# University of Southampton

Faculty of Social Sciences

Gerontology


## Late-Life Decision-Making


by

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# University of Southampton

## Abstract

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Doctor of Philosophy in Gerontology

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*'So many things that I've done, decisions have been easy, I think, until now. And now they're not so easy. Now I have the hard ones…. And now it's just me making the decision.' (Winifred, Round 1 Interview)*

People aged 85 and above are the fastest growing population segment worldwide, yet academic research on this life stage tends to focus on caregiving, ill health, disability, and dementia. In contrast, this thesis examines community-dwelling older people who are in relatively good health and living independently in a suburban borough of London. The research seeks to understand how people aged 85 and above think about and make decisions. The study examines how decision-making has changed throughout the lifecourse, what specific future decisions are anticipated and what heterogeneity exists in late-life decision-making. Using qualitative longitudinal research, 17 community-dwelling people aged 85 and above were interviewed on four occasions. Analysis used a case study approach, where each participant was a case.

Results suggest that the main goal of late-life is to continue living as fully as possible and doing activities that give life meaning. In the process, financial and social resources are deployed strategically to counter possible health decrements. Regarding decision domains, this research proposes that there are only four main decision domains throughout the lifecourse: 1) the activities of life; 2) the people and relationships that enliven them; 3) the resources that support them, and 4) identity. In earlier life, decisions are made about building resources, developing an understanding of the activities that give life meaning, and deciding on values and ethos. In later-life the focus shifts to strategically deploying resources to support continuing engagement and to protect identity. A lifetime of experience informs these decisions, but in later-life two specific emotions motivate decisions: 'want' in how much something is desired, and 'fear' in anticipation of possible adverse consequences.

The principal decisions of very-late-life concern death and end-of-life. To the participants, decisions about death concern administrative matters. End-of-life, however, is considered as a time when they are no longer able to live their lives fully and need to contemplate possible care. The process for making this decision changes because of the need to balance the goal of maintaining independence with the recognition that they may need to redefine identity, to becoming someone who needs care. In considering possible care, information will be gathered, friends consulted, strategies developed, and interim interventions employed. The final decision, for a care home or full-time care, will be deferred, waiting for a precipitating event which forces the decision. There appears to be a gender difference in decision-making in that women are more proactive about implementing interventions and continuing to build and develop social networks which can also be called upon for assistance.

This research contributes to the limited literature regarding the decision-making of community-dwelling people aged 85 and above. It will increase understanding of late-life and will counter the perception of late-life as a time of depredation to show older people as agentic and able to maintain decision control into very-late-life.

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# Research Thesis: Declaration of Authorship

Print name: Heather Lynn Mulkey

Title of thesis: Late-Life Decision-Making

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission.

Signature: ..... Date: 9 December 2021

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# Definitions and Abbreviations

ACP ..... Advance-care-planning

ADL ..... Activities of daily living

CC75C ..... Cambridge City Over 75s Cohort

CPR ..... cardio-pulmonary resuscitation

DfT ..... Department for Transport

DNAR ..... Do-not-attempt-resuscitation

EOL ..... End-of-life

EOLC ..... End-of-life care

EAP ..... Enduring Powers of Attorney

ERGO ..... Ethics and Research Governance Online

LAT ..... Live-apart-together (partners)

LPA ..... Lasting Power of Attorney

LPAHW ..... Lasting Power of Attorney for Health and Welfare

LAPPFA ..... Lasting Power of Attorney for Property and Financial Affairs

NPEOLCP ..... National Palliative End-of-life Care Partnership

OED ..... Oxford English Dictionary

ONS ..... Office for National Statistics

QLR ..... Qualitative longitudinal research

QOL ..... Quality of life

SES ..... Socio-economic status

SOC ..... Selective optimisation with compensation

SRLE ..... Subjective remaining life expectancy

SST ..... Socioemotional selectivity theory

UN ..... United Nations

WHO ..... World Health Organisation

# Chapter 1 Introduction

*"So many things that I've done, decisions have been easy, I think until now. And now they're not so easy. Now I have the hard ones … and now it's just me making the decision. I think these are the hardest." Winifred, R1*

## 1.1 Introduction

The population of people aged 85 and above is the fastest growing population in the UK and is projected to more than double from 2020 to 2050 at which time they will represent over 5% of the total population (United Nations Department of Economic and Social Affairs Population Division [UNDESAPD], 2019). The academic literature about this population segment, however, tends to focus on the depredations of ageing and decisions made *about* older people. There is little research available capturing the thinking and experience of community-dwelling older people themselves. This research adds to a limited body of research on how community-dwelling older people make decisions about and prepare for the future. This research will offer insight into their decisions, decision-domains, processes, influences, and goals in order to assist healthcare professionals, policymakers and older people themselves in understanding and preparing for the benefits and challenges of later-life.

People in the UK aged 85 and above, born between 1926 and 1935, have been termed by the Office for National Statistics (ONS) the "Golden Cohort" because they achieved increases in mortality which no other cohorts have achieved either previously or subsequently (Goldring *et al.,* 2011). This cohort lived in the shadow of two World Wars and part of the reason for their health increase is that they were too young to fight in the Second World War. Further, they benefitted from better preventative health treatments throughout life and a vibrant post war economy (*ibid.*). They were also children during the Second World War. They experienced bombings, evacuation, and absent fathers; amongst them are refugees, prisoners of war and evacuees. They experienced rationing and a collective community spirit post war. Now in their late 80s, these older people have already surpassed the average UK life expectancy, yet as they enter late-life, they may face numerous challenges: bereavement, decline in mental and/or physical health, or increasing dependence, necessitating residential relocation with attendant financial concerns. Little research exists on how people aged 85 and above negotiate the resulting transitions or make decisions regarding the challenges they face. This thesis seeks to understand late-life decision-making and how experience of weathering previous life course transitions informs future decision-making.

This introductory chapter briefly discusses theory about decision-making and people aged 85 and above, describes the proposed research and research questions, before proceeding to an explanation of the method adopted, qualitative longitudinal research (QLR), and closing with a description of the structure of this thesis.

### 1.1.1 A note about COVID and terminology

Data collection for this research began in September 2018 and ended in December 2019, before the outbreak of COVID-19. For that reason, COVID is not addressed in this thesis except as it relates to suggestions for future research. When participant quotations are referenced, their pseudonym and the interview round (R1, R2, R3 or R4) are used.

## 1.2 Gerontological and decision-making theory

Social Science theories, notably gerontological and economic theories, address aspects of decision-making which can be applied to people aged 85+. Socioemotional Selectivity Theory (SST) suggests that as people age, they are more selective about their emotional investment. As a result, older people consider their subjective remaining life expectancy (SRLE) in making decisions about the future (Carstensen, 1992). This impacts later-life goals and motivations to determine whether expected gain is worth the effort, given the time left to enjoy it. Another theory that can be applied to decision-making, Selection, Optimisation, and Compensation (SOC), posits that adapting to changes and lowering expectations provides a compensatory strategy for dealing with old age (Baltes and Carstensen, 1996). For example, an older person may recognise fading eyesight, so stop driving at night but continue daytime driving. Finally, Atchley's continuity theory proposes that adult development continues throughout the lifecourse, and that people learn from past experiences, applying them to new situations, but that there is continuity in the idea patterns, lifestyle, personal goals, adaptive capacity and the strategies for coping with changes (Atchley, 1999). The final wave of data collection in Atchley's (1999) longitudinal quantitative study found that participants had consistent mental and lifestyle patterns which inform decision-making throughout life and are incorporated into their decision-making patterns.

Specific decision-making theory suggests general patterns of decision-making. Kahneman and Tversky's Nobel Prize winning prospect theory posits that the perception of gain or loss is based on the reference point. In other words, people change their minds as their reference point changes (Bern-Klug, 2017). In applying this to late-life, older people may realise they can live well with declining health, something the younger self might not have appreciated. Two final theories offer insight into late-life decision-making. Löckenhoff (2018) has proposed a conceptual

framework for mapping age differences in decision-making which involves prioritising values whilst Heiss (2018) has taken an anthropological perspective on decision-making which progresses decision-making from being a single event to a process which may evolve over time. Elaboration on these theories and further aspects of decision-making, are discussed in Chapter Two. What is notable from the academic research is that there is little qualitative research that brings together decision-making with people aged 85 and above to understand how they think about and make decisions (see Appendix B Literature Search). This research seeks to fill that gap. This study brings together decision-making theory with the lived experience of participants aged 85 and above in order to understand how people think about and make decisions about the future.

## 1.3 People aged 85 and above

The population of people aged 85 and above (born in 1933 or before, at the start of research in 2018) is the fastest growing population worldwide (World Health Organisation (WHO), 2011). Worldwide, the population of those aged 65 and above is expected to more than double from 2020-50 and nearly triple for those aged 85 and above (UNDESAPD, 2019). The UK population of those aged 85 and above is approximately 1.7 million, approximately 2.5% of the national population; as a percentage of the total population, it is projected to increase to 5.2% of the total population by 2050 (*ibid.*).

Table 1.1 UK population of older people, 1990-2050

| | **1990** | **2000** | **2010** | **2020** | **2030** | **2050** |
|---|---|---|---|---|---|---|
| Population aged 65+ | 15.7% | 15.9% | 16.6% | 18.7% | 21.5% | 25.3% |
| Population aged 85+ | 1.4% | 1.9% | 2.2% | 2.5% | 3.0% | 5.2% |
| Increase of those aged 65+ | | 4.1% | 12.3% | 20.4% | 19.8% | 23.8% |
| Increase of those aged 85+ | | 34.3% | 24.2% | 24.5% | 24.7% | 79.4% |
| *Source: Author's table using UNDESAPD, 2019 data* | | | | | | |

Per National life tables 2017 to 2019, 65-year-olds in the UK can expect to live a further 18.8 years to age 83.8 for men, and another 21.1 years to age 86.1 for women (ONS, 2020). This means that the population of those 85 and above has already survived past 'normal' life expectancy. Two-thirds of those aged 85+ are female with a median age of 88.2 years, 87.4 years for males (ONS, 2013). Most live in private households, with only 10% of men and 20% of women residing in communal establishments (*ibid.*). Women are more likely to be widowed, 77% versus 43% for men, with 69% of women and 41% of men living alone (*ibid.*). Having lived past 'normal' life expectancy, those 85 and above represent healthy survivor effect in that the less healthy population has already died leaving the survivors as a healthier cohort (Murphy et al, 2011).

As is seen in the table below, those aged 85+ are in good health with 29.5% considering their health as good or very good and 47.1% considering their health as fair, for a total of 76.6% considering their health as fair or better. Less than one-quarter, 23.4%, self-report their health as bad or very bad (ONS, 2013). Additionally, 47.6% or nearly half, considers the activities of daily living (ADLs) as limited a little or not at all (*ibid.*). In other words, the vast majority of people aged 85 and above considers their health as fair or better and nearly half have few or no limits on their ADLs. It should also be noted, however, that a higher percentage of those in the 85+ group report their health as bad/very bad, making health an increasing concern in later-life.

Table 1.2 Self-reported health and limits on activities of daily living (English households)

| **Self-reported Health** | **65-74** | **75-84** | **85+** |
|---|---|---|---|
| **Good/Very Good** | 59.9% | 43.3% | 29.5% |
| **Fair** | 28.8% | 40.1% | 47.1% |
| **Bad/Very Bad** | 11.2% | 16.5% | 23.4% |
| **Disabilities Limiting Activities of Daily Living** | | | |
| **Not Limited** | 61.3% | 39.1% | 17.0% |
| **Little Limited** | 22.3% | 31.8% | 30.6% |
| **Lot Limited** | 16.4% | 29.1% | 52.3% |
| *Source: Author's table using data from ONS, 2013* | | | |

Whilst this cohort may have profited from better healthcare than previous generations, a post-war communal spirit, and a rising Post-War economy, they have arrived in late-life benefitting from decisions they have made throughout the lifecourse.

## 1.4 Research objectives

As has been noted there is little information about how people aged 85 and above make decisions about the future, yet this is the fastest growing population in the UK and worldwide. Healthcare professionals, policymakers, academics, and older people themselves need to understand this life-stage in order to maximise the benefits and prepare for possible needs.

As will be discussed in greater detail in Chapters Two and Three, the academic research framework for this research is founded on three main theories. The framework suggested by this literature is as follows.

1. There are specific decision domains and that these change in importance depending on the stage in the lifecourse (Kornadt and Rothermund, 2014; Kornadt *et al.*, 2014; Kornadt *et al.,* 2020).
2. The perception of both future and past decisions changes over time depending on the reference point; the theory anticipates that people will change their minds as the reference point changes (Kahneman and Tversky, 1979; Bern-Klug, 2017).

3. There are different types of decisions ranging from simple decisions involving few options to complex and evolving decisions requiring prioritising values and re-evaluating goals in a process which involves information seeking, assessment, strategy development, and contingency planning, all of which may evolve over time with intermediary steps explored (Heiss, 2018; Löckenhoff, 2018).

Finally, it is suggested that social networks support decision-making throughout the lifecourse (Wenger, 1999) and that there is continuity in decision-making patterns (Atchley, 1999) but these influences and patterns need understanding in greater depth.

### 1.4.1 Research aim

As has been noted above, there is little qualitative research involving community-dwelling people aged 85 and above and very little which addresses how they think about and make decisions about the future. There are decision-making theories and research with older people but very little which combines the two. This research seeks to fill that gap.

Current literature suggests that the main goal of late-life is to maintain independence, autonomy, and control over personal affairs (Atchley, 1999; Jagger and Brittain, 2014; Johnson and Barer, 1997; King *et al.,* 2018; Lloyd *et al*., 2017; Loe, 2011; Price *et al.,* 2014). Older people may have, however, already anticipated challenging events, gathered information, and made contingency plans, until such time as they need to act. The present study was designed to understand how people aged 85 and above make decisions about the challenges they face in late-life and how their previous experience has prepared them to face these transitions. As how people actually behave may be different from how they theorise they will behave, the research was conducted over the course of 15 months, during which time some of the participants encountered changes which required decisions. This qualitative longitudinal design made it possible to compare theoretical decision-making with reality.

### 1.4.2 Research questions

**Main research question:** How do people aged 85 and above think about and make late-life decisions?

**Sub-questions:**

1. How has decision-making changed throughout the lifecourse?
2. What future decisions are anticipated and how will they be made?
3. What heterogeneity exists in late-life decision-making?

## 1.5 Qualitative longitudinal research (QLR)

Qualitative longitudinal methodology was chosen for this project. A qualitative paradigm seeks to understand and interpret the social world of the research participants in the context of their experiences and perspectives (Ritchie and Lewis, 2003). A longitudinal approach was chosen because it focuses on change at the individual level as it evolves over time and seeks to understand the impact, consequences or outcomes as they evolve (*ibid.*). The advantages of qualitative longitudinal research are that researchers are able to follow an individual's changes in thinking, learning how participants make choices, the relationships between their actions and thinking and the conditions, and factors under which such decisions are made (Lloyd *et al.,* 2017). In practice, the greatest advantage to QLR was that it allowed relationships to build over the course of research so that topics, including sensitive topics, could be reintroduced in subsequent interviews (*ibid.*).

