as contributing a person's ability to remain safe and warm during winter.

To further explore the relationship between dementia and experiences of keeping warm at home during winter it is appropriate to examine the literature in a systematic manner to determine what is currently known about how people with dementia experience keeping warm at home in winter.

## **Chapter 3. Literature Review**

### **3.1 Introduction**

The previous chapter provided a contextual background of dementia and the effects of living in cold weather within which this study sits. However, to effectively inform and guide this study, it is appropriate to systematically review available evidence on how people with dementia experience keeping warm in winter, their strategies and their struggles. This chapter presents a scoping review of the literature that provides a critical analysis of the experiences of older people keeping warm in winter along with factors influencing this experience. The review considered older people in general due to a lack of evidence solely focused on people with dementia and a belief that the older population have a highly relatable experience to the dementia population.

The objectives of this review are:

1. To describe the challenges older people face in keeping warm in winter within their own home.
2. To describe what coping strategies are used to manage temperature management in the home.
3. To identify methods used to explore the experiences of older people.
4. To highlight how the expenses of older people may face keeping warm in winter may relate to people with dementia.

### **3.2 Literature review method**

A systematic scoping review method (Arksey and O'Malley, 2005; Grant and Booth, 2009) was used to identify, extract, and assess the relevant literature. The aim of scoping reviews is to assess the breadth rather than the depth of the literature. Scoping reviews have become a popular approach to synthesize research evidence (Levac et al., 2010; Pham et al., 2014). Arksey and O'Malley published the first methodological framework in 2005 and highlighted the ability to provide a rigorous method for mapping areas of study in a relatively limited amount of time. Scoping reviews can be undertaken as a standalone review or as planning for further research, such as a larger systematic review or primary

data collection (Gough et al., 2012; Grant and Booth, 2009). Subsequently, scoping reviews do not have to start with a predefined search question, unlike other review types (Arksey and O'Malley, 2005); the focus is on following the path of evidence that the literature reveals. Scoping reviews do not typically use quality assessment tools in the inclusion or exclusion of data (Grant and Booth, 2009). While this broadens the search base from a scoping review it does mean the researcher must weigh the relative reliability, validity, and generalizability of each piece of evidence.

In scoping reviews, the focus is on the research findings themselves rather than methods used to obtain them (Weeks and Strudsholm, 2008). Further, in contrast to more systematic reviews the scoping review also places greater emphasis and acceptance on grey searches. This review incorporated grey literature searches, e.g. reports searching, due to some evidence not emerging from academic search engines. To stimulate the breadth of literature found with the literature review a range of database searches were undertaken. Publication types include; theoretical papers, qualitative and quantitative studies, reviews, and reports.

The main phases of this scoping review included:

- 1) Searching for relevant studies.
- 2) Including or excluding studies based upon pre-set criteria.
- 3) Extracting relevant data from the studies.
- 4) Collating and summarising the results.

### 3.2.1 Literature review process

The literature searching was undertaken with an initial search and synthesis of evidence into how people with dementia experience keeping warm during winter. However, searching for the experience of people with dementia failed to provide sufficient depth of evidence to effectively inform this study, but also provided justification for the need of this study. The initial search identified papers that focused on the physiological effects of temperature on dementia, such as exploring low or high temperatures exacerbating the progression of dementia



(Cornali et al., 2004; Holtzman and Simon 1999; Klegeris et al., 2006, Prinz et al., 1992). Only one report emerged that included evidence from the perspective of carers of people with dementia (Gray et al., 2015). The lack of evidence on the experiences of people with dementia trying to stay warm in winter led to the decision to expand the population to the general older population. This decision was based upon:

- 1) The aim to capture studies with a focus on experience and behaviour.
- 2) The aim to capture evidence that could inform that data collection process.
- 3) The expectation that studies sampling older people will include people with dementia.
- 4) The expectation that the non-dementia older population will have relatable experiences to the dementia population.

### 3.2.2 Search strategy

The following search question was generated to capture these aims:

#### **How do older people keep warm at home during winter?**

This search question allowed for the generation of the following concepts to develop a search strategy: 'Older people', 'Home', and 'Keeping warm'. These key concepts were used to develop synonyms and search terms to capture evidence to support exploration of the search question. Multiple test searches, iterations, and refinements were conducted to develop an appropriate search strategy (examples of these can be seen in Appendix A). These tested the effectiveness of the search strategy in capturing appropriate evidence. An example of the final search from SCOPUS is:

*TITLE-ABS-KEY (old\* OR retire\* OR elder\* OR "over 55") AND TITLE-ABS-KEY (cold\* OR warm OR "fuel poverty" OR "thermal comfort") AND TITLE-ABS-KEY (home OR house OR alone OR accommodation)*

The literature search was conducted in November 2015 and was updated in May 2017. The update to the literature review added three items to the literature review (Chard and Walker, 2016; Gray et al., 2015; Jones and Mays, 2016). They did not materially change the focus of the review and so were integrated into the existing literature review.

Table 3-1 outlines the electronic databases and websites included in the literature search. Websites chosen for grey literature searches were identified through the researcher’s existing knowledge and in discussion with subject specialists.

**Table 3-1 Electronic databases and website included in search**

| Electronic bibliographic databases searched | Grey Literature Searched      |
|---|-------------------------------|
| ASSIA                                       | Age UK website                |
| CINAHL                                      | Cheshire Lehmann fund website |
| Cochrane                                    | EGA charitable trust website  |
| Medline                                     | Google                        |
| SCOPUS                                      |                               |
| Web of Science                              |                               |

### 3.2.3 Study Selection

The criteria used to identify relevant literature can be seen in Table 3-2. It includes language, date of publication, human participants, and relevance to the research question. All publications had to be in English and no earlier than 2005. During the pilot screening of the search strategy, it was found that there was an exponential decrease in the number of relevant search outputs, with very few occurring prior to 2007. The decision was made during the pilot searching to place a 10-year restriction upon the search. Any relevant evidence outside this 10-year range was aimed to be identified through reference searching.

The age of 55 was taken as the cut-off point for the population. Although the age of 65 is applied to dementia for diagnostic purposes, an initial review of the literature indicated that most studies set at 55 as the lower age for recruitment and so this determined the limits for the review. The review was not limited to UK

literature, however most of the studies had been undertaken in the UK. This may be accounted for in part by the fact that the UK has a relatively high level of excess winter death, compared to other European countries (Fowler, et al., 2014; Healy, 2003; Laake and Sverre, 1996). The national policy focus on issues of winter preparedness and fuel poverty (Katiyo, Dorey and Bone, 2017; NICE, 2016) will have contributed to increased research interest on these issues into the UK and this is also which is reflected in the literature.

**Table 3-2 Literature inclusion and exclusion criteria**

| Inclusion Criteria                          | Exclusion Criteria                          |
|---|---|
| 1. Published 2005 onwards                   | 1. Published before 2005                    |
| 2. Focuses on people over 55                | 2. Does not focus on people over 55         |
| 3. Captures people living in their own home | 3. Studies that capture care home residents |
| 4. Published in English                     | 4. Not published in English                 |
| 5. All study/paper types                    |   |

Figure 3-1 shows the PRISMA chart of the literature search and screening process. Inclusion and exclusion criteria, as outlined in Table 3-2, were applied in the screening of these articles. Figure 3-1 shows the searches final output, including articles method, main findings and relevant findings to the search question.

### 3.2.4 Screening of articles

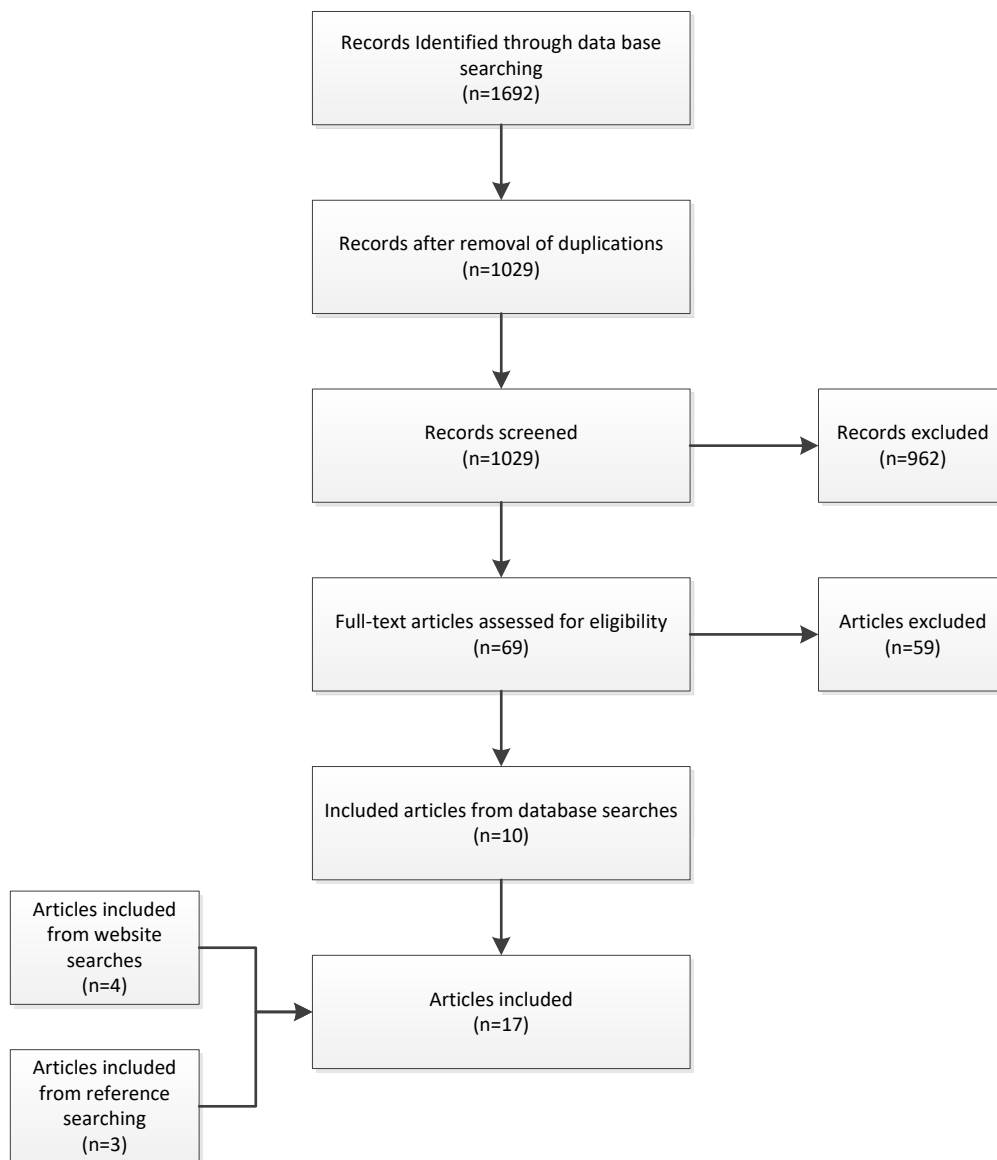


Figure 3-1 PRISMA chart of literature search

### 3.2.5 Data extraction

All of the articles were read in their entirety. Notes were made on key points, and relevant sections and possible narratives for discussion were highlighted. The methods, aims and main findings were recorded during this process. After this first read through, the evidence was extracted from the literature, with findings and quotes ordered into initial themes to assist in the write up process. Through

the writing and drafting process, this grouping of evidence was further refined to fit better the aims of this scoping review.

### 3.3 Summary of literature

In this review, seventeen articles report findings from thirteen discreet studies. All of the seventeen papers are reporting primary data collection. All but one study in this review was conducted in the UK, the study conducted in Ireland. The search strategy was not limited by country of publication. This geographical focus represents a potential weakness of the review, but also shows the development focus of the research field in the UK.

Six of the papers contained a quantitative element, such as postal surveys (Cotter et al., 2012) or in-person data collection (Burholt and Windle, 2006; Stockton and Harrison, 2012). The sample sizes of surveys ranged from 64 to 722. Qualitative approaches were more common, with all but two of the seventeen papers having some qualitative elements. Qualitative methods included interviews, focus groups, written, and photo diaries. Eleven of the papers and eight of the discreet studies contained a mixed methods approach.

One report was conducted to specifically capture the experience of people with dementia (Gray et al., 2015). This study involved qualitative interviews and focus groups with family and professional carers of people with dementia but did not collect data from people with dementia. Gray et al.'s (2015) study was undertaken with an informal focus group of professional carers and six one-to-one interviews with family carers. The people with dementia cared for by the participants in the study all had late-onset dementia, i.e. after 65, and all but two lived in their own home.

Table 3-3 Summary of literature from coping review

| Author (year)                         | Aim of paper  | Methods  | Sample   | Summary of findings  |
|---------------------------------------|---|--|--|--|
| Anderson, Anderson and Probert (2008) | To understand attitudes and behaviour of older people towards the cold, staying warm at home              | Face-to-face survey (Quantitative)   | Representative quota sample of over 60s (n=267)  | Participants more worried about fuel bills than any other expense. 35% turned heating off or down when it was cold to save money   |
| Burholt and Windle (2006)             | To investigate the association between low-income households and fuel poverty                             | Door-to-door census and interviews (Quantitative and Qualitative)                    | Sample of over 70s (n=421) from rural north Wales  | Partial support for the notion that those on low-income are more susceptible to fuel poverty   |
| Chard and Walker (2016)               | To draw attention to the ways in which older people on low incomes adapt to keeping warm at home          | Semi-structured interviews (Qualitative)   | Purposive sample of households (n=17) with at least one person over 55 living in fuel poverty.             | Coping strategies, such as wearing extra layers, used to keep fuel bills down. Keeping warm was found to be important to participants' health, but they were not clear why |
| Cotter et al. (2012)                  | To explore the lived experiences of older people in cold weather  | Postal Survey (Quantitative)   | Older people (mean age = 72.5) (n=722). Sample secured through organisations in contact with older people. | Cold homes associated with fewer social activities and higher levels of chronic illness, falls, and loneliness   |
| Day and Hitchings (2009)              | To understandings how older people respond to adverse winter cold and how they manage their winter warmth | In-depth interviews (two with each participant), diary and photo diary (Qualitative) | Over 70's (n=21). Two broad groups, one low income and one relatively affluent.                            | Participants felt that warmth was crucial to wellbeing. There are generational and cultural influences on warmth behaviour   |

| Author (year)            | Aim of paper  | Methods  | Sample   | Summary of findings   |
|--------------------------|---|--|--|---|
| Day and Hitchings (2011) | To investigate the practices used by older people dealing with cold in winter   | In-depth interviews (two with each participant), diary and photo diary (Qualitative) | Over 70's (n=21). Two broad groups, one low income and one relatively affluent.                          | Physiological of ageing, resisting policy initiatives, sense of self, and culture were seen to influence warmth experience  |
| Gray et al. (2015)       | To highlight potential risks and challenges older people with dementia have staying warm in winter                                    | Interviews, focus groups, and secondary data analysis (Qualitative)                  | One focus group professional carers, and six one-to-one interviews with family carers                    | People with dementia are at greater risk of mortality and morbidity during winter. Dementia presents particular challenges to staying safely warm.                |
| Hitchings and Day (2011) | To understand how older people relate to the winter warmth practices of their peers   | In-depth interviews (two with each participant), diary and photo diary (Qualitative) | Over 70's (n=21). Two broad groups, one low income and one relatively affluent.                          | There is a lack of understanding by older people of their peers winter warmth practices   |
| Jones and Mays (2016)    | To examine the experience of potentially vulnerable people during cold weather to inform interventions aimed at improving well-being. | Semi-structured telephone interviews (Qualitative)                                   | Over 75s living alone, over 90s not necessarily living alone or over 65s with a chronic condition (n=35) | Low unawareness of the health risks associated with cold temperatures. Social housing found to provide better thermal comfort. Social support mitigated cold risk |
| O'Neil et al. (2008)     | To investigate the perceptions and experiences of older women in relation to fuel issues  | Semi-structured interviews (Qualitative)   | Snow ball sampling of women aged 66-84 (n=10) living in a small community in North Wales                 | Heating was a financial concern. Some participants prioritised heating over bill other payments, including food   |

| Author (year)                        | Aim of paper  | Methods   | Sample   | Summary of findings   |
|--------------------------------------|---|---|--|---|
| Sheen and Jones (2013)               | To explore the effects of fuel price recesses impact on pensioners living in social housing     | In-depth interview and focus group (Qualitative)                                      | Elderly participants living in social housing aged 56-87 (n=17). At risk or had experienced fuel poverty | Identified difficulties with energy suppliers. Older people were struggling to absorb rising fuel costs |
| Stockton and Harrison (2012)         | To examine and identify how older people engage with energy and fuel poverty programmes         | Questionnaire, focus groups and in-depth telephone interviews                         | All participants aged over 55. Survey (n=386), 12 focus groups (n=113), and interview (n=15)             | Stressed the need for government interventions. Identified high levels of worry surrounding fuel costs  |
| Stockton, Harrison and Allan. (2013) | To understand how older people's social networks could be harnessed by government initiatives   | Questionnaire and telephone interviews with older people and front line staff         | Survey over 55s(n=181), interviews with over 55s (n=9), and interview with front line staff (n=7)        | Social networks have potential to increase the effectiveness of government interventions                |
| Sutton and Hill (2012)               | To understand the factors that influence making decisions on heating at home                    | In-depth interviews and focus groups  | Participants aged 65-87 (n=25) living on a low income  | Participants were seen to prioritise fuel payments as non-negotiable payments                           |
| Tod, A., et al. (2012)               | To understand the influences and decisions of vulnerable older people in keeping warm in winter | In-depth interviews (over 55s) and six focus groups (over 55s, and health care staff) | Over 55's (n=50) from community organisations and snowball sampling. Health care staff (n=25)            | Presents a segmentation model to describe how vulnerable people may be at risk of cold                  |



| Author (year)          | Aim of paper  | Methods  | Sample  | Summary of findings  |
|------------------------|---|--|---|--|
| Tod, A., et al. (2013) | To identify the factors influencing older people's ability to keep warm during winter           | In-depth interviews (over 55s) and six focus groups (over 55s, and health care staff)                | Over 55's (n=50) from community organisations and snowball sampling. Health I care staff (n=25) | Findings indicate that older people and social care staff have a lack of awareness of the importance of keeping warm to health |
| Wright (2014)          | To gain understanding of older homeowners and private renters' experience of heating their home | Face-to-face survey and in-depth interviews on participants views of keeping the home warm in winter | Participants aged 60-90 (n=64) from England, Wales, and Scotland                                | Government policies were failing to support older people in fuel poverty   |

### 3.4 Findings

In the context of the search objectives, this section summarises the findings from the scoping review. The findings are broken in to four themes:

1. 'Approaches to keeping warm'.
2. 'Looking after the bills'.
3. 'Cold, health and wellbeing'.
4. 'Social connections and warmth'.

### 3.5 Approaches to keeping warm

Older people's approaches to keeping themselves warm were captured in most studies in this review (Anderson, Anderson and Probert, 2008; Buholt and Windle, 2006; Chard and Walker, 2016; Cotter et al., 2012; Day and Hitchings, 2009 and 2011, Gray et al., 2015; Sheen and Jones, 2013; Stockton and Harrison, 2012; Sutton and Hill, 2012; Tod et al., 2012 and 2013). Approaches to keeping warm are described here in terms of, heating patterns at home, heating with visitors, difficulties with heaters, using space to keep warm, and layering up to keep warm.

#### 3.5.1 Heating patterns at home

Five studies draw the reader's attention to their participants only heating part of their homes, with participants desiring not to be wasteful of neither heating or money (Buholt and Windle, 2006; Chard and Walker, 2012; Cotter et al., 2012; Stockton and Harrison, 2012; Tod et al., 2012). Buholt and Windle's 2006 rural North Wales survey found their older participants (n=421) rarely heated certain rooms in their homes, with 31% not heating their kitchen, 34% their bathroom, and only 18% heating their second reception room. However, they found that 99% of their participants heated their living room. Stockton and Harrison's 2012 survey, of 386 households in the UK, similarly found that 43% of respondents reported they did not heat all of their rooms during winter, but did not identify specific rooms. In follow up interviews and focus groups,

Stockton and Harrison (2012) identified high fuel costs and low income as key reasons for under heating of homes.

In three qualitative studies, central heating was found to be frequently used in two distinct bursts: a few hours in the morning and then longer in the evening (Day and Hitchings, 2009; Sheen and Jones, 2013; Wright, 2004). Day and Hitchings (2009) conducted a longitudinal study of 22 older people over a single winter period, with interviews at the start and end of winter along with an ongoing photo diary. They found supplementary heaters frequently used to provide additional sources of warmth when central heating was not used in the middle of day. In Chard and Walker's recent qualitative study (2016) they portray their participants over 55 years (n=17) as being highly adaptive and flexible about the amount of and where they heated their home. When deciding where and how to heat their homes, participants reacted to external temperatures and to how they felt. Chard and Walker described their participants not wishing to heat what they did not need, so tending to limit their heating to areas of their home they were using at the time.

Participants in Tod et al.'s (2012) qualitative exploration of how older people made decisions on warmth, similarly reported they had lower heater settings or only heated certain rooms, with the aim of saving money. However, Tod et al. (2012) also found that some of those with relatively high levels of disposable income were also reducing heating use. They suggest that older people's decision on heating was driven not only by financial consideration, but also past experiences, values, and beliefs about warmth, built up over a life time. Wright's (2004) qualitative study, with older people in fuel poverty (n=64), support the finding of Tod et al. (2012), finding that experience in childhood of bedroom heating affected participants' decision in heating their bedroom. Older people who had experience of low levels of bedroom heating in childhood repeated that approach in later life.

### 3.5.2 Heating with visitors

Day and Hitchings' 2009 qualitative report and discussion paper, (Hitchings and Day, 2011) on the relationship between older people's energy consumption and winter wellbeing, observed their participants adapting their heating behaviour when visitors were expected. This included using more heating, particularly central heating, and wearing nicer clothing. Hitchings and Day linked this to participants' desire to project a positive image and to be a good host. Hitchings and Day (2011) suggest that this had the effect of making it difficult for their participants' families and peers to assess the typical warmth behaviour of their loved ones and recognise when there may be a problem. Conversely, when older people travelled or stayed with someone else they were found to adapt their behaviour to be a good guest (Day and Hitchings, 2011; Hitchings and Day, 2011). This included not commenting on the thermal environment or asking for adjustments to temperature settings. On longer stays older participants said they took extra layers to wear or spent extra time in warmer places, e.g. the kitchen, as they did not want to seem impolite. Day and Hitchings' participants' warmth behaviour highlight complexities and difficulties for loved ones or carers to be fully informed of people's warmth practices and motivations.

### 3.5.3 Difficulties with the heaters

In three studies, the complexity of heating systems emerged as a barrier to older participants being able to effectively manage their warmth at home (Gray et al., 2015; Sheen and Jones, 2013; Tod et al., 2013). Tod et al.'s discussion paper (2013), based on their 2012 qualitative study, found that some older participants found modern heating technology difficult to understand and control, e.g. setting boilers, programmers, and thermostats. By contrast Sheen and Jones's (2013) interviews and focus groups with elderly participants in social housing highlighted that some older heating systems could be harder for their participants to control. Sheen and Jones suggested modern systems could give people more control, in comparison to more cumbersome timers on older boilers, but they did not explain how these older systems were more

difficult to manage. Sheen and Jones (2013) recommend smart meters, thermostats, and timers should be installed to allow older people to effectively assess and control their energy consumption. Gray et al. (2014), in focus groups with family carers of people with dementia, reported that older people with dementia struggled to operate heating systems they had previously been capable of using. For some of Gray et al.'s participants, their family member with dementia could not identify when there was a problem with their heating system, sometimes turning it off at inappropriate moments. When unanticipated events occurred, such as the power cutting out, Gray et al. (2015) draw attention to people with dementia not being able to manage without family carers. Their study does not include, however, the perspective of people with dementia directly.

#### 3.5.4 Using space to keep warm

As has already been discussed in earlier sections, older participants in some studies were heating only certain areas of their home, concentrating heating use in spaces that they used more regularly. Two other examples of space being used to keep warm at home are going to bed earlier and going to public spaces to keep warm.

Five studies reported that study participants made the choice to go to bed earlier or spend longer in bed to keep themselves warm (Chard and Walker, 2016; Cotter et al., 2012; Day and Hitchings, 2011; Sheen and Jones, 2012; Sutton and Hill, 2012). Cotter et al.'s 2012 survey of 722 people in Ireland, found that 27% of their participants reported going to bed earlier to keep warm, while 3% of their participants took the further step of sleeping in their living areas to stay warm during cold winter periods. Cotter et al.'s findings were reflected in two qualitative studies, where older participants in fuel poverty described going to bed earlier to stay warm while controlling fuel costs (Sheen and Jones, 2012; Sutton and Hill, 2012). In Sheen and Jones's study of older people living in social housing some of their participants recognised that their behaviour of going to bed earlier was not in the best interest of their health,

but was something they had to do to keep warm. In Chard and Walker's (2016) study, with older people on a low income, they similarly described some of their participants making the choice to go to bed earlier to keep warm. For Chard and Walker, their participants viewed this strategy to keep warm as part of everyday life and a common-sense approach.

Two studies (Cotter et al., 2012; Day and Hitchings, 2009) reported that a few of their participants went to places outside of their home to keep warm. Cotter et al.'s (2012) postal survey found 5.5% of their participants used places such as libraries and cinemas to keep warm, saving money on heating bills during cold weather. Similarly, Day and Hitchings (2009) reported that a limited number of their older participants on low incomes, in their UK based qualitative study, used public places, e.g. shopping centres, as a way to keep them warm. One of Day and Hitchings participants stated he specifically visited friends' homes as an approach to keep warm, while also enjoying the company. These two studies provide limited evidence of older people using of space outside their home to keep themselves warm. Further evidence is required to draw more detailed conclusions.

### 3.5.5 Layering up

Six papers highlight older people using clothing and other layers to maintain body heat and keep warm, thus not having to rely solely on heaters (Anderson, Anderson and Probert, 2008; Burholt and Windle, 2006; Chard and Walker, 2016; Day and Hitchings, 2009 and 2011; Sutton and Harrison, 2012).

In Anderson, Anderson and Probert's (2008) survey of older people (n=267), their participants reported that putting on clothes was their most likely reaction to feeling cold, with 84% reporting that they would put on more clothes when they felt the temperature drop. To understand older people's approach to energy consumption, Stockton and Harrison (2012) found 68% of their survey participants reported they would wear extra clothing rather than turn up the heating, all or most of the time.

Attention is drawn to an economic split in clothing habits in Burholt and Windle's (2006) survey in rural North Wales (n=421). They found that the participants that were on a lower income were more likely to wear clothes to keep themselves warm. Chard and Walker's (2016) in-depth interviews with qualitative inquiry draws attention to their low income older participants taking a flexible approach to wearing a variety of clothes in an effort to keep warm, such as a dressing gown during the day. Chard and Walker's participants did not see this as a problematic practice, so long as it kept them warm. In contrast, Chard and Walker felt that a person's mental well-being might be at risk if they faced little choice in the clothing they wore to keep warm.

In Day and Hitchings's (2009) qualitative inquiry, their participants were changing clothes reactively and proactively. Day and Hitchings (2011) also draw attention to clothing choices being influenced by style, sexuality, cultural norms, and resistance to being perceived as old or frail. These influences extended to night time routines, where the suggestion of wearing a night cap met with an unequivocal no, with participants seeing it as "*unattractive and unbecoming*" (Day and Hitchings, 2011, p.890). However, Day and Hitchings reported that for participants with health problems wearing extra layers was found to be more acceptable, with some wearing extras such as a thermal vest or a cardigan in bed.

In Gray et al.'s study (2015) with family carers of older people with dementia, attention is drawn to the specific difficulties dementia presented to using clothing effectively to keep warm. Some of their carer participants highlighted that those with dementia at times struggled to make appropriate clothing choices, which resulted in some participants' loved ones wearing soiled clothing. Other carers reported that people with dementia had difficulties choosing clothing appropriate to changes in temperature, either by wearing too few layers when it was cold or too many when it was hot. Carers described an increase responsibility for ensuring those with dementia wore appropriate clothing, as their condition progressed.

### **3.6 Looking after the bills**

A reoccurring area of discussion in the literature regards older people managing the payment of fuel bills. It appeared that older people in the studies placed paying fuel bills as a priority over other household expenditures. With this prioritisation of fuel bill payment, it emerged that the cost of heating the home was an area of concern and worry for older participants.

#### **3.6.1 Worrying about the cost of heating**

Managing the cost of heating was highlighted as a point of concern for older participants in most studies in this review (Anderson, Anderson and Probert, 2008; Cotter et al., 2012; O'Neil et al., 2008; Sheen and Jones, 2011; Stockton and Harrison, 2012, Stockton, Harrison, and Allan, 2013; Sutton and Hill, 2012; Tod et al., 2013). Two survey based studies, from the UK and Ireland, drew attention to significant proportions of their samples that worried about their heating costs. Anderson, Anderson and Probert's (2008) survey of over 60s (n=267) in the UK found that 39% of respondents reported feeling worried about fuel bills, while a greater number of Cotter et al.'s (2012) Irish postal survey respondents (62% of 722 older people) reported being worried about the cost of heating their home.

Concern over the cost of heating is further explored in three qualitative studies (O'Neil, Jinks, and Squire, 2008; Sheen and Jones, 2013; Sutton and Hill, 2012). In a study focusing on perceptions and experiences of fuel poverty amongst older women, O'Neil, Jinks, and Squire (2008) draw attention to how an expectation of a big energy bill could cause a large degree of stress and worry amongst their participants. O'Neil, Jinks, and Squire (2008) highlighted that participants who had recently become widowed experienced further anxiety and difficulty in trying to take control of fuel bill payment, when a partner had previously undertaken this task. Sheen and Jones (2013) focused on the effects of fuel price rises on those living in social housing in the UK,



finding their participants worried about rising energy costs, particularly in the context of incomes not rising at the same rate.

Similarly, Sutton and Hill (2012) noted that their sample of low income older people were extremely debt adverse, including their approach to fuel payments. Sutton and Hill point to this debt aversion influencing choices on heating and keeping warm at home, with participants doing what they could to limit spending on energy bills.

### 3.6.2 **Prioritising fuel payments**

Six studies drew attention to their participants cutting back on other everyday expenses to afford their fuel costs (Cotter et al.'s, 2012; Day Hitchings, 2009; O'Neil et al., 2008; Sutton and Hill, 2012; Sheen and Jones, 2013; Stockton and Harrison, 2012). In Cotter et al.'s (2012) survey in Ireland, 51% of their respondents (n=722) reported cutting back on other household necessities over the previous winter due to cost of heating their homes. In Stockton and Harrison's 2012 survey (n=386), 41% of respondents agreed to the statement *"paying for energy bills mean we sometimes cannot afford to buy, or we buy less other essentials e.g. food"*. In follow up interviews and focus groups, they similarly found that some of their participants were reducing daily purchases of items like food to allow them to keep the heating on longer.

O'Neil et al.'s (2008) interviews with older women (n=10) highlighted two of their participants placing heating and warmth above almost any other expense, a quote from one of these participants became the title of their article: *"Heating is more important than food"*. Both Day and Hitchings' (2009) and Sutton and Hills' (2012) studies draw attention to participants cutting back on social activities, to keep on top of household bills. Day and Hitchings suggest that this could contribute to an older person becoming increasingly socially isolated.

Tod et al.'s (2013) study highlight other factors that influence expenditure on heating. They found that for many of their participants their approach to

spending on energy bills, along with other expenses, was also informed by a past life of financial austerity. Participants found it difficult to spend money on their own comfort at home, even if they had disposable income. For some, their desire for frugality was heightened by a desire to pass on what little they had to their family, further reducing what they spent on their own comfort and warmth. Tod et al.'s (2013) description provides a complex and nuanced perspective of older people's winter warmth spending.

### 3.6.3 Difficulties managing the bills

Older participants in the literature cited two sources of difficulty with managing bills. Firstly, mistrust of energy suppliers and, secondly the difficulties and barriers older people faced in managing their fuel bills or changing supplier.

Three studies draw attention to some participants having a mistrust of energy companies, at times built upon negative experiences in trying to change supplier or tariffs (O'Neil, Jinks and Squire's, 2008; Sheen and Jones, 2013; Stockton and Harrison, 2012). Some of the participants in O'Neil, Jinks and Squire's (2008) qualitative study reported having a poor experience of energy suppliers and changing supplier. For these participants, it resulted in a mistrust of energy suppliers and a reluctance to seek any further change in the future. Similarly, Stockton and Harrison's (2012) reported that their over-55 participants showed a general sense of scepticism of energy suppliers, with a particular distrust of energy suppliers acting in the best interests of consumers. Stockton and Harrison suggested this created a barrier to their participants' access to the best energy tariff. In Sheen and Jones's (2013) qualitative study, they draw attention to people living in social housing being particularly anxious about the process of changing energy supplier. Sheen and Jones suggested that people had a fear of ending in a poorer financial situation, in the context of already finely balanced finances.

Sutton and Hill (2012) draw attention to the difficulty some of their participants had in understanding and taking effective advantage of more complex tariffs that might have saved them money. These complex energy tariffs appeared

to be overwhelming to Sutton and Hill's older participants, and something they tried to avoid. While some of their participants did report a positive experience changing suppliers or tariffs, resulting in lower energy bills, others reported accruing arrears and higher energy bills. Further, some people felt pressured to reduce their energy payments by energy companies but were concerned that this would put them in arrears. Overall, Sutton and Hill's participants reported having a generally negative experience of interacting with energy companies and so were likely not to be accessing the most economic tariffs for them.

Online technology and lack of computer skills were highlighted as a barrier for some older people in accessing favourable tariffs and changing energy suppliers in two studies (Sutton and Hills, 2012; Tod et al., 2013). Sutton and Hills (2012) found that while their participants were aware of comparison websites they generally lacked confidence in using them. While findings from Tod et al.'s (2013) interviews with over 55s found that using modern bank payments systems could be a struggle, in particular managing direct debits. Tod et al. also found that the social care staff they interviewed were equally unaware themselves of how and where to change tariffs, and so were unable to support participants to change tariffs.

Gray et al. (2015) reported that the management of energy bills was a capacity commonly lost to people with dementia early in the progression of their condition, with carers having to step in to assist. It should be noted that Gray et al.'s Northern Irish sample commonly used heating systems that required prior purchase of oil delivered to each home. This added another layer of potential complexity compared to mains-supplied heating systems.

### **3.7 Cold, health and wellbeing**

Five studies (Anderson, Anderson and Probert, 2008; Cotter, et al., 2012; Day and Hitchings, 2009; Gray et al., 2015; Hitchings and Day, 2011; Wright, 2004)

captured in this review draw attention to participants linking living in a cold environment to their health and wellbeing status.

In two surveys participants who reported feeling 'too cold' (Cotter, et al., 2012) or 'cold some of the time' (Anderson, Anderson and Probert, 2008) were associated with a higher rate of suffering from long-term health conditions. However, it is not fully clear in these two surveys what conditions these participants were experiencing, and in what way this association existed, i.e. whether cold homes were exacerbating illness or those who were ill felt the cold more. Cotter et al. highlight that those participants who reported their homes being 'too cold' suffered from a significantly higher rate of falls. There was also a feeling from participants with health conditions in both surveys that being cold exacerbated the symptoms of their condition, with 54% of Cotter et al.'s sample and 76% of Anderson, Anderson and Probert's participants agreeing with a statement that living in a cold environment worsened their symptoms.

A view that long-term conditions increased sensitivity to cold environments was mirrored by older participants in two qualitative studies (Day and Hitchings, 2009; Hitchings and Day, 2011; Wright, 2004). Most participants in Day and Hitchings' study felt that as they had aged they required a warmer home to stay comfortable, particularly for those suffering from chronic conditions such as arthritis, who described being particularly careful not to get cold. Similarly, Wright's (2004) participants (n=64) described feeling colder as they aged and for those participants experiencing long-term health problems, such as strokes, heart problems, diabetes, and arthritis, Wright reported that participants felt particularly sensitive to the cold. Gray et al. (2015, p.29) draw attention to the process of the "*anorexia of ageing*", that is to say losing weight, as increasing an older persons exposure to cold related harm. Though Gray et al.'s study focused on people with dementia they note this is an effect seen throughout an ageing population.

### 3.7.1 Lacking an understanding of the health effects of cold

Participants in three studies, identified a link between living in a cold home and reduced health and wellbeing, participants were less clear on what this link might be (Chard and Walker, 2016; Jones and Mays, 2016; O'Neil, Jinks and Squire, 2006). For example, in O'Neil, Jinks and Squire's (2006) study with older women and Chard and Walker's (2016) with older people in fuel poverty viewed being warm as being linked to a general state of health and wellbeing, without specifying any condition or effect. However, participants were not always clear what the health effect of living in a cold environment would be. Some of Chard and Walker's (2016) participants mentioned general negative mental health effects of being cold; with one participant feeling "*worn down by the cold*" (Chard and Walker, 2016, p.64). From these studies it appears that only a few older people had a strong understanding of the links between living in a cold environment and health outcomes, and for those that did, their knowledge was focused on their own health condition. Similarly, Tod et al.'s (2012 and 2013) interviews with older people (n=50) found that their participants had a general lack of awareness about links between health and heating. A few of Tod et al.'s participants had the belief that overly warm rooms increase the spread of germs and this led to an increased chance of catching a cold.

Older people's perception of cold, particularly regarding health and ageing, was a well-researched area within the literature. The evidence suggests that as people age they have an increased chance of being sensitive to cold conditions. However, the process or combination of processes by which this occurs, i.e. health conditions, activity, social roles or the physiology of ageing, was not fully explored in these studies. Dementia was not discussed as a long-term condition in these, except in the work of Gray et al. (2015).

### 3.8 Social connections and warmth

Five studies highlight the support that social networks, such as family and friends, provide to older people in their endeavour to keep warm (Cotter et al., 2012; Hitchings and Day, 2011; Jones and May, 2016; Stockton, Harrison, and Allan, 2013; Tod et al., 2012). Friends and family were identified as the main points of contact for older participants when having difficulty with bills, keeping warm, or seeking advice on warmth (Cotter et al., 2012; Hitchings and Day, 2009; Stockton, Harrison and Allan, 2013, Tod et al., 2012). Stockton, Harrison and Allan (2013), in a mixed qualitative study with older people and professional carers, aimed to capture how social networks could be harnessed to improve older participants' experience of government home-energy interventions. They found that family members ranked above other sources, such as energy companies and government agencies, as the most trusted avenue for advice on energy efficacy schemes and energy bill matters (Stockton et al., 2013). This high level of trust identified for friends and family by Stockton, Harrison and Allan (2013) encouraged them to say that informal networks represent an opportunity to share knowledge on services. They drew attention particularly to using informal networks to access vulnerable households, those who: are socially isolated, have long-term illnesses, or have communication difficulties. However, while Tod et al. (2012) suggested that social connections could share available knowledge, awareness, and behaviour around staying warm at home in winter; they also highlighted for some of their older participants, who had good social connections, that they were exposed to and influenced by incorrect information around winter warmth practice (Tod et al., 2012).

Jones and May's 2016 qualitative study (n=35) focused on capturing the experiences of vulnerable older people in cold weather. They considered a vulnerable person to be over 90, being over 75 and living alone, or 65 with a long-term health condition (though they did not mention dementia as one of these conditions). They highlight that their participants' individual risks in cold weather were being mediated by informal social networks of family, friends

and community. Family and friends provided support to vulnerable older people during cold weather, such as helping with heating system repairs or bringing round hot food (Jones and May, 2016). Jones and May also reported that in communities with predominantly older people, there was a culture of 'old' helping the 'older' during cold periods, such as keeping an eye out and clearing paths.

In partial contrast, Hitchings and Day's (2011) qualitative investigation draws attention to some of their participants being unaware of their friends and peers home warmth practices. Hitchings and Day found this to be a bit of a taboo subject amongst peers. Cultural norms such as the desire to project 'successful ageing', an unwillingness to engage on money matters or on potentially 'sad' topics, such as ill health, were seen to limit open discussions. So, while friends and peers have been identified as a trusted source of support on warmth issues (Jones and May, 2016; Stockton, Harrison and Allan, 2013), it appears that this may be a restricted avenue for discussion. Hitchings and Day (2011) did find that their older participants were more likely to engage in winter warmth discussions when visiting family homes, rather than in their own. Some of their participants on low incomes relied on family members to provide financial support when there were fuel price increases. However, Hitchings and Day also noted that in some cases older people were reluctant to bother their family, seeing them as having very busy lives, so attempted to seek help through peer networks first.

In Cotter et al.'s (2012) Irish postal survey (n=722), they found that the scope of their older participants' social networks fluctuated with changes in weather. Additionally, 56.1% of their older participants stated that they stayed inside their homes during cold weather, limiting their social engagement, increasing social isolation and loneliness amongst their participants. Day and Hitchings (2009, 2011) similarly reported that as weather became colder their participants were less likely to venture out, potentially increasing an older person's social isolation.

Two qualitative studies suggested that changes to social networks could affect their older participant's winter warmth experience (Tod et al., 2012; O'Neil, Jinks and Squire, 2008). Tod et al. (2012) suggested that events such as bereavement, retirement, or illness could be trigger points for older people becoming more socially isolated. At such points, Tod et al. (2012, p.6) saw that changes to heating behaviour could occur that made their older participants potentially "*vulnerable to being cold at home*". The O'Neil et al. (2008) study similarly found that the loss of a partner could require a change in who managed warmth practices and control, with this at times leading to difficulties in a person's ability to stay warm at home.

### **3.9 A note on consent**

The consent process of older participants is often poorly described in studies' method sections. Around half of the papers do mention their approach to gaining informed consent (Day and Hitchings, 2009 and 2011; Hitchings and Day, 2011; O'Neil, Jinks and Squire, 2008; Tod et al., 2012 and 2013). In the papers that do mention consent, their approach to consent is mentioned in passing with reference to written and tape recorded consent, but detailed descriptions are not provided. The remaining papers do not discuss the approach used to gain informed consent. In no paper are issues of capacity to consent or the challenges of consenting participants with reduced cognitive capacity discussed. This is an issue that will require further consideration when designing and conducting research with participants with dementia.