To address the research questions, qualitative, semi-structured interviews were conducted quarterly from October 2018 to December 2019. Semi-structured interviews were used because participants have scope to go beyond the questions asked by the interviewer to address issues important to them, which the researcher may not have anticipated (Braun and Clarke, 2013). Purposive sampling was used to secure participation of 17 community-dwelling people aged 85 and above (Ritchie and Lewis, 2003). The participants were recruited via a variety of methods, including community organisations, events, and advertisements in local shops. The eight men and nine women aged 84-92 with an average age of 87, participated in all four interview rounds.

First round interviews averaged 94 minutes, with subsequent interviews slightly shorter on average. The first interview sought basic demographic information as well as the participants' views on their major earlier and later-life decisions, whilst also seeking to build rapport. Each subsequent interview benefitted from the previous, both in terms of questions asked, but also in the developed rapport. The second interview queried further previous decisions whilst also eliciting information on decisions not mentioned previously. By the third interview, it was possible to speak more specifically about each decision as well as probing the participants' thinking about their decisions, including possible regrets. Following amendments to the ethics application, the final interviews also probed end-of-life thinking. The methodology and analytical approach are discussed in greater detail in Chapter Four.

## 1.6 Thesis Structure

Chapter Two presents a literature review considering gerontological theories impacting decision-making, including decision-making theory, process, domains, styles and goals, and the impact of experience and emotion on decision-making. Chapter Three discusses later-life decisions including empirical research on people aged 85 and above, and specific late-life decisions. The chapter closes with the conceptual framework.

Chapter Four sets forth the methodology and develops the rationale for the research design, as well as discussing recruitment, ethical dimensions, data generation and the analytical approach.

Chapters Five through Seven introduce the research results. Chapter Five addresses the first research sub-question regarding how decision-making changed throughout the lifecourse and how earlier life experiences impacted later-life decisions. Chapter Six considers the second question in presenting late-life decisions, including discussions of future care and end-of-life. Chapter Seven addresses heterogeneity and how that impacts late-life decision-making.

Chapter Eight presents the discussion and conclusions in addressing the main research question, bringing together the academic framework with the research results, before closing with recommendations for future research and policy recommendations.

# Chapter 2 Ageing and decision-making theory

## 2.1 Introduction

Academic literature on later-life decision-making is rare and there is no qualitative longitudinal research on later-life decision-making from the perspective of community-dwelling older people. Available academic literature about late-life decision-making tends towards research on decisions *about*, not *by* older people or discusses specific decisions of later-life, e.g. residential or social network decisions, advance-care-planning or health decisions or driving cessation (see literature search, Appendix B). To understand a broader approach to later-life decision-making, the literature review is divided into two chapters. Chapter Two first considers concepts of later-life, before considering gerontological theory as it impacts ageing and decision-making, and then decision-making theory as it impacts ageing. It closes with a section on the intersection of emotion and experience in decision-making. Chapter Three focuses on later-life empirical research and research on specific later-life decisions.

## 2.2 Conceptualising later-life

As old age can range from age 60 to over 100, increasing longevity has driven greater delineation of old age. The segmentation of old age began in 1974 with Neugarten's consideration of post-pension age Americans (Neugarten, 1974). She noticed that the stereotypes of 'old age' did not apply to younger retirees who were generally healthier, better educated, more financially secure, politically active, and looking for meaningful activity. Based on this, she set out the concept of young-old and old-old, denoting the young-old as those aged 55-75, overlapping with middle age, and the old-old as those over age 75 (*ibid.*).

In 1982, Erikson enunciated his life stages theory suggesting that life is a progression of stages which must be successfully resolved before progressing to the next. His theory proposes contrary dispositions at each stage: syntonic, the more positive, and dystonic, the opposite, which must be balanced to resolve the life stage. The first four stages progress from infancy through school age, resolving issues of trust, autonomy, initiative, and industry. The next four stages from adolescence to old age focus on identity, intimacy, generativity, and integrity. The last of the stages, old age, must balance and resolve the conflict between integrity or the maintenance of a sense of self, versus "disgust and despair" (Biggs, 2005, 151). In the eighth stage, these two, the syntonic of integrity versus dystonic of despair must be balanced and resolved in facing the losses of age in order to achieve wisdom (Erikson, *et al.*, 1989). Erikson's work proposes that the

development of identity, intimacy, generativity, and integrity continues throughout the lifecourse and that these themes are brought together in old age (Erikson *et al.*, 1989; Gilleard, 2020). In late-life older people are resolving their sense of their identity, re-evaluating their experience with the perspective of time (Erikson *et al.*, 1989). Late-life intimacy and relationships must accommodate bereavement and the types of activities previously experienced, whilst the generativity or caregiving of adulthood extends to ensure the care and wellbeing of the next generations (*ibid.*). Finally, Erikson *et al.* suggest the integrity of experience, despite decline, continues to develop to create "wisdom, the involved disinvolvement with life in the face of death" (*ibid.*, p37-38).

The focus on wisdom is similar to Tornstam's conceptualisation of gerotranscendence (1989) which argued that people and society mutually withdraw from each other in anticipation of death (Bowling, 2008). Similar to and progressing beyond Erikson's eighth stage of ego integrity, Tornstam proposes gerotranscendence as a shift from a focus on the material world to a more spiritual one towards the end-of-life in order to achieve self-acceptance and inner peace (Jewell, 2014). Three aspects of gerotranscendence are noted: 1. cosmic transcendence, a spiritual transition losing fear of death, 2. connecting to a universal spirit and 3. seeking coherence of the past and present selves and seeking greater solitude for meditation (Cozort, 2008). A common aspect of both Erikson's and Tornstam's concepts is the focus on identity and the coherence of past and present selves in later life. Tornstam and J.M. Erikson, Erikson's wife, were aware of the similarities in the concepts (Bugajska, 2017). As he aged, however, Erikson considered that his theories about wisdom in older age may have been 'grandiose', leading J.M. Erikson, his wife, to propose a ninth stage where, due to physical and mental disintegration, syntonic integrity was overwhelmed, giving over to the dystonic of despair and disgust. In the ninth age, the focus is on existing in the day-to-day, like fourth age (*ibid.*).

Laslett divided old age into two stages, the third age, an era of personal fulfilment, and the fourth age, "final dependence, decrepitude and death" (Laslett 1994, p439). Laslett emphasised that fourth age is not based on chronological age but on physical condition. His original intention was to focus on the individual experience of ageing, whereby the fourth age can come at any point in life and be of varying lengths with some people perhaps skipping it entirely (*ibid.*). His third/fourth age delineation has been reinterpreted in a variety of ways. In their work, Gilleard and Higgs (2013b) considered the third and fourth ages not as developmental stages but as different paradigms of later-life in which the fourth age is a feared state, a social imaginary, that operates with unstated assumptions about possible indignities and depredations of old age. Further, fourth age is described as "a location stripped of the social and cultural capital that is most valued and which allows for the articulation of choice, autonomy, self-expression and

pleasure in late-life" (Gilleard and Higgs, 2010, p123). The authors realise that use of the fourth age as a social imaginary may lead to an increasingly difficult process of demarcating old age, framing the fourth age in terms of disability and incapacity, and leading to subtle ageism as the fourth age is contrasted with active-ageing (Gilleard and Higgs, 2013a).

Despite the perception that fourth age is an imaginary, it is used in academic literature to denote a time of life characterised by advanced age, physical decline, loss of health and mobility and increasing dependency, yet one where people can still exercise agency and where their past experience helps in the adjustment to and coping with changes (Lloyd, 2015). The differentiation between third and fourth ages is a useful distinction in marking the point at which maintaining independence becomes increasingly difficult. In academic practice, fourth age is often applied to a specific age, where the underlying foundation is chronological age and associated with the 'oldest-old' (Kafkova, 2016).

The challenge with descriptive classifications of age, is the lack of consistency across different organisations. Some classifications segregate old age into young-old (65-74), middle-old (75-84) and old-old (85 and older) (Kydd and Fleming, 2015). The challenge with combining chronological age with descriptive terms is that there is little consistency. Age UK describes the oldest-old as those in their mid-80s and above (Age UK, 2013, p.4) and uses the designation interchangeably with those in the fourth age (Age UK, 2013, p.16). The Office for National Statistics (Office for National Statistics [ONS], 2013) and World Health Organisation (WHO) define the oldest-old as those aged 85+ (ONS, 2013, 2; WHO, 2004, 42) whilst the United Nations (UN) defines the oldest-old as those aged 80+ (UN, 2015, 14). An additional complication is that terminology can change. In 2013 the ONS used the oldest-old terminology but lately the references concern the 'very-old' as being age 90 and above (ONS, 2020). Per a literature review, there is little consistency in the gerontological journals, making it difficult to compare studies (Kydd *et al.*, 2020). In this thesis, chronological age, will be used to describe the participants, in that they are age 85 and above, but descriptive terms will be used for the life stage.

## 2.3 Gerontological theories impacting decision-making

The main gerontological theories relevant to decision-making are lifecourse theory, selective optimisation with compensation (SOC), socioemotional selectivity theory (SST), and continuity theory. This section will first set the context for the research in lifecourse theory before discussing SOC, SST and continuity theories as they relate to decision-making.

### 2.3.1 Lifecourse theory

Lifecourse theory is a longitudinal perspective of life (Milne, 2020), examining the interlocking personal, social, biological, and historical factors impacting the entire course of life (Alwin, 2016; Bengtson *et al.*, 2005; Milne, 2020). Additionally, the lifecourse perspective focuses on change and continuity and the interrelationships of social and individual concepts. Experience, for example, is shaped by both the cohort (the historical period) as well as the social circumstances (Cameron *et al.*, 2019). Initially conceptualised by Glen Elder, there are five main principles:

1. 'Linked lives' addresses the connections within families and generations and relationships with other people, e.g. how a grown child's divorce and relocation into the parental home can change the plans of the parents.
2. The impact of historical time and place considers how context shapes people, e.g. the impact of World Wars, financial depressions, or social change.
3. The impact of transitions and their timing studies the intersection of social change with lifecourse stage, e.g. the social change of the 60s and 70s would impact and elicit different responses from a teenager as opposed to a retiree.
4. The concept of human agency recognises that people construct their own lives and are influenced not only by personal traits and agency, but also by circumstances.
5. Aging and development occur throughout life, with earlier life behaviours, circumstances and decisions impacting later-life (McDonald, 2011; Bengtson, 2005; Milne, 2020).

The lifecourse framework is an over-arching paradigm of ageing considering life and its transitions from the perspective of how the individual is situated in their personal, social, cultural, biological, and historical environment and how factors impact personal development (Milne, 2020).

### 2.3.2 Identity theory

Erikson's identity theory focusses on the individual and personal resolution of identity (Erikson *et al.,* 1989), whereas, increasingly, identity research considers not only how people create and develop their own identities but how this is impacted by other factors. Initially, gender, sexuality, kinship, political, economic, and cultural factors, were considered the main external factors impacting identity (Gilleard and Higgs, 2020; Hendricks, 2010; Hockey and James, 2003; Twigg and Martin, 2015). As identity theory began to intersect with lifecourse theory, however, historical time and timing, cumulative effect, linked lives, and personal agency were also noted to impact identity development (Hockey and James, 2003; Heinrichsmeier, 2020; Twigg and Martin, 2015). Given the diversity of influences on identity development, it follows that the ways that people construct identity and present themselves changes throughout life and may be situationally influenced and flexible across different situations (Heinrichsmeier, 2020; Westerhof and Tulle, 2007), and that the ageing body impacts both personal and societal views of identity (Hockey and James, 2003). Research also proposes that the impact of intersectionality (combining two or more aspects of identity) provides an additional consideration of identity, reflecting not only

social, personal and physical factors, but their interrelationships and contexts (Calasanti and King, 2015; Gilleard and Higgs, 2020). This suggests that identity is created at the intersection of personal and public domains, that it is contextual, fluid, relational and intentional, and because of agency, people make decisions about identity.

### 2.3.3 Selective optimisation with compensation (SOC)

SOC is a model of successful ageing, defining "success as goal attainment and successful ageing as minimisation of losses and maximisation of gains" (Baltes and Carstensen, 1996, p405). SOC specifies the three processes of selection, optimisation, and compensation, which should be implemented together to achieve their goals, given changes in physical capacity, motivations, and environmental demand. Selection refers to prioritising individual goals, compensation refers to altering strategies to reach the same goals whilst optimisation refers to the largely environmental support for selection and compensation (*ibid.*). An example given is of a marathon runner, who wishes to continue winning races (selection) but with age, spends more time in training and warm-up and taking health supplements to increase physical capacity (optimisation) and chooses to race in less challenging races (compensation) (*ibid.*). SOC is a formalised process of adaptation, defined as the process of adjusting to new conditions (*ibid.*), which occurs over the life course, not just in old age. The theory assumes that selectivity is based on age-related decline, which brings about the need to optimise reduced resources. Thus, as people age, they become more proficient at selecting situations which demand less emotional regulation. The terminology used by emotion researchers is emotional regulation, which is the same as the concept of selection preferred by developmental psychologists (Sims *et al.*, 2015). Increasingly, SOC is used by a variety of disciplines as a framework for successful coping, e.g. its use in occupational contexts to maintain competence, work-family balance, work engagement and job satisfaction (Müller *et al.*, 2018), as well as working with older people to improve health outcomes, e.g. self-management of multiple chronic conditions (Zhang, 2018). It has become a strategy for managing health losses by maximising what can be done, rather than focussing on what cannot (Hayman *et al.*, 2017), as such it can be a strategy employed throughout life when circumstances may necessitate a change in priorities. SOC focusses on selections made to minimise the impact of decline or changed priorities. SST, considered next, also focuses on selection, but bases the theory on selections made in response to a limited time horizon (Sims *et al.*, 2015).

### 2.3.4 Socioemotional selectivity theory (SST)

SST is a life-span theory of motivation which postulates that when time spans are short, present-oriented goals are prioritised over longer-term goals. In other words, perceived time frames shift

motivations and goals, and older people, or those with a limited time span, prioritise emotional meaning and well-being (Carstensen and DeLiema, 2018). There are two aspects of this theory, first, that subjective remaining life expectancy (SRLE) impacts the goals and motivations, and second, that with a more limited life expectancy, people become more selective about their emotional investment, preferring strong emotional bonds over casual relationships in order to maximise socio-emotional gains (Carstensen, 1992). Noting that this is a lifelong process, SST specifies three dimensions concerning what people gain from social contact: knowledge in what you learn from them, the potential for future contacts or expanding your own social network, or affective rewards, the emotional satisfaction from the relationship (*ibid.*). In other words, social goals change over time in that younger people seek to expand social networks, whereas older people reduce them to more salient, emotionally satisfactory connections. There are similarities to SOC in that people are making selections to maximise wellbeing.