### **3.10 Discussion**

This review necessarily focused on older populations because of the lack of dementia specific evidence available. Only in one study, Gray et al. (2015), is the experience of people with dementia captured, though in this case through the eyes of family and professional carers. Older participants in these studies



described a range of strategies available to them to keep warm during winter including using the heating, layering up, and choosing to use different physical space to keep warm. For those with dementia these studies highlight two aspects of keeping warm that those with dementia may have difficulty with: using heating systems and dressing appropriately (Gray et al., 2015). These assertions fit with previously identified the difficulties with daily tasks caused by declining sensory perception in dementia (Bakker, 2004; Burge et al., 2012; Chan et al., 2015; Desai, Grossberg and Sheth. 2004). However, a greater exploration of the approaches and challenges to keeping warm from the perspective of people with dementia is needed to understand their experiences of winter warmth and safety.

Challenges and approaches to managing bills were commonly covered topics in the literature, in part because of the focus on older people on low incomes and in fuel poverty. Several studies draw attention to their participants prioritising heating payments over other expenses, notably food and social events. These finding highlight the sacrifices to wellbeing some older people were willing to keep warm. Linked to this, some studies identified older people, particularly on a low income, being worried and anxious over heating costs and expected larger bills, with the implication that this worry limited a person's spending on heating. Bill management emerged in this review as a problem for older participants in terms of: online payments systems, dealing with energy companies, and understanding tariffs. These difficulties are suggested to create barriers to older people accessing the best financial package for them, resulting in them limiting their heating use (Day and Hitchings, 2009; Sutton and Hill, 2012; Tod et al., 2013). In only one study (Gray et al., 2005) were cognitive difficulties suggested as possible reason for the difficulties participants had in managing their bills. Gray et al.'s finding that the carers of people with dementia were forced to assume management of bill payments, as a person's cognitive capabilities declined. The cognitive changes associated with dementia are known to reduce a person's ability to independently manage their finances along with using modern technology,

such as the computers (Price and Meyer, 2016; Gilmour, Gibson, and Campbell, 2003). This is an aspect of keeping warm that likely affects people with dementia more acutely than the general old age population.

A strong theme in the literature is how older participants' perception of age and health status impacted, how they experienced cold and how they approached keeping warm. Studies draw attention to older people with long-term health conditions making them more sensitive to cold (Day and Hitchings, 2009; Hitchings and Day, 2011; Wright, 2004), with conditions such as arthritis keeping people sedentary. Dementia was not cited as a condition that directly affected a person's sensitivity to cold but the reduced physical activity associated with the later stages of dementia (Burge, 2012; Resiberg and Franssen, 1999) may create a more sedentary routine, possibly making it harder to keep warm.

The literature highlights the important role that close social connections appeared to make, in supporting older people keeping warm effectively. Family and friends were seen as trusted sources of information on warmth and cold information, though Tod et al. (2012) draw attention to incorrect information on cold being passed on through peers. Jones and May (2016) drew specific attention to the supportive role communities of older peers played during cold weather, looking in on each other or bringing around food. Social isolation is recognised as a common secondary effect of the symptoms of dementia (Gilmour, Gibson, and Campbell, 2003; Kane and Cook, 2013, Fratiglioni et al., 2000; Miranda-Castillo, Woods and Orrell, 2010), with communication and memory difficulties making the maintenance of social bonds increasingly challenging. It may be harder for those with dementia to maintain existing or forge new social bonds as their condition progresses and in the period they require the greatest support to continue living in their own home. Jones and May (2016) themselves highlight how changes to social networks may affect an older person's ability to keep warm effectively. It is possible that a diagnosis

and progression of dementia may also similarly act as a trigger event, changing an older person's social network and ability to access support.

### 3.11 Chapter Summary

This scoping review represents current knowledge and understanding of how older people experience warmth at home during winter. It has identified a field of research that has significantly developed over the last decade. There are, however, significant gaps in knowledge in terms of how those with cognitive impairment and dementia may experience keeping warm at home. It is the assertion of this review that people with dementia are likely presented with particular challenges to keeping warm and safe at home during winter, in addition to the general old age population, captured by studies within this review.

This scoping review has identified several areas where people with dementia may be presented with further challenges to keeping warm at home. This chapter began with stating four objectives for this scoping review. To describe older people's 1) challenges and 2) strategies to keeping warm at home; 3) to identify methods used to capture older people's experience; and 4) to highlight how older people's experience may relate to people with dementia. In addition, older people with dementia are presented with the same challenges to keeping warm that the general old age population are presented with. These findings from this scoping review are a baseline by which research into people with dementia's warmth experience will be developed.

The methods findings from this scoping review offer direction for the design and implementation of this study. Qualitative and inductive enquiries, with a limited number of participants, were seen to be the most effective at capturing the complex interaction of factors that created a participant's experiences of keeping warm at home. Some notable examples are Day and Hitchings series of reports and publications from a single study (2009 and 2011; Hitchings and

Day, 2011) and Tod et al. (2012 and 2013) two articles exploring older participants factors, decisions and barriers to keeping warm. Studies that focused on capturing the perspective of older people, rather than carers, were notably successful at capturing an older person's experiences. However, carers perspectives were able to provide useful insights in areas where older people did not have full knowledge, such as carer burden. There is a particular gap in capturing evidence from the perspective of people with dementia. The papers in this review have not considered how winter warmth and safety experience can be effectively captured from people with reduced cognitive capacity. This has particular relevance when cognitive difficulties may hamper consent and effective data collection. Consent was an issue only superficially discussed in the studies with older participants. In this study, the consent process for participants with dementia will require more detailed examination.

The next chapter will discuss the key methodological considerations and decisions that were taken in this study. The discussion will reflect the findings of this scoping review and the contextual literature in Chapter 2.

## Chapter 4. Methodology

### 4.1 Introduction

This chapter presents the methodological approach to this study beginning with a look at the philosophical foundation and position of this study concerning people with dementia. This is followed by a discussion of some of the challenges associated with conducting research with people with dementia, such as recruitment and conducting interviews. Issues of consent are then discussed in a separate section, due to the challenging nature of gaining informed consent from participants with reduced capacity. The process consent method, as described by Dewing (2008b), is highlighted as an approach that places people with dementia in greater control of the research process. This is followed by a section discussing research design choices and the approach used in this study. A multiple constructivist case study design, as suggested by Stake (1995 and 2006), is the chosen approach of this study. This design is best supported by qualitative methods, such as interviews, to build an understanding of each participant's experience. This study is centred on interviews with people with dementia and their caregivers, supported by other evidence. Finally there is a section discussing research choices and approach, including the reflexive stance of the researcher, used in this study.

### 4.2 Researchers philosophy

A researcher's philosophical stance is more than a convenient way to frame method choices. Adopting a philosophical research position "*literally permeates every act even tangentially associated with enquiry*" (Lincoln, 1990, p.81). It provides a view of reality, a theory of knowledge and helps define how such knowledge can be obtained (Savin-Baden and Major, 2013). Similarly, Guba and Lincoln (1994) see a philosophical paradigm as a set of basic beliefs, which in the context of research guides the researcher's process of enquiry.

Research paradigms in the qualitative tradition are not static, having developed with the rapid growth in the field of qualitative research and with researchers looking for direction in the acquisition of knowledge. Qualitative researchers have not coalesced around a single research paradigm, in the same way as the natural sciences (Denzin and Lincoln, 2011; Lee, 2012). Qualitative enquiry remains a broad church that encompasses a wide range of methods, methodologies, and philosophical paradigms, spanning different research disciplines. Qualitative research has seen a rapid development since Guba and Lincoln's (1994) description of the competing paradigms of positivism, post-positivism, critical theory and constructivism. This process of philosophical development is ongoing and can be overwhelming to those entering the methodological debate (Ritchie et al., 2014). As Creswell (2013) notes, there is an ever expanding number of frameworks used within qualitative research, and this is a journey that is still unfolding. Creswell proposes qualitative research methods can be broadly organized into five categories according to their focus of enquiry, Table 4-1.

**Table 4-1 Five qualitative research methods (Creswell, 2013)**

| <b>Method</b>    | <b>Focus</b>                               | <b>Sample Size</b> | <b>Data Collection</b>                       |
|------------------|--|--------------------|--|
| Ethnography      | Context or culture                         | --                 | Observation & interviews                     |
| Narrative        | Individual experience & sequence           | 1 to 2             | Stories from individuals & documents         |
| Phenomenological | People who have experienced a phenomenon   | 5 to 25            | Interviews                                   |
| Grounded Theory  | Develop a theory grounded in field data    | 20 to 60           | Interviews, then open and axial coding       |
| Case Study       | Organization, entity, individual, or event | --                 | Interviews, documents, reports, observations |

It is important for researchers to articulate their place within the wider philosophical debate of their discipline, to inform their method choices.

This research takes an ontological approach grounded in constructivism and an epistemological view of how we can come to understand such versions of reality based in interpretivism. How these positions fit with the researcher's interpretation of truth and reality and how they are appropriate to the research question will now be expanded upon.

### Ontology

The constructivist research paradigm was used in this research and is well articulated by Schwandt (2000, p.197):

*"We invent concepts, models, and schemes to make sense of experience, and we continually test and modify these constructions in the light of new experiences".*

The constructivist paradigm focuses upon the meanings that individuals construe of events, within a given context. It suggests that knowledge and truth are subjective constructs, which can only have meaning in the context of the knower. As Raskin (2002, p.4) describes, knowledge is a *"compilation of human-made constructions"*. From a constructivist perspective, there is no single social reality or objective truth, rather there are multiple realities. Each reality is subjectively understood by an individual, with each being equally important. These multiple realities are created by personal perspectives and shaped and constructed by shared experiences, ideas and discourse and, are thus, relative. This is in contrast to an objectivist position that assumes a fixed reality exists external to our consciousness and that we inhabit and interact with.

### Epistemology

Intimately related to the ontological, assumptions of reality are epistemological understandings of how we can come to know or investigate such realities. For constructivists, meaning is not created in isolation. Historical and sociocultural dimensions create the backdrop of meaning (Schwandt, 2000). Further, constructivists often hold an antifoundational view that there is not a single

unvarying way truth can be known and that valid knowledge only arises from interactions (Lincoln and Guba, 2000). Researchers should therefore look to gather experiences from a naturalistic setting (Guba and Lincoln, 1994) and take an interpretivist view of truth, i.e. that there is not one objective truth but that social actors interpret their world. In this approach, the researcher should aim for a partnership with the participant, encouraging them to tell their story of reality and truth. With this partnership a researcher's subjectivism is not only inevitable, but is a necessary tool to reconstruct a participant's view of reality and truth. The drive for subjective understanding supports an inductive approach to enquiry that is driven by patterns emerging from rich data, rather than a theory led or deductive approach (Creswell, 2009).

### **4.3 Theoretical Framework**

The starting point for this study is a social constructionist perspective, fitting with the researcher's interpretivist and constructivist philosophical stance. Social constructionism has its roots in the Sociological tradition, (Berger and Luekmann, 1966) and earlier roots in philosophical thought. More recently the theoretical position has been summarised by Burr (2015), Creswell and Poth (2018), Crotty (1998), and Schwandt (2015). These scholars believe that individuals create a subjective view of the world in which they inhabit. This position leads to there being multiple and varied meanings applied to the same object, event, or phenomenon (Creswell and Poth, 2018). Social constructionists argue that objectivity is impossible; rejecting the realist notion that knowledge is a direct perception of reality (Burr, 2015).

Social constructionism can be seen in two main forms, sometimes referred to as strong or weak (Schwandt, 2015) while Burr (2015) prefers the more neutral micro or macro. Burr's terminology is used here. In a micro stance there is no reality or existence beyond an individual's perception of it, in this micro view, language is very important to the construction of meaning. Shotter's (1989) deconstruction of the language of identity exemplifies the micro approach,



where language is more than a vehicle to communicate intent or information. For Shotter, language is formative in allowing the creation of new interpretations and modes of thought, but the speaker cannot control the construction of reality by the listener.

Macro social constructionism acknowledges the construction of reality from individual interpretations of language and experience, but sees this bound with social processes, relationships and institutions (Burr, 2015). This strand of social constructionism focuses on how social actors create and reproduce shared meaning, with its accompanying power relationships. Berger and Luekmann's (1966) work on the social construction of language and knowledge in everyday life, socialisation, is a good example of this strand. This approach to social constructionism is useful in exploring the construction of self and knowledge for those with cognitive impairment. Sabat and Harre (1992) applied this form to highlight how a person with dementia has multiple versions of self, each deconstructed and constructed through social interactions and social bonds. It is this macro view of social constructionism that forms the theoretical framework in this study.

#### **4.4 Challenges of research with people with dementia**

Involving people with dementia in research presents unique challenges, such as engaging them in the research process or building an understanding of their world. Along with this there has been a growing methodological discussion of the need to involve people with dementia in the research process (Dewing, 2008b; Hellstrom, et al., 2007; Hubbard, Downs and Tester, 2003; Mckeown et al., 2010; McKillop and Wilkinson, 2004; Pesonen, Remes and Isola, 2011; Sherratt, Soteriou and Evans, 2007). What follows is an outline of some of the considerations that went into the design of this study.

Consent and capacity are stand-out issues when conducting research with people with dementia and so are discussed in a separate section below. The

current section begins with a discussion of a person-centred approach to dementia research, which supports best practice in conducting treatment and research. This is followed by a discussion of some of the challenges in recruiting people with dementia into research studies. Finally, this section will highlight some of the challenges in conducting interviews with people with dementia, along with some of the approaches that can be used.

#### 4.4.1 **Person-centred approach**

The person-centred view of dementia (Kitwood, 1997) aims to empower a person with dementia and place them at the centre of their treatment and care. Person-centred care is a way of thinking about how we can place an individual at the heart of care decisions, whatever their level of cognitive impairment. Person-centred care has become the expected standard for health care professional involvement with people with dementia (NICE, 2016b), as previously highlighted in Chapter 2. This contrasts with earlier approaches to care decisions in which, care decisions were more likely to be taken without consideration of a person with dementia's wishes as the person's capacity reduced.

Similarly, in research a person-centred approach recognises that a person with dementia can and should be placed at the heart of the research process (Hellstrom et al., 2007; O'Connor, 2007). To not facilitate a person with dementia to have control of the research process raises serious ethical concerns (Dewing, 2002). Research concerning people with dementia should be conducted with, rather than on or for them. Though such an approach may be more time consuming, it has the advantage of allowing a researcher to build a greater understanding of a participant's view of reality, thus allowing for a potentially more meaningful research process.

With this, a researcher should engage with people in a warm, empathic and responsive manner (Hellstrom et al., 2007; Mckillop and Wilkinson, 2004), and place the comfort and wellbeing of a person with dementia in prime position in the research process. This could mean conducting interviews in a familiar

place or allowing a person time to control the direction of interview discussions, to give them a sense of control of the research process. To allow a person-centred approach to occur requires additional time to build a rapport with a person, which in turn can foster a good research partnership (Dewing, 2008a and 2008b; Hellstrom et al., 2007; Mckewon et al., 2010). However, Pesonen, Remes and Isola (2011), in discussing the experience of a nurse researcher conducting in-depth research with a people with dementia, highlight the need for a researcher to maintain their role. To support this, it is suggested that researchers clearly state their role and engage in a self-reflective process after contact with participants.

The aim in this programme of study was to place the person with dementia at the centre. However, it was recognised that the role of the researcher must be sustained and not drift in to a supporting role. It was recognised as important for the researcher to capture the experience of a person with dementia, without over-identifying with participants.

#### 4.4.2 **Challenge of recruiting people with dementia**

This section will outline the challenges of recruiting people with dementia to research; along with the role gatekeepers can play to alleviate some of these challenges. Recruitment and inclusion of people with dementia in research is recognised as a challenge for achieving effectively run studies (Grill and Karlawish, 2010; Hellstrom et al., 2007; Mckeown et al., 2010; Pesonen, Remes and Isola, 2011; Sherratt, Soteriou and Evans, 2007; Watson et al., 2014).

The language of research studies, couched in complex terminology, presents a specific barrier to recruitment and engagement with people with dementia (Grill and Karlawish, 2010; Hellstrom et al., 2007; Mckeown et al., 2010; Watson et al., 2014). McKeown et al. (2010) suggest that in the aim of active involvement in studies, researchers should seek open and honest dialogue with participants. To achieve this, a researcher can engage with people with dementia on their own terms, including language that they are comfortable

with. Hellstrom et al. (2007) give an example of avoiding the word 'dementia', with the negative connotations it held for participants. Using terms such as 'memory loss' were found to place participants at greater ease and encourage a more open dialogue (Hellstrom et al., 2007), supporting a positive research partnership with a participant. Further, the complexity of research and medical language should also be limited when recruiting participants with dementia as this can be a barrier to understanding and recruitment to a study (Grill and Karlawish, 2010; Watson et al., 2014).

People with dementia are a protected, or hard to reach, group that have been seen to have several layers of gatekeepers, be they family or health care professionals, protecting them and with whom a researcher must negotiate to gain access (Hellstrom et al., 2007). The layers of gatekeepers could also prevent a person with dementia participating in research in which they would otherwise wish to engage. In this way, gatekeepers can be said to at times act to open or close the research process to people with dementia.

This can place the success of a research study on requiring positive perceptions of gatekeepers to its importance or worth, along with a trust in the researcher's capabilities (McKeown, 2010). If an appropriate gatekeeper does 'buy in' to a research study, they can offer a larger degree of flexibility and support to recruitment. Pesonen, Remes and Isola (2011) describe how working closely with clinicians in memory clinics provided potential participants with information about their study while maintaining anonymity for longer than a typical recruitment process. In my own previous experience of conducting interviews with people with dementia (Chrisp et al., 2013), having the support of well-connected gatekeepers was integral to the success of data collection. In Chrisp et al. (2013), the gatekeepers were mental health nurses in a memory clinic conducting diagnostic tests on people who potentially had dementia. At the point of testing the mental health nurse informally screened people and, if appropriate, introduced people to the study. This experience highlighted the importance of building a rapport and collaboration with the

gatekeepers, to enable effective recruitment and ultimately more productive research.

In this study, a gatekeeper to the participants was involved in the recruitment, data collection, and welfare of participants. The gatekeeper was included in the study from the point of pre-protocol consultation. They assisted with developing the recruitment and data collection approach, in this way they formed an understanding of the research study and the researcher's capabilities.

#### 4.4.3 Interview challenges

The symptoms of dementia, memory loss, verbal difficulties and confusion, present significant challenges to the interview process. These symptoms can make the interview process more time-consuming and less productive than with people who do not have cognitive difficulties. As a starting point, it is important to engage a person with dementia in a time, setting, and manner that they find comfortable (Beuscher and Grando, 2009; Hellstrom et al., 2007; Hubbard, Downs and Tester, 2003; Mckewon et al., 2010; McKillop and Wilkinson, 2004). In preparation for the interview process, it has also been suggested that building a rapport with a person with dementia can allow for a researcher to have an understanding of when the person with dementia is likely to be in the best position to undertake an interview in terms of quality of data generated and from an ethical dimension (Dewing, 2007 and 2008b; and Mckeown et al., 2010). The wellbeing of a person with dementia can change through a day or even during an interview (Hellstrom et al., 2007, Mckewon et al., 2010). Building a rapport and understanding of a participant's wellbeing can allow a researcher to identify and react to these changes.

Reflecting on the experience of conducting a qualitative study with 15 people with dementia, Beuscher and Grando (2009) explained how setting aside fifteen minutes prior to a formal interview to engage in general conversation with the participant had allowed them to gain a broad understanding of a person's cognitive processing and communication ability. Dewing (2008b),

when discussing how to judge capacity, goes further and suggests one should have one or more prior meetings with a person with dementia to build an understanding of the capacity to engage in research.

An approach to improve the productivity and effective communication in an interview, with a person with dementia, is to conduct an interview in a setting that is comfortable to them, such as in their own home (Beuscher and Grando, 2009; Hubbard, Downs and Tester, 2003; Pesonen, Remes and Isola, 2011). In a comparative study with people with dementia living in institutionalised care versus their own home, Hubbard, Downs and Tester (2003) found that interviews in the more natural settings, i.e. a person's own home, rather than a formal care setting, were able to cover greater depth and breadth, leading to more productive interviews. Pesonen, Remes and Isola (2011) similarly described a benefit to conducting interviews in a participant's home when investigating emotionally charged issues, helping to minimize potential stress that could be brought on by the interviews.

The nature of the research process with people with dementia can be highly emotive. Hubbard, Downs and Tester (2003) recall moments in interviews when people could not remember if they were married or the names of their children. These events can cause embarrassment or frustration for a participant. Hubbard, Downs and Tester (2003) emphasised the use of non-verbal cues and verbal utterances in the assessment of a person with dementia's wellbeing and whether they are willing to continue to participate. McKillop and Wilkinson (2004) suggested allowing a person with dementia freedom and control over the interview process; if a person repeats themselves or talks over a researcher it is important give way to them, allowing them time to present their opinions in their own way and to have a sense of control over the interview process. This may mean pausing or stopping interviews if the researcher is in any way concerned about the participant's wellbeing. A guiding principle for a researcher should be the allocation of greater time than for interviews with non-cognitively impaired participants.

## 4.5 Consent

The hallmarks of dementia, i.e. impairment to cognitive capabilities, short-term memory loss, and confusion, affect a person's ability to consent. This section discusses current and past approaches to consent of people with reduced capacity.

### 4.5.1 Consent, capacity and the Mental Capacity Act 2005

The Mental Capacity Act (Great Britain, 2005) states that people are deemed capable of providing consent unless evidence exists to the contrary. Thus researchers, as with medical professionals, must begin from the point that a person has the ability to consent to participating in research (McKeown et al., 2010), rather than assuming their reduced capacity would limit their ability to consent. The act enshrines the principle that all practical and appropriate steps should be taken to enable a person to make a decision for themselves, including:

- Providing relevant information on treatment and its appropriate alternatives.
- Communicate the information in an appropriate manner, i.e. what is the most effective approach for the person.
- Approaching the person in a manner to make them feel at ease; what is the best time and place to engage with them?

These guidelines from the Mental Capacity Act (Great Britain, 2005) and Department of Health (2009) refer to treatment, but the principles for non-medical research should remain the same. For valid consent to exist consent should be informed and given voluntarily, i.e. no coercion should be applied.

Where doubts exist about the capacity of a potential participant then it is incumbent upon a researcher to ascertain their capacity to consent (Great Britain, 2005). Though this is not a simple process, the Mental Capacity Act

(Great Britain, 2005) should not be seen as a barrier to the inclusion of people with impaired capacity from engaging with research. The Mental Capacity Act aims to enable people to have a greater say in their treatment or participation with research, in preference to the wishes of a proxy, such as a family member.

#### 4.5.2 **Informed consent in research**

The principle of voluntary participation with informed consent is a central tenet to the ethical principles that researchers must follow (Denscombe, 2014; Layder, 2013; Royal College of Nursing, 2011; Silverman, 2013; Sheffield Hallam University, 2015). Informed Consent is an ongoing process (Royal College of Nursing, 2011), particularly when data collection occurs over an extended period of time. The researcher must:

- Continuously provide the participant with the appropriate information so they understand what their participation involves.
- Provide any new information to participants that may affect decision to continue within the study.
- Ensure that the participants continue to consent throughout the research process.

When consenting to medical treatment or research, informed consent must be gained from a *"person who has the capacity to consent"* (Department of Health, 2009, p.9). Assessment of capacity can be based on a person's ability to make a specific decision at the point it needs to be made. Greater care should be taken to establish informed consent with a participant if they are part of vulnerable groups, i.e. children, those with learning difficulties, people with mental illness, and those in a weakened power position, e.g. a patient in a hospital. These vulnerable groups, including those with cognitive impairment, are likely to have a reduced capacity to reach an informed position to be able to consent to participate in a study. However, for those with reduced capacity, their wishes must still be central to any consent process, along with the principle of beneficence.



### 4.5.3 Consent for people with dementia

Research, particularly longitudinal research, with people with dementia presents challenges to reaching informed consent, such as how can a person with changing cognitive facilities provide informed consent through the life of a study? However, as Gelling (2004, p.7) states; "*failure to include any patient group in research could be described as discrimination*". If researchers limited people with dementia's access to research they may in turn prevent this group from benefiting from potential advancements in their condition, wellbeing, and care that may arise. Thus it is incumbent upon researchers to, where possible, engage with all appropriate patient groups.

Traditionally, in primary research involving people with dementia, a proxy consent would be used (Dewing, 2008b; Royal College of Nursing, 2011); this proxy being a family member, carer or appropriate health care professional. In light of the Mental Capacity Act (Great Britain, 2005), the approach of using a proxy to consent is now an unusual occurrence. However, some mainstream methods texts continue to state a need to use a proxy when consenting a person with dementia. For example, Silverman (2013, p.170) states that "family, carers and care managers will all have to be consulted" when consenting a person with dementia, this is a position that does not fit with the Mental Capacity Act's (Great Britain, 2005) guidance on consent. It illustrates the challenges that even experienced researchers can have with navigating an appropriate consent process for people with dementia.

Qualitative research with people with dementia has often focused on the experience and opinions of carers and then applied study findings to the situation of a person with dementia, thus avoiding the need for a proxy to provide consent (McKeown, et al. 2010). This limits the role of people with dementia have had within the research process, restricting their contribution of knowledge and experience to a study. For those with very advanced dementia it may not be possible or in their best interests to interview them, but wherever possible their perspective should be captured.

#### 4.5.4 **Process consent**

Process consent offers an alternative approach to consent challenges and opportunities that the Mental Capacity Act (Great Britain, 2005) present. It was first suggested by Ramos (1989) as an ongoing consensual consent process where the participant is kept informed of the ongoing vulnerabilities the research might produce. Usher and Arther (1998) revisited this method as an approach to provide enhanced consent applying it to mental health nursing treatment. It is an approach that fits well within the development of person-centred participatory research in dementia. Applied to dementia research, informed consent process assumes that people are able to make choices and make their preferences known about involvement in a study and that a researcher should look to optimise their awareness of these preferences (McKeown et al., 2010).

#### 4.5.5 **Dewing (2007 and 2008b) process consent approach**

In 2008, Dewing designed and suggested a process consent method for use with participants with dementia. The aim of this approach is to allow for the inclusion of more people with dementia in research, where existing proxy methods to consent could be considered exclusionary, both to the wishes and ultimate participation of people with dementia. Dewing (2008b) outlines five key steps for application of a process consent method to research:

1. Background and preparation
2. Establishing a basis for capacity and other abilities
3. Initial consent
4. Ongoing consent monitoring
5. Feedback and support

The initial background and preparation stage aims to build a biographical picture of a person with dementia and approach them in their best state of wellbeing. This should be achieved by working with gatekeepers, such as

relatives or health care professionals, to build an initial picture of the person with dementia. Dewing indicates that, as a minimum, a researcher should know *"how the person usually presents themselves when in a relative state of well-being"* (2008b, p.62). In the second stage of establishing a basis for consent, a researcher should aim to build an understanding of a participant's capacity to consent to the study. This can be done by reviewing existing assessments of the person and by spending time with them, to build a more detailed understanding of their abilities. If capacity to consent does not exist the researcher should assess in what manner a person with dementia can be included in a study. The next step asks a researcher to establish an initial consent, based on what has been learned about the participant's capacity in the initial two stages. The exact form of this consent will vary based upon the person's *"abilities and preferred ways of receiving information"* (2008b, p.63), such as written or verbal.

After initial consent has been established, the fourth stage asks for consent to be *"revised and re-established on every occasion"* of meeting and even at multiple times in the same occasion (Dewing, 2008b, p.63). Where possible an outside observer, e.g. gatekeeper or peer, can be asked to assess whether consent has been provided and then a researcher can adjust their approach to gaining consent accordingly. Finally, feedback and support must be provided to a participant with dementia, on any issue raised from a study. The approach to feedback and support should be agreed with a participant beforehand. If a researcher feels that participant requires further support, discussions should be had with the participants in the usual bounds of confidentiality. If further support is needed for the participant's health or wellbeing to be maintained, a gatekeeper may be able to act as a useful point of reference for further discussion with the participant.

To achieve this pathway to consent, it is incumbent upon a researcher to engage with a person with dementia in a reflective and critical manner, in all

of their communication and interactions. In these interactions, Dewing states three questions should be part of a researcher's reflective process;

1. How do I know this person is consenting?
2. What type of appreciation does this person have of their consent?
3. How would this person demonstrate reluctance and/or objection?

(Dewing, 2008b)

As a person with dementia's condition worsens, or fluctuates, the process consent model will become increasingly difficult to manage. Within this a researcher must understand what is in the best interests of the person, and whether they should or should not be included in the study.

Though not one of Dewing's (2008b) five steps, she also discusses gaining access to a person with dementia, which reflects the background and preparation. The permission to access a person with dementia should be gained from a member of staff, relative or other known person to the potential participant. The gaining of permission to access does not suggest an attempt to replicate a proxy consent approach, but ensures gatekeepers are not eliminated from the research process. This is a potential area of critique for a model that aims to empower those with lower levels of capacity in the research process. Dewing (2008b) answers such criticisms highlighting that person-centred research should be transparent, engaging with those who are significant to the person with dementia, ensuring clarity.

The process consent method relies on the skill and expertise of the researcher to engage with a person with dementia and to be critically reflexive. The researcher needs to reflect upon firstly "*is this person consenting?*", secondly "*does this person have (informed) appreciation of their consent?*" and thirdly whether "*any lack of objection [is] genuine?*" (Dewing, 2007, p.15). The participant with dementia must clearly answer the first question in order for the research to proceed. The second and third questions may, however, be

challenging depending upon the severity of the person with dementia's condition. However, by allowing for time to build an understanding of a person with dementia, these questions should become easier to answer.

The process consent method is not a short cut or circumvention of a rigorous process to consent, quite the opposite. It involves an expanded consent process compared to a proxy consent approach. It allows for a robust and inclusive consent process, which provides a reassurance of the rigor of a study. To be successful a researcher must be patient, flexible, and reflective at each stage. Consent is not gained at a singular point but is an on-going process that requires continuous re-assessment.

## **4.6 Research Design**

This section discusses the research design selected for this study, that of a constructivist multiple case study design (Stake, 1995 and 2006). There is an initial discussion of some of the considerations that went into choosing an appropriate research design. This is followed by a description of the chosen case study design. This description is further focused to a constructivist multiple case study design, as described by Stake (1995 and 2006). The multiple case study design is explored in terms of its philosophical positioning, applying the design to a research study, and the validity issues raised in its application.

### **4.6.1 Choosing a research design**

The choice of study design was informed by a social constructionist framework, to explore an individual's view of reality, using qualitative methods. This approach to study design is appropriate to exploring a person with dementia's experience of warmth and safety in respect to a person-centred approach to research (Dewing, 2007, 2008a and 2008b; Hellstrom et al., 2007; McKeown et al., 2010) and the studies of experience highlighted in Chapter 3 (Day and Hitchings, 2009 and 2011; Hitchings and Day, 2011; Tod et al., 2012

and 2013). The literature review also highlighted the strength that multiple sources of evidence had in capturing experiences of older people. This finding has been taken in to consideration when choosing a research design for this study on the basis of including alternative accounts of events and experience may add substantial understanding to a person with dementia's experience. Therefore, the research design in this study includes in-depth exploration of the phenomenon from multiple perspectives, within as natural a setting as possible.

Several methodological approaches were considered in the design phase of this study such as a grounded theory or a phenomenological approach. A phenomenological approach was dismissed, due to the depth of interviews required to support micro level coding and analysis would have been inappropriate for people with dementia (Creswell, 2013). A grounded theory approach was considered to be a possible design solution, but grounded theory central tenants of theoretical sampling and deterministic theory building (Breckenridge and Jones, 2009; Strauss and Corbin, 1990) were felt to be inappropriate in this study. It was decided that a case study design offered an effective approach to capturing multiple perspectives and different sources of evidence to build a picture of people with dementia staying warm at home. The following section describes case study design in general and the particular design chosen for this study.

#### 4.6.2 Case study design

A case study approach focuses on understanding a bounded system or systems, commonly known as a case, which exists within a natural context (Brown, 2008; Hyett, Kenny and Dickson-Swift, 2014; Stake, 1995 and 2006; Yin, 2014). Case studies aim to capture real-life phenomena through detailed contextual analysis of people, events, and their inter-relationships. Case studies can pull upon multiple sources and types of evidence to bring light to a phenomenon. Yin described case studies as exploring *"the particularity and complexity of a single case [or cases], coming to understand its activity within*

*important circumstances*" (Yin, 2014, p.ix). The case study approach is applicable when the boundaries between a phenomenon and its context are unclear, pulling upon multiple sources of evidence or perspectives to bring about clarity.

At its centre, case study design focuses on capturing the complexity of the object of interest, or unit of analysis (Stake, 1995) and a case study can consist of a single case or multiple cases, each focusing on the object of interest within each case. The data collection instruments within case study method are selected for their utility in exploring the research question and the phenomenon it captures. Previously, case study design has been seen as a precursor to further research (Flyvbjerg, 2006; Green & Thorogood, 2010; Yin 2014). This stems from the case study's position of investigating an issue where the boundaries between the phenomenon and context are not clearly defined, thus acting as an exploratory investigation. However, Flyvbjerg (2006) feels that case study design has been consistently inaccurately described and maligned within mainstream methodological texts. Flyvbjerg argues that descriptions of case study design are commonly over simplified and fail to recognise its ability to provide general descriptions of phenomena and to generate hypotheses.

Case study design can encompass post-positivist (Eisenhardt, 1989; Flyvberg, 2011; Yin, 2014) and social constructivist (Merriam, 2009; Stake, 1995 and 2006) traditions. From these two traditions there are different ideas for how case studies should be conducted and what the intent of the case study should be. For Yin (2014), a case study is an empirical enquiry exploring a phenomenon within a natural context. Yin's (2009 and 2014) post-positivist approach offers a comprehensive and structured approach to conducting a case study, which aims to answer the critiques of those who saw case study design as having insufficient rigour, precision, and objectivity (Brown, 2008).

The approach used in this study draws heavily from the works of Stake (1995 and 2006). His constructivist approach to case study methods fits with the

philosophical position described in section 4.2. It also provides an appropriate approach to explore the research question and objectives.

Stake (1995 and 2006) does not focus on a prescribed method or process; rather he asserts the methods and process of enquiry should allow personal experience to emerge within a naturalistic world. For Stake, the truth of the social world is not fixed but is being constantly created by actors within in it. Thus, the constructivist case study aims to *"take a particular case and come to know it well, not primarily as to how it is different from others but what it is, what it does"* (Stake, 1995, p. 8). This approach is known as an intrinsic case study, when a researcher is focused on understanding the particular traits or problems of a case. This is in contrast to those known as instrumental case studies, where a case is examined to provide insights in to a particular phenomenon. This examination of a case or cases is also likely to lead to generalisation or the generation of theory. The intrinsic case, as Stake 2006 sees it, should allow for the story of those within in it to be told. Through this story researcher may shed light on aspects of a phenomenon that may otherwise be lost by studies with broader intent. An appropriate example is Hellstrom, Nolan and Lundh (2005) use of an intrinsic case study with 20 married couples living with dementia to explore dementia's impact on everyday life, their home, and their relationship. However, there is no clear distinguishing line between intrinsic and instrumental case study design, rather there is a zone of combined purpose (Denzin and Lincoln, 2011; Stake 1995).

In a constructivist case study, the role of the researcher is as an interpreter of events and affairs occurring within the bounds of a case (Merriam, 2009; Stake, 1995 and 2006). In this role, a researcher is not searching to uncover an external reality but rather to build a deeper understanding of the phenomenon under investigation, from the perspective of the people and data in the cases. The case study's aim is to represent the case or cases, with its events, experiences, and perspectives, and not to attempt to explain a wider



external reality. However, at their core both constructivists and post-positivists agree that a "case" as the object of study should be in a natural setting.

The present study draws mainly from the constructivist approach of Stake (1995 and 2006), using an intrinsic approach. This design focuses on the story of each case to offer a strong foundation to understand each person's winter warmth and safety experience. However, it is recognised that this study has elements of an instrumental approach with an aim to reach a greater understanding of winter home warmth and safety for people with dementia. The focus remains though on the particularities and stories emerging from each case. The potential of the study to reach a wider understanding of phenomenon may emerge in the discussion of the findings; the findings themselves should focus on the particularities of the cases. What follows now is a wider description of some key elements of case study design: unit of analysis, case sampling, inter-case analysis, and case study validity.

#### 4.6.3 Unit of analysis

The unit of analysis in case study design is an individual event or other entity that forms the locus of a case. Miles and Hubberman (1994, p. 25) describe the case as a *"phenomenon of some sort occurring in a bounded context"*. Operationalising the unit of analysis is important to the process of effective analysis and for supporting inter-case comparisons. The unit of analysis within the case study is very important in building strong measurement validity; its choice is one of the central decisions of case study research.

In this study, a person with dementia winter warmth experience is the unit of analysis in the exploration of the research question. The experiences of a person with dementia are in the bounded settings of their own home and the support environment around them. This bounded setting is the case, in which the unit of analysis is situated.

#### 4.6.4 Case sampling

The process of selecting the cases to be studied is fundamental to the success of a case study. Stake (2006) suggests cases should be chosen based upon three main criteria:

1. Is each case relevant to the research question?
2. Do the cases provide diversity across context?
3. Do the cases provide the opportunities to learn about complexity and contexts?

If a research question does not lend itself to the selection of a unit of analysis it is likely that the question is too vague and needs revisiting. It is further likely that such vagueness will lead to difficulties in the analysis later on. Stake's first question is asking what can we learn from a case and how does it relate to the research question. In the first instance, it is the researcher's job to describe the case in front of them, not to use it to describe other cases (Stake, 2006). This principle leads to his second and third questions. Even in multiple case study design cases are selected to provide insight to important aspects of the diversity in which cases exist. Additionally, if cases are selected well they will capture aspects of the complexity and diversity of a group, which are felt to be important to the research question. In this study, the cases selected represent the diversity within the dementia population, available support, and living situation. Cases include those living alone or with partners; different severities of dementia; different housing or tenure types; and a range of ages, including early onset dementia.

#### 4.6.5 Case study Analysis

This section explores some of the considerations and challenges in conducting inter-case analysis in studies with multiple cases. Case study design is flexible in the types of analysis it encompasses (Thomas, 2011). This is partly due to the variety of research designs within the umbrella of case study design, i.e. single case, multiple case, comparative case etc. Case study analysis,

particularly inter-case analysis in multiple case studies, is often poorly described and commonly over looked in study methods (Eisenhardt, 1989; Stake, 1995 and 2006; Yin, 2014). Though this study follows Stake constructivist approach to case study design, his approach to inter-case analysis was not well defined. Work by Eisenhardt (1989), who explores how inter-case analysis can help support theory, is presented here as a useful approach to inter-case analysis.

### Case write-ups

Individual case write-ups are recognised in case study design as a strong foundation to analysis and a key step towards effective inter-case analysis (Eisenhardt, 1989; Stake, 1995 & 2006; Yin, 2014). In a constructivist study, these write-ups may be more in the form of a narrative of the case or individual elements of the case, while a positivist study will likely follow a more regimented case description. In both approaches case write-ups or narratives allow a researcher to collate and clarify the evidence of each case, before inter-case analysis commences.

### Inter-case analysis

Cross-case synthesis (Eisenhardt, 1989; Yin, 2014) is a common inter-case analysis approach that searches for patterns and differences between cases. This approach can be used either when each case has been an independent research project or where each case is a separate eternity in the same study. Ericksen and Dyer's (2004) synthesis of three cases of team development compared their three cases to each other with the objective of identifying similarities and differences. This was complemented by comparison between data source and time of collection to further search for patterns, similarities, and differences.

The work of Eisenhardt (1989) on building theories from case study research offers a framework for inter-case analysis, which utilises cross-case synthesis. This process is driven by the "*reality that people are notoriously poor*

*processors of information*" and they require structure in the analytical process (Eisenhardt, 1989, p.540), researchers can at times leap to conclusions based on limited data. Due to the small sample size of case studies, analysis is particularly prone to this problem. Eisenhardt suggests three ways that cross-case synthesis can be structured:

1. Each case to be compared to each of the other cases with similarities and differences being noted.
2. Grouping cases by different categories, such as gender or income, to search for group similarity and inter-group difference.
3. Data can be further divided by data collection source, i.e. interviews, surveys etc. Exploiting the insights from different types of data.

#### 4.6.6 **Validity in case study design**

In an empirical study, validity refers to the extent to which a study's findings are well grounded and reflect the 'real world'. However, qualitative research with its different epistemological traditions does not look to validity to describe a 'real world' or universal truth. In qualitative research validity is focused on whether a participant's meaning and intent have been faithfully captured (Ritchie et al., 2014), whether that differs from other participants' views or not. The qualitative research process seeks understanding; with each piece of information, with each new perspective we adjust our interpretation. To achieve valid findings a qualitative researcher seeks to engage in a reflective process within data collection and analysis, to try and best reflect the intended meaning of participants.

A lack of generalizability, or external validity, is a criticism of case study design (Denscombe, 2014). This stems in part from the relatively small number of cases that are investigated within a case study. However, case study design offers the ability to compare and contrast multiple sources of evidence and types of data to illuminate a phenomenon. In the case study literature, both constructivists and post-positivist argue for the use of triangulation of evidence (Stake 1995 and 2006; Yin 2014). The process of triangulating multiple data

points to reach a single conclusion or truth comes from the empirical research tradition. There is a debate in the qualitative methodology literature whether triangulation is an appropriate approach to be used in establishing the validity of findings (Denzin and Lincoln, 2011; Ritchie et al., 2013; Silverman, 2013). Silverman (2013 ) provides a note of caution to a researcher who hopes the use of multiple data types or sources will bring clarity to their study of a phenomenon. Rather, Silverman points to the difficulty for researchers in combining different theoretical models that can occur in case studies. However, what the different traditions of constructivists and post-positivist mean by triangulation is subtly different: post-positivist seek a central truth or explanation while constructivists use triangulation as a way to shed light on different aspects of the same phenomenon.

For Stake (2006), triangulation is the process of gaining reassurances that the interpretations they see reflect their participants' meanings. The starting point for Stake's case study triangulation should be a substantial body of uncontested description. From this point, the researcher should look for reoccurring themes, events, or statements that might be present in a case or across cases. For Stake, the more central an interpretation is to a case the greater the need for triangulation and confirmation. However, it is hard to fully disassociate Stake's view of triangulation from an empirical or post-positivist view. It is possible that a single statement or event from a participant may hold great meaning to understanding a phenomenon, a position that appears not to be supported by Stake.