The empirical basis for the theory is the University of California, Berkeley's Child Guidance Study started in 1930 which followed children from birth to age 52. A flaw with this research is that it was following the same people, living in the same community throughout the research. It may be expected that people living in the same community for a long period of time, may not be seeking to expand social networks and that networks might be shrinking due to bereavement or relocation. It has been noted in subsequent research by Carstensen that there has been difficulty in replicating the results (Carstensen and Deliema, 2018) and subsequent research from 2019 on social network turnover, found that in contrast to a reduction in social networks over time as postulated by SST, that there was network stability, that even in the process of short, mid or long-term moves, network size changed only marginally (Badawy *et al.*, 2019).

Subsequent SST research focussed on the preference for positive information in older people. In contrast to the negativity bias of younger people (that threatening stimuli are better remembered than non-threatening stimuli), people in middle to late adulthood had an increase in preference for positive information in both attention and memory (Carstensen and DeLiema, 2018; Reed *et al.*, 2014). Termed the positivity effect, it impacts attention, short-term memory, autobiographical memory and has been shown in different contexts (*ibid.*). It has subsequently been noted, however, that if the information is personally salient requiring action on the information, the positivity effect is not evidenced. For example, if the information concerns information about cancer treatment and the older person has cancer and may need to act on the information, the situation will be viewed without a positivity bias. "In other words, when the stakes are high and negative material is goal-relevant, the positivity effect may not be observed" (Raposo and Carstensen, 2015 p9). Recent research questions this positivity effect. Using neuroimaging with over 100 people from the Cam-CAN research cohort, aged 23-88, reactivity to

positive and negative stimulation was studied in a multistage process involving interviews, testing and MRIs over 2 sessions. They found no evidence of SST and instead found that emotional reaction overall significantly decreased with the older participants (Schweizer, 2019). Given that there is little supporting evidence for SST, the most important aspect of this theory may be that SRLE, a type of cost-benefit analysis, impacts later-life goals and motivations.

### 2.3.5 Continuity theory

Continuity provides both empirical data and the theory. Fitting within the lifecourse paradigm, continuity theory is based on the concept of continuous adult development, that people learn from past experiences to adapt to changing situations and that this continues throughout the lifecourse (Atchley, 1999). Continuity theory is empirically based on the Ohio Longitudinal Study on Aging and Retirement to understand how people adjust to retirement. Beginning with 1500 participants aged 50+, over the course of twenty years from 1975-95, with six data collection rounds, the research assessed changes in participants' lives and how such changes impacted them (*ibid.*). Subsequent waves included questions to elicit an understanding not just adaptation to retirement, but people's thinking patterns, levels of activity, living and social arrangements, how these may change over time and the factors impacting their thinking and decision-making about the future. The research considered four specific dimensions (internal idea patterns, lifestyle and external patterns, personal developmental goals, and adaptive capacity) and found that people create mental frameworks of values and lifestyle patterns. Results showed that people learn from experience, processing the learning, revising the initial framework as necessary, then applying it to future decisions (*ibid.*). Overall, the research showed that people have consistent mental and lifestyle patterns which inform decision-making. Through experience, learning from previous decisions is incorporated into their thinking frameworks and values as necessary (*ibid.*).

Atchley's final wave was designed to understand decision-making and future planning. The results revealed the vast majority made conscious decisions (78.6%), experienced predictable results from their choices (87%) and tried solutions which worked in the past (91.9%). They know themselves well enough to make choices which fit for them (96.3%). Regarding their activities, participants continued activities which they enjoy and discontinued those they did not (96.3%). They are clear in their sense of life direction (91.5%) and have a philosophy which provides consistency to their decisions (88.6%). They have a consistent lifestyle (55.5%) and 73.7% have longstanding friendships lasting over ten years although again, this may not be surprising as the research was conducted in the same community, not following those who had relocated. Finally, their beliefs and values have remained constant over the past ten years (86.7%) (*ibid.,* p80).

These four theories of ageing provide a framework for this study. Lifecourse theory provides the overall structure, that later-life is the result of personal biography, biology, relationships, and social and historical circumstances. SOC offers a pattern for strategizing possible health decrements selecting personally salient aspects for focus, then optimising them as possible, or compensating as necessary. From SST, SRLE posits that goals and motivations change with a more limited life expectancy, whilst continuity theory proposes there is continuity adult development throughout the lifecourse as people learn from past experience to adapt to changing circumstances.

## 2.4 Decision-making and ageing

Much of decision-making theory is based on a positivist paradigm which assumes rational choices designed to create value, using elementary logic rules and with complete knowledge about current and future preferences and circumstances. Positivist decision-making theory suggests that people act in utilitarian ways which make sense to them, thus are motivated by self-interest to maximise rewards and reduce cost. In the process, they will make comparisons, consider alternatives, bargain, negotiate, invest time and resources to achieve the optimal result (Allen and Hawkins, 2017). A positivist paradigm is useful in studying consumer choices. It is a linear process of appraisal, researching alternatives, weighing them, deliberating, making the decision, then proceeding (*ibid.).*

In contrast, a constructivist or interpretive framework theorises decision-making as a series of social, interactive, and intersubjective actions within a changing environment. Decisions are subject to numerous and possibly conflicting points-of-view and interpretations as the chronology is retold and reinterpreted (Allen and Hawkins, 2017). Constructivist frameworks recognise that decisions may have delayed consequences, involve ambiguous or confusing relationships, are affected by conflicting or unclear feedback and concern rarely experienced matters which may not have been previously addressed or considered (*ibid*.). Later-life decisions are rarely straightforward, there may be overarching and interim goals and considerations in addition to personal goals and preferences. They are characterised by obscurity, where there is no obvious ‘right’ answer or a single ‘best’ choice (Bruch and Feinberg, 2017). Finally, the decisions are subject to delayed consequences and uncontrollable circumstances. For all these reasons, a constructivist decision-making paradigm will be used.

### 2.4.1 Balancing emotion and experience in decision-making

Herbert Simon's theory of bounded rationality recognises that decision-making must incorporate the role of emotion, situational constraints, and other human factors, other than just rationality in decision-making (Lerner *et al.*, 2015). People use emotion in their decisions and are impacted by context yet traditional research design attempts to de-contextualise the process and isolate processes into a single aspect (Bruch and Feinberg, 2017). In real life, all options may not be known, and people may be limited by time or resources.

Emotion and experience are inter-related aspects of decision-making. Emotion can be used as an important indicator of something requiring further attention, cutting through conflicting information to do what 'feels' right (Oatley, 2006). Experience, defined as either an event or an occurrence, is a type of learning which helps guide people in problem-solving. With age, strategies can become well-developed and employed so that the strategies become routine, requiring less cognitive demand. As not all problems are the same, experience, both personal or vicarious, may be used to generate strategies for problem-solving (Patrick and Strough, 2004). Research using vignettes to understand hypothetical decision-making, found that older people employ well-used strategies based on their own experience and other people's experience (*ibid.*). They also found that with greater experience, people were able to generate more decision-making strategies. Types of strategies used include:

- Cognitive reframing, changing the way of thinking about a situation to focus on strengths or positive aspects.
- Emotion regulation, finding happiness in the current situation in that things could be worse.
- Behavioural strategies, doing something which changes the situation entirely.
- Control strategies, finding support from other people, family, or friends.
- Discussion strategies: talking about it with others.
- Seeking assistance, from professionals about the situation (*ibid.*).

They also found that vicarious experience offers the opportunity to evaluate a situation before acting. By looking at others' experiences, they become more familiar with a problem and gain a greater understanding of challenges and possibilities, perhaps helping them avoid potential problems. Additionally, they found that older people who are considering a course of action on a decision may consult with others who are doing the same thing or considering a similar decision (*ibid.*).

Emotion impacts decisions by providing motivation or shaping the depth of thought and thought content, and, due to the integral emotion about the decision itself or the mood at the time.

People can ameliorate the impact of emotions, however, by a time delay, taking time to reconsider, or reappraising the situation, essentially reframing it in a different way (Lerner *et al.*, 2015). Emotion is embedded in the narratives people tell in order to understand themselves and make meaning of their lives and the decisions they have made. In conscious reflection, they bring together both their experience and their emotions in the decisions they have made throughout the lifecourse (Oatley, 2006).

In addition to the impact of emotion and experience, research is beginning to incorporate a greater range of factors and sociological concerns into traditional models of decision-making (Bruch and Feinberg, 2017). Recent research addresses how older people make decisions, specifically decision domains (Kornadt *et al.*, 2020; Kornadt *et al.*, 2018; Kornadt and Rothermund, 2014), the conceptual framework for decision-making (Bynum *et al.*, 2014; Löckenhoff, 2018) and decision-making strategy (Aspinwall and Taylor, 1997; Gould *et al.*, 2017; Koss and Ekerdt, 2017).

### 2.4.2 Decision-making domains

To understand the areas or domains that people make decisions about throughout the lifecourse, Kornadt *et al.* (2014, 2018, 2020) conducted mixed methods research with people aged 30-80 from two mid-sized German cities. Their initial research used qualitative interviews conducted with a convenience sample of 14 people aged 56-87 (mean age 73 years) who were asked about their beliefs, attitudes, expected and actual changes, and how that changed during the ageing process (Kornadt and Rothermund, 2014). The goal of the research was to understand decisions made in different domains and at different ages. The results of this research were used to formulate a questionnaire around nine suggested domains: finances, emergencies, mental and physical fitness, housing, looks and appearance, work and employment, health, leisure activities and lifestyle, and social relationships. This questionnaire was sent to nearly 1000 people aged 30-80 in two German cities. They found variance in earlier and later-life domains, that people set specific goals around leisure work, physical appearance, fitness and social relationships until about age 70, at which point decisions focussed on protecting safety and security, specifically in the domains of housing, finances, emergencies and health (Kornadt and Rothermund, 2014).

Research conducted four years later with the same sample, found that SRLE also impacted goal-setting, perception of gains and losses, and meaning of life. It set a timeframe on goal-setting and motivation, with decisions centred on whether it was worth investing financially and/or emotionally and psychologically in a future project (Kornadt *et al.*, 2018). It should be noted that the participants at this point were aged 84 and younger.

The most recent research by this team has sought to test the validity of a questionnaire and scale for preparing for old age (PREP) which assesses views on ageing and preparation for age-related changes using a short form (Kornadt *et al.*, 2020). For the 2020 research, they compared cohorts in the US with a cohort in Germany. The age range was 23-88, with the average of 50 for one and 56 for the other. For the PREP, individual domains evolved in that social relationships have become two domains, family and significant other, and friends and acquaintances. The conflation of family with committed relationships does not distinguish between a committed relationship with a spouse or partner, as opposed to general family relationships which could include distant nieces and nephews for those who may not have children. In old age, this could make a difference in the types of support in that friends may be more helpful than distant family. A category of personality and life management was added.

Table 2.1 Decision domains from 2014 and 2020 research

| **Domains from Kornadt and Rothermund, 2014** | **Domains from Kornadt *et al.*, 2020** |
|---|---|
| 1. Finances | 1. Financial situation: financial preparations, e.g. retirement accounts, savings, living a prudent lifestyle. |
| 2. Emergencies and exceptional circumstances | 2. Emergency situations: preparations for emergencies, e.g. future care, health proxies, wills etc. |
| 3. Mental and physical fitness | 3. Mental and physical fitness: efforts made to maintain mental and physical fitness in old age. |
| 4. Housing | 4. Housing: age-appropriate living situation, e.g. making age-appropriate alterations, arrangements with family and friends, etc. |
| 5. Looks and appearance | 5. Looks and appearance: maintaining appearance through diet, clothing and "artificial help". |
| 6. Work and employment | 6. Professional activities: preparing for professional activity in old age, e.g. through continuing education and avoiding job-related disability. |
| 7. Health | 7. Health: maintaining health through check-ups and avoiding harmful behaviour. |
| 8. Leisure activities and lifestyle | 8. Leisure activities and commitments: preparing for possible future activities by developing new hobbies or finding other ways of spending free time. |
| 9. Social relationships | 9. Personal relations and social contacts: maintaining social contacts by fostering personal relations and being included in social groups. |
| | 10. Family and committed relationship: providing for family in old age by keeping in contact with family and by avoiding or resolving conflicts. |
| | 11. Personality and life management: providing for positive personality development in old age by thinking about important life problems, developing empathy and “surrounding myself with diverse people.” |
| *Source: Author’s own with Information from Kornadt et al., 2020.* | |

In the PREP questionnaire, each domain is rated on a four-point scale ranging from “not at all”, to “a lot” in terms of the domains utilised at that point in the lifecourse (Kornadt *et al.*, 2020). The point of this research was to validate the use of the PREP short form. The research was conducted with a wide age range of participants, not delineating age groups, e.g. aged 65-75, 75-85 and those aged 85 and above. This research suggests there are different decision domains in earlier life as opposed to later-life

### 2.4.3 Decision-making process

Other researchers have noted that decision-making literature was disjointed and distributed over many disciplines and domains, focussing mainly on monetary, health and consumer choices (Löckenhoff, 2018). The discrepancy between decision-making theory and real life was also noted, in that older people tend to employ a multi-step process in real life which was not followed in lab-based research. The review brought together many aspects of the decision-making process to propose a framework for further research (*ibid.)*. It should be noted that the resulting framework is based on decision-making literature where the decisions cited appear to be predominantly consumer-related, e.g. buying a car or a CD player. The research postulates that older people like to satisfice, which the Oxford English Dictionary (OED) defines as pursuing “a course of action that will satisfy the minimum requirements necessary to achieve a particular goal” (2003, p.1568). Satisficing contrasts with maximising, where all options are extensively researched and analysed, even after good options have been identified (Bruine de Bruin *et al.,* 2016; Lockenhoff, 2018). Unfortunately, research on satisficing doesn’t specify whether the definition of the ‘best’ decision is whether it satisfies personal needs or goals, or that all options have been explored. Also not addressed in the research is the impact of experience. Older people have a well-developed sense of their decision parameters which doesn’t need to be belaboured in an extensive decision-making search (Dychtwald, 2013).

The proposed framework from the research proposes a multi-step process involving identification of a situation which may require a decision at which point the decision-maker may choose to delegate or avoid the decision, or to seek further information. Once this was determined, a strategy is selected and implemented, finally ending with the post-decision evaluation. If the evaluation points to a change in circumstances, or the emergence of an unexpected consequence creating a new situation, the process may begin again, possibly creating a constantly evolving cycle (Löckenhoff, 2018). This proposed framework is similar to the process found by qualitative researchers interviewing people aged 80 and above about their health decision-making patterns (Bynum *et al.*, 2014). This research found a consistent seven-step pattern to the decisions:

1. Recognising that a decision needs to be made

2. Identifying options
3. Obtaining information about the options through a variety of methods from previous experience of their own or friends, the internet or from healthcare professionals
4. Making their values and preferences known
5. Weighing options according to their values
6. Making the decision
7. Re-evaluating the decision, to learn from it for the future (*ibid.*).