Supporting the validity of findings in this study is a challenging process; as the research is aiming to capture subjective reality from a limited number of cases. These cases may be further complicated by the cognitive difficulties that participants have due to their dementia. In this study Stake's (1995 and 2006) approach to triangulation will be used, i.e. as a tool to explore the complexities of winter warmth experience, and not in an empirical sense to move closer to a single truth. The choice of multiple case study design offers the ability to

present multiple perspectives and data points within a single case and between cases; triangulated together the phenomenon of the experience of a person with dementia keeping warm and safe at home during winter can be better understood. Where an interpretation is more central to the findings of the study triangulation will be within a case, between cases, or concern data sources to support the validity of results.

#### 4.7 Reflexive statement

Reflexivity is the process in qualitative research where a researcher reflects continuously on how their positionality, actions, values, and perceptions impact upon the research process (Berger, 2015; Creswell and Poth, 2018; Pillow, 2003). A researcher should have an on-going self-awareness of how these factors contribute to construction of knowledge in a study (Pillow, 2003). Being reflexive allows a researcher to gain new perspectives, beyond their own positionality, to allow for an open analysis process. Subjectivity in qualitative research is both inevitable and necessary to effectively collect and interpret information. Frank (1997, p 89) highlights that reflexivity is not intended to *"eliminate 'bias' to be more neutral, but to use it as a focus for more intense insight"*. To support this open insight it is, as a researcher, to reflect upon your positionality and biographical details.

I am a white, middle class British national who has worked in academic roles for the previous 11 years. I have conducted research in the field of dementia for seven years, initially surrounding diagnosis and decision making (Chrisp et al., 2011 and 2012; Chrisp, Tabberer and Thomas, 2013). I am currently supporting a clinical trial of a psychosocial intervention, aiming to support people with dementia in the early stages of their condition. My interest in dementia grew from conducting research with people with dementia and their family members, seeing their strengths and understanding their challenges. Importantly, my understanding of dementia has not emerged from a personal experience of dementia. This has an impact on my ability to empathise with participants, not having first-hand experience of their journey. Therefore, it is

important for me to actively reflect on my experiences in research and be open to alternative perspectives and interpretations of events.

Throughout the research process I have been mindful of my position of power and subjectivity and attempt to recognise my biographical influences through data collection and analysis. Reflexivity in my research consisted of two elements: a research diary and discussions with peers. My reflections on data collection and analysis were recorded in the research diary, with reflections from data collections being coded in the thematic analysis. This allowed for thoughts and interpretations to be captured throughout this study, supporting the study's rigour. During the analysis process data extracts were discussed with peers, in a qualitative research checking group, along with the study's supervisory team. Supervisors conducted detailed joint discussions and revisions of themes and findings, allowing for my preconceived notions to be challenged.

#### **4.8 Concluding remarks**

This chapter has presented the key methodological considerations that were investigated in the course of this study. These considerations have informed the recruitment, consent, data collection and analysis process that was used, and described in the following method chapter.

Research with people with dementia is a challenging process to embark upon, but importantly it is an under researched population, in large part due to these challenges. Consent and capacity to engage in a research study for people with dementia is recognised here as of central importance to conducting this study ethically. This chapter has explored the issues of capacity and consent that must be considered in light of the Mental Capacity Act 2005 (Great Britain, 2005) and highlighted Dewing's (2008b) process consent method as a way to help place a person with dementia at the heart of a research study.

The constructivist case study design offers a framework to collect in-depth data from each participant with dementia, while supporting their experiences from other perspectives. It places a person with dementia at the centre of the research process, whilst also investigating the context of their subjective experience. This design allows for exploration of people's experience of keeping warm from multiple perspectives and to allow for multiple narratives to emerge within each case. Additionally, this approach supports an inductive enquiry of a phenomenon where the boundaries of influence are not well defined. The researcher feels that this research design offers a strong framework for the exploration of the research question and study aims.



## Chapter 5. Method

### 5.1 Introduction

The previous chapter explored the decisions and considerations that were made in designing this study. This chapter begins with a reiteration of the research question, and the study's aims and then goes on to describe in detail methods used to recruit participants, gain consent, collect and analyse data.

#### 5.1.1 Note on terminology

In this chapter, and the rest of the thesis, the term 'participant' will be used to refer only to those people in the study with dementia. Those supporting people with dementia will be referred to as carers or family carers, but not participants. The use of these labels is aimed to provide clarity to the reader and to avoid statements which infer dementia population generalisations, generated by using labels such as 'people with dementia'.

### 5.2 Research Question

The research question being investigated is:

**What are the experiences of people with dementia keeping safe and warm in their own home during winter?**

In addition, the study has the objectives:

- To elicit the experiences of people with dementia and their carers regarding winter safety and warmth in the home.
- To identify any unique challenges faced in keeping safe and warm in winter for a person with dementia.
- To describe the different challenges faced by people with dementia living within different home environments.

- To identify any strategies used to keep a person with dementia safe and warm in their home.
- To identify the input that carers have in keeping a person with dementia safe and warm in their own home.

### **5.3 Recruitment**

A purposive sampling approach was used to identify potential participants and cases. Purposive sampling was used to find five to six people with dementia, to form the unit of analysis of each case. This section describes how the sampling process was conducted.

#### **5.3.1 Sampling**

A purposive sampling approach was to maximise range of living situations and demographic variables, to help capture a spectrum of experience. Demographic variables included different ages, severity of dementia, housing type, gender, and whether they were living alone or with a partner. A target of five to six cases was set for inclusion in the study, with six cases finally being identified. This number of cases is in line with suggested number of cases for multiple cases studies, as discussed in chapter 4 (Stake, 1995 and 2006, Yin, 2014). A gatekeeper identified appropriate people with dementia to be included in the study, with all of the people with dementia had an existing relationship with the gatekeeper.

#### **5.3.2 Inclusion criteria**

Inclusion criteria are shown in Table 5-1. These criteria were used to provide continuity of context between the cases and allow for better assessment of people with dementia's experience of warmth and safety at home. The inclusion criteria were derived from reviewing previous studies with people with dementia and the pre-protocol discussions with dementia and warmth experts, including the study gatekeeper.

Table 5-1 Inclusion Criteria

| Factor                | Inclusion Measure                                   |
|-----------------------|---|
| Medical status        | Must have a diagnosis of dementia                   |
| Age                   | Over 55   |
| Type of accommodation | Not living in a care home or institutionalised care |
| Living situation      | Person with dementia living with 1 or fewer people  |

### Formal Diagnosis

The gatekeeper, a trained mental health nurse, used existing knowledge to select only people who had a diagnosis of dementia. It was not feasible or deemed necessary to verify that diagnosis, for example from medical records, due to the gatekeeper having a longstanding knowledge of each of the participants and their condition.

### Age

An age limit of 55 was set because it was used in existing studies identified in the literature review (Chard and Walker, 2016; Stockton and Harrison, 2012 and 2013; Tod et al., 2012 and 2013), see chapter 3. The use of an age limit of 55 allows for a more effective comparison of the results from this study to the literature identified in chapter 3.

### Type of accommodation

This criterion was included to better capture the effect dementia was having on warmth and safety at home. In institutionalised accommodation and care environments, it is felt that people's warmth would be in partial control of others.

### Living Situation

This criterion was included as it is felt that in large family contexts heating and warmth decisions may have been complicated by multiple occupancy.

### 5.3.3 The recruitment process

An experienced mental health nurse who worked for a community based dementia association, who support people with dementia and their families, acted as a gatekeeper in the recruitment and data collection process. The role of the gatekeeper in this study was to identify and make first contact with potential participants for the study and, with the approval of the participant, to provide background information for cases; provide post data collection information on cases and to be a point of contact for concerns and/or support of a participant. The gatekeeper worked closely with the researcher to recruit an appropriate range of participants for the study and was fully aware of the inclusion and exclusion criteria. The gatekeeper also took part in the pre-protocol consultation to this study, thus affording a further understanding of the study and its aims.

#### Recruiting participants

The study aimed to recruit participants from a range of different situations and circumstances to ensure maximum variability between the cases. This was achieved through an iterative recruitment process involving the, researcher and the gatekeeper. The identification and recruitment period spanned several months, in the winter of 2014/15. Ongoing discussion with the gatekeeper directed recruitment to include those living alone and those living with partners, males and females, and different degrees of dementia severity. A close working relationship with the gatekeeper was key in allowing for a good range of living situations and demographic variables amongst the participants to be included in the study.

The gatekeeper made the initial contact with a potential participant. The gatekeeper had a discussion with potential participants on the nature of the study, and passed on an invitation leaflet to the potential participant (Appendix B). At this point, depending on the person's wishes, either a stamped address envelope containing a permission to contact form (Appendix C) was given to the person, or an introduction meeting with the researcher, gatekeeper, and

participant was arranged. This meeting aimed for the participant and researcher to begin building a rapport in an environment that was comfortable and safe for the potential participant, this face-to-face meeting marked the beginning of the consent process with a participant. The contact details of eleven people with dementia were passed on to the researcher, by the gatekeeper, with ten people agreeing to meet to discuss the study. These initial meetings led to six people with dementia forming six cases in the study. Reasons for not agreeing to participate in the study included: the study being at an inconvenient time, difficulties in making regular contact, and health issues making participation inappropriate. One participant withdrew from the study part-way through data collection, after the temperature measurements were made in the participant's home. This participant gave permission for data already collected to remain in the study, but wished to take no further part in data collection.

#### Recruiting carers

The participant was in control of the recruitment process of carers in each case, no carer or family member was spoken to without participant's permission. After a participant had given consent to take part in the study they were asked to suggest people/carers who could be contacted for inclusion in their case. Participant information sheets, (see Appendix D), and permission to contact forms, (see Appendix E), were left with the participant in a stamped addressed envelope to pass on to the carer or, with their permission, posted to carers with details of the study. Following this, those carers/family members who agreed to take part in the study were contacted and a meeting was arranged to discuss the study and their potential role within it. This meeting was arranged in a place of their choosing.

### **5.4 The Consent Process**

The background preparation to the consent process began with the gatekeeper screening a potential participant's wellbeing. They passed on

relevant background information, e.g. whether someone had hearing difficulties, or an appropriate time to contact a potential participant. Initial contact with a potential participant occurred when a participant returned a permission-to-contact form or the gatekeeper arranged a joint visit, with the potential participant's permission. Either a face-to-face visit occurred or further information was sent to them by post, e.g. participant information sheet (Appendix F). The decision to include a person in the study was taken at a face-to-face meeting between the person with dementia and the researcher. For some people with dementia several informal visits occurred before a decision was agreed to take part in the study or decline to participate. During these visits the researcher aimed to establish an understanding of the potential participant's capacity, to create a basis for an initial formal consent to be established.

Initial consent was established in either written (see Appendix G) or verbal forms, depending on the participant's capabilities. The study began with the application of a written consent process, however two participants were found to have difficulty reading and writing. To establish formal consent, in a manner to maximise participant's understanding, an ethical amendment to the consent process was secured to allow for verbal consent to be recorded (see Appendix M). The process involved the researcher considering issues such as:

- How did a person usually present himself or herself?
- What was a person's state of health/ill health?
- Were there any triggers for their state of wellbeing?
- Were there any areas that were indicated as out of bounds?

Remaining sensitive to these issues required patience and a high level of reflexivity throughout. Thoughts and reflections throughout the consent process were noted down in a diary for each participant.

During data collection, consent was monitored, revisited and/or re-established at every point of contact with a participant. On some occasions it involved re-

establishing consent at multiple occasions during the same visit. Non-verbal behaviour was also monitored to support consent, though an imprecise process it provided moments to prompt people for their willingness to continue in the study.

When available, close family members acted as a sounding board for understanding the wishes of a participant, supporting the consent process. Such a person was not acting as a proxy for consent, by granting permission, they acted as a check on the researcher's judgement of consent. This acted as a reassuring sounding board when a person had more severe dementia. There was no one-size-fits-all approach to the consent process, each person was treated according to their needs.

At the end of data collection, feedback and support was offered to participants, to support them with any issues that may have arisen in or from the research process.

A degree of flexibility existed to act in the best interest of a person with dementia. In the pre-protocol consultation the gatekeeper felt that too rigid a process could put undue stress on a person with dementia. Taking steps such as allowing for verbal consent or having an initial visit with the gatekeeper were small alterations that made the consent process, and ultimately the study, more inclusive.

#### 5.4.1 **Consent for Caregivers**

Gaining informed consent of caregivers was undertaken in a written form with the use of a participant information sheet for carers, (see Appendix D), and consent form (see Appendix H). The caregivers were given the opportunity to discuss the study, their role, their rights, and to ask questions of the researcher before formal written consent was established.

## 5.5 Data Collection

### 5.5.1 Overview of data collection process

Figure 5-1 shows the six forms of data that were collected. The study data was collected in the winter and early spring of 2014/15 between October and April. The number of interviews from each case varied based on the size of a person's care network and who a participant gave permission to be included in the study.

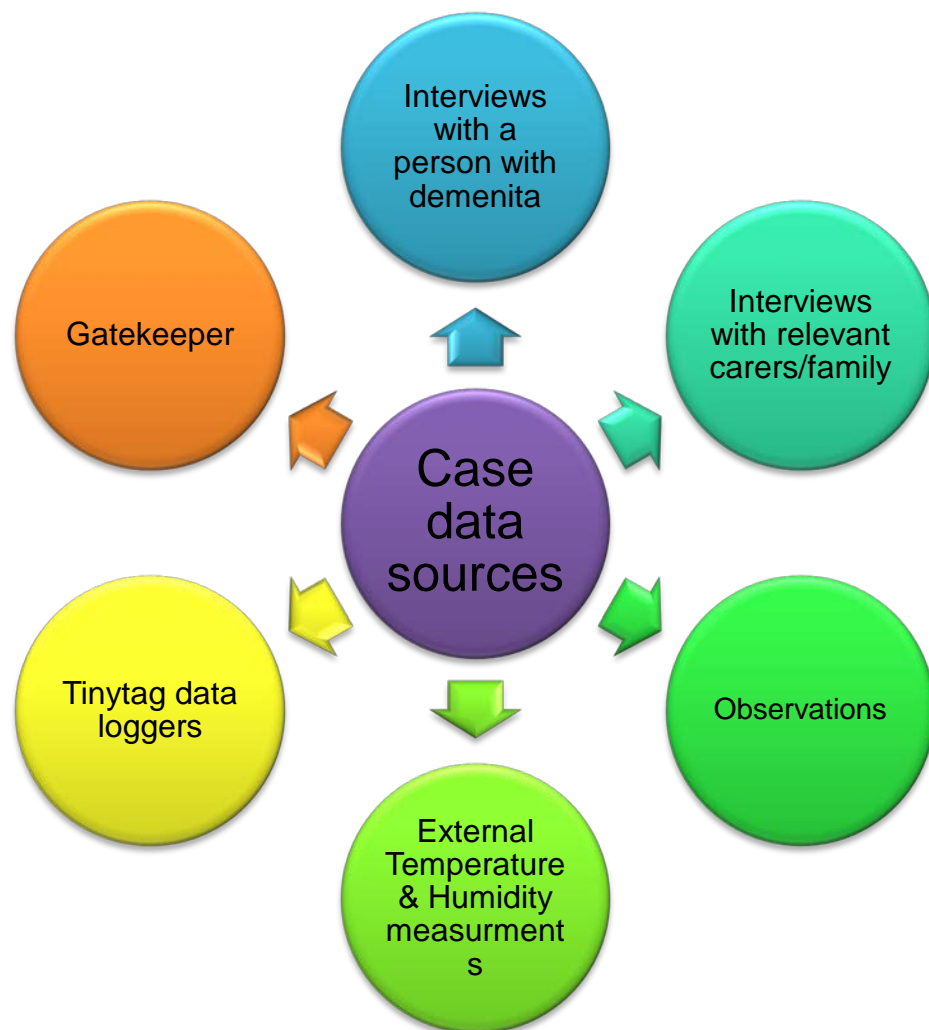


Figure 5-1 Overview of case data sources



### 5.5.2 Data collection process

The data collection period for each case ranged between three and six weeks, with the first interview with a participant taken as the start point for this period. Tinytags temperature loggers (Gemini Data Loggers, UK,) were placed in a participant's home at the first interview and removed two weeks later, on a short visit. The second interview with the participant occurred no earlier than the third week from the first interview with a participant (see). Graphs from the Tinytags were brought to the 2<sup>nd</sup> interview with a person with dementia a week later, to act as a prompt.



Figure 5-2 Data collection process

Interviews with carers were carried out after the first interview with a participant, with the aim of completing these before the second interview with a participant, to inform the interview schedule for the second interview with the participant.

The only standard interview schedule used was for the first interview with the person with dementia in each case (see Appendix I). Each subsequent interview schedule was informed by previous interviews, observations, and

Tinytag readings. This allowed for more explorative and tailored data collection process in each case.

After each point of data collection diary notes were made, sometimes by hand and at other times with voice recording for later write up. Digital recordings were found to be an effective reflexive process, allowing for more immediate and subjective impressions to be recorded. As Stake (2006) points out, there is no clear point at which data analysis begins, and in retrospect this note taking process was extremely important in the researcher's formative ideas of case narratives and inter-case themes.

### 5.5.3 **Qualitative semi-structured interviews**

Semi-structured interviews took place with the participant and caregivers in their support network. The topic areas and questions were informed by the pre-protocol consultation and literature. The lengths of interviews varied between 15-50 minutes. This variability of time occurred due to the exploratory nature of the questions and how able people were to answer questions. These interviews were recorded for transcription, and notes were taken as part of the interviewer's observation process.

The interview schedules included a series of questions to explore each person's experience of warmth at home. The topics included were:

- Their health, wellbeing and social care situation
- Their views and experience of living with dementia
- Experience of living in their home
- Experiences of temperatures (low and high) in the home
- Changes in temperature regulation for a person with dementia over time
- Strategies to manage low temperatures in the home
- Decision making on temperature management

The semi-structured interviews with participants and their carers were participant led; aiming to uncover insights from the participant's perspective. An example of an interview schedule can be seen in Appendix I.

#### 5.5.4 **Research diary**

A research diary was kept on each case. The content of this diary consisted of observations of participants, their families, and the living situation; information provided by the gatekeeper; and reflective thoughts by the researcher. Observations in each case were noted on issues related to the research question and research objectives, such as the physical state of a participant's home or their ability to control their heating system. Data from the gatekeeper was added to the diaries at two stages: providing background information during the recruitment process and additional information on a limited number of cases post data collection, with the permission of the participant.

#### 5.5.5 **Temperature and humidity**

Temperature and humidity measurements of home living space were taken using Tinytag ultra 2 data loggers, an environment measuring device from Gemini Data Loggers UK. These are programmable environment data loggers designed for indoor temperature and humidity data collection. The data loggers are about the size of a large match box. The devices used were checked for consistency by placing them in the same location over a one week period.

The Tinytag data loggers were programmed to record temperature and humidity readings at intervals of five minutes over a 2 week period. Two measurement devices were placed in each participant's home:

1. In the room where they spend most of the day.
2. In the room where they spend most of the night.

The data loggers were placed at table to head height, depending on the surface available, to replicate the environment a participant would experience.

Similarly, care was taken to place the data loggers near to the place in a room a participant would occupy, such as their favourite chair. Data loggers were also placed when possible, just out of a participant's line of sight, with their permission, such as behind a picture frame. Non-obtrusive placements of data loggers were chosen to limit the handling of the devices during data collection, to reduce errors in data collection.

Temperature and humidity measurement outside of the home was acquired through the MET office Weather Observation Website (WOW, 2015), using the closest geographical weather centre for each case.

## 5.6 Analysis

This section is a description of the approaches used to analyse the interviews, temperature and humidity readings and the process of inter-case analysis, which generated overarching themes. Figure 5-3 provides an overview of the analysis process.

### 5.6.1 Interview and diary coding

The interviews in this study were coded using the thematic approach suggested by Braun and Clarke (2006). It was chosen due to its flexibility, accessibility, and belief that it would form a solid foundation for the case descriptions and inter-case analysis. A third party transcribed the interviews, and these transcriptions were verified against the interview recordings to correct any transcription errors. This process also enabled the researcher to re-familiarise himself with the interviews. The interview transcripts were anonymised to protect the identification of participants in the reporting of findings.

The interview transcriptions were used to generate initial codes by hand; this was done whilst listening to the transcripts to notice the intonation of discussions. Initial coding was open and aimed to capture the events, behaviours, experiences and beliefs in relation to the research question also

the general lived experience of participants and their families. Each case was coded separately with a combination of in vivo and descriptive coding. The codes generated were then transferred to qualitative data analysis software NVivo. The codes across the cases were then reviewed and combined in NVivo to form a unified coding structure for the interviews and research diaries.

### 5.6.2 Quantitative Data

The quantitative temperature and humidity reading from each case's Tinytags were combined with external temperature and humidity readings from the MET office's Weather Observation Website (2015). The programme 'Tinytags Explorer' (from Gemini Data Loggers, UK) was used to extract data from measurement devices. Microsoft Excel was the primary programme used for cleaning, collating, and analysis of the quantitative data from the Tinytag measurement devices and the Weather Observation Website. Excel data from the two sources were combined to produce a comparison of internal and external temperature and relative humidity over the two weeks of data collection

### 5.6.3 Individual case write-ups

Write-ups of each case were undertaken to synthesise evidence from interviews, observations, gatekeeper, and temperature and humidity readings (see chapter 6.0). They were undertaken in a style suggested by Stake (2006), as discussed in the methodology chapter.

The case write-ups begin with narrative description, providing context to the case, the participant's living situation, a description of the warmth experiences of the participant, and a description of issues that emerged from each case in relation to the research question. The case write-ups provided a starting point for the proceeding inter-case analysis.

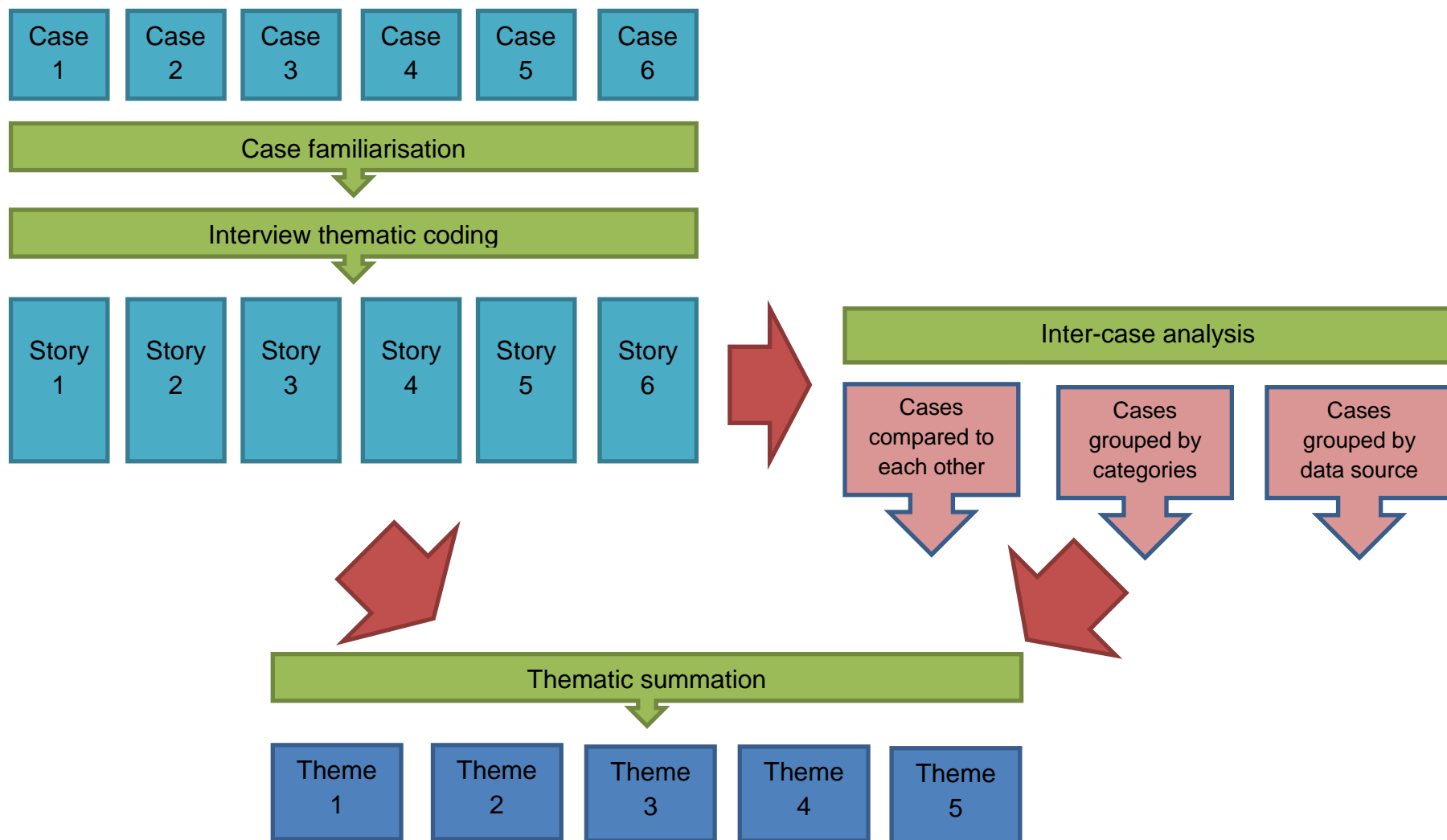


Figure 5-3 Overview of data analysis

#### 5.6.4 Inter-case analysis

The strategy used for inter-case analysis focused on the emergence of themes from across the cases and the data set, building on the previous stages of analysis. The inter-case analysis went through six phases: a re-familiarisation with the cases, merging of the codes from each case, searching for cross case patterns, initial description of the themes, an initial writing of themes, a reassessment of the themes, and finally refinement and reworking of themes. These six phases were designed to stimulate thought about cross cutting issues and themes across the cases and data set. Continuous note taking took place to keep track of thoughts and potential themes.

At the start of the inter-case analysis, the researcher re-read the case write-ups to re-familiarise with the cases and their findings. The codes in NVivo were merged to form a single group of codes for the entirety of the interviews and research diary in the study. Care was taken to keep data integrity, when merging codes, by retaining unique codes as a lower tier. Cross-case patterns were searched for with use of the approach suggested by Eisenhardt (1989), as described in the methodology chapter.

These tools were used to help stimulate the thought process for the creation of themes. Following this, initial description of themes and subthemes were created. These descriptions were kept simple to make sure each theme did not encompass too many concepts (Braun and Clarke, 2006). Stake's (2006) approach of ranking cases by expected utility was used as a way to visualise the relevance of each theme to each case. Initial drafts of these themes were then produced. This drafting process was important to the development of succinct themes that played out in the depth and breadth of the case data. Following the drafting process, the themes were refined and reworked several times until it was felt that they fully reflected the story emerging from the participant's cases. The coding structure can be seen in Appendix J and examples of coding; two codes can be seen in Appendix K.

Alternative perspectives to the researcher's on the data, coding, and analysis was provided by the supervisory team and qualitative research data checking group. A qualitative research data checking group, at Sheffield Hallam

University, examined anonymised extracts of interviews, providing their impressions in the context of the studies aim and objective. The supervisory team assisted in joint coding and ongoing refinement of codes. Additionally, iterations and drafts of the themes were shared with the supervisory team, who provided detailed feedback and discussion on the content and direction of the themes. These processes allowed alternative perspectives to be incorporated in the analysis of the study data.

### **5.7 Ethical Approval**

Sheffield Hallam University Ethics Committee approved the research on the 3<sup>rd</sup> June 2014 (see Appendix L). An amendment to allow verbal consent was approved on the 19<sup>th</sup> January 2015 (see Appendix M).

### **5.8 Concluding Remarks**

This chapter has provided a description of the steps taken to conduct this study. The approach aimed to answer the research question in a manner fitting with the researcher's philosophical position, the challenges of conducting research with people with dementia, and in the respect of the methodological traditions of case study design, as described in chapter 4.



## Chapter 6. Findings: Case descriptions

### 6.1 Introduction to findings

The findings of this study are presented in the following four chapters. This chapter presents six case descriptions, synthesizing evidence from interviews, observations, and temperature and humidity readings. In turn, Chapters 7, 8, and 9 present the outcome an inter-case thematic analysis, centred on a thematic framework of people with dementia 'Trying to stay safe' at home during winter.

The six case descriptions in this chapter capture the experiences and key issues of keeping warm at home in each case separately. The chapter begins with a case overview, including details of who was involved and the data captured in each case. The subsequent case descriptions combine together evidence from interviews, observations, TinyTag recordings in the home and external temperature and humidity recordings. The aim of these case descriptions is to provide the reader with an understanding of the context of each case and a description of participants' experience of keeping warm at home. These descriptions are a key step in the analysis process and have informed the later inter-case analysis.

Each case description follows a similar format, though there are differences based on the depth, breadth, and type of information collected within each case. The description starts with a discussion of the participant's living situation, including some details on who they are, their home, and their health and support situations. Where appropriate there are also details on the living situation of family carers, such as their health status and the support they provided to a participant.

The second part of the case descriptions focuses on how participants experienced keeping warm at home. For each case important threads relating to their warmth or exposure to cold are highlighted separately, such as 'difficulty communicating', 'choice of heaters' or 'reluctance to use the central heating' etc.

### 6.1.1 Case overviews

An overview of the participants from each case included in the study can be seen in Table 6-1. The cases include a range of ages, living situations, length of diagnosis and housing type. All of the participants and family members in this study were white British. The names that appear in these narratives are pseudonyms.

Table 6-1 Overview of cases

| Case     | Age | Living situation | Dementia type                                    | Time diagnosed | Home                |
|----------|-----|------------------|--|----------------|---------------------|
| Andy     | 93  | alone            | Alzheimer's                                      | 5 years        | Owned terrace       |
| Jim      | 84  | alone            | Alzheimer's                                      | 6-7 years      | Owned flat          |
| Alice    | 63  | alone            | Early onset Alzheimer's                          | around 4 years | Owned semi-detached |
| Caroline | 88  | alone            | unknown  | unknown        | Rented warden flat  |
| David    | 71  | with partner     | Vascular, Lewy bodies, and Parkinson's dementias | 7 years        | Owned semi-detached |
| Tom      | 86  | with partner     | Alzheimer's                                      | 10 years       | Owned bungalow      |

### 6.1.2 Who was involved in the cases

The data sources in each case are illustrated in Table 6-2, below. This table does not capture the relative involvement of individuals within each case. This is of particular importance as some participants were less able to participate in this study, due to their cognitive impairment. This led to the case descriptions emerging from those cases having a greater weight from the perspective of family caregivers.

Table 6-2 Overview of case data

|          | Interview with the participant | Interview with family/carers | Input from gatekeeper | Observations | Temperature readings |
|----------|--------------------------------|------------------------------|-----------------------|--------------|----------------------|
| Andy     | 2                              | 2                            | ✓                     | ✓            | ✓                    |
| Jim      | 2                              | 2                            | ✓                     | ✓            | ✓                    |
| Alice    | 2                              | 0                            | ✓                     | ✓            | ✓                    |
| Caroline | 1                              | 0                            | ✓                     | ✓            | ✓                    |
| David    | 2                              | 3                            | ✓                     | ✓            | ✓                    |
| Tom      | 1                              | 2                            | ✓                     | ✓            | ✓                    |

In cases one through four, the participant was able to engage fully in the interview process, with them sitting for interviews on their own. However, in David and Tom's cases the participant had reduced input into the data collection process, due to the severity of their condition. David and Tom both lived with their spouse, who was providing them with full time care. For David and Tom their first interview was conducted with their spouse. David was able to provide some information in this initial joint interview, with his wife. David was also able to take part in a one-on-one follow up interview, though it was shorter than interviews in other cases, lasting around 10 minutes. Tom was less able to engage in the joint interview and the decision was made to not hold a follow up one-on-one interview with him, due to the severity of his dementia.

## 6.2 Case 1 - Andy

*"I'm comfortable as I am like ...I don't want inconvenience of people"* (Andy)

### 6.2.1 Andy

Andy was a 93 year old retired heavy industry worker, living on his own in a mid-terrace house. He had managed the day to day running of his home since recently becoming a widower, such as food shopping, cooking, and cleaning. His daily routine was to take a trip to the local shops, to go bargain hunting

and socialise with the people he met. He had good contact with his neighbours; they passed old papers around and met weekly for a game of cards. Andy was independently minded and protective of his affairs, reluctant to accept help from his family. In the words of his daughter-in-law, he "*had a rough life*", working in heavy industry throughout his life. She felt this had shaped his attitude of wanting to remain independent and not having to rely on others. However, age and declining health was making it harder for Andy to stay independent and safe at home.

Andy had a range of chronic health conditions to manage, in addition to his Alzheimer's disease, which had impacted on his ability to look after himself and his home. In the previous year, Andy had lost around three stone in weight, through a change in eating habits. Andy had also been suffering from falls both in and out of the home, recently resulting in a short stay in hospital. His diagnosis with Alzheimer's type dementia came five years ago, however, his family were not convinced he had dementia, instead they felt that his age and frailty were directly causing any physical or behavioural changes. Andy's wider health problems were his family's primary concern, rather than his warmth at home or diagnosis of dementia.

The prospect of moving out of his home was unthinkable to Andy, saying that they will have to "*carry me out*" once he was dead. Similarly, he had been resistant to any help at home, but, with his deteriorating health, his family felt he was beginning to recognise a need for greater support, though not yet accepting it. In the words of his daughter-in-law, it's a "*fierce independence*", a strength, though at times she wishes they could "*curb it a little*". At the time of speaking to Andy, he remained reluctant to become more dependent on others. Though Andy's family felt he had built up a reasonable amount of savings through his life, they felt his desire to save money blocked off some potential avenues for support. For Andy's family, he could afford to spend more on his wellbeing, such as heating, but was reluctant to do so.

Andy's support network (Figure 6-1) illustrates that his eldest son, along with his daughter-in-law, provided the most regular support he received; they lived an hour away and tried to visit weekly. His eldest son had taken on some

financial management responsibilities from his father, when his wife died. His younger son lived abroad and therefore provided limited support, though had fitted the current plumbing system in the home. Andy's family would have liked him to accept a more formal care structure, for Andy to have spent more money on his wellbeing, and for them [the family members] to have more input into the day-to-day running of Andy's affairs, such supporting health appointments.

There was an informal support network in the local area that Andy could draw on when needed. Friends visited regularly and Andy has good contact in the community to support any ad hoc needs. Andy's family had also asked his neighbours to look in on him while they are away on holiday. A community based dementia association acted as a gateway to Andy accessing dementia support, including home visits and transportation to social events.

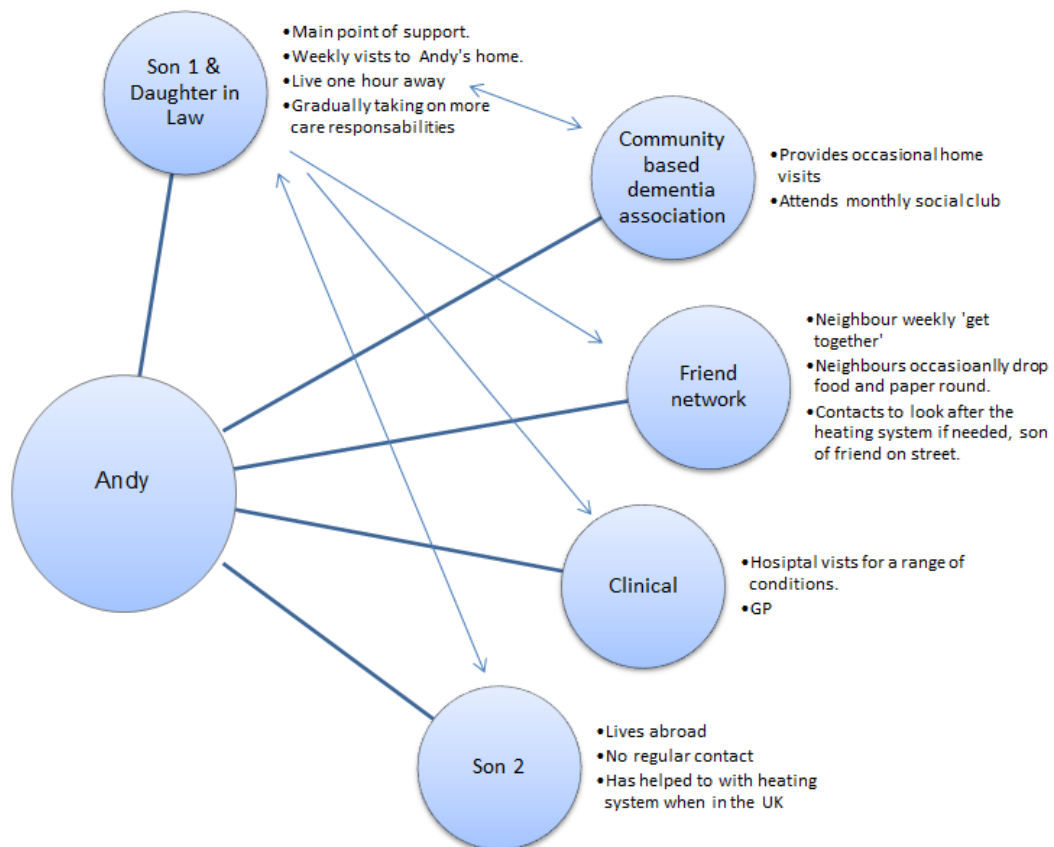


Figure 6-1 Andy's care network

### 6.2.2 Warmth at home

Andy's home had a gas central heating system and two wall mounted gas fires, one in the living room and one in the front room, both on the ground floor. The central heating was set to come on in the morning and evening, for a couple of hours each time. Figure 6-2 shows that Andy's kept his living room, the room he spent most of his time, between 20°C and 27°C for most of the two weeks of data collection. This was a period where outside temperatures were mainly in single digits. Most of the heat in the living room came from one of his wall mounted gas heaters. He also had a woollen jersey next to him on his sofa, to use when he felt a little cold. When coming in from trips to the shops Andy would keep his thicker layers on while "*knocking around*" and get the gas heater on.

At night time, Andy would put a hot water bottle under sheets and turn on his electric blanket, while getting ready for bed. He had needed his son's help to fit the electric blanket at the beginning of winter, leaving it on a low setting throughout the night. Andy's night time room temperatures were cooler than his living room temperatures, ranging between 15-20°C (Figure 6-2) though he was taking steps to keep himself warm in bed. Warmth in his bedroom came from the central heating, residual heat from downstairs and his electric blanket helping to keep him warm in his bed.

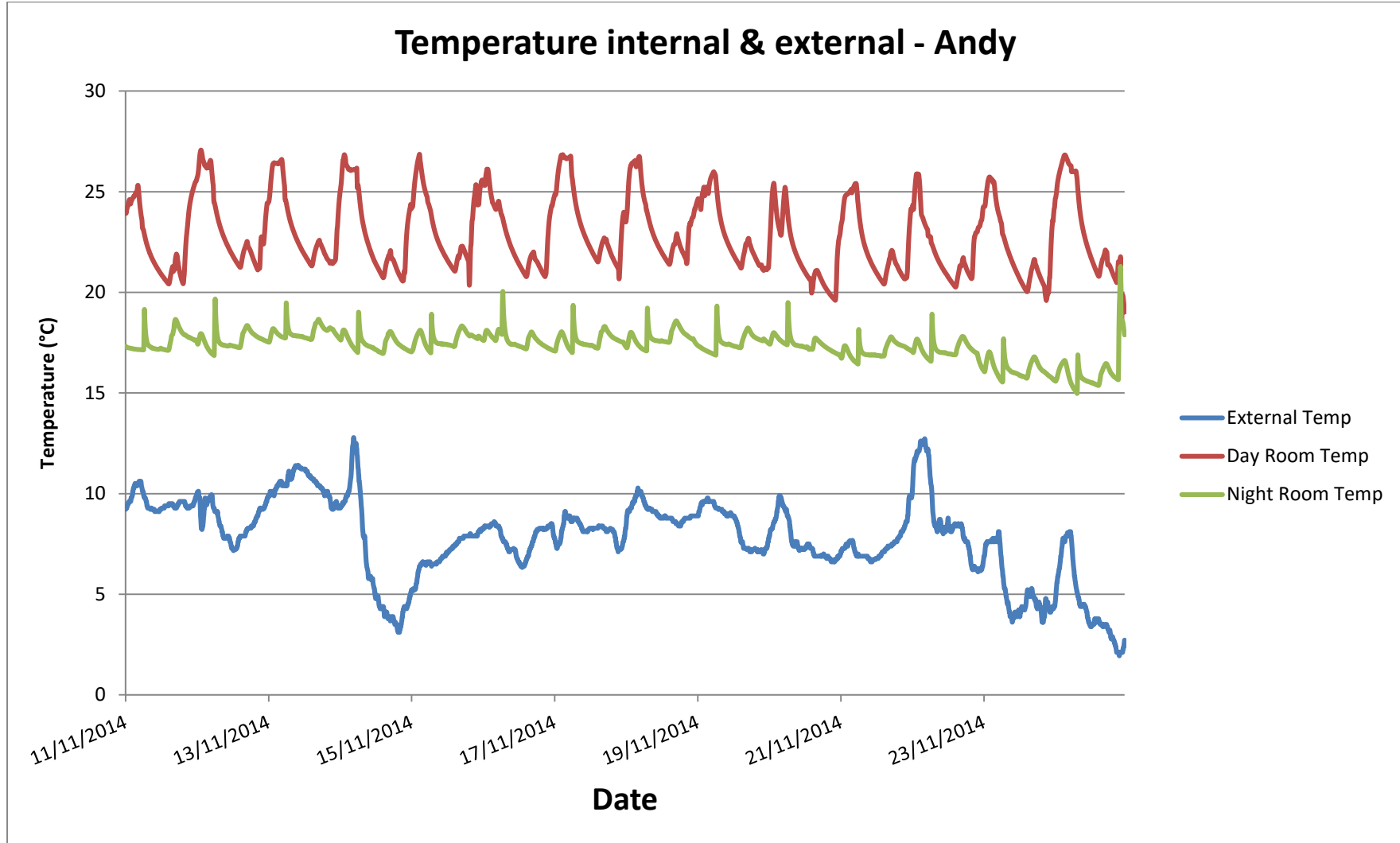


Figure 6-2 Andy's temperature measurements

### 6.2.3 *"Heating one room"*

Andy concentrated his heating into a limited living space, whether that was in his living room or in his bed. Within this space he was happy to spend money on heating to keep warm, feeling that heating the rest of his home would be wasteful. In the living room, his wall mounted heater was on a great deal of the time and in his bedroom his electric blanket was on at night throughout the winter. By using this wall mounted heater, the living room reached day time temperatures of 27°C. Other parts of Andy's home, such as his kitchen annex, were considerably cooler to be in. As much as possible Andy also limited his movement at home, staying in his living room, *"I'm not going back in here to go back in there"*.