The Bynum *et al.* research (2014) was unusual in that it was able to track actual healthcare decision episodes from the initial routine testing stage through to the decisions regarding possible surgery. Interviews were conducted at each decision-episode, creating an understanding of the decisions themselves and the results, as well as decisions about testing and treatments which were refused. The research found that the participants who sought the most information had the highest level of participation and consulted a variety of sources. Ultimately, if they disagreed with their physician, they would avoid confrontation by changing their physician or doing what they wanted, but they would not challenge their physician directly (*ibid.*).

This research suggests there is a multi-stage process for decision-making which includes subsequent re-evaluation and reflection to translate the process into future learning. It also suggests that older people avoid possible confrontation if they disagree with the advice.

### 2.4.4 Prospect theory and coping strategies

Another aspect of decision-making concerns perspective. Kahneman and Tversky's Nobel prize-winning prospect theory (1979) distinguishes between phases in the decision-making process where the change in reference point alters the perception of gains or losses. Prospect theory anticipates that people change their minds as their reference point changes (Bern-Klug 2017; Kahneman and Tversky, 1979). For instance, prospect theory can be used to understand cardio-pulmonary resuscitation (CPR) decisions. A younger person, perhaps in full health considering the impact of CPR on an infirm theoretical older person, might consider a do-not-attempt-resuscitation (DNAR) to be a rational straightforward decision, that for an older person with an already compromised quality of life (QOL), CPR should be refused as quality of life will surely be compromised, even if life is extended. An older person, however, closer to the reference point of possibly needing CPR, may have different expectations and contexts. An older person might recognise that living and adapting to physical decline may have compensations, so that length of life may be prioritised as the perceptions and expectations of QOL have changed given different

reference points (Bern-Klug, 2017). Prospect theory anticipates that people may change their minds as the reference point changes.

Because people anticipate that they may change their minds, they may also decide to delay a decision and instead consider alternatives and develop strategies (Allen and Hawkins, 2017). Proactive coping is a decision to anticipate a situation and work to avoid it or lessen the impact (Aspinwall and Taylor, 1997; Gould *et al.*, 2017). Proactive coping relates to advance efforts taken to prevent or modify a potentially stressful event before it happens. It is always active, involving the identification of potential stressors and acting before anything happens, so that the possible threat may never happen. The goal is to pre-empt problems. Benefits of proactive coping are that it minimises the degree of stress as the event may be lessened or averted (Aspinwall and Taylor, 1997). Additionally, through early identification, the range of options may be greater and fewer resources needed. Alternatively, the disadvantages to proactive coping are that the anticipated event may not occur at all, so the worry will have been for nothing. The anticipatory activities may be ineffective or exacerbate the problem and drain resources, so that resources are lower when they are needed (*ibid.*). An example might be the determination to have knee surgery before it is needed to avoid surgery at an older age when surgery is riskier. Such difficult situations may be anticipated, but there may be reasons not to actively address them. Contingent reasoning is based on the understanding that at some point in the future, a decision may be needed and forming contingent plans and strategies to prepare for that possible eventuality (Koss and Ekerdt, 2017). Many of the decisional domains of older people may require anticipatory and contingent thinking because of the uncertainty of knowing if or when the decisions or changes will be necessary (Gould *et al.*, 2017).

### 2.4.5 Decision-making goals

Research has repeatedly shown that the primary goal of older people is to maintain independence, autonomy, and control over their affairs (Atchley, 1999; Jagger and Brittain, 2014; Johnson and Barer, 1997; King *et al.*, 2018; Lloyd *et al.*, 2017; Loe 2011; Price *et al.* 2014), although it should be noted that this research is from the UK and North America, both individualistic cultures. Atchley's study found that the main goal of 97.4% of the participants was to be self-reliant (Atchley, 1999). Older people will work hard to maintain that independence (King *et al.*, 2018), seeking to maintain status quo and to prevent loss (Löckenhoff, 2018). As was noted above, in adjusting to physical decline, people reorder their priorities to make their activities congruent with their capabilities, whilst preserving what is important to them and providing continuity with their earlier lives (Johnson and Barer, 1997). They note that maintaining independence requires taking responsibility for one's health, through exercise, mental stimulation

and/or constant monitoring of their health, medication, and current research on their health issues (Lloyd *et al.*, 2017). The participants in Lloyd *et al.*'s study (2017), all aged 75 and above and followed for over 31 months, noted that perseverance, the ongoing reflexive process of accepting and adapting to changing conditions, was necessary to overcome problems and to maintain independence (*ibid.*). This is similar to longitudinal research conducted over six years with 85-year-olds in the US, which found that continuing vigilance and perseverance was necessary to maintain their goals (Johnson and Barer, 1997).

### 2.4.6 Anthropological theory

As shown as above, decision-making can be more than a single event, it can be a series of incidents and smaller decisions which extending over time (Bynum *et al.*, 2014). This is similar to an anthropological approach considering decision-making from many different perspectives, incorporating other influences like emotion, culture, societal norms and religion, and the probability the course of action will produce the expected results (Heiss, 2018). Like Bynum's research, a decision is not necessarily a discrete event, but a series of events which may extend over time. This is similar to decisions which older people may need to make in later-life, e.g. considering whether to relocate or consider care.

In his study to understand how a single decision progressed over time and changes in circumstances, Heiss studied a Hausa man developing financial independence within the context of his family and community. As his family grew and community circumstances changed, he changed and adapted his actions and thinking to work towards his goals. In other words, the decision was not a single event but a process of working towards long term goals. In the process, Heiss identified four different decision-making modes. *Simple decisions* are quick and simple, where few options are considered to satisfy a given need, generally based on experience of similar previous decisions with predictable outcomes. *Complex decisions* involve many different aspects which requires anticipating options, projecting different courses of action, and gathering advice from personal or vicarious experience to achieve desired outcomes. With these decision types, decisions can be made harmoniously within the context of family and community, allowing family life to remain stable. Conversely, in a *fundamental decision*, decision-makers are involved cognitively and emotionally in that they must choose between fundamentally important aspects of their lives, perhaps needing to balance conflicting allegiances and priorities, causing them to re-evaluate their aspirations (Heiss, 2018). The final decision style, labelled a *maturing decision,* involves a fundamental decision but is one which stretches over a long period of time, simmering in the background and re-emerging as situational aspects shift, requiring constant information-seeking and re-assessment (*ibid.*). In this research, Heiss identified the importance of goals and

the role of personal and community values, in addition to the identification of an extended timeframe as the decision evolves towards long term goals over time.

For example, the decision to consult a general practitioner (GP) about a relatively minor knee pain is a simple decision. It becomes more complex, when, having consulted a GP, a consultant is suggested, raising many more possibilities and concerns, including the degree of pain, the length of time waiting for an appointment, whether to consider paying privately, which consultant should be used, as well as short term implications for wellbeing. After an appointment with a consultant, a fundamental decision may be needed regarding whether to have a proposed knee operation, forcing a decision regarding the value of the operation in terms of improved wellbeing in the long term, versus the rehabilitation and recovery period required. It becomes a maturing or evolving decision, when the patient decides to reconsider the decision over a longer term, perhaps trying interim measures, such as curtailing activities or pursuing physiotherapy. This could evolve over years, as the pain recedes and reoccurs.

These four types of decisions are common throughout life, but the anthropological model of a maturing or evolving decision, is especially apt to many decisions of late-life (King *et al.*, 2018).

## 2.5 Summary

This chapter set out the research on ageing and decision-making. In gerontological theory, the common factors in the conceptualisations of ageing are that identity continues to develop throughout life and that in very-late-life, there may come a period when possible health declines prompt a redefinition of autonomy, so that the main goal of autonomy may be maintained by choosing to accept limits on independence in order to protect health. The overarching lifecourse paradigm situates the individual within their personal, social, cultural, biological, and historical context to understand how these factors impact personal development. SOC focusses on the processes of selection, optimisation, and compensation to accommodate changes throughout the lifecourse whilst SST suggests that SRLE impacts later-life goals and motivations. Finally, continuity theory proposes that there is continuous adult development and continuity throughout the lifecourse in goals and decision patterns.

Specific decision-making theory suggests: there are different priority domains and goals depending on lifecourse stage, that perspective impacts decision-making in that people change their decisions depending on where they are in the decision-making process, and that emotion and experience are embedded in decision-making. Theory on a straightforward multi-step process of decision-making contrasts with anthropological theory proposing an evolving process

which considers the value of experience, external communities, values, and goals in decision-making.

Chapter three will address empirical research on later-life decisions before presenting the conceptual framework informing this thesis.

# Chapter 3 Later-life decisions

## 3.1 Introduction

The previous chapter set out gerontological and decision-making theory underpinning this research. This chapter focuses on empirical research with people aged 85 and discusses specific later-life decisions concerning social networks, health and advance-care-planning (ACP), residential relocation, and driving cessation before closing with the conceptual framework.

## 3.2 Empirical research with people aged 85 and above

A number of longitudinal projects studied people aged 85 and above in order to understand how health trajectories impacted them. Whilst not specifically addressing decision-making, health is one of the major factors in later-life decision-making, thus understanding later-life health trajectories provides an indication of the factors impacting later-life decisions.

### 3.2.1 The Cambridge City Over 75s Cohort (CC75C)

The CC75C is one of the largest and longest running studies of the oldest-old. Initially begun in 1985 to study dementia and mild cognitive impairment, it recruited over 2000 people aged 75 and above from five general practice surgeries in Cambridge (Fleming *et al.*, 2007). It followed the same participants over the next 28 years (Cosco *et al.*, 2016). The initial cohort averaged 81.3 years of age; they were 65% female and 87% community-dwelling. The core measures included cognition, residence and household structure, marital status and social contact, health and social service use, medications and health problems, and information on activities of daily living (Fleming *et al.*, 2007). Whilst intended as a study of mental health and ageing, the CC75C study ultimately provided evidence on many other aspects of ageing including falls prevalence (Fleming, 2008), driving cessation (Brayne *et al.*, 2000), preference on preferred end-of-life and place of death (Fleming *et al.*, 2016), late-life health trajectories (Cosco *et al.*, 2016), and relocation and the decision to move into care in very-late-life to accommodate increasing incapacity (Fleming *et al.*, 2017; Scheibl *et al.*, 2019a; Scheibl *et al.*, 2019b).

One of the issues researched in the CC75C study was the prevalence and reporting of falls. Late-life falls are a possible indicator of the need for greater care and increased frailty which impacts thinking and decisions about the future. To understand fall prevalence and frequency, interviews

and a one-year follow-up programme were conducted. At this point, the participants were all over 90 years old. Research found that 58% had falls in the previous year, and 60% in the one-year follow-up which tracked falls on a weekly basis. Over the course of the research, only one-third of participants didn't fall at all. Further, they found that recollection of the frequency and number of falls is underestimated by more than a third and that previous falls is a predictor of future falls (Fleming *et al.*, 2008). As was noted, falling is one of the factors which may precipitate a transition into care and is an important indicator of late-life mobility (Scheibl, 2019a). At the time of death, most had moved into care prompted by health crises, mostly falls (*ibid.*). This is an important underlying factor in thinking towards the future. At some point in later-life, it is likely that older people will fall which is a possible precipitating event for greater care. Further, because the frequency of falls is frequently underestimated, the seriousness of frailty may not be recognised by family and healthcare professionals. It is not clear whether the falls are forgotten or whether the participants were trying to discount the seriousness of the situation.

Much of the CC75C research has inter-linking authors, using the later rounds and subsets of the CC75C study and researching aspects of late-life around care and end-of-life. In 2007, a series of qualitative interviews was held with 42 CC75C participants aged 95-101; most were interviewed with their proxies, only three were interviewed individually. Of the participants, 27 were female and 24 were community-dwelling. As part of the interviews, they were trying to understand the attitudes and preferences for end-of-life care (Fleming *et al.*, 2016). At this point, the participants were mostly living from day-to-day and hoped to die quickly. They accepted the inevitability of death and were fatalistic about leaving decisions to their doctors and relatives, recognising that they couldn't really plan for the unknown. Hospital admission at end-of-life was not viewed favourably (*ibid.*). Of the participants, 12 died in their own homes. Ultimately, 26 of the remaining participants relocated before death. Only four of these participants did not have cognitive impairment, 12 of the 26 had severe cognitive impairment (Scheibl *et al.*, 2019a).

The research found that a minority of participants moved voluntarily, framing the decision to move as a positive choice, to spare their family of the burden (Scheibl *et al.*, 2019a). In such cases, the decisions were made solely or in consultation with family. In some cases, the participants found greater socialising and activities in the care homes and felt safer, although some felt restricted and 'locked-in'. At the other end of the spectrum were moves into care made after a health crisis, imposed due to severe cognitive and physical decline where the family made the decision without consulting the older person. In such cases, there was resistance to move, with a protracted process involving pressure from family, neighbours and in some cases social workers and other medical personnel. Four participants had the decision imposed on them without consultation (*ibid.*).

The likelihood of involuntary moves increases with age and disability and is generally triggered by frailty, falls and hospitalisation (Scheibl *et al.*, 2019b). Better transitions have common factors in that the participants have more personal resilience, support from family, neighbours and friends and ownership in the decision. In such cases they are moving into quality residential care and are likely to talk about living in, as opposed to being placed in the care home. Those few participants who moved to be closer to their children found themselves isolated in unfamiliar surroundings (*ibid.*).

Recent research on this cohort, all of whom have now died, linked final medical assessments with previous waves of data collection to identify three main progression-to-death trajectories, which is important for a realistic assessment of the impact of health in very-late-life. The CC75C research suggests that there may be three trajectories: people who remain high functioning with no decline, those who begin as high functioning and have a gradual decline, and those who begin at a lower level of functioning and have a steep decline, progressing from third to fourth age (Cosco *et al.*, 2016). Most of the participants (over 90%) in the first two trajectories died at home whilst most in the third trajectory died in long term care (Fleming *et al.*, 2017). The CC75C participants wanted to die at home, but cognitive and physical decline in very-late-life tended to necessitate relocation into a care home. In cases of dementia, it was better to make the decision as soon as possible, before a possible crisis (Scheibl *et al.*, 2019b).

There are three important aspects of this research which impact future decision-making. The first is that there are three trajectories to death in later-life: those with high functioning and no decline; those with high functioning and a gradual decline and those starting with a lower level of functioning progressing to fourth age. Another important aspect is the prevalence of falls which may be intentionally or unintentionally under-reported. Finally, whilst all hope to die at home, it is possible that people will relocate to care and in the process frame that decision as a positive choice, sparing the families of the burden. This indicates that in later-life where the choice may be between maintaining independence or a supportive living environment, that independence will be sacrificed, but framed as maintaining autonomy.