For Andy, the wall mounted gas heater provided him with flexibility and focused heat, i.e. in the living space he was using, that the central heating couldn't provide. He also saw it as a way to save money by only heating the space he was using. When asked why he didn't use the central heating more Andy responded *"Well what's use when it's warm enough?"*. Similarly, his daughter-in-law saw this as Andy thinking it *"wasteful to warm a room up that you don't spend a lot of time in"*. If a door was left ajar Andy would quickly get up to close it. A desire not to be wasteful appeared to be part of who Andy was, seen in his regular bargain hunting at the local shops. Andy's family wanted him to spend more money on his wellbeing generally including his heating, but recognised this was an uphill battle.

### 6.2.4 **Heating priority**

*"Keeping warm, yes I would put it not at the bottom of the list"*

For Andy and his family, keeping warm at home was a low priority, in light of his wide declining health. Andy's living room at home (Figure 6-2) was very warm and during the night Andy's use of a hot water bottle and electric blanket allowed him to keep warm. For Andy's family, his deteriorating health and his difficulties managing his home were large concerns, however as his son said *"they're issues that he won't let me tackle"*. In the last year, Andy had fallen and been on his floor for six hours, with no way of getting assistance. His most recent fall in a shop resulted in a stay in hospital. This led his family to find he



had no running water at home due to a leak, leading to water damage to his living room ceiling. Within this context Andy's diagnosis of dementia was also a low priority for Andy and his family.

Andy was happy to go out and seek help on his own terms, by using friends and neighbours or taking gifts. However, the idea of his family, or anyone else, stepping in to manage his health, wellbeing or home was at the time a no go area. This included assistance with his warmth behaviour. When discussing heating issues in the interview his family discussed them as something they would like to see improved, such as using the central heating more throughout the rest of the home, but were more focused on encouraging Andy to accept any form of assistance. Therefore, if and when Andy accepted assistance from his family there would unlikely have been any changes to how Andy heated his home.

#### 6.2.5 Concluding comments

Andy's heating usage was focused on the living room; this was where he spent the majority of his time at home. Thermal comfort was important to Andy and his approach to achieving warmth fits with his desire to avoid being wasteful. It was a part of his wellbeing he was willing to spend more on than others. Andy was managing large changes in his life of health, bereavement and old age. So for Andy, and his family, changing how he kept the house or himself warm was not a priority.

### 6.3 Case 2 - Jim

*"I think as you're getting older you do feel the cold more"* (Jim)

#### 6.3.1 Jim

Jim was a retired engineer living on his own in a modern ground floor flat. Jim's wife passed away from Alzheimer's disease some years ago. Through caring for his wife, Jim had an intimate understanding of dementia. Shortly after his wife died, Jim moved into his flat. In the words of his eldest daughter *"he needed to get away"*. Jim's diagnosis of Alzheimer's type dementia came six-seven years ago. Due to his dementia he suffered from regular short-term

memory loss along with confusion, which affected his ability to communicate his needs. Jim had a range of other health problems that made it difficult to perform some daily tasks and some mobility difficulties which increased his risk of falls.

As Jim's Alzheimer's condition had progressed, his eating patterns had changed. His eldest daughter described Jim as having *"just lost the ability to cook for himself"* and *"just eating what was given to him"*. His meals were prepared for him by private carers visiting twice a day.

Jim had two daughters who helped to manage his care and support needs. His locally living eldest daughter took a primary carer role coordinating the care he received (Figure 6-3). His younger daughter did not live locally so was not able to provide day-to-day help. Jim's elder daughter was in daily contact, visiting the flat around four times a week. As his dementia progressed, she had taken on the management of most Jim's affairs, such as paying bills, buying food and organising his professional care. Professional home support was provided by a Local Government service provider twice a day. These carers prepared his food, checked on his wellbeing, and twice a week, were in the property while Jim showered, to reduce the harm from any potential fall; they did not shower him. There had been problems with the standard of care provided by the home care provider with Jim saying *"it's a bit intermittent really, you know, you never know when they're coming"*. Jim's neighbour was occasionally called upon to solve issues in the flat, such as to relight the boiler (Figure 6-3). Though there appeared to be a good degree of support for Jim, there was a reliance on informal feedback from professional carers to keep his daughters updated. However, with professional carers changing on a daily basis it was hard for Jim's daughter to build up a personal relationship to know if there had been any problems.

Memory and confusion, associated with dementia, made it hard for Jim to independently look after his bills, though he still had ultimate control. His daughter had set up direct debits and she said the household bills were at a manageable level. In the previous year Jim had changed his bank account leading to all of his direct debts stopping and had been prone to accepting cold

calling financial products. His daughters were in the process, at the time of data collection, of securing lasting power of attorney to take full control of Jim's finances.

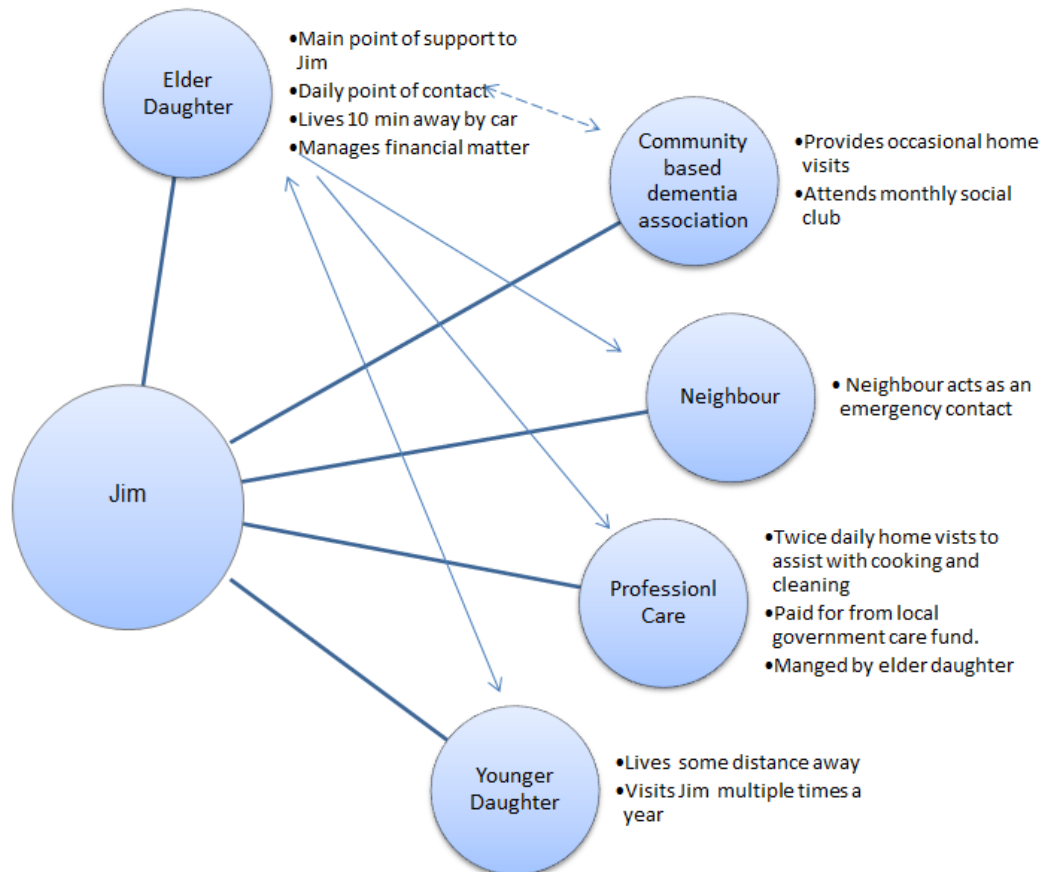


Figure 6-3 Jim's support network

### 6.3.2 Warmth at home

Jim's flat was mainly heated by a four-year-old gas boiler feeding a thermostatically controlled central heating system. A service agreement was in place for maintenance and repair needs. There was an extra, free-standing electric heater Jim used to provide additional warmth, if the central heating was not enough for his needs. Jim also kept a gansey, a woollen jumper, next to him as an extra layer to put on if he felt cold at home. His eldest daughter though was frustrated that he *"just turns the heating up"* and wouldn't *"put more clothes on or get a blanket"*.

Jim felt relaxed about using the heating system to keep himself warm and did not seem to worry about the cost of heating. Throughout the interviews Jim often mentioned feeling cold at home *"I find that I feel the cold a lot quicker than I used to"*. Jim's eldest daughter also said he *"feels the cold terribly"* and was not shy about communicating his feelings, *"he's always complaining of being cold"*. Jim's daughters described the property as being very warm for them, with his young daughter saying it felt *"amazingly hot. For me it's far too hot"*.

Over the two weeks of data collection the internal temperature in the property were in a safe range. The flat's temperatures showed little relationship to the external temperatures (Figure 6-4) suggesting that the heating system and/or flat's insulation was working effectively. Figure 6-4 shows a consistent daily pattern of temperatures, reflecting the thermostatically controlled central heating as the main heating source. The day room was regularly above 20°C and reached a maximum of around 25°C. The main living area of the flat was open plan, so the day time temperature ranges in Figure 6-4 reflect all of Jim's day time living space reasonably accurately. Night time temperatures are cooler ranging between 15°C and 21°C, but still in a reasonably safe range. The temperatures were taken during the month of December of 2014 during mainly positive single digit weather. Similarly, the internal humidity readings for the flat are within a safe range for the property (Figure 6-5). On this front, although the bedroom's humidity does reach 70% on occasion this is only for short periods and is consequently arguably not a significant issue.

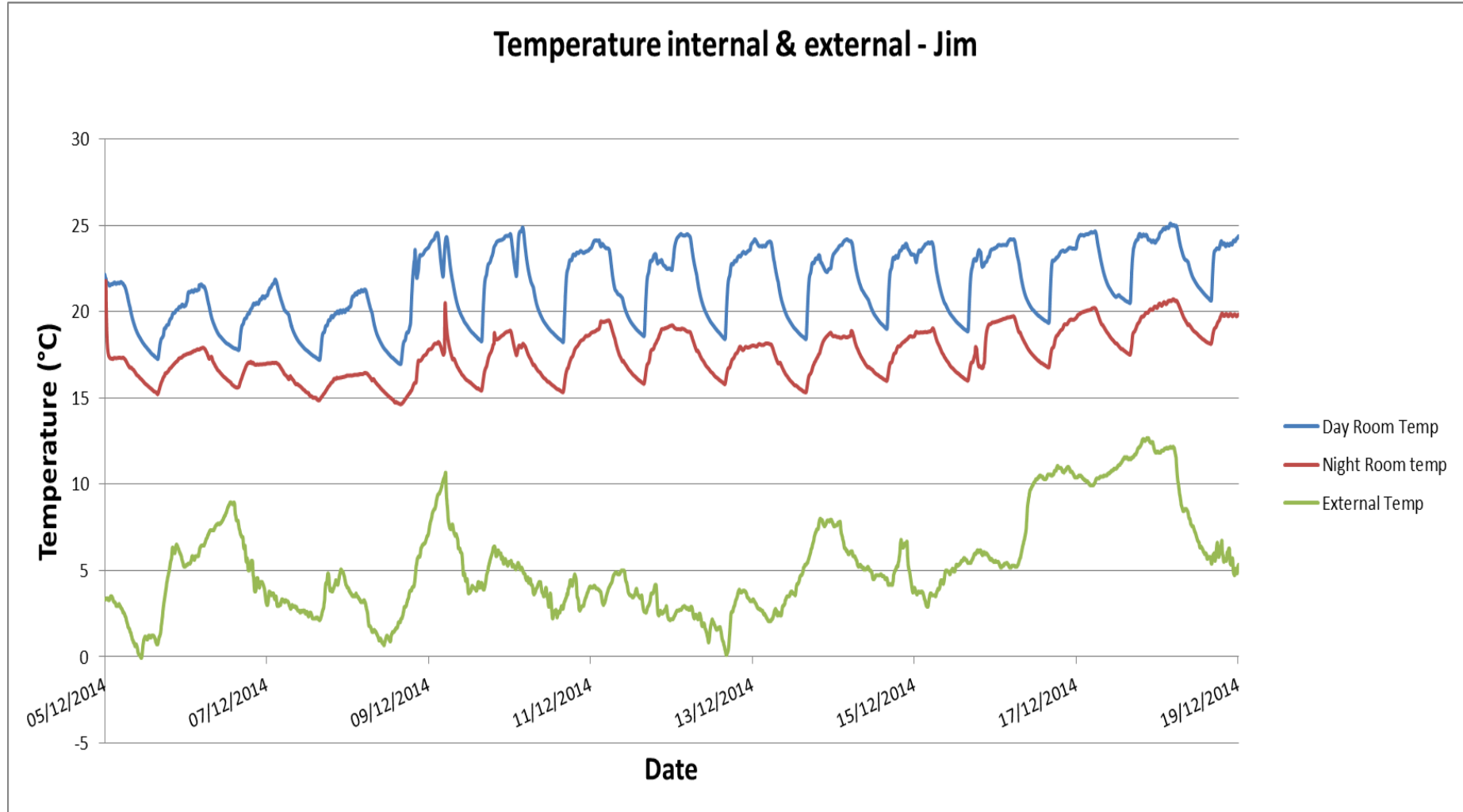


Figure 6-4 Jim's temperature measurements

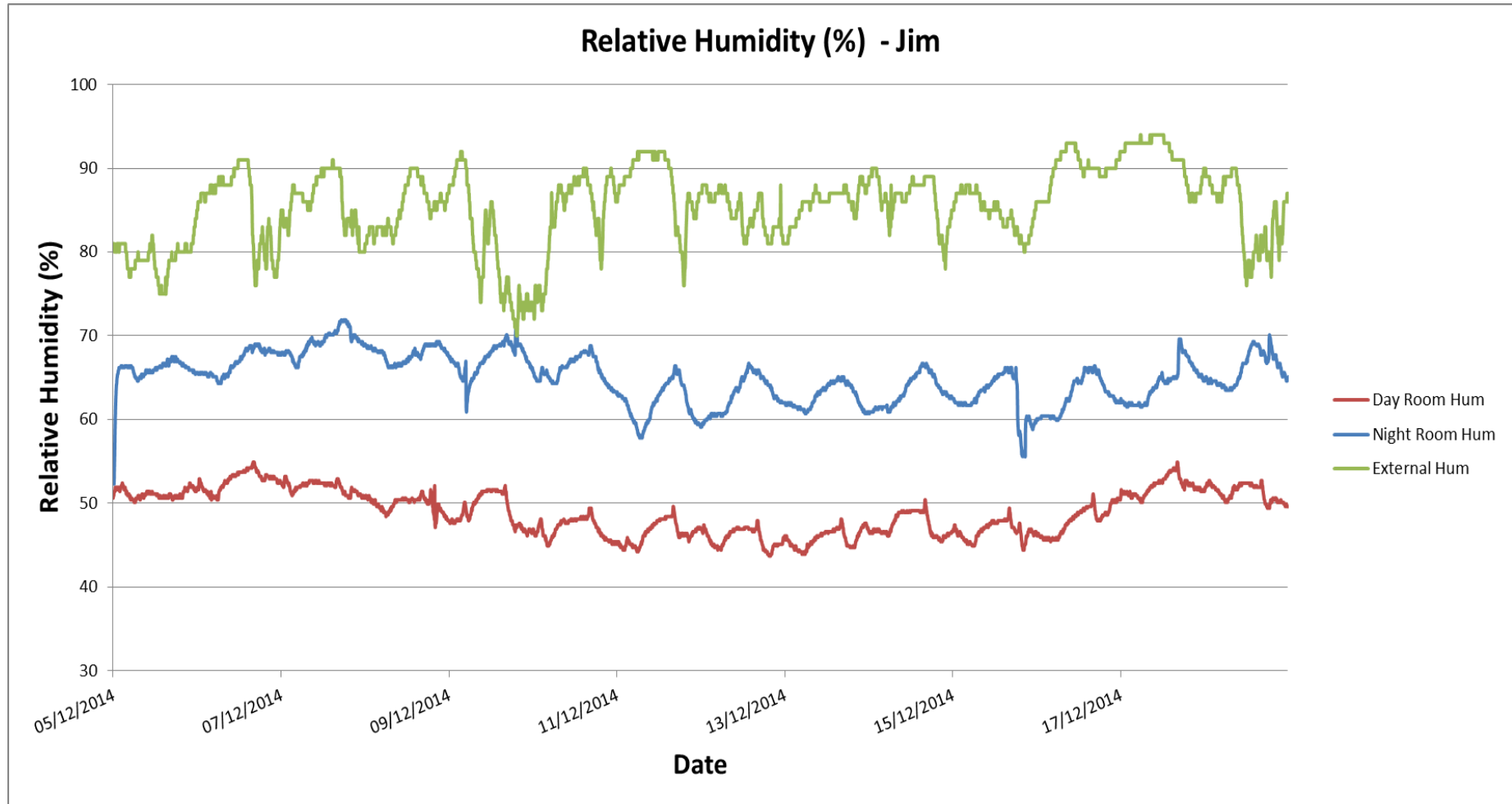


Figure 6-5 Jim's humidity measurements

### 6.3.3 Fiddling with the heating

*"fiddled with the heating" (Jim's younger daughter)*

Jim liked to regularly adjust the heating settings on his boiler rather than his thermostat, *"sometimes I might I sort of mess about with it two or three times a day"*. His family described these adjustments creating an on-going issue with the boiler cutting out. His daughter's encouraged him to adjust the thermostat and not the boiler. Jim's adjustment of the boiler's settings had led to the boiler cutting out on several occasions. This had led to hot water not being available in the property for six days and in the past there being no heating in the property for short periods of time, with his family not being aware. In the past, Jim had been very capable of managing his own heating system effectively, particularly with his previous experience as a mechanical engineer. Through his dementia, Jim struggled to manage his heating system, as he had once been able to, as his eldest daughter said:

*"he's got a cold, he gets, his memory and things around him become more confusing. So obviously he'd decided it was cold, he was going to sort the boiler out, fiddled with the boiler and had actually turned the boiler off."*

An incident of the boiler cutting out happened during data collection, though not the TinyTags data collection period. To help, a large sign was placed on the boiler, prompting Jim to not adjust the boiler settings. His daughter had also encouraged him to put on his gansey or use a blanket when feeling cold to try to prevent him from adjusting the heating. These steps had reduced but not stopped the boiler problems.

### 6.3.4 *"He forgets, he just forgets"*

Jim said he was feeling the cold more as he had gotten older and was vocal about feeling cold to his daughters. However, when things have broken down in the flat Jim had not always let his family know. Jim's eldest daughter puts this in large part down to his dementia: *"He just forgets. Either forgets to tell us or forgets it's not working"*. Jim's family relied on carers relaying when there has been a problem in the flat, including if there are any problems with his heating, but this was not a formalised process and so did not always work. The

incident when water was not being heated in the flat for six days was either not picked up by the carers or not communicated from carers to Jim's family. Effective communication of Jim's wellbeing and warmth needs were a challenging issue for Jim and his family.

Jim's eldest daughter expressed a desire to move Jim closer to her home to help with his wellbeing and communication, saying *"it's just a bit too far"*. It was felt, however, that moving him at that time, from a home which he had become accustomed to, would be counterproductive.

### 6.3.5 Concluding comments

Jim's winter warmth experience was shaped by his adjustment of heating and choice of adding on extra layers. Jim's 'fiddling' with the boiler was a concern to his family, resulting in the boiler cutting out several times. Jim's memory and communication difficulties meant his family were not always aware there was a problem. The signs his family have placed in the home had made a difference to the regularity of these incidences, but not prevented them entirely.

There appeared to be a good degree of support for Jim from his family and professional carers, as well as some help from his neighbour. Jim's daughters described relying on informal feedback from professional carers to keep them updated on their father's needs, but this did not appear to be an effective channel of communication. At the time of talking to Jim and his family their most pressing concern for his wellbeing was his risk of falling at home and his financial mismanagement, changing bank account and his responses to cold calls. Jim keeping warm was not his or their top priority.

## 6.4 Case 3 - Alice

*"it is cold I suppose upstairs. But it doesn't bother me."* (Alice)



#### 6.4.1 Alice

Alice was 63 with early onset Alzheimer's disease living alone. She talked passionately about her home and was reluctant to consider any changes to her living situation saying *"I love this house; I don't want to move from it"*. The house was full of clutter, with piles of different possessions throughout; there was little space within the property to move. The appearance of the property, and its contents, appears to be consistent with a form of hoarding disorder. She appeared to struggle to maintain the property in a presentable state, something that had been noticed to worsen over the previous year by the gatekeeper.

Alice's dementia had not affected her physical capabilities and she walked around five miles every day. Alice had a set daily routine of literary activities and regular exercise. She also regularly attended a local community group and carers group; but was very clear that she didn't *"go because I want a carer; you know, I go and help them"*.

It was not possible to determine how long she had been diagnosed with Alzheimer's disease, but, around the point of diagnosis, Alice started keeping a very detailed diary of all her daily events, which dated back four years. She had helped care for several close relatives, each of whom had had dementia. Through this, she had an understanding of the progress of dementia, though avoided the topic in conversation. Though she attended some voluntary groups she did not appear to have an informal network to call upon for support. Alice had no close family connections.

Since being diagnosed, Alice described struggling to hold down a job, due to her memory problems, leading to difficulties with money. With no income, Alice described having to rely on her savings. She appeared to fall between the cracks of available funds, e.g. pension and winter fuel payments. The gatekeeper expressed concern at the lack of financial support that Alice was receiving.

Alice had very few points of confirmed contact to provide support. Figure 6-6 illustrates her support network, compared to other people in the study she

appeared to be quite isolated. The gatekeeper said that Alice was reluctant to seek outside assistance or interference in her affairs. She appeared to be wary of people monitoring or reporting on her. It was difficult to assess her full support network due to a reluctance to engage in this discussion and her memory problems. It appeared Alice had a limited network of friends and was not willing to involve her friends in the study. Initially, it appeared all care decisions were made by Alice, with no obvious candidate for taking on a carer role as her condition progressed. It emerged that a solicitor may have had lasting power of attorney over her, this information being passed on by the gatekeeper. The gatekeeper described having only very limited access into Alice's care and wellbeing. The gatekeeper had struggled to increase Alice's engagement with dementia and care groups or activities.

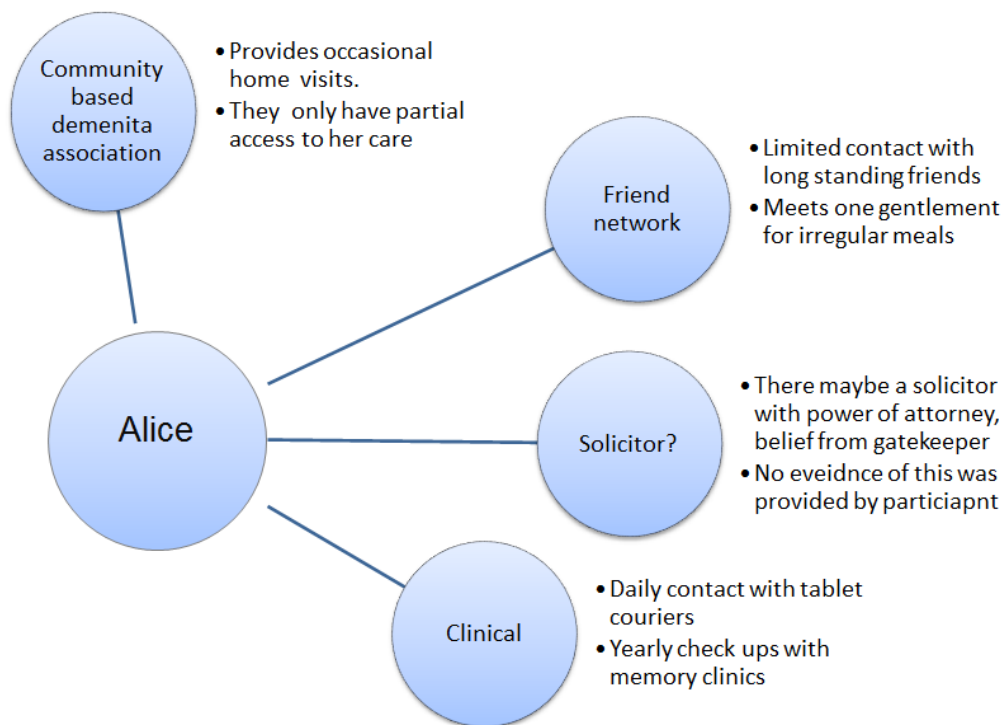


Figure 6-6 Alice's support network

#### 6.4.2 Warmth at home

Alice's property had a gas central heating system and two wall mounted gas heaters, one in the living and dining rooms. The boiler had been replaced since she moved into the property, though Alice was unable to put a date on its installation. The house had no cavity wall or loft insulation and single glazing throughout. To keep warm, Alice wore multiple layers of clothing at home,

including a heavy-set fleece and woollen hat. During cold weather, she would also wear her woollen hat to bed. When interviewing Alice in her home it was necessary to wear a thick jumper and coat throughout to keep myself warm. When shown around upstairs it was possible to see your breath in the air.

The TinyTags data loggers were in place around the coldest period of winter, with external temperatures hovering around 0°C (Figure 6-7). However, Alice did not use her central heating and so her home was only heated in sporadic bursts by the two wall mounted gas heaters. This was reflected in Figure 6-7 showing the day room having regular spikes, as the wall mounted heaters were the only heating source in Alice's living spaces. Alice could not recall when she had used her central heating last, saying that should would only consider having the central heating on when there was exceptional weather "*if the snow comes up and we're sort of trapped*". Alice's bedroom had no heating at all, with warmth only provided from residual heating from downstairs or through the walls. This was reflected in the temperature recordings at a reasonably constant temperature of 7-8°C (Figure 6-7). Alice's home was by far the coldest observed across all of the cases. The internal temperatures reflected the limited use of heating in the property and lack of insulation.

The relative humidity of the property was generally higher than other cases (Figure 6-8). The day room's relative humidity fluctuates in line with the sporadic heating use. In contrast the night room had a constant high relative humidity of around 74%. This relative humidity reflects the low temperature in the bedroom, bringing it closer to the dew point and increasing the risk of mould growth. However, Alice was clear that "*I don't feel any damp in this house*".

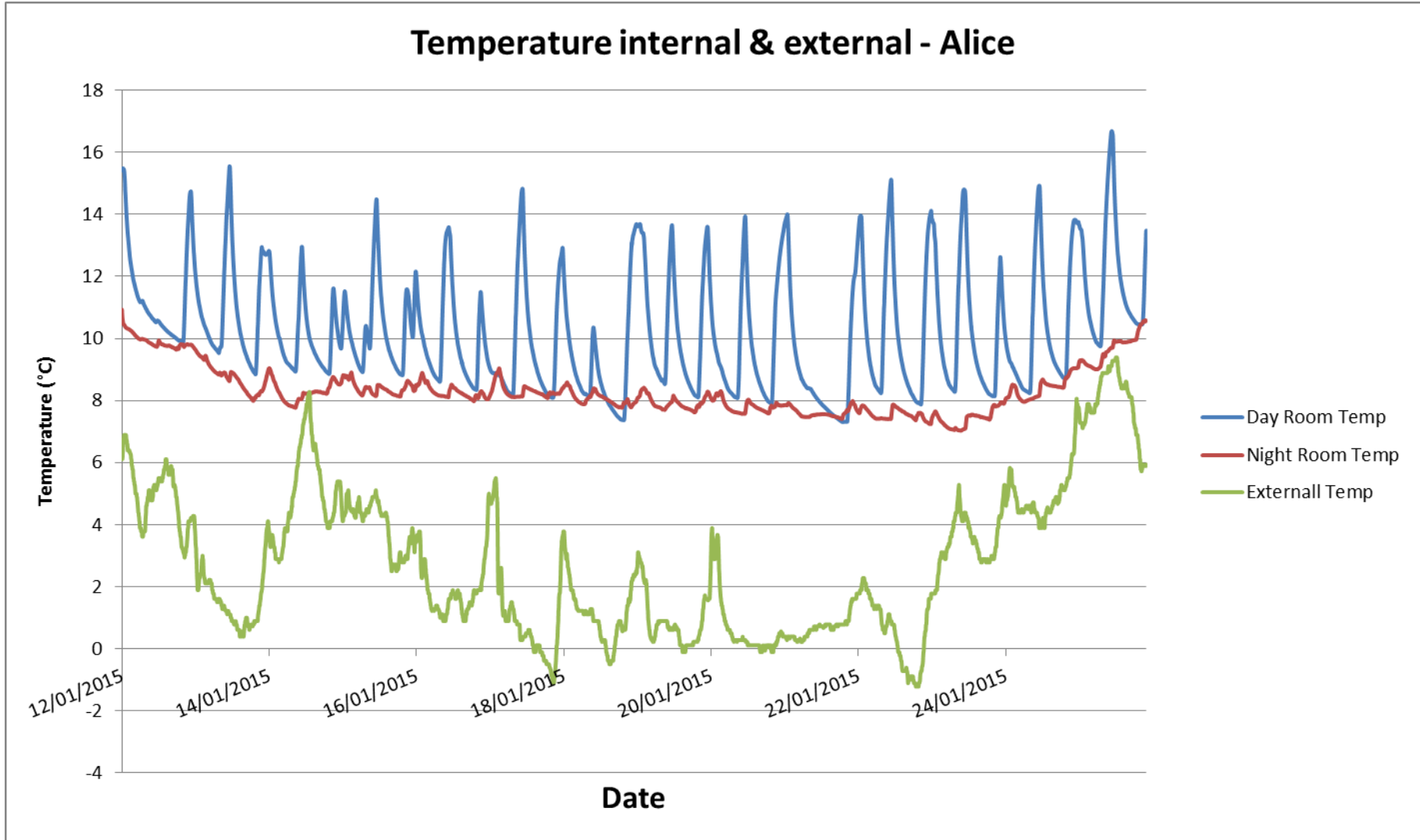


Figure 6-7 Alice's temperature measurements

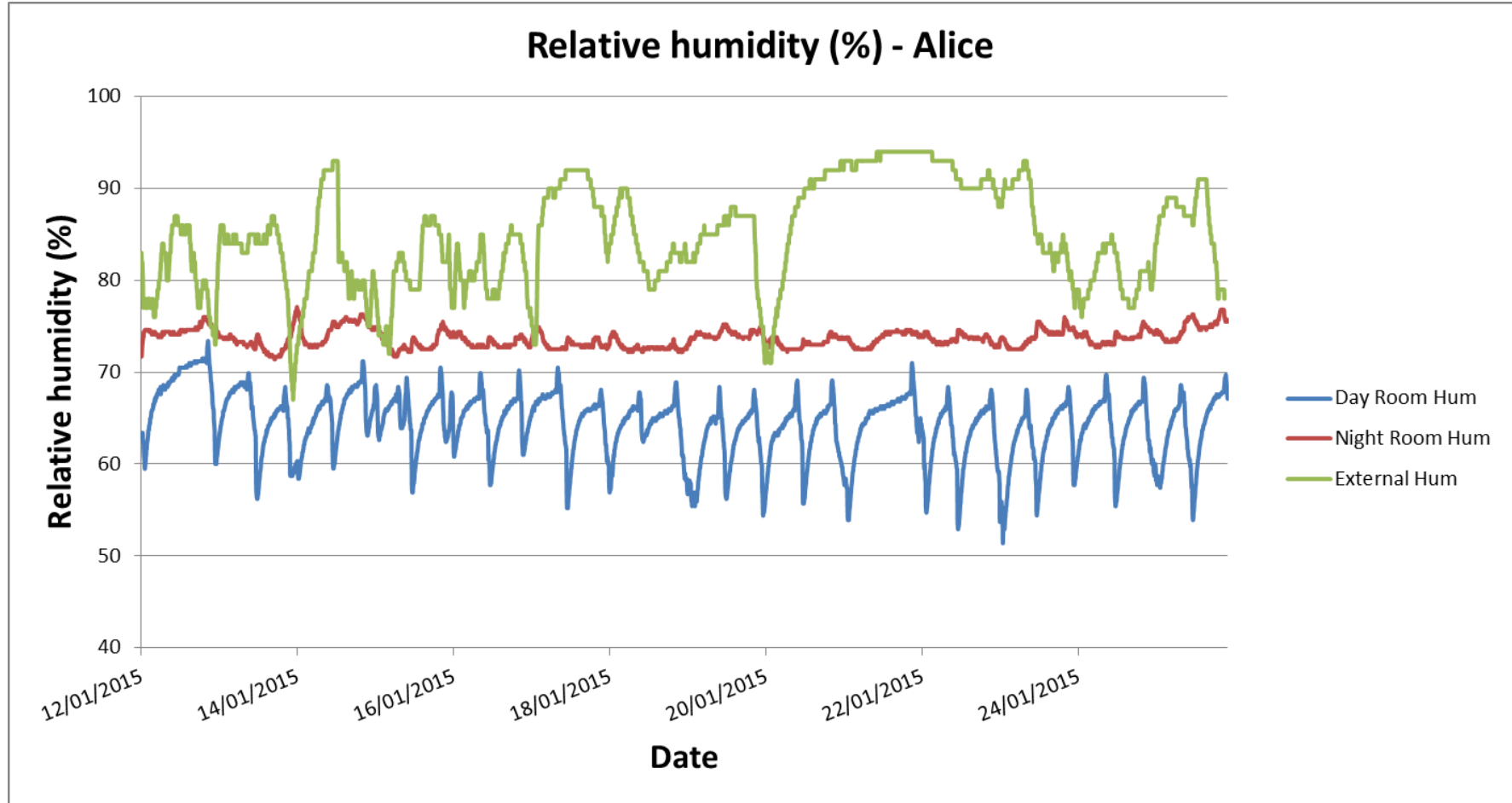


Figure 6-8 Alice's humidity measurements

### 6.4.3 Keeping control

*"I really don't want to be forced to put heating on"*

Alice was extremely resistant to the idea of using her central heating, in particular her personal warmth and wellbeing. However, Alice did consider its use if having a cold home was *"causing damage to the physical structure of my house"*. The wall mounted gas heaters were Alice's preferred way to heat her home as she could *"just heat what I need"*. This heating routine had not always been the norm for Alice. When employed Alice described having a routine of using her central heating for several hours in the morning and the evening.

Alice was not always clear why she had stopped using the central heating, at times stating that she could *"afford to have the heating on at a fairly high level"*. While at other moments Alice defined her resistance to the idea of using the central heating in economic terms saying *"I have the central heating on at lot then it does get expensive"*. She also discussed that going out to public spaces, along with being a good place to meet people, had the benefit of saving money. The cost of heating appeared to play a role in Alice's reluctance to use the central heating, though Alice was not always clear what this role was.

### 6.4.4 "that's what I've grown up with"

Alice's experiences of growing up come across as important in how she viewed warmth at home and the choices she took to stay warm. It was instilled into Alice from a young age that if you put on *"a couple of layers on inside, you didn't need the heating on"*, which then became her preference in adulthood. Similarly, Alice was clear that the concept of not having heating on at night was also instilled into her from childhood, *"Oh I've never, I've never had a heater on at night in bed"*. These are moments of conversation where Alice's descriptions were at the most vivid and forthright. These memories of childhood and family customs appeared to inform Alice's behaviour and decisions on heating and clothing used to keep warm.

#### 6.4.5 "I don't let myself get cold"

Alice's home was by far the coldest of any person in the study, but while her home was certainly cold Alice was clear that she didn't let herself get cold. When in the house Alice spent most of her time sitting next to her wall mounted heater; so it is likely that the warmth Alice felt was not fully reflected by the TinyTags data loggers in (Figure 6-7) which were placed further from the wall heater. Similarly, at night Alice was very clear that she kept herself warm despite the lack of heating in her bedroom: *"I promise you, it's not cold in my bed"*. When discussing Alice's decision to wear several layers of clothing and not use the central heating she became quite defensive and protective of her right to look after herself in the way she wished.

#### 6.4.6 Concluding comments

Alice appeared to have low levels of informal or formal support available to her. Her engagement with several voluntary groups suggested a large informal social network, but people in this network did not appear to have access to Alice or her home to provide support. At the time of talking to Alice, the lack of support was not a problem for her; she had no problems with daily tasks or mobility, with daily walks to and from the city centre. However, as her dementia progresses there were not clear candidates to help her manage her health, wellbeing, daily tasks, and home affairs.

The internal temperature and humidity readings in Alice's home reflect her low use of heating and the poor level of insulation in the property (Figure 6-7 and Figure 6-8). The TinyTag data was collected during the coldest period of the winter of 2014/15. The temperatures in the property place Alice at cold related health risk of cardiovascular and respiratory conditions. Alice kept herself warm through wearing several thick clothing layers in her home, including a woollen hat, sitting next to her wall mounted gas fire and going out to warmer communal spaces. Therefore, the temperatures she was experiencing were not always reflected in the TinyTags measurements.

## 6.5 Case 4 - Caroline

*"you've got to feel comfortable to feel warm"* (Caroline)

### 6.5.1 Caroline

Caroline was 88 years old and had lived in a wardened flat complex. The wardened controlled accommodation provided Caroline with a feeling of security and she described it as the *"main thing in my life, to live in here"*. Caroline described herself as being *"so independent"* but this was something she felt she *"had to calm down with"*. Her nephew was her only relative with whom she was in regular contact with; he supported Caroline's by helping with correspondences and managing her finances. Caroline had sight problems, creating difficulty reading letters with regularly sized fonts, and described some mobility problems, due to her age.

Caroline had been diagnosed with dementia, though could not remember what type of dementia it was or for how long she had been diagnosed. She avoided directly acknowledging dementia in the interviews; Caroline never used the word dementia. Some daily tasks were increasingly becoming a struggle with the progression of age and dementia, such as paying bills and shopping. In the interviews, Caroline's dementia appeared to be causing a degree of short-to medium-term memory loss.

Figure 6-9 illustrates that Caroline had a limited support network. Caroline's son passed away, leaving her nephew as her closest living relative and he acted as an emergency contact, looking in on her from time-to-time. He provided support with tasks she found a struggle, such as moving heavy objects. The manager of her accommodation made daily checks on Caroline, by phone, acting as a conduit to help with any problems within her home. Caroline described a fraught relationship with the new manager saying *"I don't like her"*. Caroline attended a couple of social groups in the week and the wardened accommodation provided some social interactions. She had been attending a dementia support group but left this quite suddenly; the gatekeeper said Caroline felt upset because she was the only one without family attending. Overall, Caroline saw herself as being quite isolated saying *"there's nobody there"* to help. The gatekeeper acted as a point of contact with local dementia



support; though, the gatekeeper explained that Caroline was reluctant to attend dementia support groups.

Caroline described managing most of her own daily tasks such as cleaning, paying bills, and shopping, but she was starting to struggle with some of these. Caroline mentioned two recent events, one to do with paying the bills and the other involving her clothes washing, where she was struggling and someone else had to step in to help. With respect to the struggles of managing bill payments, she said *"it sounds as if I owe a lot of money"*. She described becoming frustrated and distressed. Caroline's nephew happened to arrive and assist her by paying her existing debts and setting up direct debits for her bills.

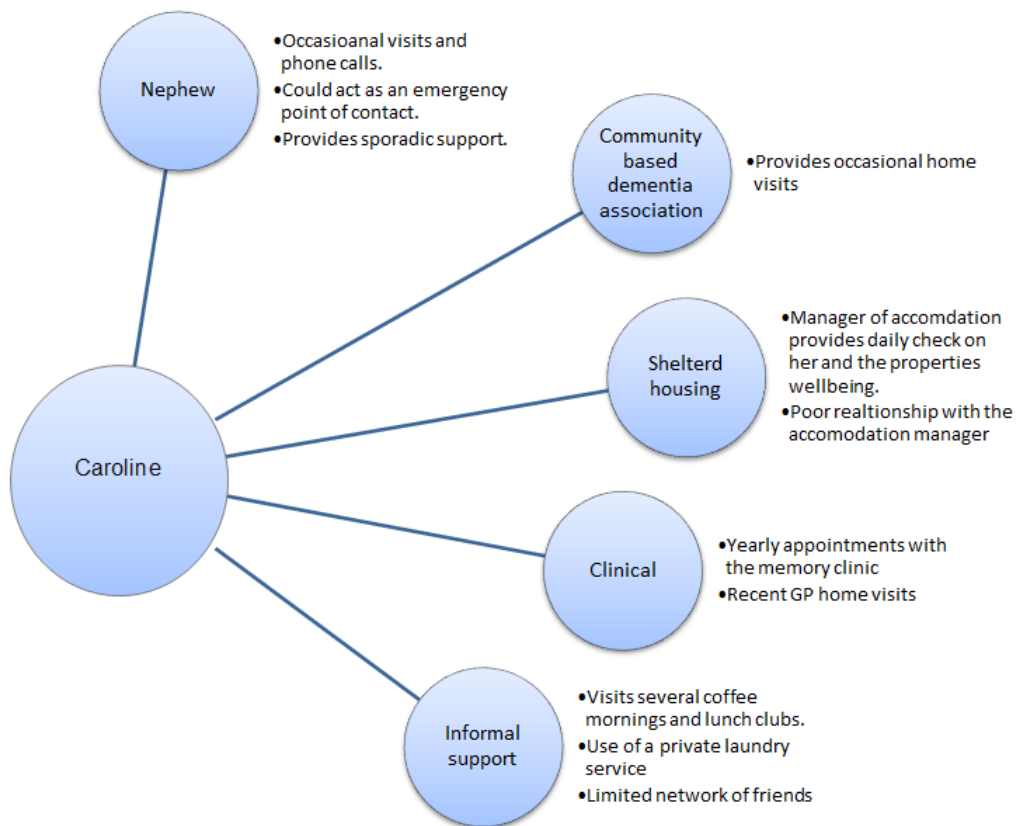


Figure 6-9 Caroline's support network

### 6.5.2 Warmth at home

For Caroline, having good heating and being comfortably warm was very important to her and was vocal about her views on the flats and her personal warmth saying *"you've got to feel comfortable to feel warm"*. She described

regularly feeling cold at home but also that she felt there was little she could do about it and just had to *"put up with it"*.

Caroline's flat was heated through three wall mounted heaters; there was a main storage heater in the living room and two electric heaters, one in the living room and another in the bedroom. The storage heater was paid at a fixed rate, included in the rental payments. The two electric heaters come out of Caroline's personal electricity budget, so she aimed to use these heaters as little as possible; she also described avoiding using her bedroom heater entirely. The flat additionally benefited from the residual heat from other flats and hallways in the property. The desire to feel warm had an effect on Caroline's clothing selection. She would wear multiple thin woollen layers; at the point of data collection she wore two jumpers, two vests and a scarf. Despite these layers she said *"I've got all these jumpers on, I can't say oh yeah, it's nice, I'm comfortably warm"*.