### 3.2.2 Life beyond 85 years

A qualitative longitudinal project, from California, USA, interviewed 150 community-dwelling people aged 85 and above five times between 1988 and 1994. Their mean age was 88.9 at the start of research, rising to 92.9 at the end. At the end of research, only 48 of the original 150 participants were still alive. The majority, two-thirds of participants, remained community-dwelling throughout, although the actual functional reporting shows a transition to greater needs.

In their seventies, most were functionally independent, but in their late 80s, only 38% were and after age 90, only 18% were (Johnson and Barer, 1997). This points to the possible age-related factors, that most are independent throughout their seventies and early eighties but become increasingly dependent so that fewer than a fifth of people over 90 are functionally independent.

Despite the fact that this cohort is from the US, the Life Beyond 85 Years research was similar to the CC75C research in that they found three main late-life health trajectories:

1. Functionally fit survivors (38%) who continued living in the community, similar to the high functioning, no decline category in the CC75C.
2. The chronically disabled (27%) who survived with high levels of disability and poor functioning, where participants experienced chronic conditions rather than life-threatening diseases, but ripple effects were noticed in that one health issue developed to something more serious, necessitating support. This was similar to the low functioning participants of the CC75C cohort.
3. The final trajectory, the increasingly disabled (35%) experienced rapid and increasing disability and in the last 15 months had the most morbidity, mortality, and institutionalisation. Changes occurred due to decline in mental or physical health, an acute illness, accident, or other precipitating incident (Johnson and Barer, 1997).

In adjusting to physical decline, participants reordered their decision priorities to make activities congruent with capabilities, whilst preserving what is important to them and providing continuity with their earlier lives. In the process, they also reoriented their sense of self to provide continuity to their previous self. This involved redefining their concept of health, in that their health was 'good for their age' (Johnson and Barer, 1997). This is suggestive of both SOC and continuity theory. Towards the end-of-life, participants noted a more detached self, disengaging and redefining their goals towards an interior world, achieving a "peaceful age of quietude" (*ibid.,* p154). They consciously note not feeling lonely, but becoming "semi-retired from life", recognising that they have already lived through painful times and that time cures the sense of loss (*ibid.,* p155). This could hint at gerotranscendence when later-life health and energy levels increasingly impact decisions. Finally, it was noted that women had more friends and deeper friendships and despite the fact that many of their friends had died, they still had close friends and were making new friends and confidants. Friends provided companionship and fun and were voluntarily maintained. Whilst family may provide support, the participants found their friends more important in improving morale: "One good friend is worth more than a dozen grandchildren" (*ibid.*, p104).

The Johnson and Barer research presents a more optimistic view of later-life, perhaps because the selection criteria sought community-dwelling people at age 85 and only followed them for six years. Similar to the CC75C research, however, the Johnson and Barer research found three trajectories. They also found evidence of SOC, continuity theory and gerotranscendence, and that women maintain social connection (*ibid.*).

### 3.2.3 The Newcastle 85+ study

The Newcastle 85+ study began in 2006, recruiting people born 1921 and aged 85 at the beginning of research from GP surgeries in Newcastle-upon-Tyne, northeast England. Ultimately 834 participants agreed to an initial health assessment and review of the GP records, plus additional follow-up assessments at 18 months, three and five years (Stephan *et al.*, 2018). The baseline assessment included collection of socio-demographic information, health status including information on pre-existing conditions, self-reported disability based in instrumental and basic activities of daily living; additionally, a multi-dimensional health assessment and functional and cognitive tests were administered (*ibid.*). Participants were divided into three groups: not cognitively impaired (69.8%), mildly impaired (14.8%) and severely impaired (14.4%). There was no significant difference at baseline in gender, education, or pre-existing conditions, although the severely impaired group had higher rates of institutionalisation, disability, and prevalence of pre-existing conditions (*ibid.*). Results showed that the not impaired and mildly impaired groups remained relatively stable in all measures at the five-year follow-up (*ibid.*). The severely impaired group experienced significant declines, but not in all measures. Education did not appear to provide a protective factor (*ibid.*). Countering a common perception that cognitive decline is part of ageing, these results "highlight that cognitive decline is not an inevitable consequence of advanced ageing and that many very-old individuals can maintain a high level of cognitive function" (*ibid.*, p303). This research provides evidence that the majority of older people maintain high levels of later-life cognition.

Another aspect of this study was to investigate the patterns of social participation. At baseline age 85, they found differences in the activities men and women do, in that men did more walking, driving for enjoyment and DIY, and maintained contact with people more by email. Conversely, women played more bingo, card or board games, visited friends and relatives and took part in religious activities. In other words, women participated in more social activities and men were more inclined towards solitary and individual activities (Rantakokko *et al.*, 2020). Education was also a factor in the range and frequency of activities in that those with higher educational levels played games, visited friends and relatives and participated in religious, club and cultural activities more frequently. Those with less education tended to watch more television and visit friends

(*ibid.*). In the five-year follow-up, they found a decrease in activity levels overall, but that people with higher socioeconomic status (SES) were more physically active, with higher levels of health, cognition, and quality of life (QOL) (*ibid.*).

This study shows that the majority of people aged 85 and above maintained high levels of later-life cognition at the five-year follow-up, whilst levels of activity had decreased, people continued with physical activity, which may imply this could be a factor in maintaining cognition. Another factor may be the correlation between higher SES and higher levels of health, cognition and QOL. People in later-life make conscious decisions about maintaining activities and socialising. They also found three health trajectories that seemed to roughly follow the previously-mentioned trajectories.

### 3.2.4 Frailty and care in later-life

Two additional QLR projects provide indications of later-life trajectories. Lloyd, A. *et al.* (2016) followed 13 older people living with frailty, their informal carers and case-linked healthcare professionals for an 18-month period in order to understand the physical, social, psychological and existential trajectories towards the end-of-life. Despite this being a smaller sample, the results help to illuminate very-late-life patterns, beyond the physical trajectory. Similar to the previously cited trajectories, this research found three patterns, those who were coping by balancing loss with adaptation, those who were struggling and those who were overwhelmed. The physical results were like the previous studies, but these focussed on the coping patterns in order to understand what maintained and what challenged capacity. Those who were coping, adjusted to their 'new normal' by maintaining social connections and living for today as opposed to thinking too far into the future. They retained their sense of self (identity) by using SOC to continue doing things that were important to them. Social connections were important both for activities and companionship and reciprocity was a factor, whether through emotional or financial support. In considering medical interventions, they considered them carefully to ensure the intervention was worth the cost. For those who were struggling, their physical, social, and psychological decline caused a consequent decline in existential wellbeing. Their frailty became a cause of frustration and sadness because they couldn't integrate it into their sense of identity. They also experienced increasing loneliness. With both of these patterns, they sought to distance themselves from their greatest fears, dementia and moving to a nursing home. The third pattern, those who were overwhelmed, found that their capacity to adjust was overwhelmed. They could not integrate their sense of self as being someone who needed care, so instead retained a value, such as self-discipline as being their defining identity (Lloyd, A. *et al.,* 2016). The research doesn't specifically detail the participants in each trajectory, but by analysing the quotations illustrating

each pattern, it appears that the five participants in the coping pattern were all female. Of those in the struggling category, three were male and two female, and those in the overwhelmed category being two female and one male. As one of the distinguishing features of the coping pattern is the continuation of social connections and activities, this is in line with both the Johnson and Barer and Newcastle 85+ which cite the importance of social participation in maintaining wellbeing. The main barrier challenging wellbeing is the loss of identity as someone independent, which was redefined by maintaining a core value (Lloyd, A. *et al.,* 2016) which is similar to the Johnson and Barer research which found a re-orientation of identity to accommodate the new reality.

### 3.2.5 Dignity in Care

A final QLR project is from the New Dynamics of Ageing programme. Dignity in Care: Maintaining dignity in later-life followed 40 participants aged 75 and above with ongoing support needs. Recruited from GP surgeries in the north of England, the participants selected were those with unscheduled hospital stays during the previous year and had ongoing support needs, or people with ongoing ADL or nursing care needs, or people who required a level of support to continue living at home (Lloyd *et al.,* 2018). This research would appear to focus on those in the middle trajectory suggested above, of people with a good level of functional capacity, experiencing a gradual decline. Whilst the point was to understand the experience of supportive care, in the process, the research also provides an understanding of the impact of declining health and the effort required to maintain wellbeing and independence. Perseverance was an important theme in the research, that whilst they recognised declining health and changes in capacity, they were determined to continue with their lives as much as possible. They continued with preventative activities, such as walking for exercise or regular flu jabs and health monitoring although increasingly, they could find the effort wearying. They strove to maintain independence which they defined as maintaining self-care and not burdening others, and exerting control over what they could do as well as the types of support they needed. Personal relationships remained important through reciprocity or helping others e.g. financial support to grandchildren or maintaining friendship groups and active social ties. Finally, they drew on values, skills and knowledge developed over the lifecourse, to help them adjust to their declining capacity and increasing care needs (Lloyd *et al.,* 2018).

### 3.2.6 Dutch Longitudinal Ageing Study Amsterdam

Not specifically addressed in the research is provision and levels of care in the last year of life. An indication can be provided by the Dutch Longitudinal Ageing Study Amsterdam which studied the

care needs and provision for community-dwelling older people in the last year of life. According to this research, there are four main providers of care.

> **Community Care** (40%) provided approximately eight hours of combined household and personal care, occasionally supplemented by family and privately paid care.
>
> **Mixed-care network** (25%) with care mostly from children but supplemented with community care, other family and non-family, and private care provided approximately 16 hours of care/week.
>
> P**artner network** (19%) provided about 30 hours of care per week, mainly from the partner, sometimes supplemented with care from other sources.
>
> **Privately-paid network** (15%) averaged three hours/week with no care from any other type of caregiver (Bijnsdorp, 2019).

These various longitudinal research projects all point towards the types of decisions which may need to be made in later-life and suggest how people will react when challenged by declining health. The research suggests that there are three differing later-life health trajectories, that some people may remain high functioning to the end, whilst others may have a more precipitous decline into fourth age. The third trajectory retains a moderate level of functioning but experiences a gradual decline. Each trajectory will require decisions about responding to or preparing for change and possible future care. It also appears that in later-life, goals of independence and autonomy remain, but that the view of self which is integral to this goal may be redefined to accommodate changes in health and need for greater support. Finally, there are suggestions about the importance of retaining activities and social connections.

## 3.3 Specific later-life decisions

Whilst there is little academic research on the overall topic of decision-making in late-life, research does focus on specific decisions, e.g. decisions around relationships and social networks, health and advance-care-planning (ACP), residential decisions including ageing-in-place, moving to a retirement community, or care home, and driving cessation.

### 3.3.1 Relationships and social networks decisions

The importance of social connections has been discussed briefly above. Social networks are essentially a collection of people and the relationships which connect them (Cornwell and Schafer, 2016), creating hierarchical layers of relationships in the process (Huxhold *et al.*, 2020). They are

defined by their structure and composition in terms of network size; the ties which connect them including intensity, duration, frequency of contact and reciprocity; and the types of contacts, whether family, friends, or some other organising factor, e.g. religious organisation or former employment (Cornwell and Schafer, 2016). Social networks provide many types of support: instrumental, emotional, companionship and informational. Different types of networks provide different types of support. Generally, kinship provides reliable and wide-ranging support, whilst friendship ties provide emotional support and companionship. (*ibid.*). Social networks can also provide social control and monitoring functions (*ibid.*). For later-life decisions, they may provide information and vicarious experience in addition to being a factor in preparing for later-life emergencies.

There are hierarchical layers in relationships – from the emotionally close family and confidant ties, to less emotional ties, e.g. acquaintances or members of a common organisation, and weak ties, or peripheral connections which encompass more distant acquaintances (Sandstrom and Dunn, 2014). Weak ties require less time to sustain but can provide novelty and access to information not available in closer network ties (Huxhold *et al.*, 2020) as they may bridge various segments of the network (Granovetter, 1973; Sandstrom and Dunn, 2014). An additional function of weak ties in that they provide sources for future closer friends. Noting that network size and structure remain roughly the same over the life course (Cornwell *et al.*, 2020), it is theorised that as close ties drop out late in life due to bereavement or proximity, weak ties may be cultivated into closer ties (Huxhold *et al.*, 2020).

Social network typologies distinguish networks according to their composition and types of support they offer. Building on Wenger's (1991) original five network types, more recent research has revised social network typology to accommodate longer life spans, lower birth rates, impacts of divorce, internet, and global mobility to four main network types (Suanet and Antonucci, 2017), essentially combining local self-contained and private restricted into restricted. The four main network types are as follows.

1. Family-focused networks depend on nearby family and are characterised by close family, high frequency contact with children and other kin, and moderate to low contact with friends and other non-kin. Family-focused networks are generally based on long term residence and active community involvement in the present or recent past.
2. Restricted networks are the smallest networks with dependence on spouse (if not widowed) and relatively low contact with children, friends, and other non-kin.
3. Diverse networks generally involve married spouses, high frequency contact with children, friends, and other non-kin and with high rates of volunteering.

4. Friend-focussed networks are large networks, often without children, but maintain the highest contact frequency with friends and other non-kin, and volunteering (Suanet and Antonucci, 2017).

It is generally expected that social networks are sources of support although provision of care is situation specific. Generally, children and their parents have greater bonds of obligation, but this depends on the type and duration of care (Finch and Mason, 1991). Whilst it is expected that older people will receive help from their children, Wenger's research (1999) found that older people provided more help overall, providing active support to their friends, neighbours, and local community, ultimately providing more care than they received. More recent research incorporates changes in demographics, finding that friendships are gaining in importance with more recent cohorts of older adults, in that their friends are more likely to provide the support formerly provided by family and that some population groups, including childless older adults, form fictive families which may supplement or replace missing or strained family ties (Huxhold *et al.*, 2020).

It has also been generally expected that due to bereavement, ill health, and relocation, that social networks shrink over time. Longitudinal research following US older adults from 2005 to 2015 at which point the participants were aged 67-95, found that whilst there was considerable turnover in social networks, the size and composition were roughly the same, that even though there were life-changing events, core networks remained the same, as did religious participation, volunteerism and involvement with organised groups (Cornwell *et al.*, 2020). The research noted that social networks maintained their internal structure over time and that there was little evidence of disengagement or socioemotional selectivity. The research found that progression of social networks over time was consistent with continuity theory (*ibid.*). This would suggest that social relationships continue to be important in late-life and that people make decisions about replacing friends lost to bereavement or relocation and that they are strategic in replacing and deploying their networks. As noted above, women continue to make friends and develop confidants (Johnson and Barer, 1997). Additionally, female friendships have been found to be more person-oriented, characterised by emotional support, intimacy, and mutual assistance whilst men's friendships tend to be more activity related, based on shared experience (Phillipson, 1997). This suggests that men's relationships are vulnerable to changes in their work or community-related activities. With a possible reduction in activity participation in later-life, there may be a consequent reduction in social connection meaning men may be more dependent on family for support.