The temperature of Caroline's flat (Figure 6-10 and Figure 6-11) shows day room temperatures ranging between 18° to 24°C, but for most of the time they did not get above 22°C. Night room temperatures stay mainly around 16°C, with a couple of peaks over the data collection period. Caroline focused her heater use in the living room, due to the location of the storage heater and the open plan living and kitchen area. This, along with her bedroom temperatures, reflects Caroline's avoidance of using the bedroom heater; as the cost of using this heater came out of her electricity bill.

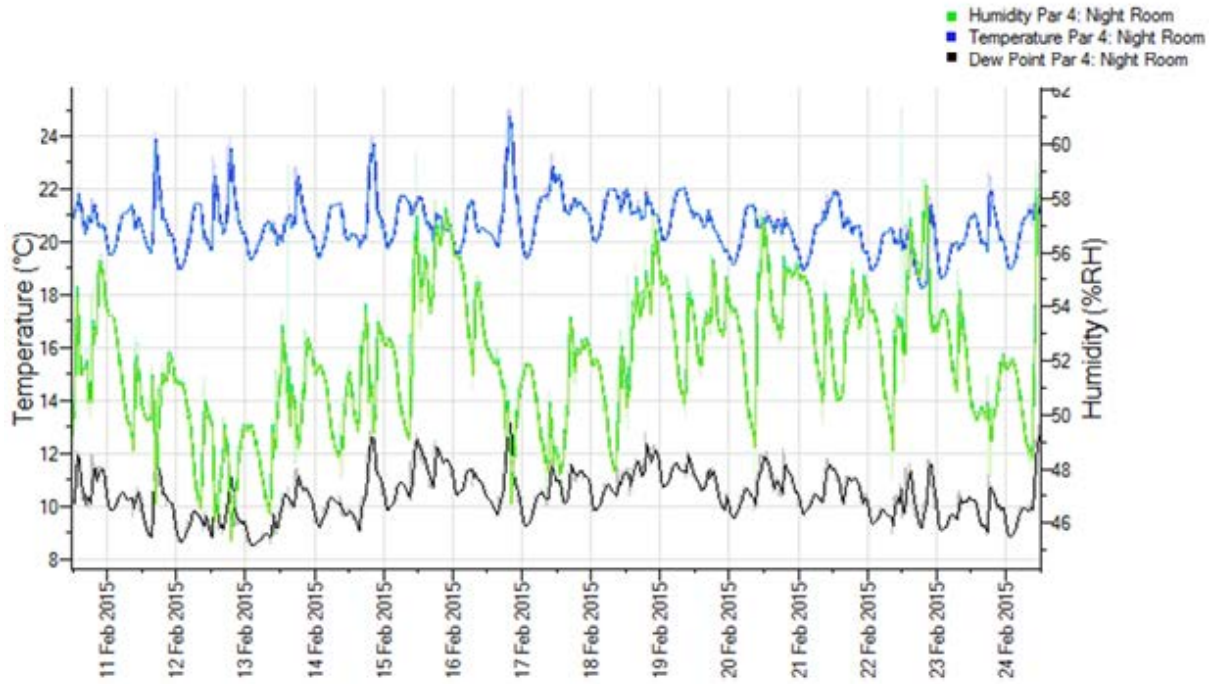


Figure 6-10 Caroline's day room measurements

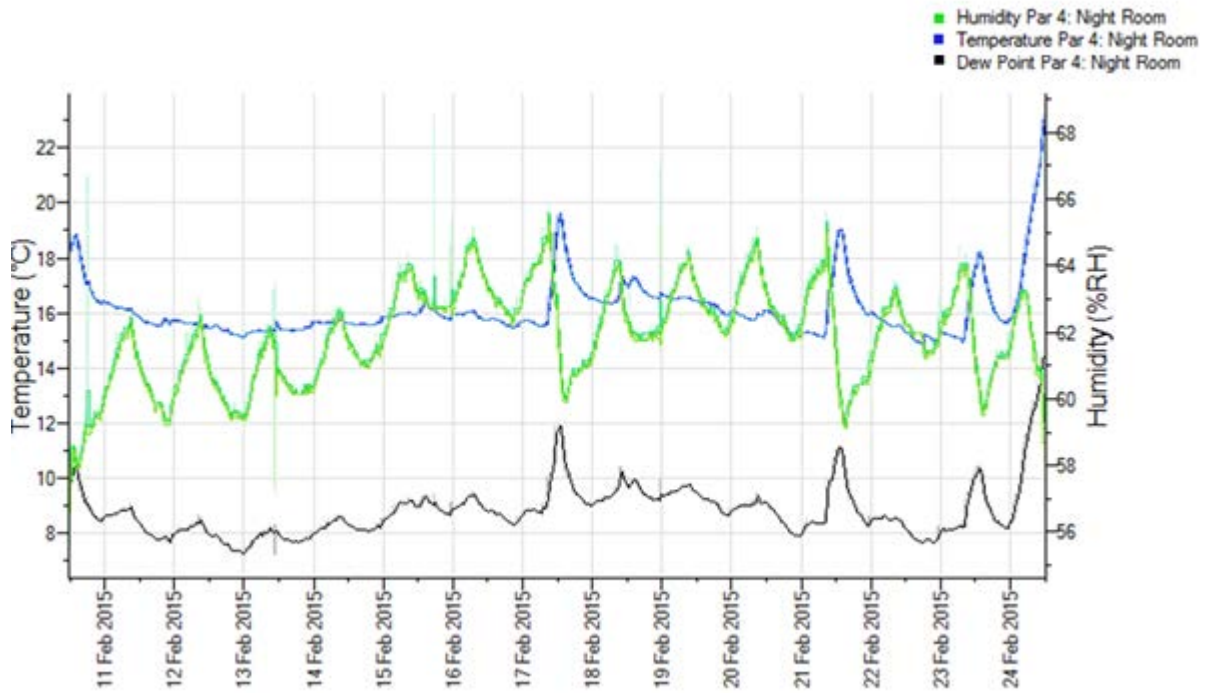


Figure 6-11 Caroline's night room measurements

### 6.5.3 Struggling to keep warm

*"I feel cold inside"*

Caroline described struggling to stay warm at home, despite wearing multiple layers of clothing in the home. At the time of wearing all of these layers the room temperature was above 20°C, and this did not provide Caroline with a comfortable feeling of warmth. Caroline said that she had *"never felt as cold"* putting it part down to getting older but also that it was *"not a warm flat"*. Talking about when she was younger she recalled her mother grumbling at her to *"get some clothes on"* because she never felt the cold.

She had lived in three flats in the complex, for her, this was the coldest. The flat itself was mainly below 22°C through the data collection period and in the last 5 days the average temperature appeared to drop by a couple of degrees (Figure 6-10). For Caroline, the flat and its heating was not providing enough warmth to reach her level of thermal comfort, leading her to put on extra layers to keep warm.

### 6.5.4 *"god knows what it's cost me"*

As far as possible, Caroline used her storage heater to keep her home warm. Caroline was reluctant to use her electric heaters, due to the additional cost. However, for Caroline to feel comfortable she said she needed to have both the storage and electric heater on in the living room saying *"it's lovely and warm when that's on, gets it nice and warm"*. The cost of using the electric heaters in the flat prohibited her from doing this saying that the electric heater was a *"bogey"* with the cost of using it *"coming out of my bank"*.

During a recent problem with the storage heater Caroline had to rely on using the electric heater to keep her warm, much to her annoyance saying *"god knows what it's cost me, but I've had to keep warm with that"*. Caroline described wanting to have a higher temperature in her living space to be comfortable and wanted temperatures higher than shown in Figure 6-10.

### 6.5.5 Concluding comments

While the flat was not the coldest observed in this study, Caroline was struggling to reach her level of desired warmth to feel comfortable. The problems with the storage heater suggested that her financial situation may not be strong or are at least was preventing her from heating her home to her desired level. Caroline was also having difficulty in managing bill payments, and the support of her nephew seemed to have been crucial in this regard.

Caroline did not appear to have an extensive support network. She described a poor relationship with her accommodation manager, and disliked her handling of the repair of her storage heater. But it was not clear this potentially weak support was having a detrimental effect on her warmth experience at the time. For Caroline having to rely on an electrical heater, and its accompanying cost, was having the largest effect on her warmth experience.

## 6.6 Case 5 - David

*"I mean not to be over warm. Obviously I've got to be comfortable, that's the thing."* (David)

### 6.6.1 David

David was 71 and lived with his wife in a semi-detached home. They had moved into their current property nine years ago, to be closer to their family. David had two daughters, one living nearby and the other did not live locally. David had been fully diagnosed around seven years ago with a triple dementia consisting of Vascular, Lewy bodies, and Parkinson's. His initial symptoms of dementia started around 10 years ago, and prevented David from continuing in employment. Through his dementia David experienced short-term memory loss and increasing mobility problems. His condition had progressed to the point where communication was a challenge, particularly in terms of expressing his needs. Daily tasks were also a struggle, for example while David could dress himself, clothes had to be laid out for him and he had difficulty showering on his own. David and his family described the fact that he also had additional difficulties including: recognising objects, such as his

jumper; suffered from a disturbed sleeping pattern; and his wife felt that he *"doesn't move about very much"*, leading to him feeling the cold more. For David's family, his condition had progressed to the point where he *"couldn't be on his own, I don't leave him on his own"*. David's dementia appeared to be one of the more advanced of the participants in this study.

Due to these issues, David's wife had taken on all of the household tasks, with David no longer able to provide any support, *"He can't even make a cup of tea"* (David's wife). David's wife had to retire early to care for David. Combined with an endowment that failed, David and his wife ran a tight budget. As illustrated in Figure 6-12, David's wife was his primary carer, with support from her family, day centres, respite care, and a professional carer that came round once a week. David's wife was managing her own long-term health problems, which severely limited her ability to sustain even low levels of activity, such as gardening. When David's wife had been in hospital their local daughter and grandson were able to provide support for him at home. However, since this time David's wife felt his condition had progressed to the point where dementia specialised respite care, that they had used previously, would have to be used in the future, organised by their eldest daughter. Overall, David's family described his care at home as a team effort, with his wife and daughter in daily contact; with his local daughter saying *"we like to do things together"*.

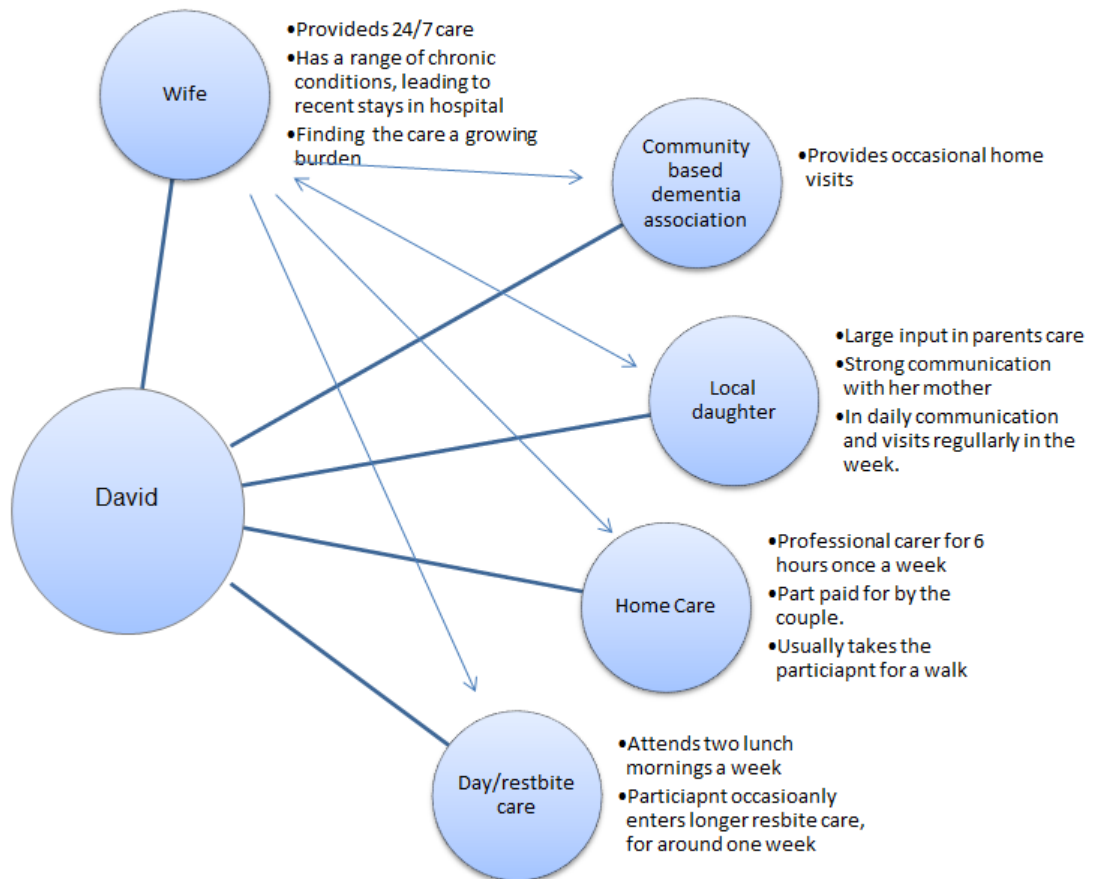


Figure 6-12 David support network

### 6.6.2 Warmth at home

Keeping warm at home was a priority for David and his wife: *"I think it's essential to keep warm really"* (David's wife). With this they both placed spending money on keeping warm as a high priority: *"it's going to cost more but you've got to have it"* (David). David's wife also saying that they didn't *"smoke. We don't drink very much because we don't go out. So to me our enjoyment is being warm"*. For the most part David felt *"we manage to keep warm"*, and so it appeared that for most of the time David was comfortably warm at home. It is worth noting that his family believed David felt the cold more since his diagnosis with dementia. In particular, they noted that David *"doesn't move about very much so he feels the cold"* (David's wife). The health conditions of David's wife influenced her need to keep warm at home as well.

David's home was heated by a gas fired central heating system and a gas fire in the living room. The central heating system, placed on a timer, was used for most of the home heating. The extra gas heater in the living room was used in

a flexible manner, to provide additional warmth. It was used when they had just come in from outside, during colder periods, or if they are waiting for the central heating to click on. The central heating was set to come on twice a day, but, through the previous few months of cold weather, it had been on for most of the day. The heating was solely controlled by David's wife, as David no longer had the ability to light the gas fire himself or control the central heating system. They had extensive work done to improve their home, including loft insulation, double glazing, a new front door, and a new central heating system. The new boiler had been installed two years ago under a government scheme for those on pension credits

External temperatures (Figure 6-13) ranged mainly between 0°C and 10°C during data collection; only going above 10°C once on the 11<sup>th</sup> day of recording. The internal temperatures show a daily variance consistent with David and his wife using their central heating set to a timer rather than a thermostat. There appears to be a reasonably consistent daily pattern of heating with temperatures ranging between 16°C and 23°C in their day room. Their night room follows a similar day night cycle of heating, from the central heating, but did not reach such high temperatures, not exceeding 20°C. The humidity readings (Figure 6-14) were in a healthy range mainly between 40 to 60 % relative humidity. This is in line with the good use of heating within the property and good insulation throughout.



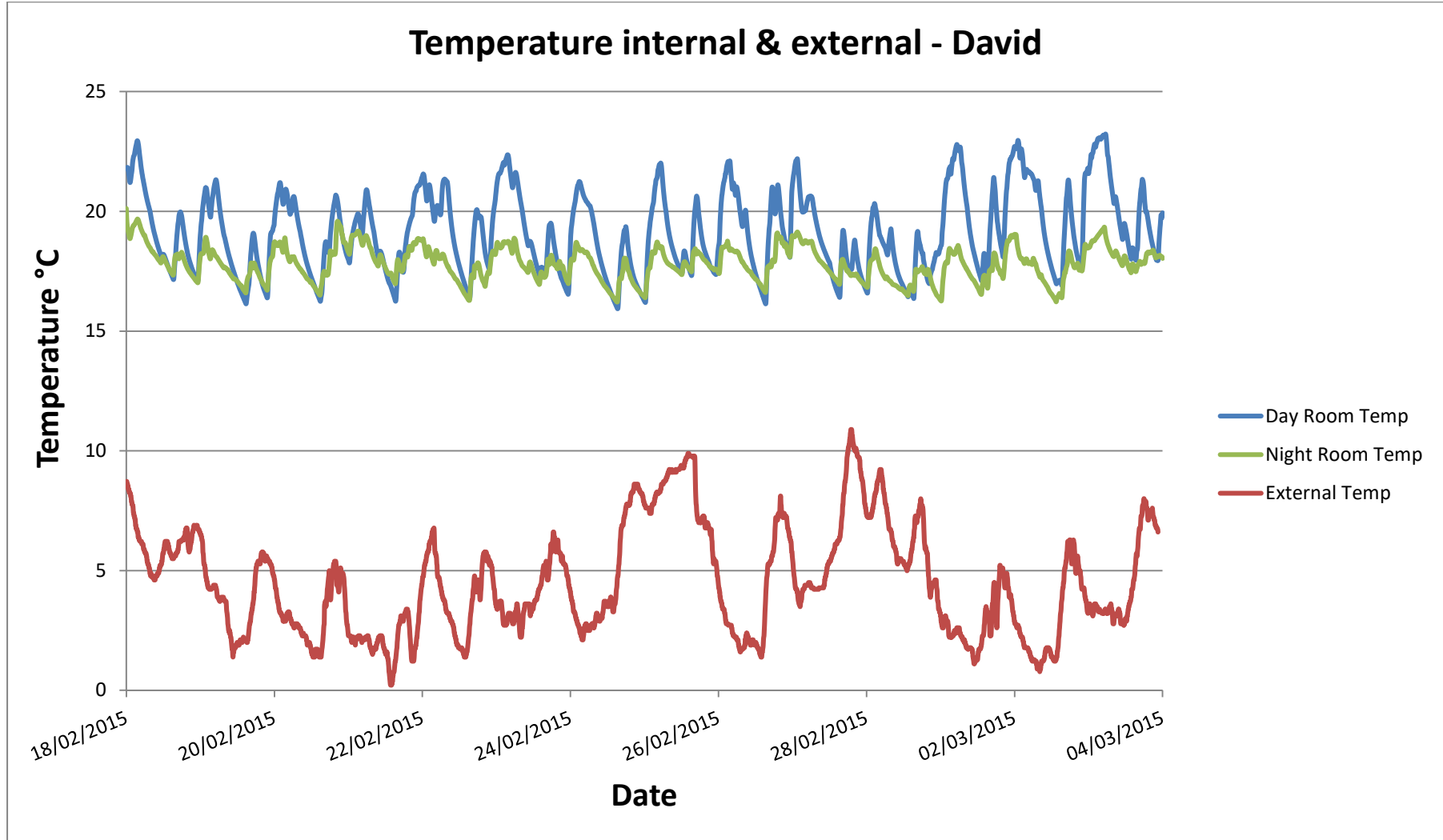


Figure 6-13 David's temperature measurements

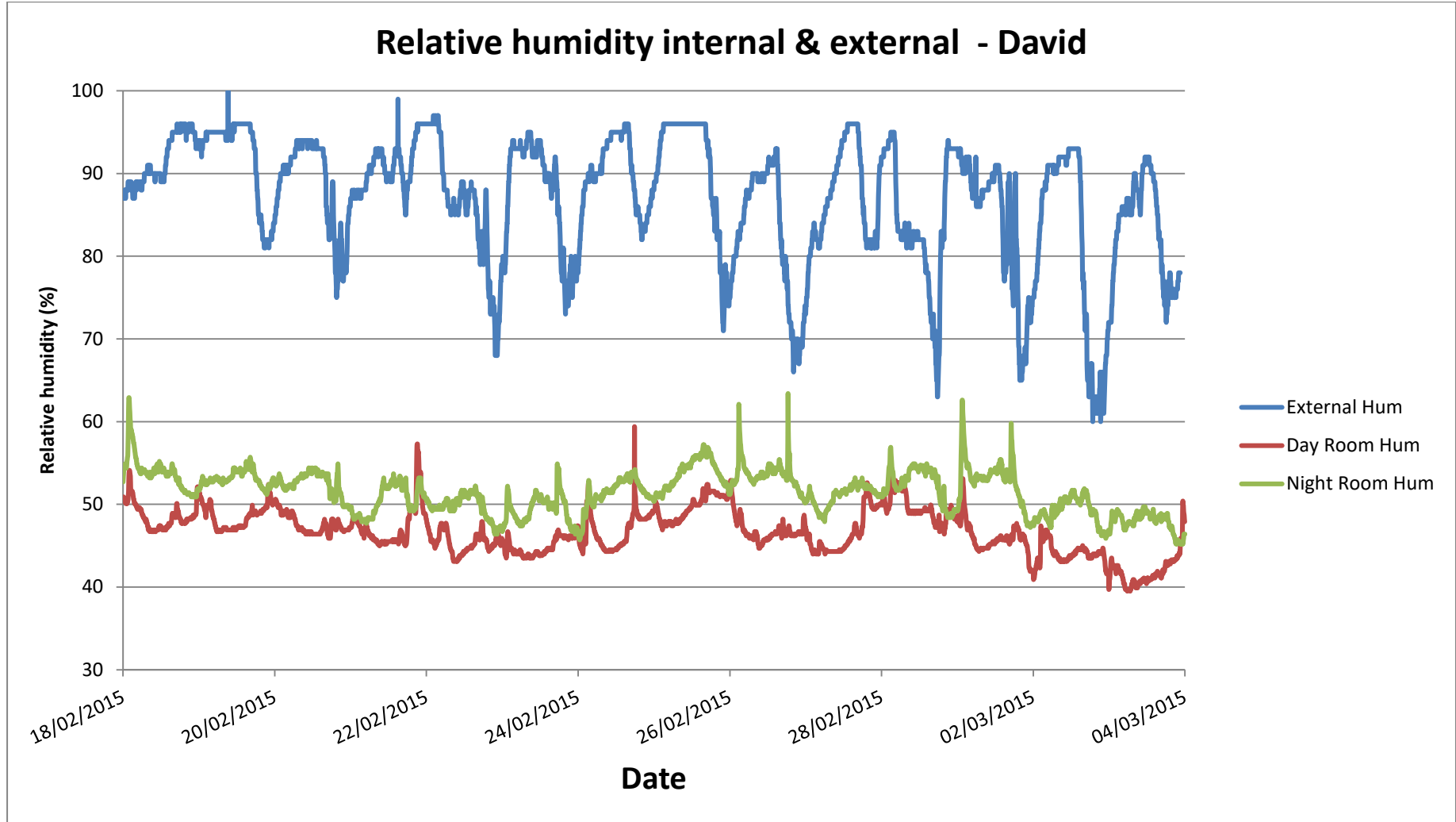


Figure 6-14 David's humidity measurements

### 6.6.3 *"he can't find the words"*

For David and his family, his dementia was making it hard for him to communicate effectively with people, due to an inability to find the words needed, changes to his short-term memory, and difficulty in recognising everyday objects. This was something David was finding frustrating: *"embarrassing, I mean you can talk to somebody and then you, you try to carry on and you can't"*. David attributed some of this difficulty to this difficulty to his short-term memory problems *"it's just I forget everything"*.

When David felt the cold he and his wife said the first thing he would likely do is come and tell her that he felt cold, with this she could decide whether to adjust the heating or suggest he could put on a layer of clothing. His communication problems were making this harder for him. David's daughter described how *"sometimes he can't remember the word for jumper"* so it could take longer for her to understand. Additionally, David's family said that he sometimes had difficulty recognising objects, such as his own jumper, limiting his ability to make his own warmth adjustments.

David's daughter and wife both described that in the end they understood what David was trying to get at and usually guessed that he was cold. David's daughter spoke of *"prompting"* him with suggestions of clothing he might need or be looking for, when she believed he was cold or was struggling to find the words.

### 6.6.4 **Family as a team**

*"we'll work out things together usually"*

David's family described working closely together to support his wellbeing and issues with the home. Since David's diagnosis of dementia his wife had taken on household responsibilities, such as managing bills, that he had previously been under the control of David. David's daughter felt that her mother sometimes needed a bit of a *"boost confidence-wise"* in contacting people to manage paying bills or push forward work that was being done on the house. Their daughter and grandson had been particularly helpful in using technology, such as using the internet, email and adjusting their modern boiler.

Due to David's wife's health conditions, their daughter and grandson acted as their emergency contacts. Either to provide direct support in their home, as their grandson had done on a planned trip to hospital, or as their daughter had done to arrange for David to go into respite care. There was a very close relationship between the family members spoken to in this case, with daily communication.

#### 6.6.5 Concluding comments

David's home temperatures (Figure 6-13) appear to be quite stable and reflect his and his wife's priority for keeping warm at home, and willingness to use the heating. David himself described feeling warm most of the time at home, but, his family talked about him feeling the cold more than he used to, putting this down to his decreased levels of activity. David had difficulties communicating his warmth and wider needs due to a combination of his short-term memory, language problems and the fact that he sometimes had difficulty recognising objects. His wife and family discussed being used to these problems and for the most part being able to recognise his needs, including warmth related ones. His family were working closely together supporting David's wellbeing at home.

### 6.7 Case 6 - Tom

*"I see to it all. He doesn't know how to put the heating on now."* (Tom's wife)

#### 6.7.1 Tom

Tom and his wife were both 84 and lived in a bungalow in a remote suburb. They had lived in their home for over 50 years. Tom was a retired worker from heavy industry who had been diagnosed with Alzheimer's type dementia for around 10 years. He was in the late stages of dementia and required 24 hour care, provided almost entirely by his wife. She had a series of her own long-term health conditions, that made managing Tom's care an increasingly physical and emotional burden.

Tom's general health was described by his family as being in a good state. However, his activity levels had decreased markedly with the progression of his dementia and he was generally sedentary. In the words of his wife, he *"just*

*sat about*", and had become *"so plump"*. Tom's dementia had produced pronounced short-term memory loss, changes in behaviour, e.g. aggressiveness, loss of ability to self-care, and he had lost control of some bodily functions, e.g. incontinence. The severity of his dementia had led to large changes to his habits and behaviour; for his wife it wasn't *"him anymore"*. Initially talking to Tom the severity of his dementia was not immediately apparent, he had become adept at holding a conversation, despite the effects of his dementia. Tom's son said a *"stranger can come and have a perfectly good conversation with him. And my dad's probably talking gobbledygook"*. Tom had the most advanced dementia of any of the cases. For most people with Tom's severity of dementia they would be in a specialist residential home, this was under discussion at the time of data collection. Their son described the attentive care his mother had provided Tom saying he *"had a damn good innings"* and *"put that down to the care that my mum's been giving him"*.

Tom's wife had always managed the bills payments at home and she described their current situation as manageable and not having to dip into their savings. She said that their income was *"sufficient to allow us to have plenty of heat"*. Though, recent reductions in government spending on fuel payments were a frustration for her.

Tom's wife was providing him with the majority of his personal care needs (Figure 6-15). At the time of data collection, professional carers would arrive every morning to wash and dress Tom. This had been set up at the request of their GP, with his wife saying *"I didn't request it at all"*. The cost of this care came out of the couple's budget and Tom's wife was keen for this service to stop at weekends, saying, *"I wanted my home back"*. She was, however, very happy with Tom attending three activity and lunch groups weekly, describing these as providing respite to her care along with physical and mental stimulation for Tom. Health care professionals and social services were talking with Tom's wife about providing further support at home and the possibility of more permanent residential care. There was, however, scepticism from their son about the intentions of social and health services towards his parents and

their money saying they *"dangle the carrot, get you used to it! And then say sorry but you've got to pay for it"*.

Tom's wife described feeling isolated in her local community, with her family being their only regular visitors. Their son and daughter both live locally, but, only their son was able to provide support., Their son had practical skills and expertise and was able to, help his parents with the repair and maintenance of the physical structure of their home, including their heating system.

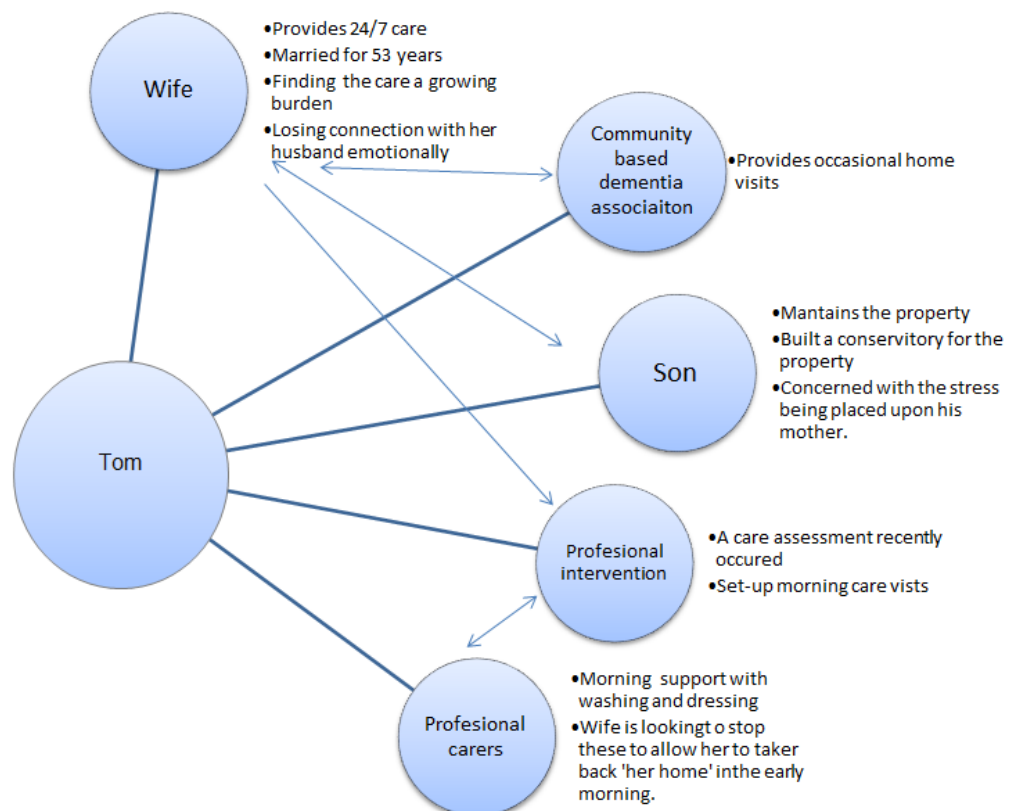


Figure 6-15 Tom's support network

### 6.7.2 Warmth at home

According to his wife Tom felt the cold more than he previously had. It was difficult to gain an accurate answer from Tom on how he judged and maintained thermal comfort, due to the fact that Tom had difficulty in communicating. Consequently in this case most of the details on Tom's views and approach to warmth have come from his wife and son. His wife had noticed Tom struggled to reach a comfortable temperature, saying *"he does feel the cold very much"*. Tom's son described a lack of a regular pattern to how Tom experienced warmth and cold; Tom could be outside in winter not

wanting to put a coat on or in the summer being inside and feeling "*a bit shivery*". But for both his wife and son Tom's thermal comfort was important, and they made steps to make sure he was comfortable, including changes to the property.

Their home had a 97% efficient thermostatically controlled condensing boiler installed two years ago. The central heating operated during the day but did not operate between 11pm and 8am in the morning. There was an additional wall mounted gas fire in the living room, used as a top up if they felt cold. The day room temperatures (Figure 6-16) show a regular daily heating cycle, mainly ranging between 17°C to 26°C but peaking at around 28°C as outside temperatures increased. The data collected in this case went into spring, and the second half of data collection saw a marked rise in external temperatures (Figure 6-16). While the night room temperatures do follow the same daily heating pattern they are colder than the day room. At the lowest point, Tom's night room drops below 15°C, but overall it was mainly in a safe night time temperature range for older people. Tom could no longer operate any of the heating systems, as he once had; it was all under his wife's control.

The relative humidity readings in Figure 6-17 show the day room's readings to be in a range safe to health, mainly between 40%-60%; the cooler night room readings were regularly of 60% relative humidity. In the past, Tom's son had noticed rising damp in the home and fitted a damp proof membrane to prevent it.

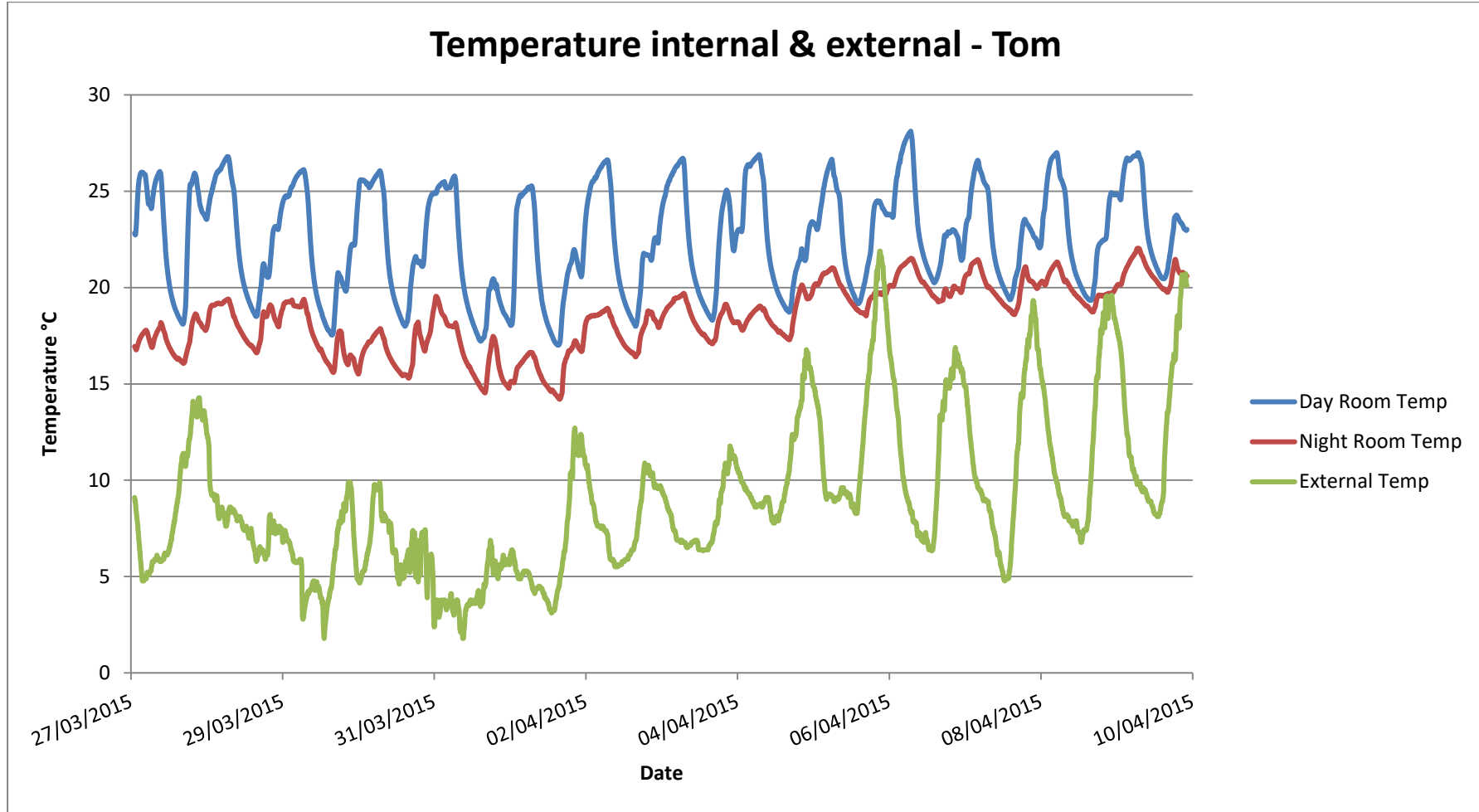


Figure 6-16 Tom's temperature measurements



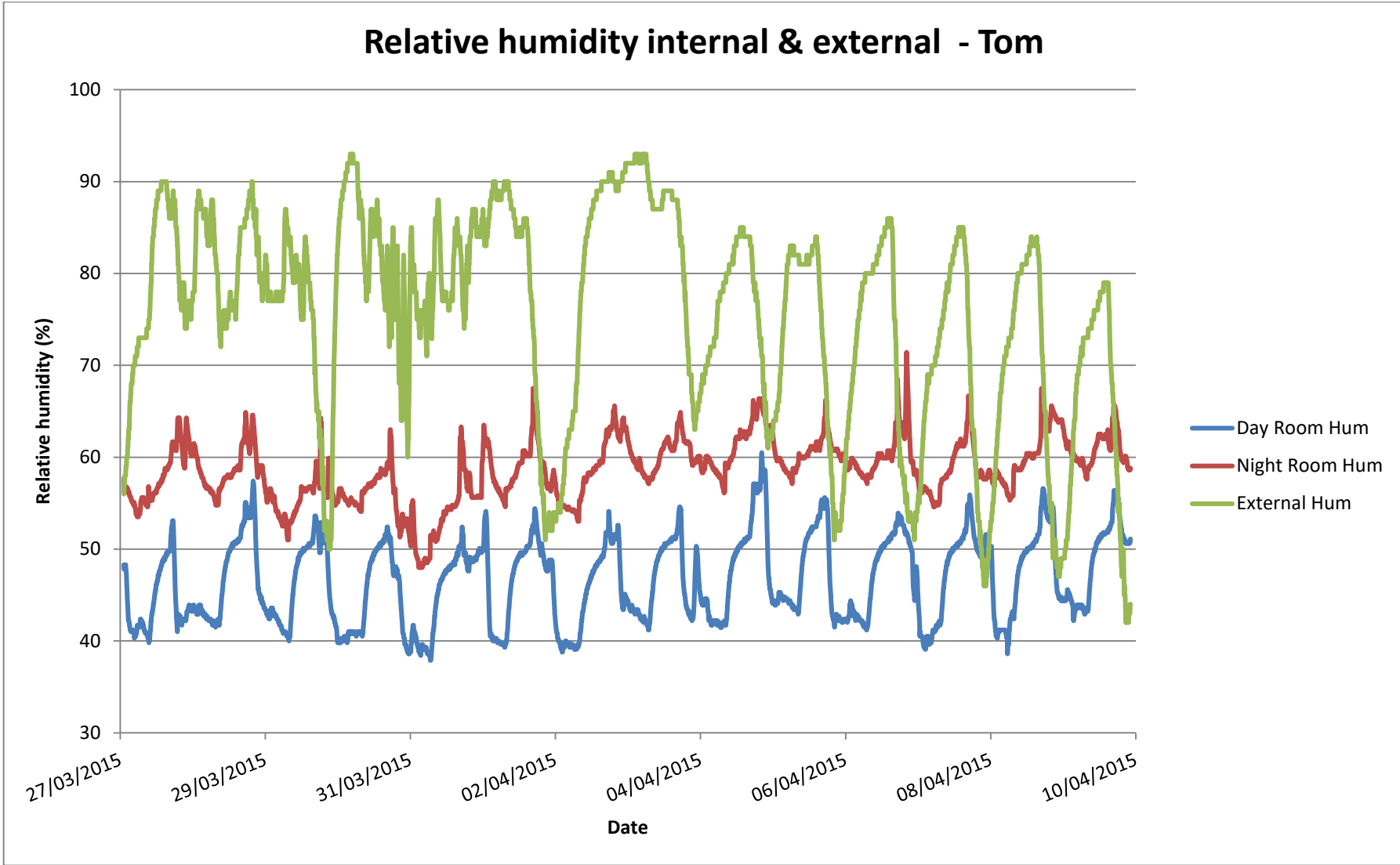


Figure 6-17 Tom's humidity measurements

### 6.7.3 Family maintaining the home

*"Me, I don't accept it, it's unacceptable."* (Tom's son)

Tom's home had seen extensive renovations carried out by their son, over the last two years. Their son was also their first point of contact for any acute problems with their home and heating, with Tom's wife saying *"if I need anything I let him know"*. The renovations had included cavity wall insulation, the building of a conservatory, installing a new boiler, re-plastering, and placing a damp proof membrane in the property to prevent rising damp. Their son filled a role that Tom previously would have been capable of. An example of this is when rising damp occurred in the front room of their property; Tom's son said she *"doesn't notice these things"*. In the past, Tom's son felt he would have taken action to correct the problem but *"because of his condition with the Alzheimer's and dementia, he wouldn't think twice about doing anything about it"*.

Due to his wide range of building skills, their son was able to take an active role in helping them to maintain their property and support their warmth at home. The changes to the boiler and insulation in the property allowed Tom and his wife to *"have the heating on longer"* with there not being *"much difference in the money saving side"* (Tom's son). While it is not possible to know how Tom's experience of wellbeing and warmth at home may have been different without the support of his son, it appeared that Tom's son was playing an important supportive role to his parents, in a way they were no longer able to due to their age and health conditions.

### 6.7.4 Concluding comments

Tom presented with the most advanced dementia of any of the participants, at around 10 years since diagnosis. Tom's wife was providing him with a level of care that their son attributed to Tom's relatively good standard of health and wellbeing at home, despite the health long-term health conditions that she had. The care situation for Tom and his wife was in flux at the point of data collection, with health and social care professionals discussing ways they could provide support for Tom in his home. A potential path for Tom to be moved into residential care was also under discussion, though at the time Tom's wife was apprehensive at the notion of Tom leaving their home.

Tom's son supported his parents through the maintenance and installing of improvements in or to their home. These improvements had enhanced the heating system and insulation in the property. Their son expressed a strong desire to allow his parents to live comfortably in their own home. The TinyTag recordings reflected the standard of heating and insulation in the bungalow, with day room temperatures in particular being in a safe temperature range. Making further adjustments to warmth at home was not a priority for Tom's family, as the situation was for them in a stable state. The future care provision for Tom was a more pressing concern.

## **6.8 Case descriptions summary**

The cases discussed in this chapter capture a range of different contexts in which a person with dementia lives, in terms of their home, health status, age and care situation. The case descriptions also reflect a diversity of warmth experiences of people with dementia in how they view and approach heating and warmth at home. The temperature measurements from the TinyTags and the external readings were found to be very useful in providing context to the description of warmth at home by the people with dementia and their family, allowing for the emergence of further assertions in the cases.

## **Chapter 7. Findings: Thematic framework and Theme 1: Losing me**

### **7.1 Introduction**

The previous chapter examined the cases in isolation, highlighting narratives that emerged from each case with respect to the research question. This chapter describes an overarching thematic framework of 'Trying to stay safe in winter' and the first of three themes in this framework. The thematic framework presents a story of people's physical and cognitive changes that affect their capacity to stay safe in winter. The themes emerged through the process of inter-case and thematic analysis, described in Chapter 5 section Figure 7-1.

### **7.2 Thematic framework: Trying to stay safe in winter**

In what started initially as seeking to explore participants' experience of keeping warm during winter, a deeper and more profound narrative emerged: that of 'Trying to stay safe in winter'. It identifies the ways in which dementia, and other age related problems, were threatening the ability of the participants to live at home. This is explored through the themes of 'Losing me', 'Hanging on', and 'Winter wellbeing'. Together they describe how participants and their carers perceived a range of physical, psychological, and social factors that appeared to threaten their ability to function safely at home. 'Trying to stay safe in winter' also captures the ways in which participants and their family members responded to maintain a state of stability and reduce the likelihood of harm. The central concept is organised around three themes: 'Losing me', 'Hanging on', and 'Winter wellbeing'. Through these themes, a narrative of 'Trying to stay safe in winter' is played out (Figure 7-2).



Figure 7-1 Thematic framework

### 7.3 A story of 'Trying to stay safe in winter'

Participants were confronted by dramatic challenges and changes to their physical and cognitive capabilities which made it hard for them to achieve safety, comfort, and stability in their lives. David's communication difficulties, Caroline struggling to manage her finances, or Andy's increasing frailty and fall risk, were all challenges to people's safety. 'Trying to stay safe winter' is not a goal unique to these cases or people with dementia, but participants were presented with physical and psychosocial challenges, such as communication and social isolation, which increase as dementia progresses. To remain safe at home in winter it will likely require a person to be willing to accept ever-greater levels of support from those around them.

The ways in which participants' sense of self was being eroded through dementia, and to a lesser extent old age, are highlighted in the theme 'Losing me'. Along with affecting a person's willingness to accept caregiver support, the process of 'Losing me' could be argued to be a broader threat to psychosocial wellbeing. People were trying to stay themselves as their cognitive and physical capabilities degraded. With the support of family members, people were taking steps to hold

on to the person they were, such as maintaining the social connection and social roles they were accustomed to.

Participants appeared to focus on trying to hang on to the world they had known, to create a sense of continuity and stability in their lives; this is captured in the theme 'Hanging on'. Physical and cognitive changes of dementia appeared to be causing slips in control. At these moments of slipping participants were not always seeing the risks to their safety and wellbeing, they tried to keep going as they were accustomed. Family members, with their nuanced understanding of their loved one, were playing a vital role in these cases of helping to support, or hold them up, when their control and safety was starting to slip. At times participants resisted support. This resistance appeared connected to participant's desire to remain in control of their world.

Participants had a desire for comfort, safety, and stability, keeping warm was important but not participant's priority, this is captured in the theme 'Winter wellbeing'. Participants, and their family members, had multiple complex long-term health and conditions to manage simultaneously, including dementia. Whereas it appeared that participants and their families, considered warmth at home was either being effectively managed or managed well enough to not be of a great concern. This is an important finding to guide future interventions to people with dementia's warm, wellbeing and safety at home in winter.

## 7.4 Theme: Losing Me



Figure 7-2 Thematic framework: Losing me

The first theme, in the framework of 'Trying to safe' during winter, is 'Losing me' (Figure 7-2). The theme 'Losing me' captures, for the participants in this study, perhaps the most damaging effect of their journey through dementia. In this theme, the term 'sense of self' will be used to capture features that a person takes special pride in or views as unchangeable, and socially consequential. Participants' experience of trying to hold on to who they were serves as a backdrop to how participants and their loved ones viewed and acted on safety in winter, with participants wishing to maintain continuity in their lives. For some participants the very word 'dementia' being taboo or avoided.

The experiences of participants 'Losing Me' are captured through three sub themes: 'Trying to stay me', 'Keeping my place', and 'Holding onto me'. These themes tell the story of the challenges participants faced as their sense of who they were was at risk. The initial sub theme 'Trying to stay me' discusses some of the challenges participants had to their sense of self, such as cognitive changes brought on by dementia. The second sub theme 'Keeping my place' illuminates the links made in the cases between participants sense of self to their physical

and social surroundings. The final sub theme 'Holding onto me' explores how participants, with the support of their caregivers, tried to maintain who they were through the challenges they faced, and how at times this was not always possible.

### 7.5 Trying to stay me

This sub theme captures the challenges people had staying who they were, while living with the progress of dementia and old age. As participants' conditions progressed, they appeared to regress from the person they were and revert to an earlier outlook in their lives. Coupled with this change in outlook, people with more advanced dementia struggled with communication, presenting a difficulty in expressing themselves and altering how others perceived them. In addition to dementia, people also faced the challenges of old age, such as frailty, retirement, and bereavement. Due to their dementia, these changes or events of ageing could present particular 'Trying to stay me'.

Confrontation with the diagnosis of dementia appeared as a challenging moment for a participant's sense of who they were. In the interviews, those in the earlier stages of dementia were noticeably reluctant to discuss their diagnosis of dementia. While discussions on diagnosis were not an intended focus of conversations, its effect on people 'Trying to stay me' emerged as a thread in the cases. A reluctance to engage with the diagnosis was noticeable for those in the earlier stages of their dementia. When talking to Andy, Alice, and Caroline the word 'dementia' itself felt taboo. To move forward our conversations it seemed better to me as the interviewer to avoid discussing their condition directly, or use terms such as 'memory problems' instead of dementia.

Though Caroline described struggling with confusion when trying to pay bills and doing her clothes washing, she did not appear to make the connection between confusion and dementia, saying:

*"Well dementia's when you're forgetting, isn't it? I mean you can't say I've got dementia and I'm full of pain, because it isn't pain ". [Caroline]*



Some caregivers also showed a reluctance to engage with the diagnosis of dementia. Andy did not reference his dementia and his family expressed strong doubts about his diagnosis. When asking Andy's son about his father's diagnosis he turned the question around saying "*do you think he's got dementia?*" whilst his daughter-in-law directly challenged the diagnosis suggesting that she felt he no more had dementia than he was "*flying to the moon*". She explained the fact that he had received this diagnosis by suggesting that Andy had likely "*bamboozled*" or "*conned*" those assessing his memory, as he knew with a poor memory score "*he'll get money*". This is an interesting perspective and it is not clear why Andy's daughter in law was sceptical about his diagnosis but it is clear that the family still had a sense of who Andy is and/or perhaps did not want to engage with losing Andy, as they knew him.

As people's dementia progressed, the cognitive changes it brought presented further challenges 'Trying to stay me'. Family caregivers spoke of their loved one living more in the past. Jim's elder daughter made a link between her father's memory changes and changes to the way he perceived the world around him. As Jim's dementia progressed his daughter described him not being able to "*remember yesterday or the day before, but then you can't remember last week or last month or last year... so he lives a lot more in the past*". In a poignant moment, Tom's wife described struggling to see the man in front of her as the man she loved, and it seemed obvious from her demeanour that this was an immensely distressing process for her to go through. Due to the severity of his dementia, it was not possible to capture how Tom felt his sense of self was being challenged. Nevertheless, it was his wife's view that he now lived in the past and was "*right back in his childhood*".

For those with more advanced dementia their ability to hold a conversation and express their needs to those around them had become a considerable challenges 'Trying to stay me'. Communication problems for David were challenging in terms of being able to express who he was as a person. When trying to talk to somebody, David said he found himself forgetting words and losing the flow of conversation

*"Well it's embarrassing, I mean you can talk to somebody and then you, you try to carry on and you can't, you've forgot. But you have to keep going" [David]*

David's family felt that his symptoms of dementia, particularly communication challenges, were altering how he viewed himself and his place in his social world, weakening social ties with his family and leading to him feeling isolated.

*"he'll just tell us he's crazy and mad sometimes and stupid, and that's just so heart breaking to hear because I know he's not crazy or mad. But to him I think that's how it feels. I think he does feel so isolated sometimes. So I think Alzheimer's for me is, I think it's just, for the person, they're just shut in aren't they?" [David's daughter]*

Tom was also having difficulty in communicating, but with his more advanced dementia, shared meaning with his wife had become very difficult. Tom's wife described how he did *"not always understand the meaning of words"*, she went on to say Tom's making *"things up, it's as if he's telling lies, but he believes it in his mind"*. Tom's wife went further saying we *"don't have a conversation because he can't remember the things we've enjoyed in the past. Holidays or anything"*. In Tom's case not only were his symptoms a challenging him to stay himself but also for his wife to continue to see him as the man she had known for 70 years.

While changes due to dementia were challenging to people's sense of self, these effects did not exist in isolation. Participants were also experiencing other issues that those in the older population experience, such as leaving the working world, changing health status and other losses that were challenging to a sense of self. The death of Jim and Andy's wives presented a significant challenge to their sense of self, as it would for a person without dementia. Jim's wife passed away a few years before his diagnosis with dementia and at the time his family supported him with a move closer to them, and away from his marital home.

*"We moved him in there after my mum died, just because he needed to get away" [Jim's elder daughter]*

This could have been a very positive change for Jim but also presented challenges to how he viewed himself, with loss to the easy access to the social

community, he was accustomed. Andy had been widowed in the last year, it appeared in conversation with him it had noticeably affecting how he lived his life.

*"Well when she was here I used to come back for one o'clock. If it was after one she was worried.... But now I don't bother. I can sit down and watch the world go by."* [Andy]

It is difficult to say in what way, if at all, dementia affected Jim and Andy in dealing with the loss of their partners. However, dementia added another layer of complexity to the situation.

Alice's early onset dementia had affected her regular routine, being forced into early retirement. Alice saw her difficulty in using computers as a particular barrier that had prevented her from working. As she explained:

*"it's the remembering. And I think if you're not doing it every day as part of your job you don't always remember".* [Alice]

David similarly took early retirement from a clerical position when his writing started deteriorating and mistakes were made, though it was not until four years later that he received his diagnosis of his triple dementia. In this way, dementia appeared to have changed Alice and David's role in society, presenting a difficulty 'Trying to stay me'. The interaction of life course events and dementia increased the challenges of holding on to who they were as they aged. Whilst the available data limits analysis of this issue, it does identify the challenges to self-resulting from the intersection of dementia and non-dementia related life course changes, e.g. retirement and bereavement.

The cognitive changes associated with dementia were challenging people's sense of who they were, seemingly causing some people to live more in the past. Communication difficulties appeared to present challenges to how people expressed or projected themselves, communicated their needs, along with how others viewed them. The challenges to communication that emerged were more obvious in cases where there was more advanced dementia, with David becoming frustrated at not being able to follow and engage in conversations.

In addition to dementia, people faced life changes, such as bereavement and retirement, which people without dementia are also subject to. Dementia adds an additional layer of complexity to already challenging life changes. In the later sub theme, 'Holding on to me', participants and caregivers' approach to managing some of these challenges will be explored. First, there will be an exploration of how participants and caregivers viewed physical and social place as linked to a sense of self and how dementia threatened people's ability to stay in their own home, sustaining a link to who they were.

## 7.6 Keeping my place

This sub theme captures the links participants made with 'Keeping their place', physically and socially, to a sense of who they were. People's home and community appeared to be linked to a sense of self. With the challenges and changes that dementia and ageing were creating, people's homes and community could be an anchor to a sense of who they were. Conversely, the loss of a person's home or community, in the way that they knew it, could make it harder for them to keep their sense of place and self. Community also appeared to have the potential to act as an anchor to people's sense of who they were, at times encouraging social interaction. People further described how changing communities' altered social interactions and connections they were accustomed to. The theme will begin by exploring the links between home and a sense of self.

For Andy, Alice, and Caroline their attachment to their home seemed to be linked to a sense of who they were. For Caroline her rented sheltered accommodation did not have a nostalgic link that a lifelong home might have. Caroline *living in sheltered* provided her with a sense of security and control, while other aspects of her life, such as financial management, were moving out of her control.

*"I mean my main thing is living in sheltered is safety, I'm safe. Because you could give me a house on the outside, you can furnish it, free rent, no thank you. I'm safer in here, and I think once you're in sheltered housing, you're safe, and this is my main thing in my life, to live in here, and I feel I'm safe."* [Caroline]

Caroline had been happy to move between different flats in her sheltered accommodation; she was discussing moving to a ground floor flat with her nephew at the time of the study. However, for Caroline, there would likely have needed to be a dramatic change in her circumstances for her to consider a larger move, such as to residential care. Alice's attachment to her Victorian home appeared to be more focused on her home itself and her need to stay in it, rather than the sense of security expressed by Caroline. While normally very softly spoken in conversation, Alice spoke with great passion and force when she expressed her intention to remain in control of and continue to live in her own home as she wished.

*"I don't find it a problem, you know, I mean it's my choice to be in the house and just heat the room that I'm using. And This house, it's my choice to have this house and I don't want to move from it. I really don't, I love this house; I don't want to move from it."* [Alice]

Alice's desire to keep her place, her home, led her to consider increased use of her heating if cold *"was making problems for the house"*, by causing damage to her property. But, she was reluctant to turn up the heating to keeping herself warm. Alice's desire to avoiding damage to her home appeared to be a greater motivator to turn up the heating, compared to keeping herself warm. In different ways Alice and Caroline's homes were a symbol of their security and independence, and this came with a keen sense of wishing to stay there. It was clear that they wanted to hold on to their homes for as long as possible.

In Andy's case, he expressed an intense desire to remain in his home for the rest of his life; though his wife had recently passed away following a fall down their stairs, only one year ago. When asked if he was considering moving he was clear about his desire to stay in his home:

*"Yeah, [I'll stay here] while they carry me out... if worse comes to the worst I shall have to have a bed downstairs"* [Andy]

Andy's family recognised his desire to stay in his home, with his daughter in law saying *"he will not go in a home"* even if his house was *"falling around his ears"*;

he had expressed his desire to *"die in his own home"*. For Andy the state of his home and his ability to manage it appeared to be rapidly declining. During the study, Andy's home suffered water damage, due to a burst pipe. In response to the situation, he filled the bath so he had some water and then turned the stopcock off rather than seeking help to repair the pipe; it was not until Andy was admitted to hospital following a fall at home that his family discovered his plumbing problems. Though Andy was having difficulty in managing his home it remained clear that he wished to continue living in his home on his own terms, in a similar way to Alice and Caroline. In this desire for living independently and to keep his place, Andy appeared willing to endanger elements of his personal safety.

Having a place in and living in a familiar community also appeared, for some participants, to support a sense of self. However, changes to community over time could alter a person's sense of their place in that community. Alice and Tom had lived in their communities for many years, though both only had a limited local network to call upon. Their communities had gone through substantial demographic change. Alice's community had become a transient student area and Tom's increasing in affluence, his home stood out as a small bungalow surrounded by larger modern homes. This limited their contacts in their local community as well as a potential detachment from the communities' shared norms and values, limiting their ability to call upon local support.

*"With us having so many students, its like made the older people become more isolated in a way. You're not seeing your neighbours like you used to."* [Alice]

Andy, by contrast, was living alone but able to call upon a diverse range of social contacts to support his home, wellbeing, and sense of who he was. Andy having lived in the area for so many years and built up strong links in the community:

*"I suspect that he knows a lot of people, and he knows what they do. He'll go and knock on their door and ask for help"*. [Andy's son]

Andy's situation, of having a network of support from friends and neighbours to call upon appeared to fill an important role in supporting his continuing effort to remain in his home, particularly with the recent death of his wife. Further, having

local people who knew him able to come round and *"play cards" [Andy's son]* or when the neighbour *"brings me a paper" [Andy]*, perhaps helping Andy to avoid 'Losing me'.

In the cases, participants' discussions of their home and community were intertwined with their view of who they were. People's homes acted as an anchor, a point of stability, as their condition and other factors pulled against their sense of self. However, the progression of people's condition, along with other factors that may accompany ageing, presents challenges to people's ability in 'Keeping their place': living in their own home and being socially active in their community. Communities changing around participants made 'Keeping my place' an increasing challenge; with communities no longer able to provide the social interactions reinforcing a sense of self, as they once had. Breaking the bonds between a person's home and community has a potential to further pull against their sense of self, a self that was already being eroded by dementia.

### **7.7 Holding on to me**

This sub theme captures how participants, supported by their families, tried to hold on to a sense of self through the 'challenges to me' they faced from dementia. The challenges that emerged from these cases were explored in the earlier sub theme 'Trying to stay me'. 'Holding on to me' highlights how people addressed some of these challenges. Social connections, engagement in activities, and supporting communication, appeared to help participants hold on to a sense of self. However, as people's dementia progressed this became increasingly difficult, both for participants and for their family.

Stable social connections can be viewed as fundamental to the creation and maintenance of any person's sense of who they are. The changes brought on by dementia and other factors associated with ageing, such as decreased mobility and memory, were affecting people's ability to hold on to their social connections. To counteract some of these changes, participants described maintaining their social connections and roles they had established through their lives, at times supported by caregivers. In Caroline's case she was resistant to a change in a

social role she had enjoyed, brought about by a new younger accommodation manager, she wished to hold on to the positive relationship she held with her previous accommodation manager. Caroline disliked the new manager's view of what their relationship and roles should be, saying:

*"She knows what she's coming in to, and she knows she's in charge. She's not the boss. I don't need a boss, none of us do... I'm forced to speak to her in a situation like that, but otherwise don't you come near me."* [Caroline]

Caroline described herself as being *"so independent"* and wanted to maintain this position and protect herself from unwanted interference. Similarly, Andy, with his strong desire to live independently, worked to keep his own social connections. Though he was at a high fall risk, he would go out daily to the local shopping area, sit, and *"get talking to some old people"*. This was a routine Andy was holding on to; though having suffered falls on the bus and at the shops that required medical attention. This simple social activity was for Andy important enough to expose him to a degree of risk.

Family caregivers also played a role in participants holding on to social connections. Both Jim and David had moved from their previous communities to be closer to their families, with this it became harder to socialise with their friends. Jim's elder daughter and David's wife were keen for them to maintain these social connections, taking them regularly to see their friends.

*"I always go to the pub on Thursday night, you know, and she takes me up there... And I've got friends up there and it's a nice sort of company."* [Jim]

*"if I can on a Thursday night I take him over to meet up with [friend] to just have a social hour and a pint."* [David's wife]

Participants, at times with the support of their family, were 'Holding on to me' by maintaining social connections and the social roles to which they were accustomed. However, it is likely that as people's dementia progresses, along with getting older, the ways in which people view and interact with others will change. This may have been the situation with Caroline's experience of her new accommodation manager, and this change challenged her in trying to hold on to who she was.



In 'Holding on to me', some participants continued with activities that they viewed as having significance to who they were. Alice had cared for family members in their later life, when they developed dementia. She had continued to attend a weekly carers group, after they passed away. Alice was keen to stress she did not view herself as someone who needed care:

*"I don't go because I want a carer; you know, I go and help them, I do some bits of voluntary work... I used to be a carer because I had my [family members] who I was responsible for both of them for several years, so I do have experience of being a carer."* [Alice]

This caring activity and role appeared to have significance for Alice; it allowed her to meet other people *"who are or who have also been carers"*, reinforcing her own view of herself as a carer. This was an aspect of her life she wished to hold on to, not wanting to identify with a new label as a sufferer of dementia.

Family members were also trying to maintain their loved one's sense of self by engaging them with their past activities and habits. David's wife helped him to continue walking in the outdoors, an activity that held particular importance to him. Though physically fit and able to walk, David's memory changes led to him easily getting lost. However, due to her own health problems David's wife could not walk with him, so she employed a home support worker that David had known for a long time to walk with him. It came at an extra expense as the *"council provide so much towards that, and I have to pay the rest...Because that's what he likes"* [David's wife]. David's wife felt supporting him with walking was a worthwhile endeavour to provide him with a better quality of life and perhaps allowing David to hold on to an important aspect of who he was for a little longer.

Communication between a participant and their relatives seemed to be playing a role in social reciprocation of a person's sense of self. As previously discussed in the 'Trying to stay me' sub theme, struggling with communication was evident in some cases, and particularly described in Tom's and David's with their more advanced dementia. David's family spoke of how they and David had to work harder with communication to get to a point of understanding his needs as he was *"struggling to find the words"* [David's daughter]. They would perhaps *"have*

*to ask a few questions or suggest a few things" [David's daughter]. For Tom, with his more advanced dementia, there had been a greater impact on his ability to communicate freely. However, Tom's family, with their understanding of his speech pattern, had a more intimate understanding of his intended meaning in conversation.*

*"A stranger can come and have a perfectly good conversation with him. And my dad's probably talking gobbledygook, you know, but the stranger doesn't know this if you understand. [Tom's son]"*

Tom's and David's families were able to maintain regular communication with their loved one to a depth that an outside carer would likely struggle to do. In this way, their families were playing a perhaps vital role of social interaction for Tom and David, and supporting their work of 'Holding on to me' through dementia. However, while Tom's family were still able to understand some areas of his communication, his behaviour changes had presented a difficulty for his wife in particular, to view him as the same man she had married. For Tom's wife it was *"sad but it isn't him anymore"*, with only glimpses of the man she loved left; *"he can make a joke. He always did joke"*. Tom's wife was struggling to see the man she known, because of changes to his behaviour and personality. Tom's wife felt he had become *"confrontational at times"* and he went as far as to *"threaten[ing] to smash my face in"*. This aggressive behaviour was also placing her in some degree of physical danger, perhaps making it harder for her to provide the emotional and physical care Tom needed at home. Their son felt she did not fully acknowledge or appreciate the changes in Tom and at times, *"she just doesn't help herself"* pushing him *"almost to breaking point"* but forgetting that *"he doesn't know what you're talking about"*.

Participants, with support from caregivers, tried to hold on to a sense of who they were as dementia progressed. The social connections, activities, and communication changes appeared to be affecting how people were able to hold on to a sense of self. The common thread between the areas discussed in this theme is the importance of how social interactions were affecting how people viewed themselves.

Maintaining social interactions and connections emerged as an approach used in holding on to a sense of self. People were at times resistant to change in their social interactions and roles, with family members keen to support those with advancing dementia keep a semblance of stability in their social interactions. For those with more advanced dementia the ability to effectively communicate and hold on to social connections and social roles was being particularly eroded. In some cases family members were able to establish joint meaning in communication by dedicating more time to their loved one. This allowed for a continued dialogue of shared meaning in a way an outside carer would likely have struggled to do, with this supporting a person with dementia's sense of self. The memory and wider cognitive function changes caused by dementia were driving the harmful process of 'Losing me'.

## 7.8 Summary comments

The journey of people 'Losing me' through dementia was apparent in all the cases. For the participants in this study, the physical and cognitive changes brought on by dementia seemed to be eroding their sense of self; with this erosion perhaps the most damaging effect of dementia that they described. The issues that were challenging people to try to stay themselves included the process of living with dementia, their progressive cognitive decline, and wider life course changes.

In these cases 'Keeping my place', emerged as an important thread in preventing 'Losing me', in terms of continuing to live in their home and community. For those living alone, there was a particularly strong voicing of the link between remaining living in their own home and their sense of self; there was a strong resistance to the idea of moving or making alterations to their home. For Andy, Alice, and Caroline remaining in control of their home from outside interference, appeared to be of strong importance to them. Their homes, it appeared, were a point of stability in their lives as their sense of self was being eroded by their dementia.

Through the challenges to who they were, participants showed an understandable desire to hold on to who they were. Participants, along with their

family, took steps to hold on to aspects of their lives they deemed to be important. These efforts in 'Holding on to me' lead into the next theme and chapter 'Hanging on', where participants losing control of the various aspects of the world around them is discussed. In this way, people 'Losing me' can be viewed as perhaps as a wider narrative of the loss of control the people experienced through their journey through dementia. However, the loss of a sense of self appeared to be the most harmful aspect of dementia, for both participants and their families.

The theme 'Losing me', capturing perhaps the most damaging effect of dementia in these cases, acts as a foundation to understanding how people in this study viewed and acted upon winter warmth and safety. Participant's desire to hold on to who they were, whether it was their social role or physical space, was affecting their approach to warmth and safety; at times constraining their ability to act. Warmth and safety decisions could be viewed through the context of threats to a sense of self and a desire to hold on to the control of their physical and social worlds. In this sense dementia added an additional layer of complexity to how people approached warmth and winter safety.

## Chapter 8. Findings: Theme 2: Hanging on

### 8.1 Introduction

The previous theme, 'Losing me', discussed participants' desire to hold on to a sense of self, through their cognitive and physical changes. In this chapter, the theme 'Hanging on' brings to light the challenges participants faced when trying to engage with and stay with the world they had known.



Figure 8-1 Thematic framework: Hanging on

'Hanging on' (Figure 8-1) encompasses the perception of those challenges to the control they had over their world, how people around them supported them to hang on to their world, and finally the process of letting go of control. 'Hanging on' contains four sub themes: 'Starting to slip', 'Not seeing the risk', 'Holding them up', and 'Letting go'. The first sub theme, 'Starting to slip', discusses the challenges that participants and caregivers faced as they tried to control the environment, provide care, and maintain wellbeing, at the juxtaposition of old age and dementia. The second sub theme, 'Not seeing the risk', describes moments when participants did not recognise risks they faced, due to their changed cognitive capabilities. The third sub theme, 'Holding them up', describes the

support provided by caregivers to enable participants to hang on to their world, along with participants' level of willingness to accept this support. Finally, the sub theme, 'Letting go', aims to capture the journey that participants and caregivers were taking together moving towards a state of greater dependence and less control for a participant. The process of 'Letting go' is seen across the cases in terms of reactive and proactive elements, both from participants and their families.

Within this theme, there emerged a story of changing control and support that has commonality to other risk taking activities as part of life. Being an amateur climber, it became natural for the researcher to frame the discussion in terms of staying on the wall, assessing the risk and trying to remain in control. As climbers make progress up a wall they are challenged physically and psychologically, at times faltering and falling. Keeping the climber anchored to the ground and motivated on the path is a belayer, a friend controlling the rope to prevent a fall if there is a falter. The journey of dementia that emerged from these cases mirrored elements of a climber's struggle, with challenges to control and at times movement from independence to greater dependency. The language of this theme and accompanying sub themes at times draws on the climber's imperative to hang on.

Participants were trying to hang on their lives, as they had known them, as their condition brought about physical, cognitive, and social changes. Staying in control of health and social care decisions, such as simply being able to do your own clothes washing, was being challenged by participants' conditions. 'Hanging on' depicts how running through the cases there seemed to be a desire for people to maintain their independence and continue to experience their life and environment as they were accustomed. However, the progress of their dementia, limited social networks, age, and associated declining health status made 'Hanging on' a significant enterprise.

## 8.2 Starting to slip

In this sub theme, the difficulties people had in hanging on to their physical and social surroundings are explored. Participants described or could be seen to be facing challenges to live their lives as they were accustomed. Discussed in this sub theme are the physical and cognitive challenges and changes due to dementia decreasing participants control over their lives. However, the effects of dementia did not exist in isolation. People were experiencing the physical and social effects of old age and other long-term health conditions. Due to these challenges participant's ability to continue to live in their own home was slipping. This was most apparent for those participants living alone.

Some physical tasks were becoming a challenge for participants. Mobility issues due to their long-term health conditions, such as joint problems and fall risk, affected people's ability to remain active. Jim spoke of several health problems:

*"I sit down quite a lot. Because I've had a pace maker fitted, and I've also had a knee joint replaced, so I've had a full service". [Jim]*

In Andy's case, his son felt *"for his age his activity [was] quite remarkable"* despite that his father was *"in a lot of pain"*. The physical challenges of Andy and Jim had resulted in them experiencing a series of falls. Jim had a professional carer twice a week to be in his home when he showered, to help him if he fell. Though Andy had experienced several falls, with the most recent leading to a stay in hospital, he was resistant to receiving further assistance. Due to this resistance, it could be argued that, Andy's fall problems were a greater risk to his safety and wellbeing compared to Jim.

The cognitive effects of memory loss and confusion were also constraining people's ability to keep physically active. David and Tom, with reasonably advanced dementia, had retained much of their physical capability; their limitation was more remembering where to go. David's wife spoke of how David *"would walk a lot more if he could go out on his own"* but she could not let *"him out on his own"*. Similarly, Tom had previously been very active, taking his son's dogs for long walks. Tom's son described how although his father's age meant it was harder for him to *"get up steps and climb into somewhere"*, it was his confusion

and reduced memory that resulted in Tom walking to *"another village further up the road"* [Tom's son] by mistake. Since then Tom's family prevented him from going out on his own. Together, physical and cognitive changes were contributing to a loss of control of participant's personal care and environment, leading to an increased reliance on caregivers. Examples emerged of memory loss or confusion playing a role in people's ability to dress, cook, and control electrical devices in ways they previously had been able to:

*"I have to dress him in a morning otherwise he could have his pyjamas on underneath his normal clothes, or back to front or inside out"* [David's wife]

*"he just lost the ability to cook for himself and, so was less motivated, you know, he was just eating what was given to him"* [Jim's daughter]

*"I was struggling with my washing... when I started forgetting what to press and what not to press"* [Caroline]

These previously simple physical and cognitive tasks had become a substantial challenge for people. They represented moments when participants' ability to have independent control of their lives were starting to slip from their grasp. When talking to participants and their caregivers, these changes were some of the most poignant moments of the interviews, where core elements of people were being described as slipping away.

Effective communication of thoughts, desires and needs was a cognitive capability that was eroding, as people's dementia progressed. Jim was having difficulty telling his family about his needs. When there were problems with his heating, Jim's daughter said, *"he isn't always able to tell us"* because *"he just forgets"*. Being unable to communicate effectively could be an emotionally difficult development for both participants and their family caregivers to go through. Tom's wife spoke of her husband making *"things up, it's as if he's telling lies, but he believes it in his mind"*. It was hard for her to hold a conversation with Tom as they no longer had a shared history *"because he can't remember the things we've enjoyed in the past"* [Tom's wife]. These communication challenges were most noticeable in cases with more advanced dementia, where communication of more complex needs is likely to be more important. Not being able to communicate



effectively appeared to contribute to people being unable to express needs, leading to both participants and their family having less control over the participants' wellbeing and safety.

The cognitive task of managing bill payments and finances were also slipping away from participants, with no participant in the study in full control of their financial arrangements. Again, for those with more advanced dementia, such as David, this cognitive challenge was particularly noticeable, and his wife had taken control since his diagnosis:

*'[she] deals with all that anyway. She's the person that worries about that' (David)*

While no person with dementia in this study had complete control of their finances, those with less advanced dementia retained a greater control. Andy, Alice, Jim, and Caroline retained some ability to pay the bills or make day-to-day payments, but larger financial decisions appeared to be in the control of other people. In all but Alice's case it was a family caregiver making these financial arrangements. Caroline vividly described how her confusion managing finances and paying bills, leading to her nephew to take over some control.

*"Maybe it were coming on for a while and I just passed it off, I don't know, but I'd got my rent book out and that and I'd put them all there ready, like you do, and buzz off, my shopping list. And I thought I don't know what I'm doing here, and it came on as quick as that. As quick as that, yeah." [Caroline]*

It took a timely visit from Caroline's nephew for the issue to be resolved; she described relief that her nephew had found her at her moment of crisis. It was a frustrating and scary experience for Caroline to be losing control, with the angry initially being directed at her nephew:

*"I was snapping his head off. I says I'm not poorly, I just want, I don't know, I don't know, I don't know. And I were right cross with him. Then he made me sit down and he made a drink, and he says look, leave these and I'll go and fetch them for you". [Caroline]*

Participants being able to control their affairs and environment were increasing challenge across the cases, due to effects of dementia and ageing. People had a decreasing ability to complete physical and cognitive tasks, leading to people becoming increasingly dependent on others to support their wellbeing. Their control of simple daily tasks, such as dressing or cooking, was slipping from the grasp along with cognitive abilities such as communicating effectively. For those participants with more advanced dementia, Tom, David, and Jim, family caregivers were recognising when participants were 'Starting to slip'. For the cases of Alice, Caroline, and Andy, with minimal outside assistance and living alone, it was more incumbent on them to recognise when their control was 'Starting to slip', and seek assistance accordingly. However, participants were not always recognising when their ability to control safely the world around them was slipping, potentially risking their safety.

### **8.3 Not seeing the risk**

'Not seeing the risk' describes how participants had an impaired awareness of their physical and cognitive changes and capabilities. In the same way that climbers might overestimate their capabilities and misread the difficulty of the rock face, leading to slips and falls, the nature of dementia posed risks that were not always appreciated. The fluctuating nature of dementia, coupled with a participant's desire to remain living as they had, at times made it difficult for people to effectively perceive their capabilities, and judge the difficulty of an action. In cases where family caregivers were living with a participant it was possible to control some of the risks associated with a participant, not immediately apprehending their changing capabilities. Although this sub theme draws mainly on family caregivers' perspectives of risk, there will be an initial description of some participants', albeit limited, discussion of appreciation of their changing capabilities.

There were examples of participant's growing awareness of their inability to engage in some activities. They appeared to have come to accept that some tasks were no longer within their capability, recognising the risk it presented to them. Caroline freely discussed her difficulties in managing her bills, explored in

the previous theme 'Starting to slip', or David discussing coming to terms with his embarrassment at struggling to communicate. David spoke of finding it "*embarrassing*" to forget what to say, he also appeared to be quite stoic about his changes saying: "*but you have to keep going*". However, for the most part discussions of ability and risk emerged from family caregivers and these narratives suggested the concept of 'not seeing the risk'

In cases where the caregiver was not living with a participant, family caregivers spoke of their loved one placing themselves in risky situations to their wellbeing or safety, due to 'Not seeing the risk'. Andy and Jim living on their own created instances when 'Not seeing the risk' were problematic for their family to manage and resolve. In Andy's case, his family felt he was not seeing the risk to his health and safety, of his series of health issues and his poorly maintained home, much to their frustration. Andy's daughter-in-law spoke of his sight "*deteriorating really quickly*" but not being able to "*get him to talk about it*"; she went on to say:

*"he calls it glaucoma but researching through the doctor he hasn't got glaucoma. We think he's got cataracts."* [Andy's daughter-in-law]

Andy did not speak specifically about problems with his sight, but did recognise his health changes in his health saying: "*It's deteriorated these last two or three months I think... It makes me feel old*". It was not clear if Andy did not recognise the risks arising from his health problems, was un-willing to confront them, or perhaps that he simply did not wish to involve his family in these issues. Andy's family view was that he was not appreciating the risks that his age and declining health presented.

For Jim's family the focus of their concern was more around how he managed his finances and heating at home. Jim's daughter spoke of him changing his bank account leading to "*the direct debits [not being] paid*" and Jim accepting cold call financial products leading to him having "*six insurances on his Skybox*". Jim did not recognise any problems in paying the bills when asked saying, "*not really no, only grumble[ing]*" about the cost. Jim's daughter said her father could not remember changing his accounts or taking out these products, so for his family it created "*big issues*" [Jim's elder daughter] for them to resolve; at the time of

speaking to Jim and his family they were moving towards establishing a Power of Attorney.

The dynamic of impaired awareness also played out in cases where participants lived with their spouse. Differing perceptions of capabilities in couples were discussed in ways that suggested risk was being managed by spouses. Spouses described preventing their loved one from undertaking tasks where they were having trouble perceiving the risks. David's wife, and family, described monitoring his capabilities and guiding him away from actions that may have been hazardous in light of his reasonably advanced dementia. In their joint interview, David and his wife spoke of his ability to use their wall mounted gas heater:

*"Well I haven't had to use it because [my wife] usually."* [David]

*"Yeah, but you can't use it can you, you can't turn on the fire and you can't turn it up."* [David's wife]

*"Well I could if I tried probably but."* [David]

*"No, I wouldn't like to think you were messing about with the gas put it that way."* [David's wife]

In a similar respect, Tom's family talked of being able to recognise when Tom was no longer able to go for a walk on his own safely, before Tom himself did. As his son said, if Tom did get out *"once he's gone past that gate it's anybody's guess"* where he would end up, though Tom remained more confident in his ability to go for a walk on his own, this was not a problem or risk that Tom perceived.

Like a climber not always knowing whether they are capable of hanging on to the next hold, participants were not always aware of their capabilities until they slipped. Miscalculating the level of capability, as seen through the eyes of caregivers, appeared to lead to a participant not seeing the risks under which they were placing themselves.

In these cases, there appears to be a trend of impaired awareness of capabilities, with the potential to impact on a participant's ability to remain safe at home. If a participant was living with a spouse, their presence appeared to mitigate potential risks, associated with a perception of risk. David's wife prevented him from using

household appliances and described how she had slowly taken on more tasks such as paying the bills and controlling the heating as David's dementia had progressed.

#### 8.4 Holding them up

In the same way a belayer physically and emotionally supports a climber up the wall, catching them if they slip and fall, caregivers could be seen in these cases to be a participant's point of safety, 'Holding them up'. Participants spoke of family caregivers being their first point of contact when problems emerged with them personally, their home, or with warmth. This was true even for those who showed a strong desire to maintain their independence, such as Andy saying that if something went wrong with his home and heating system: *"Well yeah, I'd get in touch with our [son] and he'll sort it out for me"*. This sub theme has three threads: the role family caregivers played in providing support, what happens when caregivers support was rejected or not available and lastly how family members worked with others to hold up not only the participant but also other caregivers, who may have their own health and wellbeing challenges.

Participants were not alone in desiring the ability to hang on to their way of life; loved ones around them also wanted them to maintain their wellbeing and happiness. It was family caregivers who were the main point of social support, with limited assistance in these cases from friends and professional caregivers. Though professional caregivers were providing assistance in situations where a participant's condition was more advanced, it was family members who were the main source of support to enable people to hang on in these cases.

*"My aim is to keep him here as long as I can possibly"* [Andy's daughter-in-law]

*"he's had a damn good innings, and I put that down to the care that my mum's been giving him"* [Tom's son]

Family members across the cases were supporting participants in daily tasks, maintaining the home, observing a participant's needs, and organising health and social care provision. This included intimate daily tasks that made continued living

at home possible, such as Tom's wife helping with dressing and washing. Within this role, family caregivers appeared to have a nuanced understanding of a loved one's needs and so were able to provide holistic support and adapt to a participant's developing situation. In David's case, his daughter spoke of how as a family they could understand his needs despite the problems he had communicating: *"I mean we're all pretty good at reading him aren't we"*, including if he was cold: *"you can usually guess that he's cold"*. This nuanced understanding appeared to be more useful for cases with more advanced dementia, with participants perhaps not able to express their needs. So the role of family caregivers in 'Holding them up' could be seen to intensify as the severity of the dementia increased.

At times, participants were rejecting or resisting the support offered to them by existing or potential caregivers. This is a process similar to the previous sub theme where participants were 'Not seeing the risk'. However, in this context a person with dementia may recognize there is an issue with the safety, health, or wellbeing, but be reluctant to accept support. Resistance to support was most noticeable from participants who were living at home on their own and experiencing the earlier stages of dementia. Caroline was strongly resistant to assistance from her accommodation manager, while she was *"forced to speak to her in"* [Caroline] some situations Caroline didn't want her to *"come near me"*. In Alice's case, she was keen to stress when she attended a care centre she attended as a volunteer but *"[didn't] go because I want a carer"*. In Andy's case, his family was keen to provide more assistance to him in light of his declining health and death of his wife. However, Andy viewed himself as able bodied, at least for the present, and was very resistant to the idea of having any help at home in any way.

*"I'm comfortable as I am like, but I don't want inconvenience of people saying I'll come in at 10 o'clock and this, do you know what I mean. You've got to be at their beck and call more or less haven't you, you've got to be here when they want to be here, so anyway, while ever I'm able bodied, there'll be a time come when I'll have to have somebody but that's, as it happens now I'm all right.."* [Andy]

For his family his resistance was frustrating and in their view detrimental to his wellbeing:

*"He won't do meals on wheels, he won't have a cleaner, which we could organise all that for him, but he won't have it. He said he can manage it himself, and it's obvious he can't"* [Andy's son]

While Andy did have family members who were keen to provide greater support, this was lacking for Alice and Caroline. This lack of close family appeared to limit their access to quick social and care support. Though Caroline did have a nephew who provided some help she did not see him regularly and she did not want to contact him too often or for what she saw as minor problems:

*"I mean if I were to ring him, providing he's at home, and said [nephew], will you come, he will come, but I don't want to do that unless it's necessary."* [Caroline]

Alice, with no family caregivers, was the only case without an identified point of contact to call upon for help. She described a more informal path to gaining assistance, which relied upon her being proactive about problems rather than being held up by others. If problems were to arise with her heating Alice spoke of *"ask[ing] around people I know and find somebody who would be able to come and do it"*. Alice appeared at the time of talking to her still to be able to hold herself up. However, as her dementia progressed it was not clear who would, or could, step in to support her to stay safe and well at home.

A thread of 'Holding them up' could also be seen in family caregivers working together to provide a network of support. These networks helped family caregivers to provide complex and demanding physical and emotional care, which their loved one's dementia and other illnesses required. This was compounded with some family caregivers having their own long-term health conditions to manage, David's wife was suffering from extreme fatigue and Tom's wife having recently undergone a heart operation. When David was diagnosed with dementia he and his wife *"needed to be nearer her help"* [David's wife] so moved to be closer to their daughter. It had become a team effort with David's daughter and grandson *"try[ing] to help as much as we can"* with David's care. Though Tom's son was not in as close proximity as David's family he had made

efforts to make his parent's home warm, comfortable, and safe for winter. By renovating his parent's home, it had allowed his mother to focus more on Tom's needs, rather than their home.

Family caregivers described regular communication between one another as being important to support effectively the participant and each other. David's family were in regular communication so when things went wrong "*mum will ring me and we'll work out things together usually*". Similarly, Tom's son would ring "*most days. If they don't ring me I'll ring them. If there's a complete day gone by and she hasn't rung me I'll ring her the next morning*".

The support provided by caregivers appeared to allow participants to hold on to the world and independence as their dementia progressed. Family caregivers were the most active source of support of the participants that could be seen in the cases. In the cases with limited caregiver support or caregivers not available to hold people up, such as Alice, Caroline, and Andy, while they were getting by as their condition progressed, their path to maintaining safety in winter and control through the progression of dementia was not as clear. Finally, it could be seen that 'Holding them up' could be viewed as a team endeavour between carers, including the caregivers holding each other up.