#### 3.3.1.1 Later-life re-partnering

A subset of social network literature discusses re-partnering. After a late-life bereavement or divorce, people may decide to enter a late-life relationship, either re-partnering or remarrying. In this context, re-partnering refers to a commitment to a long-term relationship based on love and where they are recognised as a couple, with or without marriage (Bennett *et al.*, 2013). A qualitative study of 60 British widowers aged 55-94 found three main approaches to considering re-partnering:

1) Those who will not consider it due to feelings of loyalty or because they did not want to make the emotional investment,
2) The uncertain group who didn't want to make a 'mistake' in later-life or possibly alter the relationship with their family,
3) Those who have re-partnered or married, making the positive decision to enter a relationship despite logistical issues which could include assuming a caring role (Bennett *et al.*, 2013).

Not mentioned in this research, but the focus of a Dutch study of decision-making after divorce or widowhood, is the frequency of living-apart-together (LAT) relationships which is defined as those in an intimate couples arrangement where they share accommodation intermittently, but maintain separate households and finances (de Jong Gierveld and Merz, 2013). The study used results from the Netherlands Kinship Panel Surveys (n=350) with follow-up qualitative interviews on the topic of LAT (n=35). It was noted that the LAT participants generally lived in urban areas, were older (mean age of 60.9 vs 57.7) and more frequently retired, 63.6% of whom had children over the age of 18 (*ibid.*). Generally, re-partnered parents less frequently provided support or were in contact with their children and that re-partnering may transform relationships into conflicted ones with less connectedness (*ibid.*). The children of re-partnered parents, even though not living at home could be negative and actively attempt to sabotage the relationships (*ibid.*). As close relationships either with partners or children are a likely source of support in late-life, decisions about them may also impact future care.

Empirical research has noted the importance of social networks in later-life, this section on relationships and social networks has shown that people make conscious decisions about their networks, replacing them when they are lost due to bereavement or relocation, and that they receive support from and provide support to their network members. The difference between women's more person-oriented and mutually assistive relationships and men's more focussed, shared-experience relationships was also noted which has implications regarding sources of support in later-life.

### 3.3.2 Health and ACP

Despite the fact that two-thirds of the oldest-old in the UK consider their self-reported health as fair, good or very good, all but 17% are living with disabilities limiting their activities of daily living (ONS, 2013a). This means that they are monitoring and making decisions about their health on a regular basis. Qualitative US research with people aged 80 and above suggest that there is a straightforward process for making decisions about prescriptions, medical procedures, or surgery (Bynum *et al.*, 2014). The first step was to recognise the need for a decision, either because they are anticipating an event, or recognising a possible concern which needs addressing (*ibid.*). The next step is to identify the options with the doctor. After exploration of options, information was gathered from personal or vicarious experience or from written materials and/or the internet, before conveying their preferences and values to their doctor (*ibid.*). The internet is increasingly considered a source of health information, although UK statistics show that whilst 80.2% of those aged 65-74 consider it a viable source, only 44% of those 75 and above do (ONS, 2016). The final stage in the process was making the decision, based on the decision control, i.e. who actually makes the decision (Bynum *et al.*, 2014; King *et al.*, 2018). The decision-making participation styles were: paternalistic where the patient accepted the doctor's decision completely; shared with equal participation by the healthcare professional and the patient; and patient-driven where the healthcare professional provides information but does not participate in the decision-making (King *et al.*, 2018). The levels of participation remain relatively stable over time, although they may be impacted by health status and feelings of vulnerability due to symptoms (*ibid.*). The main theme in this research was the determination to remain independent (*ibid.*).

A decision which all people ultimately face is thinking about and preparing for their own death. Preparing for end-of-life (EOL) helps people have the death they want (Abel *et al.*, 2013). A national framework for End-of-life Care (EOLC) specifies that people should be made aware of approaching end-of-life (EOL) so that they can work with their family, carers and healthcare professionals to ensure a good death (National Palliative End-of-life Care Partnership [NPEOLCP], 2017). A good death is defined as one where palliative care is provided so the death is relatively pain free, planned for and expected, supported by family, in the preferred place of death and with the dying person in control (NPEOLCP, 2017; Teggi, 2018). Unfortunately, research shows that although those 85 and above represent 39% of all deaths, only 16% of those deaths benefitted from palliative care (Teggi, 2018) because it is difficult to predict impending death given the unpredictable trajectories of older people (NPEOLCP, 2017).

Other than preparing wills or planning funerals, research has shown that many older people are reluctant to consider or prepare ACPs (Clarke and Seymour, 2010; Samsi and Manthorpe, 2011;

Lloyd-Williams *et al.*, 2010; Mathie *et al.*, 2011; Ke *et al.*, 2017; Gott *et al.*, 2008; Sutton and Coast, 2012) which are defined as a general discussion or plans people make regarding future treatment (Seymour *et al.*, 2013). Prospect theory (Kahneman and Tversky, 1979) can be used to partially explain this reluctance as people realise that their wishes might change given the context of the situation at that time (Clarke and Seymour, 2010; Samsi and Manthorpe, 2011; Ke *et al.*, 2017; Sutton and Coast, 2012). Whilst proving reluctant to prepare for death, older people still have a clear concept of their goals in a good death in that they would like to be pain free, with their affairs in order, supported by family and healthcare professionals, with their wishes respected (Lloyd-Williams *et al.*, 2007; NPEOLCP, 2017).

To understand why people still will not plan, a listening event involving 74 people in small discussion groups and focus groups found a lack of knowledge about options, but the greater factor was the reluctance to commit. A longitudinal qualitative study of 63 care home residents interviewed up to three times over a year about living and dying, found that only two former healthcare professionals had made specific advance care plans, refusing resuscitation, invasive treatment and unnecessary hospitalisation (Mathie *et al.*, 2011). A subsequent study which involved training peer counsellors in ACP found that the training helped peer counsellors initiate presentations about ACP, and that a number made their own ACPs (Seymour *et al.*, 2013) which would imply that education is a critical element. A different approach was taken by the town of LaCrosse, Wisconsin that requires every person admitted to hospital complete a four-question EOLC discussion regarding resuscitation and aggressive treatments (Gawande, 2014). Results have shown that the importance of the EOLC questions besides eliciting preferences, is that the process normalised conversation about EOLC (*ibid*). Although reluctant to make EOLC plans, over 77% of those aged 75 and above have written wills, with those in higher social classes more likely to have wills (NatCen Social Research, 2012).

### 3.3.3 Residential decision-making

One of the major later-life decisions is the possible future decision about the need for care and possible relocation. This section presents applicable theories about residential relocation, the process and factors involved as well as what makes for successful transitions.

#### 3.3.3.1 Theories of residential decision-making

Two commonly cited theoretical frameworks for late-life relocation were developed from migration theory: Lee's (1966) push-pull theory and Nahemow and Lawton's (1973) theory of environmental press.

**Push-Pull Theory.** In this theory, the push is a stressor which encourages people to leave whilst a pull is an attraction to move to another place (Lee, 1966). Relocation factors for older people may be both, in that the push of ongoing house repairs becomes a pull to a retirement flat (Boldy *et al.*, 2011). Generally, younger movers are motivated by pull factors but in later-life, push factors may provide the prompt (*ibid.*). Older relocators may seek a location with greater access to services. Additionally, upkeep and maintenance issues, retirement, health or mobility changes, or the desire to move closer to family are push factors which drive a relocation (*ibid.*). This contrasts with prevalent pull factors to remain in the current home: comfort, safety and security, desire to remain in current residence for life, financial viability of current situation, good location with easy access to services, house design/layout supports ageing, neighbourhood attachment with good neighbours, and easy maintenance of both house and garden (*ibid.*). Gender impacts the decision in that after a health decline, bereavement or onerous home maintenance, older women tend to relocate to congregate housing where they have an individual apartment, but shared common areas. Pull factors include the need for companionship and the goal of not burdening family (Ewen and Chahal, 2013). Men are more likely to move due to a health decline (*ibid.*).

**Environmental Press.** Nahemow and Lawton's ecological theory of adaptation and ageing (1973), considers the relationship between behaviour and the environment, that change or decisions may be caused by individual characteristics, and the surrounding environment, with the environment exerting a greater impact than individual characteristics (Nahemow and Lawton, 1973). The theory is that people adapt to the appropriate level of environmental press, which refers to environmental aspects working with personal characteristics to evoke behaviour, regardless of whether the individual is aware of the external environmental aspects. For instance, traffic, crime, graffiti may impact behaviour, although people may adapt behaviour to mitigate the impact (*ibid.*). Too much environmental press and the individual may try to escape, physically or psychologically, whilst too little challenge and individuals adapt downward, diminishing their overall competence (*ibid.*). This interrelationship between the environment and ageing, specifically the incongruence between environment and physical capacity, may prompt later-life relocation (Sergeant and Ekerdt, 2008; Ewen *et al.*, 2014). Nahemow and Lawton's theory on environmental press correlates mental and physical competence with environmental demand (Ewen and Chahal, 2013; Ewen *et al.*, 2014; Golant, 2015; Koss and Ekerdt, 2017; Nahemow and Lawton, 1973; Sergeant and Ekerdt, 2008; Wu *et al.*, 2015). Time is an important aspect of this theory because the impact of environmental press diminishes over time as the individual adapts. To maintain higher levels of competence, environmental press must constantly increase as lack of environmental press leads to reduced personal competence (Nahemow and Lawton, 1973). An example could be of a widower who, after his wife dies, doesn't know how to cook or do the

housework, so places himself in a care home. Too long in the environment without activities which provide environmental stress and he adapts downward, becoming lethargic and losing competence. The main principles of the theory are that support and demand are equally important to maintaining competence, and that tension reduction and tension creation can be personally satisfying (*ibid.*).

#### 3.3.3.2 Residential relocation process and factors

A common factor in the theories of late-life relocation is that the process can be lengthy and have intermediary steps. Shortly after retirement, younger retirees often respond to the pull factors of greater amenities and increased friendship networks, but as they age and respond to increasing frailty, they may relocate to neighbourhoods or venues with greater support services, with a possible final move to institutional care (Ewen *et al.*, 2014; Gottlieb *et al.*, 2009; Krout and Wethington, 2003; Sergeant and Ekerdt, 2008). The decision may be fluid, operating on a continuum from ageing at home without modifications, adding modifications and/or care, moving into a continuing care or assisted living facility, and finally to a nursing home. Those who did not move, generally had higher incomes so they could pay for home modifications and onsite services (Krout and Wethington, 2003).

**Residential Normalcy.** Noting that the real-world decision-making of older people is complicated and idiosyncratic due to the vast differences in demographics, personality, and life histories, gerontologist Stephen Golant (2015) devised the theory of residential normalcy. This theory posits that when older people experience incongruity in their environment, they initiate assimilative action to counter the impact, then accommodate their thinking to the new reality thus re-establishing residential normalcy (Golant, 2015). An example would be if someone is finding vacuuming the stairs too difficult, a cleaner might be hired to do it on a regular basis. This theory draws on both push-pull and environmental press theories but adds the intermediary steps of strategy development and assessing costs and benefits prior to action (*ibid.*). The theory proposes that people use their personal coping strategies to maintain residential normalcy, but that the process is not a discrete event but may fluctuate as circumstances change, or the strategies implemented introduce new challenges. Through the process, people engage in a process of continual adjustment to regain residential normalcy (*ibid.*).

Using data from the ENABLE-AGE study of Swedish and German older people, researchers followed 16 participants aged 80+ at the first interview in 2003 and subsequently re-interviewed in 2011 to understand how they balanced their desire to age-in-place with increasing health decline (Granbom *et al.*, 2014). Focussing on residential normalcy, i.e. how older people adapt to maintain their comfort and mastery in their homes, they noted that people may subconsciously

implement many strategies to maintain normalcy, before committing to a move. Generally, a move will only be considered when all other strategies have been exhausted and they think a move will improve the situation (*ibid.*). In this process, people constantly make subconscious adjustments e.g. hiring cleaners or gardeners, to maintain their lifestyle whilst continuing to live at home. When or if they move, those who make successful transitions have brought what they like from their previous home, whether it is a physical object like an armchair or activities and comforts, to their new environment (*ibid.*).

Whilst the vast majority of older people are planning to age-in-place (Boldy *et al.*, 2011; Ewan *et al.*, 2014; Granbom, 2014; Krout and Wethington, 2003; Krout *et al.*, 2003; Loe, 2010; Luborsky *et al.*, 2011; Roy *et al.*, 2018; Sixsmith and Sixsmith, 2008; Wu, 2015), that may not always be possible. A 2018 systematic review of factors impacting later-life relocation found 88 factors, very few of which have been studied extensively. Further they found that the complexity of the decision and factors involved are underestimated (Roy *et al.*, 2018). Later-life relocation is different from relocation earlier in the lifecourse because the reason for moving is generally due to push factors, notably declining health. People typically move to a smaller place and part of the process is the difficult one of 'disbandment', disposing of a lifetime of personal objects and mementos (Sergeant and Ekerdt, 2008).

The main reason cited for considering or actually relocating is the declining health of the individual or his/her partner and the increasing incongruence between the physical environment and physical capacity (Boldy *et al.*, 2011; Brownie *et al.*, 2014; Ewen and Chahal, 2013; Granbom *et al.*, 2014; Koss and Ekerdt, 2017; Krout and Wethington, 2003; Luborsky *et al.*, 2011; Sergeant and Ekerdt, 2008; Wu *et al.* 2015). There is a difference between self-assessed health and functional limitations. Functional limitations, a growing sense of personal limits, serve as a prompt to move to a more supportive environment (Koss and Ekerdt, 2017; Luborsky *et al.*, 2011). Self-assessed health was not a good predictor of a move, but functional limitations were (Sergeant and Ekerdt, 2008; Wu *et al.*, 2015).

Another commonly cited reason for relocation was family, although its impact was both positive and negative (Ewen *et al.*, 2014; Gottlieb *et al.*, 2009; Krout and Wethington, 2003; Luborsky *et al.*, 2011; Sergeant and Ekerdt, 2008). Whilst moving towards grandchildren was a strong pull factor, moving closer to family could prompt a shift in power relationships, especially noted with widowhood (Sergeant and Ekerdt, 2001). In research with community-dwelling older people, independence was valued above all, even if it meant "intimacy at a distance" (Ewen *et al.*, 2014, p304). This US research shows that in general, it was felt that staying in one's own community, where one has social ties, activities and a role is to be preferred over relocating to be near family

(Ewen and Chahal, 2013; Gottlieb *et al.*, 2009; Krout and Wethington, 2003). The only exception concerned neighbourhood changes, impacting safety and feelings of security (Sergeant and Ekerdt, 2008; Wu *et al.*, 2015). As noted previously, those moving to be closer to their children, often found themselves isolated in unfamiliar surroundings (Scheibl, 2019a).