## 8.5 Letting go

As participants identified that their control was slipping, perhaps having not seen the earlier risks, they passed on control of some areas of their lives onto others. This letting go could be very difficult for people. The process was not always smooth and it was often focused around points of risk or accidents.

This 'Letting go' in the cases appeared to be a mixture of two general approaches: a participant acting in a proactive or reactive manner, to the functional changes presented by dementia and old age. A reactive approach can be visualised as a stepwise change to dependency, with a participant reacting to emerging deficits in his or her capabilities, potentially from trigger events. Alternatively, participants could let go of control proactively, where either a participant or caregivers confronted difficulties before an event forced change. Cases showed some



aspects of both proactive and reactive approaches to letting go of control, and moving towards greater dependency.

Reactive approaches to letting go occurred when events or triggers for participants encouraged them to pass on control of aspects of their lives to caregivers. These events were at times revealing to participants and their families the increasing vulnerability that dementia and ageing had brought. At these moments people could recognise the difficulty participants were having managing actions that they were previously fully capable of, creating trigger events. Trigger events in the cases took many forms: accidents, e.g. falls; bereavement; cognitive changes, such as memory loss; or loss of physical function, such as motor skills. These events have a common thread of changing the perceptions for a participant or a caregiver to risk. An example is Jim's family who were in the process of setting up Power of Attorney with Jim due to the difficulty he had managing his finances:

*"he did change his bank account and all the direct debits didn't get paid. And then when we tried to reset it back up again we got all sorts of issues, so it took us a while to sort out. So that was a bit of an issue. The other issue is cold calling."*  
[Jim's eldest daughter]

In reality, trigger events for a participant were often several events leading to a decision to accept support. In Andy's case, he suffered from a series of falls but it was only after a fall resulting in a stay in hospital that he accepted his family's overtures to wear a fall alarm:

*"Because of this incident Andy has agreed to wear an alarm around his neck and apparently taken to it well. This was certainly a trigger point both for Andy to accept more care and for his children to be more assertive over his needs."* [Data collection diary notes from a discussion with gatekeeper]

Though his family saw the need for further support earlier, it took the trigger event of Andy's most recent and severe fall for him to accept the need for change.

Letting go of control could alternatively occur when participants or caregivers proactively sought to make changes. For the most part in these cases it was family caregivers and not participants engaging in a proactive approach. This

could be seen in Jim's case where his daughter pushed for his earlier diagnosis of his dementia against the wishes of the rest of the family, from her perspective she *"took a lot of flak"* for the decision, but for her it allowed her to put systems in place to keep him safe. The intimacy of care that close family could provide suggested that a smoother, more supported transition to letting go of control could occur. Caroline stands out as a case where a participant actively sought out solutions to her care problems in some areas of her life, which allowed her to remain living independently. She described struggling with her clothes washing:

*"I went in laundry room to do my washing, and I were getting that I couldn't see, that's when I started forgetting what to press and what not to press. And I thought I don't know what I'm going to do, because you've got to do your washing. And I were thinking I don't know what to about it, and it were worrying me and worrying me "* [Caroline]

In response to her difficulties, Caroline sought out a person who washed clothes for other residents in her accommodation, asking them to look after her washing. 'Letting go' of this aspect of her life helped Caroline to continue living in her home. However, when Caroline decided to let go of control of her finances to her nephew it required a trigger event, of her struggling with bill payments to make a change. The two broad approaches of a proactive or more reactive 'letting go' could occur within the same case or they could also act on the same issues, such as Caroline deciding to seek help with her washing triggered by her own experience of difficulties.

Family caregivers appeared to support a smoother process of 'Letting go', with their nuanced understanding of their loved ones, and implementing a solution before a crisis event occurred and encouraging a smoother process of 'Letting go'. However, when a person with dementia did not have a family member or caregiver either available, or if like Andy they are resistant to 'Letting go', there appeared to be a reasonable chance that participants were being placed in risky situations to the health and/or safety in winter.

## 8.6 Summary comments

A narrative of participants trying to hang on to control of their lives, in the way they had known them, ran through all of the cases. A participant's desire to remain independent of others and hold on to control was at times in conflict with the challenges arising from the progressive nature of dementia and age related issues. For those with dementia the psychosocial changes they experienced appeared to present a challenge to their ability to hang on to their lives, at times causing an unwanted shift to dependency on others.

As people's dementia and age, progressed, their ability to hang on safely to the physical and social world was slipping. Physical and cognitive tasks, such as paying the bills or dressing themselves had become unachievable for some participants and they became increasingly unable to see the risks arising from their reduced cognitive and physical ability. Some participants had family caregivers who were able to act in the way a climbing partner would and hold them up when they slipped or fell. However, when a safety rope was missing, this placed people at potentially higher risk to their health, wellbeing, and ability to live independently. For those cases with more advanced dementia, they had let go and cede control over aspects of their safety and wellbeing to family members, to continue living safely at home. Without doing this, it is difficult to envisage how Tom, David, or Jim could have continued to live in their home, and remain outside institutional care. In these cases the family members appeared to have a nuanced understanding of their loved ones needs. This nuanced understanding appeared to be a protective factor from winter related harm. Conversely, participants living alone without strong family or social support appeared to be at greater risk from winter related harm.

Participants in this study were not always able to recognise their changing ability to complete day-to-day tasks, threatening their ability to 'Hang on'. This could be seen with David no longer being able to use his boiler effectively or Caroline being unable to manage her bill payments. The inability to recognise their changing capabilities presented an additional layer of complexity in terms of how participants could approach keeping warm and safe during winter. It challenged their perception of risk and with this to their wider wellbeing and safety. The

inability to recognise or acknowledge a reduced ability complete day-to-day tasks can be understood with the help of the previous theme 'Losing me'. Participants were perhaps at times less likely to recognise they had a lost a capability when it was closely linked to their sense of self, such as Andy and maintaining his home. Conversely, when a person did not view an ability or completing a task as being linked to their sense of self they may have been more likely to cede over control to another person, such as Caroline with her clothes washing. This varying willingness to recognise and perhaps cede over control allows for a greater understanding of how people with dementia in his study approached winter warmth and safety.

The next chapter focuses on how participants with the support of their family were trying to stay warm and well at home during winter, the approaches used and how people describe balancing competing priorities to try to stay safe at home during winter.

## Chapter 9. Findings: Theme 3: Winter wellbeing

### 9.1 Introduction

The theme 'Winter wellbeing' discusses participants and in some cases their families' aim of maintaining health and wellbeing, while living at home during winter (Figure 9-1).



Figure 9-1 Thematic framework: Winter wellbeing

Two sub themes emerged from the cases, 'Keeping warm' and 'More than keeping warm'. 'Keeping warm' explores people's approach to keeping warm at home in terms of: personal warmth, keeping the home warm, and managing the heating bills. The sub theme also captures participants' and their families' views and beliefs on keeping warm that emerged from the interviews. Participants' wider need and desire for winter health wellbeing, beyond warmth is explored in the second sub theme 'more than keeping warm'. Participants had to balance their care needs, long-term health conditions, and their dementia to maintain their winter wellness. 'Keeping warm' was not ignored in managing these health and care needs, but participants being able to pay the bills generally or, for example, look after their decreasing eye sight would often take priority in maintaining health and wellbeing during winter. This theme will start by looking at how participants

and their families viewed and approached keeping themselves and their homes warm during winter.

## 9.2 Keeping warm

The participants all spoke of their desire to stay warm. There was a desire and determination from participants not to *"let myself get cold"* [Alice]. People were making a link between keeping warm and keeping comfortable with Caroline saying *"you've got to feel comfortable to feel warm"*, while David spoke of wanting to find the right temperature for him to be comfortable, not too hot, not too cold.

*"I mean not to be over warm. Obviously I've got to be comfortable, that's the thing."* [David]

Participants only gave a few descriptions of the health effects of being cold or the health benefits of staying warm. Caroline felt being cold affected her arthritis, though was not clear how. From David's perspective he spoke of cold inhibiting his ability to get things done:

*"I mean it's, I think, well you can't do as much when you're cold I don't think. Because it doesn't just, I know if you're cold in-house, but if you're cold outside as well it does really affect you."* [David]

Alice, with the coldest home in the study, was reluctant to speak about potential health effects of living in a cold home, though like other cases spoke of the importance of keeping warm for general *"health reasons"*, but was very reluctant to dwell on. However, Alice spoke more openly about the effects of being too warm at night, rather than too cold:

*"I do not want the heating on all night or anything because, I mean I'm in bed and I would be too hot with - I mean I'm hot in bed I've got a warm bed, and I don't want the heating on at night. I definitely don't want the heating on at night, that's what I - and also that's what I've grown up."* [Alice]

All the participants suggested that thermal comfort had become a bigger issue for them as they grew older because they felt they had become more sensitive to the cold. Several reported that they regularly felt cold at home. Jim spoke of feeling the cold more than previously.

*"But I do feel the cold much quicker than I did say five years ago, you know. I think as you get older you do, you know."* [Jim]

Similarly, Caroline said, *"I think you feel cold, as you're getting older, you know.... I never used to be cold"*. For Caroline 'Keeping warm' at home appeared to be more of a priority, compared to other participants. Family members similarly felt their loved ones were feeling the cold, more than they used to. Tom and David's wives had both noticed them feeling colder with David's wife saying, *"he feels the cold a lot more than he ever did"*. Similarly, Tom's wife believed he felt *"the cold very much, compared to myself"* and would no longer be *"bare armed"* at home as he used to. Jim's elder daughter put down him feeling colder to him *"getting old"*, along with having *"lost a lot of weight since he's been diagnosed"*.

People had very different approaches to using heating systems available to them, to achieve what for them was a comfortably level of warmth. In each of the cases there was a combination of heating sources available to participants; with a central heating system existed in all of the cases apart from Caroline's, where there was a storage heater in her flat. For Jim, David, and Tom their central heating system provided most of the warmth in their property, set to come on at regular times during day or with a controlling thermostat. Supplementary heaters were also available if they needed. David's wife would turn on the extra heater if it was *"not long before the [central] heating's due on"* or Tom's wife would choose to use their extra heater if the central heating was *"not sufficient"* for their warmth. Jim, David, and Tom were the cases with the greatest level of family caregiver involvement.

For the more independent Alice and Andy, while they did have central heating systems they decided not to rely on them for most of their home warmth. They preferred to use their wall mounted gas heaters to heat only the space they were using during the day, though Alice in a more restricted manner. When Alice was

at home, she would sit next to her living room gas fire, as the only source of heating in her property. While Andy similarly preferred to concentrate his heating, he would keep his living room to a reasonably high temperature, reaching 27°C during the daytime. However, the rest of Andy's home felt considerably cooler, as his son described:

*"He keeps a room where he's in nice and warm and toasty, but god forbid anybody opening the door and letting the cold out."* [Andy's son]

Andy did not like to be wasteful in the way he heated his home, he only kept parts of his home warm saying *"what's use"* in using more heating *"when it's warm enough"* where he was. His family felt the home had a *"damp feel about it"* [Andy's son], but Andy appeared satisfied with his approach to 'Keeping warm' at home. While, Andy's night room had the lowest average relative humidity in the cases, at 49.6%, his day room was higher, averaging 63% over the two weeks of data collection. The difference between his two rooms likely reflects the way he tried to keep the warmth sealed into the living room when he used it, reducing air flow. Alice's limited financial resources appeared to be a key factor to her using her central heating. When asked about the possibility of having her central heating on a low setting she was adamant it was not in her means and she would keep herself warm in her own way:

*"But it really did get very expensive and I'd be, as I say I'm willing to have the heating on, the central heating on in the morning and the evening, but if I'm going to be in the house during the day then I'll decide whether I'm just going to have a fire on or whether I want the whole heating on. I'll decide that when I'm in and it depends what I'm doing"* [Alice]

Alice's limited use of heating contributed to her home being by far the coldest home of the cases, concentrating her heating to where she was sitting was her approach to 'Keeping warm' at home on limited finances. However, in referring to her heating, Alice remained in her words *"very happy with the way that I do things now"*.

Across the cases, only Caroline described dissatisfaction with the heat of her home. Caroline spoke of not being *"comfortably warm"* in her flat but being



reluctant to use her supplementary electric heater, due to its cost saying *"god knows what it's cost me"*. Though Caroline's home showed 'safe' temperatures, with her day room ranging between 18°C and 25°C and her night room 15°C and 20°C, yet she was not able to reach her level of warmth comfort, due to a limited budget preventing her heating her home as she wished. Caroline's limited budget was compounded by her difficulties managing bill payments, explored in the sub theme 'Starting to slip' (8.1). These different approaches to using heating highlight the different views on warmth and 'Keeping warm' across the cases.

Along with heating their homes, people had options to keeping themselves warm, such as: adding extra layers, having warm food or drink, keeping active, or going out to somewhere warmer than their home. Putting on extra layers of clothing was the first thing that most participants would do if they felt cold at home; as Andy said, *"if I'm cold I'll put a jersey on"*. In a couple of cases, Andy's and Jim's, the participant had a specific extra item of clothing near them in their living room they could use to make quick warmth adjustments. Though Jim did have a blanket nearby, his elder daughter was frustrated that *"he just turns the heating up"* and would not *"put more clothes on"*. As people's dementia progressed, they appeared to need greater assistance in clothing choice, with David's family helping him get dressed and if he needed an extra layer on his wife said, she *"would have to do it"*. In Tom's case, with his more advanced dementia and deteriorating cognitive state, his son felt while his father was happy to put on extra layers, there was also an inconsistency or confusion in how he approached keeping warm.

*"it can be a day like today and he'll put a jumper on and then put another jumper on top and then put his coat on and come and sit in here in the sun."* [Tom's son]

Alice and Caroline relied more heavily on adding on extra layers of clothing to keep warm at home than the other participants. When speaking to them in their home they both wore several layers of clothing to keep warm. Caroline appeared to do this primarily because she was dissatisfied with the heating options in her home. Although her day room was not too cold, ranging between 18°C and 25°C, Caroline struggled to make herself feel warm:

*"I always just say yeah I'm all right. But I couldn't say to you now, you could say oh it is cold outside, and I might just say well it's nice and warm in here, it isn't. It's not comfortably warm, as I call it."* [Caroline]

Alice similarly relied on wearing several layers of clothing to keep warm, though her home was much colder than Caroline's. During interviews with Alice, it was necessary for the researcher to wear a thick jumper and coat to keep warm in her home. Alice herself wore three or four layers, including a fleecy coat and a thick woollen hat both day and night. However, from Alice's perspective she was keeping herself comfortably warm and resisted suggestions that she was not able to keep herself warm, saying of her night time routine *"it's not cold in my bed. I promise you"*, though her night room averaged only 8.3°C through data collection. While during the day she was clear that *"I've got a fire on here and I don't let myself get cold"* or she may go out to the local library to keep warm. Alice was keeping herself warm, while managing on limited resources, even though her home was quite cold with her day room averaging 10.3°C, over the two weeks of data collection.

Participants' options on keeping warm were limited in the cases by the availability of an optimum heating system, their financial situation, and their views on keeping warm. For example, Andy was not particularly financially limited in his approach to heating his home, but did not see the point in heating parts of his home he did not spend much time in. However, overall there was not a consistent approach to how people approached keeping themselves or their loved one warm and well.

There were some consistent views on cold and keeping warm, with people seeing 'Keeping warm' as being important to general wellbeing; but not always being clear why 'Keeping warm' was important. Though when pressed they were less clear on what the effects of being cold would be to their health and wellbeing, beyond generalities of good health. There was a feeling that participants were feeling the cold more than they had previously, before their diagnosis, with some family members linking an increased feeling of cold to the ageing process and being less active. Though there was an importance placed on 'Keeping warm', it was not the focus of attention in the cases. The next sub theme explores some

of the wider issues of health, wellbeing and safety that emerged from the cases, which appeared to be more pressing concerns in the cases.

### 9.3 More than keeping warm

This sub theme discusses the health and wellbeing issues of participants that were related to 'more than keeping warm'. Facing people were health problems such as decreased mobility, weight loss, fall risk, and long-term health conditions, including dementia. There were, as discussed in other themes, also other issues affecting participants' wellbeing such as managing bill payments or maintaining their home to a safe standard. It emerged that participants and their families considered these problems to be more pressing and impactful on wellbeing than keeping warm. For some participants, this meant managing a complexity of health and wellbeing needs or conditions all at the same time. This sub theme also discusses the health and wellbeing needs of participants' family members, with some having their own health and wellbeing needs they needed to manage in conjunction with those of their loved ones. There are examples in the cases where family members, particularly spouses, were putting their own health and wellbeing needs at risk to look after their loved one. Together, the wider health and wellbeing needs of participants and their families appeared to present a more pressing concern to health and wellbeing compared to keeping warm alone.

Jim's case is an example where while his heating had cut out on several occasions, due to him "*fiddling*" with the boiler, his and his family's health and wellbeing concerns were more focused on his decreased mobility, weight loss, fall risk, and difficulty managing the bills. Jim's family were concerned about his ability to manage his finances safely, as he had been accepting cold call financial products and recently changed his bank account without transferring bill payments, previously discussed in the sub theme 'Starting to slip' (section 8.2). Jim was also struggling to stay physically active at home, he had received a knee joint replacement, a pace maker, arthritis, and difficulty keeping his balance. Taken together Jim's activity and mobility were greatly reduced, in his words "*I sit down quite a lot*". Jim's elder daughter felt that his poor "*spatial awareness*" and

"dizziness" was of concern to his safety and wellbeing at home, with Jim having experienced several falls both at home and outside

To reduce the fall risk, Jim's elder daughter had arranged for a fall alarm, that he "doesn't wear" [Jim's elder daughter], and a support worker to come round when he showered, Jim was quite stoic about it:

*"I can do the shower but I've had one or two falls like, so there's somebody there so if I do have a fall they're there to rescue me... I just do the shower myself and then if I do have a mishap there's somebody there to pick me up."* [Jim]

Taken together Jim's health and care needs were felt to be much more than his difficulty in managing his heating and warmth, in Jim's family's consideration of his 'Winter wellbeing'. Similarly, Andy, at 93, had decreased mobility and suffered from falls, though, unlike Jim he was unwilling to accept support from his family. One of Andy's most recent falls resulted in him spending four hours on the floor of his home, without assistance to call on.

*"I fell down in house I crept over... on my backside and put fire on. And I thought I'm exhausted now, I'll have a sleep, and I laid on floor for an hour, and then I come back, and then I had another go at getting up. It were four hours."* [Andy]

Though Andy's frailty was placing his safety at risk, he was clear that he was "comfortable as I am like" and did not want the "inconvenience" of relying on other people for consistent support. Along with his declining mobility, Andy's sight was deteriorating, he had rapidly lost weight, and his teeth were falling out. His eyesight had reached such a point that when his family asked him to sign his name they had to "put the pen where [they] want[ed] him to write" [Andy's daughter-in-law]. However, with Andy comfortable as he was he had "refused any help of any description" [Andy's daughter-in-law], though, Andy did recognise that his general health had "deteriorated [over the] last two or three years". Andy's daughter-in-law "quite admire[d]" his "fierce independence" but felt by "curb[ing] it a little bit we'd all be a lot better off". For Andy's son and his wife, while Andy didn't "have the heating on enough to heat the whole house" [Andy's son], the more pressing concern was that his health was deteriorating, potentially reducing his ability to live safely at home.

*"For me keeping warm, yes I would put it not at the bottom of the list... for me his eyesight, his lack of eating are more of a worry to me than, and the state of the house rather than the heating." [Andy's daughter-in-law]*

Andy's resistance to confronting these wider health and care issues, as well as the issue of warmth, appeared to be placing his safety in jeopardy. Caroline, similarly, seemed to be unwilling to confront, or even discuss, her health problems; unlike Andy, Caroline did not have close family able to provide her with support on a regular basis. In the study, Caroline showed signs of deteriorating eyesight but was reluctant to engage with it. When pointing to a stack of correspondence there was a large magnifying glass and she said her nephew, who irregularly visited, would help sort them out. She also spoke of going to a local support group, but did not want to associate her own position with the *"poor souls"* who went there. Caroline said without encouragement from her accommodation manager, *"I'd never have gone there [support group]"*. It was unclear whether this was because Caroline's accommodation manager recognised Caroline's need for support or perhaps saw it simply as a nice place to socialise. However, it appeared that Caroline was unwilling to engage directly, or at least discuss, the issues that could affect her health and wellbeing. Caroline remained tight-lipped about her health and wellbeing challenges, and did not want to rely on others for support. For participants with more advanced dementia living with their partners, David and Tom, their health and wellbeing was able to be supported by their family, unlike the more isolated position Caroline appeared to be in.

As people's dementia progressed, decisions surrounding their health were increasingly in the control of their family members, as seen in Tom and David's case and to a lesser extent Jim, with their more advanced dementia. Tom's wife, with the support of their son, closely cared for Tom; who was struggling with basic activities of daily life:

*"he does dress himself but you have to give him the clothes. These are your clothes [Tom], there. But you've to keep an eye on him... he'll put his trousers on over the top of his pyjamas, and his shirt over the top" [Tom's son]*

With Tom's cognitive difficulties, the management of his health and wellbeing resided with his family. David similarly was struggling to manage independently his own comfort at home. With his dementia not being as advanced as Tom's, David's wife guided him through daily tasks. When dressing and showering she would *"keep an eye on" him and "try and let him do as much as he can himself"*, giving him a continued sense of agency. Along with his dementia, David was also suffering from a range of long-term health conditions. However, similarly, and additional to the support he required for dressing, David needed somebody to assist him with his medication as he would *"not just forget.., he would take the wrong tablets"*. Tom's family also had to support Tom's health and wellbeing. However, due to Tom's wife's own health problems this was a role she was struggling with. At 84, despite having recently undergone a heart surgery, she was providing Tom with 24 hour care *"getting up two to three times a night with him"* to manage his incontinence. This did not always go well. One evening, she went into the toilet and *"found him asleep in the bath"* in his pyjamas. Not being able to *"pull him out, and he couldn't get out"* [Tom's wife], due to the frailty of both, she made him as comfortable as possible until she could call her son in the morning.

Tom's wife appeared to be sacrificing elements of her own health and wellbeing to support that of her husband. Similarly, David's wife was also managing her own health problems. She found supporting David to be an increasing *"toll"* and was worried *"what's going to deteriorate"* in David's health next and whether she would be *"able to cope with it"*. By comparison, Tom's dementia had progressed to a point that required his wife to provide 24-hour care, but even with her own long-term health conditions it was still *"difficult for [her] to consider putting him in a home"*. She recognised that he was *"really ready for it but it's so hard to do"*. With Tom no longer able to fully express his needs his wife was put in a situation where she had to assess what Tom needed to remain healthy and well.

Declining physical and cognitive health and wellbeing were threatening participants' ability to live safely at home. Participants were suffering from a series of long-term health conditions, not only including dementia, which they and their family had to manage and prioritise to maintain their health and wellbeing.

Adjustments and recalculations had to be made to keep people on an even keel, as their health wellbeing declined. The examples discussed in this sub theme illustrate some of the complexity of managing health and wellbeing of participants, though it is hard to fully capture the complexity of their situations. Within this context keeping warm was not an issue that emerged as a priority for participants or their families. Rather, what emerged was that health and wellbeing was 'more than keeping warm' with people trying to focus on their most pressing needs or concerns at that moment; whether that was fall risk, managing finances, or declining eyesight. As people's dementia progressed more issues had to be managed simultaneously, and increasingly family members were taking on a controlling role of participants' winter wellbeing, allowing participants to remain healthy and safe at home for longer. Family members were going to great lengths to allow their loved one to remain comfortable, at times sacrificing their own wellbeing. Within this context it is understandable that winter wellbeing was 'More than keeping warm'.

#### 9.4 Summary comments

Participants and their family showed a strong desire to live comfortably and safely at home during winter, with this came a necessity for the health and wellbeing of participants to be maintained. Whilst taking obvious importance in winter months, 'Keeping warm' did not emerge as being the focus of people's wellbeing, in the context of more pressing concerns of health and care issues. Even for Alice, living in by far the coldest environment, her priority was for continuing to live in her home; if maintaining her home by heating it more would achieve this aim then she would consider it, but not to improve her personal health or wellbeing.

In these cases, hanging on to safety and stability was certainly 'More than keeping warm'. This finding allows for greater understanding of participants' and their families' view of keeping warm, along with how they prioritised it. Across the cases a struggle to manage and control the health and wellbeing was revealed, such as the difficulties surrounding David taking his medication or paying his bills. With participants' decline in cognitive and physical capabilities, confronting them was an increasing number of challenges to their health and wellbeing, occurring

at the same time. To stay safe these were challenges that needed to be prioritised and managed, and it appeared in some cases where a participant was acting on their own, such as with Caroline and Andy, this was a significant issue. From these cases it appears to maintain winter wellbeing it would perhaps help participants to pass on some control of their health and wellbeing to those around them. However, participants letting go of control or their family members taking control of health and wellbeing decisions come with the challenges to a sense of self as discussed in chapter 7. Thus, to keep people physically and psychologically safe a balance must be struck between what could be considered in a person's best winter safety or wellbeing interest, and a person with dementia maintaining a link to who they are.

Participants and their families in this study were presented with the same challenges to warmth and safety that older people without dementia would face. However, participants' challenges to their sense of self, changing perception of risk, reduced social connections, altered physical or cognitive ability. increase the vulnerability of this population because it adds an additional layer of complexity to managing winter wellbeing . The following discussion chapter draws together the themes discussed in this chapter, along with the narrative description of the cases, with the context provided by the background chapter 2 and the scoping literature review, see chapter 3.



## **Chapter 10. Discussion and conclusion**

The aim of this chapter is to place the findings of this study within the wider academic and policy context. To support this, this chapter will restate the aims and objectives of the study; critically assess its strengths and limitations; highlight the contributions to knowledge; and present recommendations for research and practice.

### **10.1 Purpose of this study**

The aim of this programme of research was to understand the challenges that people with dementia have in keeping warm and safe in their own home during winter. This aim was achieved by conducting a constructivist multiple case study, with six participants with dementia. The programme of research had the following objectives:

- To elicit the experiences of people with dementia and their carers regarding winter safety and warmth in the home.
- To identify any unique challenges faced in keeping safe and warm in winter for a person with dementia.
- To describe the different challenges faced by people with dementia living within different home environments.
- To identify any strategies used to keep a person with dementia safe and warm in their home.
- To identify the input that carers have in keeping a person with dementia safe and warm in their own home.

### **10.2 Summary of findings**

New findings have been made on people with dementia's efforts to stay warm and safe during winter. This study found that:

1. In these cases people with dementia psychosocial and cognitive changes, associated with their conditions, presented an additional layers of complexity to keeping warm and safe at home in winter.
2. In this study the cognitive and physical changes of dementia appeared to make it harder for participants to control the temperature at home, in particular struggling with heating system controls, managing finances, and in the later stages of dementia being able to dress appropriately.
3. Some participants in this study were not always able to recognise their changing ability to complete day-to-day tasks, these occurrences presented a challenge to people's perception of risk to their wellbeing and safety.
4. The experience of participants' safety at home could be viewed through the context of threats to their sense of self and a desire to hold on to the control of their physical and social worlds.
5. Participants had difficulty communicating their warmth and safety needs to others, but family members appeared to be adept at reading a person's needs.
6. In this study, the nuanced understanding family members showed of participants needs appeared to be a protective factor from winter related harm. Conversely, participants living alone or without family support appeared to be at greater risk from winter related harm.

### **10.3 Strengths and limitations of the study**

#### **10.3.1 Strength: Study design centred on people with dementia**

This study has aimed to place people with dementia at the centre of the study design and study methods. People with dementia have not been always been included in research, due to difficulties of consent and reliability of evidence. There has, however, been a growing recognition that people with dementia should be placed at the centre of the research process (Dewing, 2007 and 2008b; Hellstrom, et al., 2007; Hubbard, Downs and Tester, 2003; Mckewon et al., 2010; McKillop and Wilkinson, 2004; Pesonen, Remes and Isola, 2011; Sherratt, Soteriou and Evans, 2007); this was the aim in the design of this study. The

recruitment and data collection process in this study aimed to place those with dementia in control of research decisions within a case, such as who was contacted or included in a case. Similarly, the data collection process was led by participants, such as allowing them time to guide interviews. It is felt centring cases and data collection in control of participants, while at times leading to a longer process, created richer data, because of their engagement with the study.

### 10.3.2 **Strength: Focus on the voice of people with dementia**

This study focused on allowing the voice of people with dementia to emerge within cases. The interpretivist epistemological and constructivist ontological stances of this study informed the focus on understanding people with dementia's view of reality and interaction with their world. The process consent method fostered a deeper understanding between participant and researcher. This allowed the researcher to build an initial understanding of a participant's world and participants forming a trust with the researcher. This understanding allowed for the interviews with people with dementia to tell the story of their world, through warmth and safety in winter. This voice of warmth and safety has not previously been captured in research on cold and winter with older people and those with dementia.

### 10.3.3 **Strength: Case study design incorporating multiple data sources**

A methodological strength of this study is the incorporation of multiple data sources, within individual cases. Case study design encourages multiple data sources and data types to be used to gain understanding of a limited number of cases (Stake, 1995 and 2006; Yin, 2014). The cases in this study incorporated: interviews with the person with dementia; interviews with family caregivers; information provided by the gatekeeper; researcher observations; Tinytag and external temperature and humidity recordings. In this study interviews, particularly participants with dementia, were the foundation of data within a case. The incorporation of other sources of data allowed the information from interviews to be triangulated, such as comparing feeling of cold to temperature meanings. This triangulation was not undertaken in a positivistic sense, to locate a single 'truth'. Rather, the incorporation of multiple data sources, within cases, allowed for a greater understanding of the subjective 'truth' of participants to emerge. This

approach was of particular use in this study, where cognitive changes at times made communication a challenge.

#### 10.3.4 **Strength: Capturing a range of dementia situations**

This study has succeeded in capturing a range of situations in dementia, considering the relatively small size of the sample. The stated aim of the sampling process was to maximise the capture of a range of living situations and demographic variables. The six cases include a good spread in the severity of dementia; both early and late onset dementia; a range of social isolation; different types of housing; a mix of genders; and different levels of family and professional caregiver support. It is not suggested that these range of variables allows the study to be generalised to the experiences of the dementia population. This range of variables does, however, allow for the understanding of issues of winter warmth and safety to be seen within different situations.

#### 10.3.5 **Limitation: Relatively small number of cases**

This study has a relatively small sample, involving only six participants with dementia living at home. While this number of participants is appropriate within case study research (Stake, 1995 and 2006; Yin 2014), it does limit the generalizability of the findings. The limited numbers of cases has, however, supported a richer understanding of the subjective world of participants. The sample itself was therefore appropriate and successful at illuminating participants' experience at different moments of their journey through dementia, having different levels of support, and being in different living situations.

#### 10.3.6 **Limitation Lack of ethnic diversity in the sample**

This study is limited by a lack of ethnic diversity in the sample, with all of the participants being white British. The number of older people from black, Asian and minority ethnic groups is rapidly increasing in the UK, and there is an expectation that black and minority ethnic (BME) groups have a higher prevalence to dementia (Husaini et al., 2003; Prince et al., 2014), due to higher rates of contributory conditions such as vascular disease (Ahmed, Yates-Bolton and Collier, 2014). The inclusion of a wider range of ethnic backgrounds in this study would more accurately reflect the UK's health and social care challenges of dementia. The scope of case studies cannot include a full range of all relevant

demographic variables. This study therefore does not claim to reflect a range of ethnic groups.

#### 10.3.7 **Limitation: Limited amount of data for some cases**

There is a relatively limited amount of data in some cases. This limits the inferences that can be made in these cases. The lack of carer interviews in case 3 (Alice) was due to there being no carer being involved, and Alice having no close family connections. The limited number of interviews in case 4 (Caroline) was in part due to the small size of the Caroline's care network, with limited family involvement. She also expressed a wish to take no further part in the study after temperature devices were removed from the property, but consented for data already collected to be included. Unfortunately, in this case the Tinytag data was corrupted, so a comparison of external versus internal recordings could not be created. However, it was possible to retrieve a graphical representation of temperature and humidity from the Tinytag Explorer programme. This decreases the richness of analysis for the case, but the available graphs were sufficient for a description of the case.

#### 10.3.8 **Limitation: Not utilising creative approaches to the engagement of people with dementia**

This study could have utilised more creative methods to include people with dementia in the research processes, beyond semi-structured interviews. While this programme of study made efforts to be considerate to the wishes of people with dementia through the dementia process, such as through the use of the process consent method (Dewing, 2007 and 2008b; McKeown et al., 2010), more creative methods could have been used to further the subjective understanding of participants. Qualitative research with people with dementia tends to rely on typical methods, such as observations or interviews, as was the case in this study. However, alternative approaches such as the use of visual or audio diaries (Bartlett, 2012) and participatory design may have allowed people with dementia, with reduced ability to communicate, to have their perspective on warmth and safety at home better captured in this study.

## 10.4 Discussion

It has become clear in this study that the lived experience of the participants to keeping warm at home during winter was placed within a wider need for safety at home. This need was in the context of participants wishing to maintain autonomy, control, and a sense of self, through the progression of their condition. The discussion in this section focuses on three threads in the findings on warmth and safety:

1. The differing experience of warmth and safety between those with dementia and the general old age population.
2. Participants not always seeing the potential risks to winter related harm they were in.
3. The role social connection and social isolation played in keeping participants warm and safe at home.

### 10.4.1 Warmth and safety: the same and different

People with dementia in this study confronted with the same challenges to keeping warm and safe that the general old age population have. The cost of heating, suffering from falls, struggling to use the heating, eating regularly, and a relationship between warmth and health were all issues that were seen in this study, along with being reflected in the general old age population, see Chapter 3. Participants in this study faced an additional layer of complexity, due to their cognitive difficulties. Previously, simply tasks of dressing, cooking and eating, using the heaters, and managing finances had become challenging to participants, affecting their ability to stay warm and safe. These tasks were made harder by people's memory changes, difficulty communicating, struggling to complete daily tasks, and difficulty making complex decisions. Previously, dementia has been noted to affect a person's ability to manage daily tasks, such as cooking, personal hygiene, or dressing (Desai, Grossberg and Sheth, 2004; Prince et al., 2014; Woods, 1999). Tasks which were previously simple or manageable becoming a challenge can threaten a person's ability to live independently (Evans, Price and Meyer, 2016; Gilmour, Gibson, and Campbell, 2003).

Perhaps, the most consistently challenging daily task facing participants in this study had been in their ability to manage their financial arrangements. No participant in this study was in complete control of his or her finances. In Caroline and Jim's cases, their difficulty in managing money had led to crises, which triggered a greater dependency on family members. Due to the complex decisions that accompany financial management, it is recognised as one of the abilities that a person with dementia may lose early on in their condition (Gilmour, Gibson, and Campbell, 2003; Manthorpe and Samski, 2013). Difficulty in understanding and managing fuel bills has been seen in the wider old age population. Complex modern fuel tariffs being a particular problem (Sutton and Hill, 2012) accompanied by a general mistrust and reluctance to engage with energy suppliers (O'Neil, Jinks and Squire's, 2008; Sheen and Jones, 2013; Stockton and Harrison, 2012). The experience of participants in this study mirrors Gray et al.'s (2015) research with carers of people with dementia, which suggested that the capacity to manage energy bills was lost early in the progression of dementia. This finding is important to the understanding of people with dementia's ability to stay warm and safe at home during winter, particularly if there is not a family member to support them.

Wearing extra layers is a practical approach used by older people to keeping warm, while limiting spending on fuel bills (Anderson et al., 2008; Burholt and Windle, 2006; Chard and Walker, 2016; Day and Hitchings, 2009 and 2011; Sutton and Harrison, 2012). However, participants with more advanced dementia had difficulty choosing appropriate clothing and dressing without assistance. For Tom and David, dressing had become too complex a task to complete on their own, though they remained physically capable. Their family guided them to make appropriate clothing choices by putting out clothing and helping them dress. Without this support, Tom's son described his father at times wearing a T-shirt in cold weather or a thick coat in the summer. In a similar manner, some people with dementia in this study appeared to find heating controls increasingly difficult to operate as their condition progressed. Older people without dementia have previously been found in some studies to struggle with modern heating systems (Sheen and Jones, 2013; Tod et al., 2013), but it appears from this study that cognitive changes of dementia presented a wider challenge. The finding from

Gray et al. (2015) was mirrored in this study, where people with dementia were struggling to use heating systems they had previously been capable of controlling. Though severity was not measured in this study, those with mild to moderate dementia were able to use heating systems they were familiar with, though learning to use a new heating system was for Jim a struggle. For those with more advanced dementia, they had fully lost the ability to control their heating systems, even if they had used them for many years.

Advice and interventions aimed at improving warmth and safety in winter are targeted at vulnerable groups, with interventions particularly focused on the general older population (DoECC, 2015; Hills, 2012; Katiyo, Dorey and Bone, 2016). Cold weather interventions are situated in what Beattie (1991) describes as an authoritative and individualistic position. In other words, existing interventions use top down advice aimed at modifying individual's behaviour through informing people of the 'best' warmth and safety practice, such as through advice material.

There are extensive online and leaflet advice on keeping safe and warm for older people coming from governmental and third sector organisations, such as Age UK. The comprehensive, at times technical, nature of this advice material is better suited to those who have the cognitive ability to have their values, attitudes, and behaviours challenged. There is also some limited advice aimed specifically at people with dementia and their carers (Alzheimer's Society, 2017; Dementia Services Development Centre, 2015), though this material takes a similar technical, authoritative, and individualistic approach. In this respect it struggles to address the difficulties people with dementia face in a suitable manner, it is better suited for carers.

The main financial assistance available to older people are Winter Fuel (Gov.uk, 2017a) and Cold Weather payments (Gov.uk, 2017b); these provide funding to older people during cold periods. These payments can be conceptualised as a nudge approach (Sunstein and Thaler, 2008) to encourage behaviour change, i.e. to use more heating during cold weather. However, this nudge is likely to be ineffective for those with dementia as the structure of these payments require older person to proactively apply for this financial assistance; a process those



within this study would have struggled to accomplish independently. Further, Winter Fuel (Gov, 2017a) and Cold Weather (Gov, 2017b) payments are targeted at the over 65s, so those with early onset dementia do not receive this support. Existing winter safety advice and financial support for older people and those with dementia are based upon several assumptions about a person's ability to process and act on information, which those with dementia may not be able to meet.

Models of behaviour change, such as Social Cognitive Theory (Bandura, 1986), Theory of Planned Behaviour (Ajzen, 1985), or Health Belief Model (Rosenstock, 1966), rely on a person making some degree of rational assessment of: their situation, possible solutions, barriers, and cost. McGuire's (1989) model of communication behaviour change highlights the complexity of the persuasion process in public health messaging. It illustrates the difficulties an authoritative approach, such as those applied to winter warmth and safety, will have being successful at persuading a person with dementia to alter their behaviour. McGuire's (1989) communication-behaviour-change model, suggests 12 sequential stages, which an intended recipient must consider to be moved to take action. McGuire's 12 stages include several that a person with reduced cognitive capabilities will struggle to move through, including comprehension, skill acquisition, attitude change, remembering a message, and being able to recall a message. The cognitive changes of dementia make it highly unlikely a person could independently move through these stages, to a point of acceptance and action. A top down and authoritative approach to warmth and safety behaviour change faces significant barriers, a more person centred and bottom up approach should be considered.

An emancipatory theoretical foundation (Laverack and Labonte, 2000; VanderPlaat, 1998) may be more effective at communicating to a person with dementia the benefits and needs for warmth and safety in winter, orientated to support them in their own emancipatory interests. Ryan, Meredith and MacLean (1995) description of a communication enhancement model views good communication, modified to an individual and situation, as an essential components of strong health care and health promotion interventions. The model suggests a continually refined process recognising a person's physiological,

psychological, and sociocultural cues, then using these to refine an individually focused intervention to enhance empowerment, optimise well-being, maximise communication, and ultimately increase the effectiveness of an intervention. In this way, a communication enhancement model can be seen to be closely associated with a person centred view of dementia care (Kitwood 1997; Sabat and Harre, 1992). A person centred, emancipatory, enhanced communication approach would be considerably more expensive than a top down approach to communication and health behaviour change. The Alzheimer's Society in the UK, for example, operate a system of dementia advisors (Alzheimer's Society, 2010) tailoring support for people with dementia, though these advisors have a limited capacity. It is likely that a more person centred and emancipatory approach to winter safety and warmth would require substantial training to those health care professionals involved, at further expense, particularly in light of Tod et al.'s (2013) findings from professional carers, who found they themselves lacked the ability to provide aspects of winter warmth advice to those they were providing care.

#### 10.4.2 **Not seeing the risks**

An ongoing challenge of dementia is the increasing levels of risk a person faces as their condition progress, such as managing money (Manthorpe and Samsi, 2013), or the risk of social isolation (Kane and Cook, 2013). Having an effective system to manage risks can allow a person to retain as much control of their lives as possible, for longer (Manthorpe and Moriarty, 2010). Participants in these cases were trying to complete daily tasks, such as paying the bills or turning on the heating, while their fluctuating cognitive capabilities led them to miss read their abilities and risk to their safety and wellbeing. This was a theme that was explored in Section 8.3 'Not seeing the risk' in the wider theme of people trying to hang on to control of their world. Miscalculations by participants were placing them in potentially harmful situations to safety and wellbeing. Jim's adjustment of his boiler leading to the heating cutting out; Tom lacking awareness of appropriate clothing; or Alice, Andy, and Caroline resisting recognition of their dementia symptoms. This finding reflects existing knowledge that dementia can alter a person's perceptions of risk in their daily life and create an impaired awareness of changing capabilities (Bond et al., 2002; Morris and Becker, 2004; Rymer et

al., 2002). Studies have also found that those with dementia are more likely to overestimate their level of cognitive function and/or their level of behavioural disturbance, while caregivers have been seen to underestimate a person's capabilities (Dourado et al., 2007; Lehmann et al., 2010; Ott, 1996). Before this study perception of risk has not emerged as an important thread in understanding people with dementia's approach to warmth and safety at home in winter. In qualitative studies with older people without dementia, it has been found that people have an incomplete understanding of the health effects and risk of living in a cold environment (Chard and Walker, 2016; Jones and Mays, 2016; O'Neil, Jinks and Squire, 2006), something that was seen in this study. However, older people without dementia have not been identified as having the same problems perceiving risks in day-to-day warmth and safety that emerged in this study.

The term 'risk' is not a fixed construct; it has different meanings to different people in different situations (Mitchell and Glendinning, 2007). Conceptions of risk are likely to be based on social and cultural perceptions, rather than on a person's statistical interpretation of an event occurring (Bond et al., 2002; Manthorpe and Moriarty, 2010; McDermott, 2010; Stevenson, Savage and Taylor, 2017). The effective assessment of risk requires the understanding of a hazard, its relative harm, balancing a risk vs reward, and finally deciding to take a particular action. For those with reduced or changing cognitive capabilities they will likely struggle at several of these stages to understand and react safely to risks. Within dementia care the conception of risk and risk management are particularly complex and important to a person's safety, with people's continually changing cognitive and physical abilities (Clarke et al., 2009; Manthorpe and Moriarty, 2010).

There is evidence that people with dementia, caregivers, and health care professionals' different perspectives of risk can lead to conflicting views of safety and its management (Beattie et al., 2004; Gilmour et al., 2003; Harris, 2006; Robinson et al., 2007). Similarly in this study, family caregivers and those with dementia perceived risk related to warmth and safety differently. Robinson et al. (2007) suggested that those with dementia focused on biographical domain of risk, i.e. loss of self-identity or social ties. A focus on biographical risk emerged in this study where identity coalesced with warmth and safety such as Alice

focusing on protecting her identity of independence and reluctance to see the risk, in her approach to heating the home. People appeared to be balancing the risk of losing touch with their sense of self with risks to their warmth and safety at home, e.g. Andy's reluctance to accept support. In these cases, family caregivers showed a greater focus on day-to-day risks to safety, as Gilmour et al. (2003) suggested that were not being seen or acted on by those with dementia. There were also instances where family members were acknowledging and supporting people's sense of self, such as David's wife supporting his walking or Andy's family reluctance to take away his independence though wishing to curb it a little.

Existing social care policy aims to support people with dementia to live independently in their own home and community for as long as possible (Great Britain, 2009). For this policy to be successful there is a need to manage risks to safety and wellbeing that emerge as dementia progresses. All people with dementia are entitled to an assessment of their care needs (Alzheimer's Society, 2015). A person with dementia, the caregivers, or certain healthcare professionals can request these assessments. Local authorities and social care have a duty of care to support the wellbeing and safety of people with dementia, with best-practice advice to take a person centred approach to care (NICE, 2016b). However, the degenerative nature of dementia may mean care assessments, and their accompanying plans may struggle to keep track with a person with dementia's changing needs and perceptions of risk. It may only be at crisis events were a person with dementia's inability to manage safely their care might become known, such as entering the emergency health system. At these moments of crisis or change a person with dementia's ability to maintain their independence may be called into question and their autonomy become constrained (Berry, Apesoa-Varano and Gomez, 2015; Bond et al., 2002; Chrisp et al, 2013; Holm, 2001). Alternatively, a safety first approach in risk management, where safety controls are introduced pre-emptively, can lead to disempowerment for people with dementia (Clarke et al., 2009). There is a difficult balance to be struck in care provision between protecting a person from physical harm and the risk of psychological harm in acting against a person's wishes, with likely negative consequences to a person's sense of self.

Family members or close social contacts of people with dementia can assist with risk management along with supporting people in a transition from independence to greater dependence, in a manner they are less likely to resist (Berry, Apesoa-Varano and Gomez, 2015; Hellstrom, Nolan. and Lundh, 2005; Gilmour, Gibson and Campbell, 2003; Keady and Nolan, 2003). A close family member, particularly those living with a person with dementia, will likely have a strong understanding of the needs, risks, and biographical tensions, e.g. preservation of self, that a person with dementia experiences (Manthorpe and Moriarty, 2010). In this situation, the provision of information to caregivers on risk and risk management may be effective at supporting a person to stay safe at home, when they themselves cannot see the risks. Though as Berry, Apesoa-Varano and Gomez (2015) highlight management of risk by family members is highly challenging if a person with dementia does not themselves recognise their declining capabilities.

In these cases, people with dementia were not always seeing or understanding how their changing capabilities could place them in a risky situation, this was a thread explored in the 'Hanging on theme' (see Chapter 8). This finding potentially separates people with dementia from the wider old age population, who have not experienced the same level of cognitive change or difficulties. Support from close social contacts appears to be effective at identifying moments when a person with dementia may not see risk to the warmth and safety at home. Existing social care support may struggle to identify day-to-day risks a person with dementia experiences

#### 10.4.3 **Social contact**

This section discusses the role the close social contacts and family members filled in keeping participants warm and safe. Social support in this study was mitigating some of the harmful effects of dementia on winter warmth and safety. Family carers, in particular, were supporting participants as they charted a path through staying warm and safe at home, as they sort to hold on to control and independence in their world.

#### Isolated people

People living alone account for around one third of those with dementia (Miranda-Castillo, Woods and Orrell, 2010). Those living alone have poorer health and wellbeing outcomes (Lehmann et al., 2010; Gilmour, Gibson and Campbell, 2003) and higher levels of unmet needs (Miranda-Castillo, Woods and Orrell, 2010). In this study, those living alone appeared to be most at risk of cold and winter related harm, such as having a cold home or suffering from falls at home. This was despite those living with partners having significantly more advanced dementia. Family members appeared to limit the physical risks to warmth and safety at home, such as Tom wearing the right clothes or David wanting to use the gas fire.

People with dementia are at high risk of becoming socially isolated and experience loneliness due to their condition (Kane and Cook, 2013); this risk is on top of decreased social engagement associated with old age (Cattan et al., 2005; Victor et al., 2000). Maintaining good social contacts can mitigate the risk of social isolation for people with dementia, but maintaining good social contacts can be difficult due to declining cognitive capabilities (Kane, and Cook, 2013).

The social networks of those living alone in this study (Jim, Alice, and Caroline) mirrored what Miranda-Castillo, Woods and Orrell (2010) called private restricted, detouring social contacts not living in the local community, this could be seen with This type of social network was found to be ineffective at noticing and supporting a person with dementia's health and social care needs. These cases highlight that to be effective community support to winter wellbeing and safety must not only be available but a person with dementia must be willing to accept it. This was exemplified by Andy having good community contacts but unable or unwilling to utilise them to help keep home safe at home. The ineffectual nature of community support networks in these cases mirrors what is known about older people's interaction with non-familial social contacts, that they are an underused medium for winter support (Anderson, Anderson and Probert, 2008, Day & Hitchings, 2009, Hitchings & Day, 2011). Stockton, Harrison and Allan (2013) hope that older people's informal social networks could support in the sharing of winter warmth knowledge and services was not seen in these cases.

#### Family support

Family caregivers in this study, when available, were the key contacts supporting and managing participants' warmth and safety at home. Family members appeared to have what Berry, Apesoa-Varano and Gomez (2015) called a 'nuanced understanding' of their elder loved ones' capabilities and deficiencies. Through this understanding, family members were helping to hold their loved ones up as their ability to control the world around them started to slip. This created a distinctly different experience of winter warmth and safety relative to those more isolated from family, in this study. David and Tom's families both spoke of their ability to understand and to read their loved ones needs in a way non-family members struggled to do, such as recognising when they were feeling cold or knowing to keep them up a little longer so they slept through the night. Having a family member live with a person with dementia appeared to be the most supportive option, but any family member involvement appeared to support people in staying safe and warm at home.

Professional health and social care, in its existing form, may struggle to provide the same level of care and support as family members in this study. Social care and support can intrude upon personal areas of a person with dementia at a time when their sense of self and identity is being eroded (Kitwood, 1997 and Sabat & Harre, 1992), as a person moves towards being cared for (Borley, Sixsmith and Church, 2016). Ceding control over some care actions or decisions may not be an emotional challenge for a person. Additionally, a person with dementia can place greater relevance on certain actions or decisions to their self-esteem (King, 1997) or to their sense of self (Kitwood, 1997), and so resist interference in these areas. A person with dementia's involvement in decision-making can be seen through a lens of their changing autonomous status (Holm, 2001; Horowitz, Silverstone and Reinhardt, 1991; Keady and Nolan, 2003; Menne and Whitlatch, 2007; Samsi and Manthorpe, 2013), with care, health, and safety decisions-making moving towards caregivers' control. Family members involved with a person with dementia have been found to encourage engagement with health and social care systems (Chrisp et al., 2011); mitigate a person's exposure to risk (Berry, Apesoa-Varano and Gomez, 2015); or support a connection to self through the journey of dementia (Keady and Nolan, 2003; Hellstrom, Nolan, and Lundh, 2005). In this study, an incremental movement of decisions and control

was occurring towards family caregivers, often being triggered by events such as non-payment of bills or suffering from falls. Even for the most independently minded participants they were allowing family members to provide support, if only a little at a time. These incremental movements of decisions to family members could allow a person with dementia to remain living at home safely for longer, thus maintaining a certain degree of independence for longer. Similarly, Berry, Apesoa-Varano and Gomez (2015) conceptualisation of family risk management could be seen to play out in this study, where family members and a person with dementia were moving from a state of collaborative support to unilateral support. A transition to unilateral support i.e. increased control, by family members, offering protections to a person with dementia's safety.

Though a family member can play this supporting role in keeping a person with dementia safe and warm at home, the caring process places a significant burden upon them (Burns and Rabins, 2000; Etters, Goodall and Harrison, 2008; Papastavrou, 2007). Caregivers can experience negative physical and psychological health effects along with social isolation due to the intensity of care they must provide. This has implications for a family member's ability to sustain warmth and safety support to a loved one. Family caregivers have also been found to struggle to sustain similar emotional ties to the person they are caring for, particularly in spousal relationships (Hellstrom, Nolan, and Lundh, 2007; Kaplan 2001). Kaplan (2001) suggests that as a person's symptoms progress it can be hard for a caregiver to reciprocate with affection, as they once had. This for Kaplan can lead to a situation where couples can be in limbo, where ultimately though still legally married the non-affected spouse can no longer see themselves as part of a couple. Tom and his wife, being the furthest in this study along their path of dementia, mirror this theoretical trajectory of 'couplehood' (Hellstrom, Nolan and Lundh, 2005), as Tom's wife struggled to see the man she had known whilst having to provide ever more intimate care. It is within this emotional backdrop that support and care for people with dementia should be considered. Family members and spouses must be supported in this role, with the understanding of the carer burden they face and the trajectory of family support from cooperation with a person with dementia to increasing unilateral support.



In this study, social support was seen to mitigate some of the harmful effects of dementia on winter warmth and safety. However, not all social contacts were seen to be equal. Community and peer social support, while playing a role in supporting a person's sense of self and identity, was not in this study effective at supporting people to keep safe and warm at home during winter. The nuanced understanding family members were able to bring to cases appeared to supply a level of protection that non-family connections could not replicate. This finding on warmth and safety at home for people with dementia underscores and reiterates the risk those living alone face. Those with the most advanced dementia in this study inversely appeared to be at the least risk of harm during winter, due to the close family support they were receiving. However, this level of support could place great strain on relationships and people's identities, particularly seen within couples. In the wider dementia population of people living alone, we must consider how to replicate the close support that family members were able to provide. For family caregivers supporting them in this endeavour and limiting their burden could allow them to continue to support their loved ones warm, safety, and wider needs as their condition progresses.

### **10.5 Contribution to knowledge**

This programme of study has contributed to the fields of dementia studies and winter related harm. The study has furthered an understanding of how people with dementia view and approach warmth and safety at home during winter. This understanding has been captured from the perspective of people with dementia. These contributions to knowledge represent an expansion of the evidence base in the fields of dementia studies and winter related harm.

### **10.6 Conclusion**

In conclusion, this study found participants viewed keeping warm at home as important to their health and wellbeing, but this existed in a wider context of trying to stay safe through the progression of their dementia. It emerged that the ability of participants with dementia to stay warm and safe at home in winter was

compromised by their condition. For the participants in this study their changing memory, ability to communicate, complete physical tasks, and ability to make complex decisions were found to add an additional layer of complexity to their ability to remain safe and warm. In particular, the cognitive changes effects on perception of risk and a participants' ability to complete daily tasks, influenced their capacity to keep warm and safe at home in a way not previously identified.

Family caregivers in this study were adept at supporting participants' ability to keep safe at home; extending the time a person could live safely in their own home. For participants who were living alone and / or isolated from family support, challenges to safety at home appeared to escalate more readily to situations that were more serious. This escalation was in part because participants were not always aware or ready to accept their changing capabilities. Family caregivers, when involved in a case, appeared to be able to guide a participant to make 'safe' choices, though at times meeting some resistance.

These findings have to be considered within the strengths and limitations of this study. This study stands out as the first to engage directly with people with dementia to explore their perspective of winter warmth and safety at home. To achieve this a constructivist multiple case study design was conducted, including six cases. While this is an appropriate number of cases in case study design, it limits the generalizability of this study's findings. In a broader context, it is the policy of the UK government to support people with dementia to live independently in the community. Building a greater understanding of the approach of people with dementia to warmth and safety at home is important in this policy aim.

## **10.7 Recommendations for practice**

### **10.7.1 Recognition of people with dementia's vulnerability to cold**

People with dementia, particularly those living alone, appear to be particularly vulnerable to winter related harm than the general old age population. As

highlighted in chapter 2, there is little recognition of this in current social care policies that relate to cold weather preparedness.

1. There should be greater recognition of people with dementia as a vulnerable group in national policy, to direct targeting of funding and resources towards this population.
2. This recognition would also enable dementia to be given greater prominence in winter health and social care guidance and planning.
3. Throughout the year provider organisations, and frontline health and social care staff should work to identify people with dementia vulnerable to cold conditions.
4. Those people with dementia who are considered to be vulnerable to cold conditions should receive increase monitoring by front line health and social care during periods of forecasted severe winter weather, severe and major weather incidences, as defined by the Cold Weather Plan (Katiyo, Dorey and Bone, 2017).

#### 10.7.2 **Winter fuel and cold weather payments**

Chapter 2 highlighted that currently those with early onset dementia under 65 are not eligible for UK winter fuel and cold weather payments. This study found instances where a person's diagnosis of early onset dementia had forced a person with dementia to leave the working world earlier than expected, limiting their financial independence. Therefore, it is recommended that:

1. Fuel and cold weather payments should be extended to all people with a diagnosis of early onset dementia.
2. Additionally, memory services and social care support should assist people with dementia accessing these payments. Such assistance is most pertinent to socially isolated individuals, without family to provide assistance.

#### 10.7.3 **Supporting family carers**

The findings in this study identified the supportive role close family members can have on a person with dementia living at home, being well placed to understand their loved ones nuanced needs. It is the recommendations of this study that:

1. Where appropriate, family caregiver's role in supporting a person with dementia should be recognised in cold weather and winter safety policy.
2. During cold weather family members / supporters of people with dementia should also be contacted during cold weather alerts. Such a person should only be included as a contact with the permission of a person with dementia.

### **10.8 Recommendations for future research**

This study has provided insights in to a previously unexplored area of people with dementia's experience staying safe and warm at home during winter. The people in this study appear to be at greater risks to their safety at home during winter due to their cognitive changes. However, the size and scale of this study means that there are a number of questions still to be addressed. This study was conducted with a relatively small population, capturing their experience of participants over one month in winter. This study also struggled to capture effectively the experience of people with more advanced dementia. Therefore, it is recommended that:

- Longitudinal research over a winter period should be conducted with people with dementia who live alone in the community, to assess how their needs and approaches to safety and warmth progress.
- Future studies should take greater steps to give greater voice to those with more advanced dementia. Methods that give greater scope for people with more advanced dementia should be used, such as visual aids and/or photographic dairies in conjunction with interviews.
- Future research should capture demographic groups not included within the scope of this study, such as ethnic minorities. Further, future studies should consider whether any socio-demographic groups are more at risk of winter related harm.
- Future research should also be considered that uses methods to capture a larger sample of experiences related to winter safety and warmth, such

as through the use of surveys, Rater scales, and/or the use of temperature measurements in a larger number of homes.

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# Appendices

## Appendix A: Literature review test examples

## Literature search testing, run in the Scopus search engine

TITLE-ABS-KEY ("old age" or retire or elder or "over 65") AND TITLE-ABS-KEY (cold\* or "fuel poverty" or "thermal comfort") and TITLE-ABS-KEY (home or house or alone or accommodation)

49 results

TITLE-ABS-KEY (older or "old age" or retire or elder or "over 65") AND TITLE-ABS-KEY (cold\* or "fuel poverty" or "thermal comfort") and TITLE-ABS-KEY (home or house or alone or accommodation)

724 results

TITLE-ABS-KEY ( old\* OR retire\* OR elder\* OR "over 65" ) AND TITLE-ABS-KEY ( cold\* OR warm OR "fuel poverty" OR "thermal comfort" ) AND TITLE-ABS-KEY ( home OR house OR alone OR accommodation )

1114 results

TITLE-ABS-KEY ( old\* OR retire\* OR elder\* OR "over 65" ) AND TITLE-ABS-KEY ( cold\* OR warm OR "fuel poverty" OR "thermal comfort" ) AND TITLE-ABS-KEY ( home OR house OR alone OR accommodation ) AND ( LIMIT-TO ( PUBYEAR , 2015 ) OR LIMIT-TO ( PUBYEAR , 2014 ) OR LIMIT-TO ( PUBYEAR , 2013 ) OR LIMIT-TO ( PUBYEAR , 2012 ) OR LIMIT-TO ( PUBYEAR , 2011 ) OR LIMIT-TO ( PUBYEAR , 2010 ) OR LIMIT-TO ( PUBYEAR , 2009 ) OR LIMIT-TO ( PUBYEAR , 2008 ) OR LIMIT-TO ( PUBYEAR , 2007 ) OR LIMIT-TO ( PUBYEAR , 2006 ) OR LIMIT-TO ( PUBYEAR , 2005 ) )

666 results

# **Appendix B: Leaflet for person with dementia**



## Keeping Warm in Winter Research

Hello, my name is Ben Thomas. I am a PhD student at Sheffield Hallam University and I would like your help with my research.

I am investigating people with dementia's experience of keeping warm at home in winter. You are being contacted because you have some involvement in <insert name>'s care. <Insert name> has given me permission to contact you. If you are willing to help with the research it would involve you talking to me once at a time and place that suits you.

I would like to send you some more information about what the research involves. If that is OK with you please return the 'Permission to Contact' sheet in the envelope provided. Doing this does not mean you have to take part.

Regards

Ben Thomas  
Sheffield Hallam University  
Montgomery House  
32 Collegiate Crescent  
S10 2BP  
[b.thomas@shu.ac.uk](mailto:b.thomas@shu.ac.uk)



# **Appendix C: Permission to Contact Form**

Hello, I would like to speak to you about the keeping warm in winter research and what it would involve if you did agree to take part. Please read through the leaflet before completing this form.

Filling in and returning this contact form does not mean you have to take part in the research. It only gives permission for me to talk to you about the research. You can back out at any stage you would like. If you have any questions please contact me using the contact details below.

Thank you

Ben Thomas  
Sheffield Hallam University

I ..... give permission for Ben Thomas to contact me about the keeping warm at home research.

Please fill in below the way/s you would like to be contacted by

Telephone number: .....

Email:.....

Address:.....  
.....

Please return this form in the stamped address envelope.

Thank you.

# **Appendix D:**

## **Participation information sheet: Carer**

Keeping Warm at Home for People with Dementia:  
Participant Information Sheet for Carer

You are invited to take part in a research study about keeping warm at home for people with dementia. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please read the following information carefully. Take time to decide whether or not you wish to take part.

The research is being conducted by a PhD Doctoral student (Ben Thomas) at Sheffield Hallam University. Do feel free to contact Ben Thomas if there is anything that is not clear or if you would like more information. Contact details are at the end of this sheet.

**Why have I been contacted?**

You have been approached because you know and have an input in the support or care of (insert name). They have suggested you may be able to help with the research and given us approval to contact you.

**Do I have to take part?**

No you don't. It is entirely up to you whether you take part.

**What do I do if I want to help?**

If you would like take part with the research please read through this information sheet carefully. Spend some time thinking about it.

If you are interested in taking part in the research please return the permission contact form in the provided stamped address envelope. The researcher (Ben Thomas) will contact you to discuss the study in more detail.

### What are we doing?

Keeping warm during winter can be a struggle for many people. But little is known about the difficulties people with dementia face keeping warm in their own home. This research will investigate how people with dementia keep warm at home.

We have talked to (insert name) about their experience of keeping warm at home and put two small temperature measuring devices in their home for two weeks. We would now like to talk to other people who support (insert name) in their care and keeping warm at home.

### What would it involve?

If you agree to take part in the study Ben would talk to you a time that is convenient to you about your experiences of keeping (insert name) warm at home. It would involve an interview of 30 - 45 minutes with the researcher at a location of your choosing. If difficult to arrange it can be done by telephone.

### Benefits of participating - what will happen to the information you provide?

There are no direct benefits to taking part, although some people enjoy the opportunity to take part in discussions of this nature. Your experience, along with the experiences of others, will be used to improve services.

The information that you give in the research will be anonymised and written up in a PhD thesis. Findings will also be reported in published articles, at conferences and distributed to interested organisations working with people with dementia. Any identifying information will be removed from these reports.

### Will the information I give be kept confidential?

We will keep all information you disclose fully anonymous. Only the researcher and his supervisors will know who said what. Any personal information will be kept in a secure location and not passed onto anyone else.

### Is there any risk in participating?

Taking part in the study will not affect the care of (insert name) in anyway and there is no foreseen risk to you or them. However if any concern is raised during the research regarding their health or wellbeing we will discuss them with you and the possibility of referring them on to someone who can help, in consultation with (insert name).

### If you want to ask anything about the study?

You can talk to Ben Thomas who will do their best to answer your questions.

### Contact details of the researcher:

Ben Thomas, 34 Collegiate Crescent, Sheffield Hallam University, S10 2BP.  
01142252224. [b.thomas@shu.ac.uk](mailto:b.thomas@shu.ac.uk)



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Ben

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Ben will always show you his University ID card when talking to you face-to-face.

### What if there is a problem or I want to complain?

You can contact Peter Allmark (Chair Faculty Research Ethics Committee)  
[p.allmark@shu.ac.uk](mailto:p.allmark@shu.ac.uk); 0114 225 5727.

### An independent contact who can offer advice about Alzheimer's Disease or dementia

Alzheimer's Society, Sheffield, Venture House, 105 Arundel St, Sheffield S1 2NT,  
0114 276 841

# **Appendix E: Permission to Contact Form**



## Permission to Contact Form

Hello, I would like to speak to you about the keeping warm in winter research and what it would involve if you did agree to take part. Please read through the information sheet before completing this form.

Filling in and returning this contact form does not mean you have to take part in the research. It only gives permission for me to talk to you about the research. You can back out at any stage you would like. If you have any questions please contact me using the contact details below.

Thank you

Ben Thomas  
Centre for Health and Social Care Research  
Montgomery House  
32 Collegiate Crescent, Collegiate Campus  
Sheffield, S10 2BP  
[b.thomas@shu.ac.uk](mailto:b.thomas@shu.ac.uk)

I ..... give permission for Ben Thomas to contact me about the keeping warm at home research.

Please fill in below the way/s you would like to be contacted by

Telephone number: .....

Email:.....

Address:.....  
.....

Please return this form in the stamped address envelope.

Thank you.

# **Appendix F: Participant information sheet: Person with dementia**

## Keeping Warm at Home for People with Dementia: Participant information Sheet

I am inviting you to take part in a research study about keeping warm for people with dementia. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please read the following information carefully. Take time to decide whether or not you wish to take part.

The research is being conducted by a PhD student (Ben Thomas) at Sheffield Hallam University. Do feel free to contact Ben if there is anything that is not clear or if you would like more information. Contact details are at the end of this sheet.

### Why have I been contacted?

You have been approached because you have a diagnosis of dementia. Someone from the *[a community based dementia association]* will have approached you initially about the research.

### Do I have to take part?

No you don't. It is entirely up to you whether you take part. Your decision about taking part in the research will not affect the care or support you receive in any way.

### What do I do if I want to help?

If you would like take part with the research please read through this information sheet carefully. Spend some time thinking about it.

If you are interested in taking part in the research please return the permission consent form in the stamped address envelope provided. The researcher (Ben Thomas) will contact you to discuss the study in more detail.

#### What are we doing?

Keeping warm during winter can be a struggle for many people. But little is known about the difficulties people with dementia face keeping warm in their own home. This research will investigate how people with dementia keep warm at home.

#### What would it involve?

If you agree to take part in the study Ben will meet you at your home and talk about your experiences of keeping warm at home. It would involve two interviews of 30 - 45 minutes with Ben over a three week period. These interviews will be recorded on a tape recorder.

We would also like to leave three very small temperature measuring devices, about the size of a plug, in your home for 2 weeks. An additional short visit is needed to pick these up.

If you would like someone at the meetings, (for example your husband/wife or family member), that is absolutely fine. Please let Ben know so that this can be arranged.

#### Who else we would like to talk to

As part of the study we would also like to talk to people that help you keep warm in your home (for example family, friends or professional carers). Ben will leave some information for you to pass on to anyone you suggest, at the interview. We will only contact people you give us permission to contact. It's up to you to decide.

### Benefits of participating - what will happen to the information you provide?

There are no direct benefits to taking part, although some people enjoy the opportunity to take part in discussions of this nature. Your experience, along with the experiences of others, will be used to improve services.

The information that you give in the research will be anonymised and written up in a PhD thesis. Findings will also be reported in published articles, at conferences and distributed to interested organisations working with people with dementia. Any identifying information will be removed from these reports.

### Will the information I give be kept confidential?

We will keep all information you disclose fully anonymous. Only the researcher and his supervisors will know who said what. Any personal information will be kept in a secure location and not passed onto anyone else.

### Is there any risk in participating?

Taking part in the study will not affect your care in anyway and there is no foreseen risk to you. However if any concern is raised during the research regarding your health or wellbeing we will discuss with you the possibility of referring you on to someone who can help. If there is any serious risk to your wellbeing we may raise this concern with the advisor from the *[community based dementia association]* shown below but let you know we have done this if possible.

### What if there is a problem or I want to complain?

If you have a concern about any aspect of this study, you should ask to speak to Ben Thomas who will do his best to answer your questions.

Contact details of the researcher:

Ben Thomas, 34 Collegiate Crescent, Sheffield Hallam University, S10 2BP. 01142252224. [b.thomas@shu.ac.uk](mailto:b.thomas@shu.ac.uk)



Ben will always show you his University ID card on arrival at your home.

If you would rather contact an independent person, you can contact Peter Allmark (Chair Faculty Research Ethics Committee) [p.allmark@shu.ac.uk](mailto:p.allmark@shu.ac.uk); 0114 225 5727

[An independent contact who can offer advice on Alzheimer's disease or dementia](#)

*[a community based dementia association, address included]*

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Ben

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# **Appendix G: Consent form: Person with dementia**

## Consent form

*Please answer the following questions by ticking the response that applies*

- |   | <b>YES</b>               | <b>NO</b>                |
|---|--------------------------|--------------------------|
| 1. I have read the Information Sheet for this study and have had details of the study explained to me.  | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. My questions about the study have been answered to my satisfaction and I understand that I may ask further questions at any point.             | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. I understand that I am free to; withdraw from the study without giving a reason or to decline to answer any particular questions in the study. | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. I agree to provide information to the researchers under the conditions of confidentiality set out in the Information Sheet.                    | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. I wish to participate in the study under the conditions set out in the Information Sheet.  | <input type="checkbox"/> | <input type="checkbox"/> |



6. I consent to the information collected for the purposes of this research study, once anonymised (so that I cannot be identified), to be used for any other research purposes.

7. Would you like someone else to be present during the interview process (for example a partner or relative)

8. If so who would you like to be present?.....

9. Do you agree for the researcher to contact family members, friends or health care professionals to seek their opinion on how you keep warm in winter? (This will not happen unless you agree first).

**Participant's Signature:**

\_\_\_\_\_ **Date:** \_\_\_\_\_

**Participant's Name (Printed):**

\_\_\_\_\_

**Researcher's Name (Printed):**

\_\_\_\_\_

**Researcher's Signature:**

\_\_\_\_\_

# **Appendix H: Consent form: Carer**

**Keeping Warm at Home for a Person with Dementia**

**Participant consent form**

|   | Please initial<br>here |
|---|------------------------|
| I have read and understood the information sheet  |                        |
| I have had the opportunity to ask questions and have received answers that I am happy with. |                        |
| I understand that I can withdraw at any time. Without giving a reason for my withdrawal.    |                        |
| I understand that the interviews will be recorded and transcribed.                          |                        |
| I consent to take part  |                        |

Participant Name: .....

Participant Signature.....

Date: .....

Name of researcher taking consent: .....

Researcher Signature.....

Date: .....

# **Appendix I: Sample interview schedule**

# 1<sup>st</sup> Interview PWD

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- Introduction
- Restate who I am and why I am here today.
- Make sure they have all of the necessary documentation and they have read through it.
- Cover all of the information in the information sheet.
- Confirm they understand what is expected of them as a research participant.
- Go over the interview process.
- Confirm they understand everything and ask if they have any questions
- Go over the consent form with the participant and re-establish consent
- Inform them they can stop at any time for any reason and they do not need to explain the reason.
- Check it is ok to record the interview and make some notes

## Recorder on

### Questions

*I am going to ask you questions around how you keep warm in your home and problems you have had. If there is any question you are uncomfortable with you don't have to answer and I will move on. We can stop or take a break at any time. Is it ok to start?*

### Environment

1). Tell me a little bit about your home, how long have you lived here? (Follow up; Do you own the home or rent? If rent who from?)

2). Tell me about how you heat your home? (Follow up; Can I see....? Do you use anything else when it gets cold? Do you have any difficulties using ...?)

3). Do you have/have you had any problems keep your home warm in winter? (Follow up; Does it keep you warm? Is it expensive?)

4). Have you had any difficulties paying your bills? (Follow up; Have you made make any changes? Did anyone help you?)

5). If you had a problem with your heating would you seek anyone to help? (Follow up; Who would this be?) (Prompts; family, carers, neighbours, friends)

6). Has anything been changed in the house to keep it warmer? (Did anyone help you with this?)

7). If the house gets very cold what do you do? (Prompt; turn up heating, extra layer, heat only one room etc...)

### Personal

*Some people with dementia have difficulty keeping warm in winter so I would like to ask you a few questions about your experience if that is ok?*

8). Do you get out and about much? (Follow up; What kind of places? How regularly?)

9). Do you have people look in on you at home? (Follow up; If so who and roughly how often? Is there anyone/service that helps asks about how you are getting on at home?)

10). Do you ever feel cold in your home? (Prompt; What about last winter?) (Follow up; Is there any specific times of day you feel cold?) What do you do if you are cold?

11). Do you think being warm is connected to your health? (Follow up; What health issues?)

12). If you felt cold at home is there anyone you would speak to? (Follow up; Who would this be? Has this happened before?)

13). What medical conditions do you have? (Prompt; Type of dementia?) (Follow up; Any other conditions? How are/Are they being treated?)

### Dementia Influence

14). Do you feel your condition has affected your ability to keep warm at home? (Prompt, dressing, moving around, eating regularly, use heating devices) (Follow up; In what way has this happened? Have you done anything to help this?)

Is there anything else you would like to add?

### Demographic

I have just a couple of questions about you to finish on, if that OK?

When is your date of birth?

What was your occupation?

What is your income? (pension, savings, help from the family)(Do not need to know figures but source)

## **Recorder off**

### Post questions

*Discuss the TinyTags and place them around the home.*

*Discuss contacting carers, leave information for them or if appropriate get contact details.*

*Arrange follow up interviews and picking up the TinyTags.*

Is there anything you would like to be explained?

Is there anything you would like to know?

Do you have any concerns?



# **Appendix J: Coding Framework: Themes, sub- themes, and codes**

## Theme 'Losing me'

| Sub-themes   |                                   |                             |                                   |
|--------------|-----------------------------------|-----------------------------|-----------------------------------|
|              | Trying to stay me                 | Holding on to me            | Keeping\ my place                 |
| <b>Codes</b> | Challenges to me                  | Communication in the family | Moving to be closer to family     |
|              | Ability to dress                  | Family visiting             | Wanting to be independent         |
|              | Decreasing activity               | Going out and socialising   | Wanting to stay in their own home |
|              | Having help with personal hygiene | Keeping active              |                                   |
|              | Loosing track of time             | Reluctant to spend money    |                                   |
|              | Professional care at home         | Resisting help at home      |                                   |

## Theme 'Hanging on'

| Sub-themes   |  |   |                                      |                               |
|--------------|--|---|--------------------------------------|-------------------------------|
|              | Holding them up                              | Letting go                                | Not seeing the risk                  | Starting to slip              |
| <b>Codes</b> | Care planning                                | Family supporting finances                | Ability to dress                     | Ability to communicate        |
|              | Communication in the family                  | Family supporting the PwD to live at home | 'couldn't be on his own'             | Condition of the home         |
|              | Family helping with heating system           | Resisting help at home                    | Financial situation                  | Cooking                       |
|              | Family maintaining the structure of the home | Wanting to be independent                 | Having problems with the heating     | Paying the bills              |
|              | Having contacts to help with heating system  |   | Having to prompt to add extra layers | PwD unable to use the heating |
|              | Local help for the PwD                       |   | Heating prompt                       | PwD's other health conditions |
|              | Using government schemes                     |   |                                      | Spouses care difficulties     |

# Theme 'Winter wellbeing'

|              |                                    | Sub-themes                       |                               |
|--------------|------------------------------------|----------------------------------|-------------------------------|
| <b>Codes</b> | Keeping warm                       | Approaches to heating            | More than keeping warm        |
|              | Feeling the cold                   | Feeling warm                     | Appetite                      |
|              | Going out to save money on heating | Having a hot drink               | Decreasing activity           |
|              | Having heating insurance           | Night time warmth habits         | Disturbed night sleeping      |
|              | Putting on extra layers            | Placing importance on being warm | Paying the bills              |
|              |                                    |                                  | PwD losing weight             |
|              |                                    |                                  | PwD's other health conditions |
|              |                                    |                                  | Risk of falling               |
|              |                                    |                                  | Spouses care difficulties     |
|              |                                    |                                  | Structure of the home         |

# **Appendix K: Coding examples of two codes/nodes in NVivo**

# Code: Wanting to stay in their own home

[<Internals\\Case 1\\Par 1 2nd int>](#) - § 1 reference coded [1.97% Coverage]

Reference 1 - 1.97% Coverage

**Let me ask you this then Andy, and this may be a bit personal so please bear with me, would you consider moving out of his home to somewhere?**

No, not now, I've finished now.

**You'll stay here for good.**

Yeah, while they carry me out.

**What if, so there's nothing that would make you move out?**

No, if worse comes to the worst I shall have to have a bed downstairs.

**Fair enough, determined to stay.**

Eh?

**Determined to stay.**

Aye.

[<Internals\\Case 1\\Par 1 daughter in law>](#) - § 2 references coded [2.11% Coverage]

Reference 1 - 1.50% Coverage

He will not go in a home; he wants to die in his own home. I fully support that. I have to say my aim is to keep him here as long as I can possibly do it. When I can't do it then I'll have to think. My gut feeling is he would not go, even if this place was falling round his ears, we wouldn't get him out.

Reference 2 - 0.61% Coverage

No, we've tried a home, I've broached the subject, especially when mum died, and really got quite a very aggressive response.

[<Internals\\Case 3\\Par 3 - 2nd interview>](#) - § 3 references coded [3.50% Coverage]

Reference 1 - 1.96% Coverage

I don't find it a problem, you know, I mean it's my choice to be in the house and just heat the room that I'm using. And this house, it's my choice to have this house and I don't want

to move from it. I really don't, I love this house; I don't want to move from it. But it is a family house, you know, that's what people say. I mean the identical house next door to me, there are two adults, two offspring if you like, they're not really kids now, two teenage boys and a dog all living in the house next to me.

Reference 2 - 0.96% Coverage

No. I moved from a smaller house into this one because, well I'd sold my parents' house, or I was getting to selling my parents' house or, I can't remember just what was what, but I wanted to invest the money and I've invested it in the house, you know.

Reference 3 - 0.57% Coverage

I'm happy with what I've done, and believe me I've been in this house for [many years] and I've been all right in it. I've been all right in it.

[<Internals\\Case 4\\Par 4 - Interview 1>](#) - § 2 references coded [1.50% Coverage]

Reference 1 - 0.99% Coverage

I mean my main thing is living in sheltered is safety, I'm safe. Because you could give me a house on the outside, you can furnish it, free rent, no thank you. I'm safer in here, and I think once you're in sheltered housing, you're safe, and this is my main thing in my life, to live in here, and I feel I'm safe, because I could not live on the outside.

Reference 2 - 0.51% Coverage

And I'm quite comfortable in here. I don't, I'm not scared. I am, I can be scared of anything, but I don't feel uncomfortable and on edge and scared in here. I'm quite comfortable.

[<Internals\\Case 6\\Par 6 - carer 1 int>](#) - § 3 references coded [3.70% Coverage]

Reference 1 - 1.15% Coverage

It's difficult for me to consider putting him in a home. He's really ready for it but it's so hard to do.

### **Is it the financial reasons or is it the emotional?**

H: More emotional I think. Well and that, because I've only just had an assessment. I've not had a care, I've not had a, what do they call, social worker.

Reference 2 - 0.55% Coverage

And I want him to be assessed to see if I can get a respite. I don't want to put him in permanent, but if I could have a few days respite and rest up a bit.

Reference 3 - 2.00% Coverage

over the borderline for [location]. Well my grandson and my granddaughters, they're all settled there. So I want one that is, it's just over the borderline and I don't know if they'll accept that. I don't want them to have to come to [location] and...

**Well if you talk to them they may be able to help you out.**

So I've explained that to her, and they're wanting me to move to be over the borderline. And I know which one I want him in, and I've told them. It is just over the [road], the [road] divides [location] and [location].

[<Internals\\Case 6\\Par 6 - carer 2 int>](#) - § 1 reference coded [0.56% Coverage]

Reference 1 - 0.56% Coverage

My mum wants him to stay here as long as he possibly can. My mum is frightened that they will lose their home if he should go into that situation.

[<Internals\\Case 6\\Par 6 - join int>](#) - § 1 reference coded [0.37% Coverage]

Reference 1 - 0.37% Coverage

Then they had to share having him, you know. But you see they like their own surroundings.

# Code: Family supporting finances

[<Internals\\Case 1\\Par 1 1st int>](#) - § 1 reference coded [0.67% Coverage]

Reference 1 - 0.67% Coverage

**Who changed the name, did you?**

No, our [son] did all, he did all office work.

**So [son] helped you out there.**

Oh aye.

[<Internals\\Case 1\\Par 1 Son>](#) - § 1 reference coded [0.75% Coverage]

Reference 1 - 0.75% Coverage

We arrange everything through direct debit. Everything was in my mum's name, everything's now in my dad's name, it's just direct debit.

[<Internals\\Case 2\\Par 2 1st int>](#) - § 1 reference coded [0.40% Coverage]

Reference 1 - 0.40% Coverage

**Do you check your bills or do your daughters check your bills?**

My daughter checks them yeah.

[<Internals\\Case 2\\Par 2 Daughter 1 int>](#) - § 2 references coded [1.04% Coverage]

Reference 1 - 0.40% Coverage

**So, when it comes to the bills, who manages those?**

Me.

**And have there been any problems with the bills?**

No, it's on direct debit.

Reference 2 - 0.64% Coverage



Because they should at least have contacted us. And he did say my daughter deals with this, but they didn't ring me. So, can cause, that sort of thing, you can spend a lot of time rectifying little things like that.

[<Internals\\Case 2\\Par 2 Daughter 2 int>](#) - § 1 reference coded [1.28% Coverage]

Reference 1 - 1.28% Coverage

They're mainly on direct debit, I think, or [elder daughter] deals with things, the sort of the bill places that need to be done that's not on direct debit.

[<Internals\\Case 4\\Par 4 - Interview 1>](#) - § 1 reference coded [1.12% Coverage]

Reference 1 - 1.12% Coverage

I pay, after that scene, well [nephew] did everything for me, and he were ringing these people up. It sounds as if I owe a lot of money, but he straightened it all out for me, and he said look, would you like to pay like your rent through bank? My money, I don't receive my money, it's paid in the bank. If I want, and now and again I go and draw several pound out, and then I'm okay for, well next time

[<Internals\\Case 5\\Par 5 - follow up int with PwD>](#) - § 1 reference coded [1.34% Coverage]

Reference 1 - 1.34% Coverage

Well no, [wife] deals with all that anyway. She's the person that worries about that.

[<Internals\\Case 5\\Par 5 - carers Mandy Alex>](#) - § 3 references coded [1.09% Coverage]

Reference 1 - 0.49% Coverage

Initially when mum took over starting paying the bills we went through all the bills and we got a list of all the standing orders and direct debits out, so we could work out where everything was going.

Reference 2 - 0.32% Coverage

So we've tried to as much as we can sort all that out. So they are covered for things, but they're not paying twice for things.

Reference 3 - 0.29% Coverage

So we did that together so mum does pay, she does all the bills and she keeps a really good eye on the bank account.

# **Appendix L: Letter of approval from Faculty Research Ethics Committee**

Date: 03062014

Ref: 2013-4/HWB/HSC/STAFF/17

Dear Ben Thomas

This letter relates to your research proposal:  
Keeping Warm at Home for a Person with  
Dementia

This proposal was submitted to the Faculty Research Ethics Committee for ethics and scientific review. It has been reviewed by two independent reviewers and has been passed as satisfactory. The comments of the reviewers are enclosed. You will need to ensure you have all other necessary permission in place before proceeding, for example, from the Research Governance office of any sites outside the University where your research will take place. This letter can be used as evidence that the proposal has been reviewed ethically and scientifically within Sheffield Hallam University.

The documents reviewed  
were: THOMAS Ben  
SHUREC2.pdf  
THOMAS Ben Supporting Docs.pdf

Good luck with your  
project. Yours sincerely



Peter Allmark  
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# **Appendix M: Letter of amendment from Faculty Research Ethics Committee**

19 January 2015

Ref: GWB141013

Ben Thomas

Centre for Health and Social Care  
Research Chestnut Court  
Sheffield

Dear Ben

This letter relates to your research proposal

Keeping Warm at Home for a Person with Dementia and the amendment received  
on 12 January 2015

This amendment to your proposal was submitted to the Faculty Research Ethics  
Committee for review. It has been reviewed by an independent reviewer on behalf of the  
Committee and is now passed as satisfactory. You may need to get further permission for  
the amendment from other governance bodies, such as R&D departments or NHS ethics  
committees.

The documents we reviewed were:  
Major amendment form Ben  
Thomas.pdf

Good luck with your project.  
Yours sincerely



Peter Allmark  
Chair Faculty Research Ethics  
Committee Faculty of Health and  
Wellbeing  
Sheffield Hallam