#### 3.3.3.3 Care and successful transitions

As noted in the CC75C research, the most successful moves into care are those in which the older person controls the decision (Ewen and Chahal, 2013; Golant, 2015; Gottlieb *et al.*, 2009; Scheibl, 2019b). The main reasons behind a care home move are to ensure continuing care (85%), reduce household upkeep and maintenance (53%) and to avoid becoming a burden on family (44%) (Krout and Wethington, 2003). Similar to the Löckenhoff model (2018), American research with older people moving into care, found that the process proceeds along four levels: information gathering (what they've learned through their own or vicarious experience), assessment of the success of others' residential adjustments, their own predisposition in how willing they are to act on the information and assessment, finally formulating plans and acting on it, even if the decision is not to act (Gottlieb *et al.*, 2009).

Whilst ageing-in-place (AIP), with or without modifications, is the preferred option (Ewen *et al.*, 2014; Gottlieb *et al.*, 2009; Granbom *et al.*, 2014; Jorgensen *et al.*, 2009; Krout *et al.*, 2003; Lee *et al.*, 2013; Loe, 2011; Lundh *et al.*, 2000), at some point, a care home may be considered. The stigma around retirement facilities include the admission of dependence, and anticipated social isolation (Sergeant and Ekerdt, 2008). Moving to a care home is viewed unfavourably, as a place of last resort (Gould *et al.*, 2017). The decision-making process is generally sharply curtailed, as almost half of care home residents in England come directly from hospital which means they must find a place urgently, possibly in a week or less (Trigg *et al.*, 2018). Whilst AIP is symbolic of independence, moving to a care home is symbolic of reaching fourth age, and the marker of the transition from third to fourth age (Koss and Ekerdt, 2017). Older people with positive experience of care homes based on the experience of their parents or peers, note the positive aspects of safety and socialisation, and have authorised their children to place them in a care home if they are no longer capable of making the decision themselves (Gottlieb *et al.*, 2009). The challenge in making the care home decision is that two decisions must be made simultaneously – the decision to move into a care home and the choice of a provider (Trigg *et al.*, 2018).

Typically, the choice of care home is made on basic criteria: location, activities, whether it smells, 'feel' and price. Once the choice is made, people are unlikely to move again, but to 'make-do' with the care home (Trigg *et al.*, 2018). From research conducted in three council areas of England from 26 interviews and 27 focus group participants, the determination of a good home

was based on soft measures e.g. good staff providing quality care and good food. Conversely, a bad home was one with serious problems, where residents might be given the wrong medications or residents not properly cared for. The most important aspects centred around location, whether situated in their current community, near family and friends, or in a good neighbourhood (*ibid.*). In making the decision, people consult their personal networks -- relatives, care home residents, home care providers and doctors, in addition to council and social workers. Their information-seeking is enriched further by the previous experiences of their friends, families, and carers; people who may have had respite care in a facility; care workers or volunteers and visitors to homes. In one case, a participant learned of the Care Quality Commission because of a contact who was an educator familiar with OFSTED reports and how to read them. If there is time, people visit two or more homes, sometimes many times to see if there is a different experience depending on time of day or whether an unannounced visit (*ibid*.).

A major problem, however, is that most of the documentation for selecting a care home is located online and there is a lack of basic information regarding vacancies, services provided, potential funding and care prices. Options are generally narrower than they appear because of the need to find a vacancy in a home which provides the appropriate care (Trigg *et al.*, 2018). According to a literature review of UK care practice and funding, only 3.2-5% of older people may need residential care, yet few understand the system or how it works until they need care urgently. Funding is difficult to negotiate, information is hard to find, both on costs and funding entitlement. Because of the complexity of the system, most people generally make decisions without full knowledge of the options, accepting whatever is offered (Higgs and Hafford-Letchfield, 2018). As part of the move to a care home, a thorough professional assessment must be carried out to ensure appropriate rehabilitation is conducted. Given that most people will be in a crisis situation, the assessment may not be given and there is little independent advocacy which means the most vulnerable may not receive the care needed (*ibid.*). In a study of financial planning for social care, they found that despite a lack of specific information, people have a general idea of the costs and recognise that they may not be able to afford it. They recognise the problem but are not looking for a solution because they consider the costs of care as wasted money, that they want to die before the money runs out. The reasons for the issue avoidance are that they try not to think of negative things and that they expect to die without needing care. They are hoping for the best and are not preparing for the possibility of needing care (Price *et al.*, 2014).

For discretionary moves to care homes, one of the considerations is the socio-emotional cost involved in the move and whether the emotional cost of a move will provide a benefit, given SRLE (Golant, 2014). In most cases, however, moves are precipitated by a health event, prompting

feelings of loss of control and choice. Additionally, feelings of grief and loss may be prompted by the sense of loss at leaving the family home and the recognition that they might be in the last stage of life (Brownie *et al.*, 2014; Jorgensen *et al.*, 2009; Lee *et al.*, 2013). Those who transitioned more successfully had more control and were more fully involved in the decision (Brownie *et al.*, 2014; Jorgensen *et al.*, 2009; Lundh, 2000; Rioux, 2010; Scheibl, 2019b). Additionally, they brought objects and possessions from their past into their new home, and were helped in the transition by initiatives designed to help them begin forming new social relationships (Brownie *et al.*, 2014; Lundh *et al.*, 2000), results confirmed in the CC75C research (Scheibl, 2019a).

### 3.3.4 Driving cessation

Driving provides more than just transportation. It represents freedom, spontaneity, independence, and control. For older people it can provide mobility when there may be loss of physical capability, and in providing transportation for others, a role in society. Driving is linked with wellbeing and QOL benefits, the ability to socialise and pursue hobbies, and travel for fun and enjoyment (Gaidezi *et al.*, 2006; Musselwhite, 2011).

The Department for Transport (DfT) classifies older drivers as those aged 70 and above. As of 2016, approximately 57% of older people (59% male, 41% female) had driving licences, representing 12% of licence holders in Great Britain. Older drivers have a lower casualty rate than all other drivers with 292 casualties per billion travel miles as opposed to 306 for the general population. Older drivers generally travel shorter distances than other drivers (DfT, 2018). Primary driving reasons are utilitarian, for shopping, enjoyment, pursuing a hobby, or visiting nearby friends and family, or for medical appointments (Siren and Haustein, 2014). Secondary travel needs are affective. Driving provides independence, control, status, and identity. Especially for men, cars are associated with personal identity, financial status, and power. Driving also allows older people a role in the community by providing transportation for others, including grandchildren and other family members and friends. Tertiary travel needs are aesthetic, answering the need to travel for its own sake, to interact with nature. The loss of driving represents the “beginning of the end” (Musselwhite, 2011).

Driving cessation happens over a period of time, with multiple influences. Most drivers plan to continue driving as long as possible, noting they will know when to give up (Gaidezi *et al.*, 2006). Initially, senior drivers may notice **intrapersonal** physical changes such as loss of night vision or a medical condition impacting their driving which causes them to investigate strategies to maintain driving (Rudman *et al.*, 2006). The most common strategies employed are ceasing to drive at

night, on motorways, during bad weather or in heavy traffic (Adler and Rotunda, 2006; Musselwhite and Shergold, 2013; Rudman *et al.*, 2006). **Interpersonal factors**, such as comments from a physician or family further raises awareness. Generally, older people are more receptive to advice from their physicians or ophthalmologist (Musselwhite and Shergold, 2014; Gaidezi *et al.*, 2006). **Environmental factors**, whether due to licencing laws requiring visual or medical checks, the increasing availability of public transport or media information, further raise awareness of the possibility of driving cessation (Rudman *et al.*, 2006). In the UK, driving licences must be self-declared after age 70 and renewed every three years, the only qualification being that drivers must meet the minimum eyesight requirement of being able to read a car number plate from 20 metres (*Renew your driving licence if you're 70 or over,* 2020). Generally, drivers proceed with self-regulation and self-monitoring, adapting behaviour to maintain a level of comfort until they reach an unacceptable level of confidence and decide to stop driving (*ibid.*).

In the decision to cease driving, older people want to self-evaluate their own driving and make their own decisions (Gaidezi *et al.*, 2006). Influences on the decision include health, especially vision problems (Musselwhite and Shergold, 2014) and cost, when drivers realise the annual distance travelled may not justify the expense (Adler and Rottunda, 2006). There are three main approaches to the decision: the proactive quitters, those who made the decision and went forward with it; reluctant acceptors who proceed slowly, resigned to the impact of increasing disability and possibly prompted by others; and the resisters, those who others think should not be driving, but continue to do so (*ibid.*). Whilst others recognised the resisters' faulty driving, they were reluctant to talk to them about it, but also refused to accept rides from them (*ibid.*). It is generally noted that women are more likely to stop driving at a younger age and in better health than men, citing the stress of driving. (Gaidezi *et al.*, 2006; Adler and Rottunda, 2006).

There is general agreement that driving cessation impairs QOL (Musselwhite and Shergold, 2014; Adler and Rottunda, 2006) with losses of independence and spontaneity and the need to pre-plan activities (Adler and Rottunda, 2006). The most successful quitters, generally female, had done the most planning prior to cessation, trialling the decision and gradually weaning themselves from driving, a process which took from one to five years in total (Musselwhite and Shergold, 2014). The decision was generally harder for men, citing loss of confidence and their role as being the main driver (Adler and Rottunda, 2006; Musselwhite and Shergold, 2014). Men found driving cessation as symbolic of end-of-life and the accumulation of losses. It was also noted, however, that these individuals were generally forced into the decision and had to stop driving abruptly, meaning they did not have time to plan for the decision (Musselwhite and Shergold, 2014).

CC75C research on driving cessation completed by over 400 of their participants found 11% stopped driving before age 50, 18% before age 70, 9% from 70-74 years old, 14% from 74-70, 29% from 80-84 and 20% from 85-89 years old. They mainly stopped driving due to lack of confidence, health problems or on advice of relatives or friends. Only one stopped driving at a doctor's recommendation (Brayne *et al.*, 2000). Drivers were more likely to be male and married.

The specific decisions of late-life include decisions about social networks, their composition and how they're used and late-life re-partnering; decisions around health and ACP, and the administrative matters of death; residential decision-making including moving to retirement or care homes; and driving cessation. There appears to be a similar process in the decision-making in that there is recognition of a possible decision, exploration of options, information gathering and making the decision. Interim strategies may be developed and deployed to postpone or avoid making the decision.

## 3.4 Theoretical framework

The purpose of this research is to understand how people aged 85 and above think about and make decisions about later-life. Specifically, I am interested in how decision-making may have changed throughout the lifecourse, what current and future decisions are to be made, and what heterogeneity exists in decision-making.

There is no QLR on late-life decision-making, and very little research which considers later-life decisions from a lifecourse perspective and from the viewpoint of the older people themselves. Further, the focus of current late-life decision-making literature tends towards considering how to make decisions about the depredations of ageing, not how community-dwelling, relatively healthy older people themselves think about and make decisions about the future. Yet with an increasingly ageing population, it is important to understand how older people think about and make decisions about the future. To fill this gap, this research seeks to understand later-life decision-making from the perspective of people aged 85 and above, including changes in thinking as circumstances change over the course of research.

As has been noted in the literature review, gerontological and decision-making theories suggest aspects of later-life thinking and decision-making. As set out in Chapter Two, lifecourse, continuity, and identity theories, in addition to SOC and SRLE, are the main gerontological theories underpinning this dissertation. Lifecourse theory provides a framework for understanding the impact of timing, historical time, cumulative effect, and linked lives and how this interacts with personal agency to shape how people live and make decisions. This intersects with theory on identity which suggests that identity is both personally shaped but also influenced by other factors including gender and the lifecourse, as well as the intersectionality of these factors. Continuity theory suggests there is continuous growth throughout the lifecourse and continuity in the personal and decision-making patterns. SOC and SRLE address later-life goals, specifically. SOC proposes that people choose to continue pursuing activities they enjoy, but that they minimise the impact of possible decline through optimising their capabilities and compensating with a lower level of activity. SRLE impacts later-life goals and motivations in that activities are weighed to determine whether the expected gain is worth the effort, given the amount of time left to enjoy it.

Much of the literature addressing how older people make decisions is based on a positivist model useful for making consumer decisions, but less useful for the evolving later-life decisions. More recent research considers decision-making from a constructivist viewpoint, trying to understand how ageing impacts decision-making over the lifecourse. Research has suggested there may be

different types of decision domains which change depending on the lifecourse stage and that decision-making involves a multi-step process with clear steps and goals. Prospect theory notes the value of perspective as it impacts decision-making. Anthropological research proposes a more protracted decision-making process with decisions evolving over time as circumstances and external influences change, new information is presented, and goals are redefined and adapted as a consequence.

Providing specific data on later life and decision-making, empirical research suggests that health is increasingly a major factor in later-life decisions, that the main goal is to retain control and autonomy in decision-making, that later-life decision-making is supported by social networks in providing support, information, and companionship, and that in later-life, identity may be re-framed to accommodate physical challenges whilst maintaining a sense of self.

# Chapter 4 Methodology

## 4.1 Introduction

As has been shown in Chapter Two, there is very little qualitative academic research on later-life decision-making and much of decision-making research tends to focus on economic or financial matters and a positivist paradigm. The attempts to move beyond this model have narrowed decision-making to simple decisions studied in a laboratory setting which bear little resemblance to how people make the complex and multi-faceted decisions of later-life. The studies on later-life tend towards researching specific medical issues or medical trajectories. Because much of the literature around decision-making is narrowly focused and very little applies to community-dwelling older people, qualitative longitudinal research (QLR) was chosen to address the gap in knowledge and explore late-life decisions in depth with people from the community who were not pre-selected because of a specific medical condition. Because of this decision, the OurTown research is very broad, in essence charting the depth and breadth of the topic. The topic was kept very broad deliberately, to capture the participants' opinions and priorities in their late-life decisions.

This chapter will discuss the research design with justification of the methods chosen. Additionally, an overview of the study's ethical considerations, recruitment, and data generation will be presented before closing with a section on the analytical approach.

## 4.2 Research design

To understand how community-dwelling people aged 85 and above make decisions about the challenges they face in late-life and how their previous experience has prepared them to face these transitions, a qualitative longitudinal study design was developed. Qualitative methodology was chosen for this project because the goal is to explore how people comprehend and describe their experiences and understand the meaning they place on these experiences (Willig, 2013). Qualitative methods provide descriptions of phenomena, identify patterns and attempt to understand the subjective experiences of the participants (*ibid.*). Rather than a positivist epistemology, which assumes the goal of research is the production of objective knowledge, this project took an interpretive approach where meaning and knowledge were co-constructed between the interviewer and participants (Braun and Clarke 2013; Scotland, 2012). Interpretivism focuses on how the researcher and the social world impact each other, exploring meaning and agency, in order to understand phenomena through the participant's and researcher's co-

construction (Braun and Clarke, 2013; Snape and Spencer, 2003). Interpretive epistemology seeks to understand phenomena from the viewpoint of the individual within their cultural and historical contexts (Scotland, 2012). The challenge to interpretive epistemology is that it is highly subjective and contextual, which can be partially addressed through the use of reflexivity to understand the ways in which researcher' values, experiences, and social identities impact the research, as well as how the research design might bias results (Willig, 2013; Scotland, 2012). A relativist ontology will be employed as it attempts to highlight the great diversity of interpretations (Willig, 2013). Relativism acknowledges that reality is impacted by context and that there are many constructed realities (Braun and Clarke, 2013). In line with this epistemology and ontology, a longitudinal approach was taken in order to understand how people's thinking may change over time (Kornadt *et al.*, 2018). QLR enables the possible identification of patterns and trends as well as an understanding of the possible causes, effects and sequencing (Menard, 2004) which for this research include patterns of decision-making styles and processes.

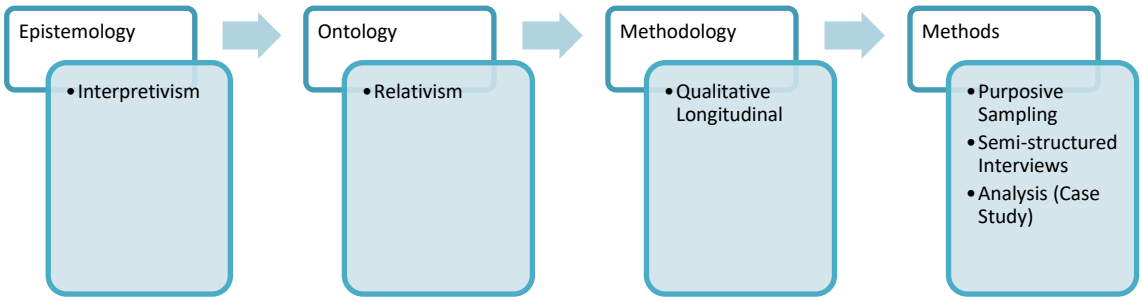



Figure 4-1 Methodological decisions (*Source: Author's own after Crotty, 1998, p4-5)*

### 4.2.1 Qualitative longitudinal research (QLR)

The QLR methodology was adopted for this PhD research because it captures change – or stasis – over two or more time points using a qualitative approach (Neale, 2019; Saldaña, 2003). QLR follows the same people over time, to understand how they think about their lives in real-world contexts (Neale, 2019). QLR is built on qualitative paradigms in that it seeks to understand how people think about and understand their lives. Use of the longitudinal design, introduces the element of change in order to understand changes in thinking as well as how circumstances may provoke a reaction and possible adaptation to change (*ibid.*). QLR illuminates the lived experience of change or stability over time, focussing on the causes and consequences, thus allowing the stories, trajectories and processes of transition and adaptation to be studied (Calman *et al.*, 2013). An additional advantage to QLR is that rapport between the researcher and the participants can

build over time making it easier to discuss sensitive topics. Intensive questioning or following-up on a specific issue can seem confrontational in a one-off interview, but with the possibility of re-introducing the topic at subsequent interviews, difficult issues can be approached in a more neutral line of questioning (Cameron *et al.*, 2019; Lloyd *et al.*, 2017). There is little guidance on how 'long' is longitudinal. Lloyd *et al.* (2014) and Cameron *et al.* (2019) chose an 18-month time period, expecting that change would be noticeable during this time. For practicality in completing a PhD, data collection lasted one year, in order to understand how seasons of the year might impact participants. It was also expected that given their age, change would be noticeable during this time. Ultimately, the research took 15 months and only two participants experienced change in circumstances. The most valuable aspect of QLR was in developing a trusting relationship.

There are many different types of change possible in QLR: narrative change, participant reinterpretation, researcher reinterpretation and absence of change (Lewis 2007); social change and continuity, how this unfolds and the role of structural forces in shaping people (Neale, 2019); and the process of evolution and development (Saldaña, 2003). The changes may not be expressed chronologically because as trust develops in the research relationship, or due to the recursive nature of interviewing, the participant may not have mentioned the issue or considered its importance previously. Participant reinterpretation is the implicit or explicit retelling/rethinking which changes over time. Something which may previously have been considered positive, may be seen in a different light in subsequent interviews and told differently due to changing circumstances. This helps to show the mental, emotional, and chronological journey. Researchers also change interpretation as they gain a better understanding of the participant and his/her circumstances, e.g. something at first viewed as resistance could actually be due to vulnerability or inflexibility. Finally, the absence of change may reflect stability, consistency, or maturity (Lewis, 2007). As will be seen in the results chapters, over the course of data collection for the OurTown research, there was narrative change, participant and researcher reinterpretation, participant change but also great stability, in that thinking and circumstances tended to reinforce past decisions and confirm current thinking.

## 4.3 Recruitment

Purposive sampling was used to find participants who were community-dwelling and aged 85 and above (Morse, 2004). It was hoped that fifteen participants could be recruited in order to approach both code saturation and conceptual and meaning saturation (Hennink *et al.*, 2017). Given the longitudinal nature of the project, oversampling was used to accommodate possible attrition (Calman *et al.*, 2013; Lloyd *et al.*, 2017; Neale, 2019; Saldaña, 2003) and given the age of participants, they were given the option of selecting a supporter to be with them during

interviews (Lloyd *et al*., 2017). Ultimately, neither precaution was necessary. None of the 17 participants wanted a supporter and all completed all four interview rounds.

My local community of OurTown was selected for recruitment, both for convenience and because of the importance of having local connections in recruitment of research participants (Liljas *et al.*, 2017). As is noted below, the local connection was important in gaining trust of gatekeepers and the participants themselves. These two factors outweighed the disadvantage of possibly seeing participants in High Street Shops, the GP surgery or local pub, situations that never actually occurred.

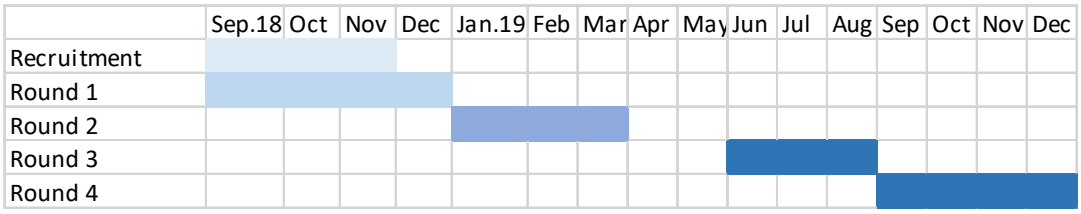
A variety of methods were used to recruit participants. Posters were placed in local community centres and shops, visits were made to the local community centre, and letters were sent to the local Women's Institute and the Parish Magazines. The most successful recruitment device, however, was hiring a stall at the OurTown Heritage Day, an annual community celebration which raises funds for community projects. During Heritage Day, I had innumerable conversations, and 25 passers-by took flyers about the research. As important, contacts were made with local organisations including the British Legion, the local heritage association, two churches, the Women's Institute, a former city councillor, the local community centre, and local almshouse association. From this, two important contacts were made, one with a representative of the multi-faith forum responsible for six participants, and the other a director of a local apartment complex for over 55-year-olds, The Manor, responsible for three participants. These two gatekeepers thoroughly vetted the project and me. In addition to University ethics approval, the appropriate Disclosure and Barring Police check and references from my university supervisors, the gatekeepers required local community references to attest to my commitment to and participation in the community and lengthy conversations about the research project. After this process, I was given access to possible participants from the multi-faith forum and allowed to make a presentation at The Manor.

Had I not actively participated in my local community and found community volunteers willing to provide references, it is questionable whether the gatekeepers would have referred potential participants. After the presentation at The Manor, three additional people agreed to participate. One participant joined after visiting the stall, another was a referral from the local councillor with whom I had previously volunteered, three were referred by other participants, two responded to local publicity, one was referred by his son and one learned of the study from speaking with another participant. Ultimately, seventeen participants, eight men and nine women agreed to participate in the study.

The recruitment process confirmed academic research suggesting that links to the local community and contacts with local organisations help with recruitment, and recruitment is more successful if handled through someone known and trusted by the potential participants (Liljas *et al.*, 2017). It has also been noted that generally men and people with higher levels of education, employment and socioeconomic status are more inclined to participate in research (Kelfve *et al.*, 2017). This is consistent with recruitment efforts for the OurTown research. Women proved more reluctant to participate in research on decision-making.

In line with local demographics which show the female population at this age closer at 64%, I had hoped that eleven of the potential fifteen participants would be female. Women, however, were more reluctant than men to participate in this research on decision-making. A common comment from possible female participants was that they didn't think they could contribute to a study on decision-making because they didn't feel they made decisions or that they didn't want to participate in an academic study. This could explain why just over half of the participants are female (nine of the 17 participants).

Table 4.1 Recruitment and data collection timeline *(Source: author's own)*




### 4.3.1 Insider/outsider positionality

Insider/outsider positionality brings advantages as well as challenges. Being an insider, someone who identifies closely with the group being studied (Ross, 2017), and who possesses deep insights about the cohort, place or history (Chavez, 2008) offers advantages as is shown in having easier access to potential participants (Ross, 2017). Additionally, insiders can develop a deeper understanding of the context of the participants and the community (*ibid.*). Conversely, the outsider positionality offers the advantage of impartiality (Chavez, 2008). Commonly, however, the positionality may remain fluid throughout the course of the research (*ibid.*) as happened with the OurTown research.

As I have lived and worked in the community for approximately 25 years, I have seen it change and have an understanding of the many references participants made to local places, events and people. This level of local knowledge made me an insider, which partially made up for my American accent and that I don't understand some references to British history. The benefit to

my accent was that it reminded participants that I may not understand some British references which induced them to give fuller descriptions in their narratives (Adamson and Donovan, 2002).

Throughout the data collection, my positionality changed to a more 'insider' relationship as the participants learned to trust me and I, in turn, better understood them and their decisions. The participants seemed to relate to me, someone in her early 70s, older than their own children, but younger than they. This was helpful for data collection, but made leaving the field, ending the last data collection round more difficult (see section 4.5.2). Ongoing reflexivity was helpful in maintaining an outsider positionality, but ultimately, the analysis stage with increasing emphasis on abstraction and less enmeshment in individual data was critical to maintaining an impartial stance.

### 4.3.2 Study participants

At the start of research, the participants were aged 84-92 years old. The majority of participants considered their health as good or very good compared with approximately 25% of those aged 85 and above in England (ONS, 2013). The participants' good health may be partly explained by the healthy survivor effect whereby over time, unhealthy people drop out of the population with the healthier individuals remaining (Baillargeon and Wilkinson, 1999). Eight participants still do some regular form of exercise, typically walking, although swimming, yoga, golf, table tennis and tennis were also mentioned. Most were still actively participating and volunteering in community activities including choirs, book and bridge clubs, the British Legion, and church, drama, health advocacy, and political organisations, as well as attending concerts, lectures, and foreign language classes.

Table 4.2 OurTown Participants *(Source: author's own)*

| Pseudonym | Age | Marital Status | Changes during course of research |
|---|---|---|---|
| **Men** | | | |
| Albert | 87-89 | Married | None |
| Clarence | 84-86 | LAT relationship | Health improved due to exercise |
| Ernest | 84-86 | Married | Cataract operations on both eyes |
| Eugene | 90-92 | Widowed | R1 leg scrapes healed by R2; R4 son's ill health |
| Frank | 84-86 | Widowed | Heart operation; blood pressure problems; polypharmacy |
| Glenn | 84-86 | Married | Increasing vision problems |
| Norman | 84-86 | Widowed | R3: broken ankle; R4 wrenched back |
| Ronald | 90-92 | LAT relationship | Angina; oedema |
| **Women** | | | |
| Bonnie | 84-86 | Divorced | Chest infection; fall & broken hip; heart and vision problems. Wet room installed |
| Dolores | 90-92 | Widowed | Fall necessitating care; stopped playing tennis; using a stick |
| Gladys | 87-89 | Widowed | Atrial fibrillation treated with medication |

| | | | |
|---|---|---|---|
| Judith | 87-89 | Widowed | Pre-cancerous skin lesion operation; chair yoga instead of regular yoga |
| Mildred | 90-92 | Widowed | Increasing macular degeneration; using a stick |
| Shirley | 84-86 | Widowed | Broken nose due to a fall; walking with a stick |
| Virginia | 87-89 | Married | Her cat died and she got a new one |
| Wanda | 87-89 | Widowed | Pulmonary fibrosis diagnosed due to her inspection of her CT scan |
| Winifred | 87-89 | Widowed | Knee operation; driving cessation, two falls, broken ribs; driving cessation and stairlift. |

Pertinent demographic information on the OurTown Participants is shown below in Table 4-3. Overall, the participants are more male, of higher educational attainment and socioeconomic strata than the comparable population of England. During the course of data collection, 14 of the 17 participants had medical events, including operations, diagnoses of continuing health issues, falls, or other medical problems, and one has stopped driving. Over half of the participants travelled abroad and two travelled great distances within the UK. (For more detailed information about the research participants, see Appendix C).

Table 4.3 Research participant demographics *(Source: author's own)*

| **OurTown Participants Characteristics** | **Men** | **Women** | **Total** |
|---|---|---|---|
| Gender | 8 | 9 | 17 |
| **Age at start** | | | |
| 84-86 | 5 | 2 | 7 |
| 87-89 | 1 | 5 | 6 |
| 90-92 | 2 | 2 | 4 |
| **Marital Status** | | | |
| Married | 3 | 1 | 4 |
| LAT Partner (previously widowed) | 2 | 0 | 2 |
| Divorced | 0 | 1 | 1 |
| Widowed once | 3 | 4 | 7 |
| Widowed twice | 0 | 3 | 3 |
| **Highest Qualifications** | | | |
| No qualifications | 1 | 0 | 1 |
| Age 16 leaving certificate | 0 | 3 | 3 |
| Sixth Form | 0 | 3 | 3 |
| University | 4 | 3 | 7 |
| Professional Qualifications | 3 | 0 | 3 |
| Secretarial school (in addition to above) | 0 | 5 | 5 |
| **Previous Employment** | | | |
| A: Higher Managerial | 7 | 0 | 7 |
| B: Intermediate Managerial, administrative & professional | 0 | 3 | 3 |
| C1 Supervisory, clerical & junior managerial, administrative & professional | 0 | 5 | 5 |
| C2 Skilled manual | 1 | 0 | 1 |
| Housewife | 0 | 1 | 1 |

| OurTown Participants Characteristics | Men | Women | Total |
|---|---|---|---|
| **Self-reported Health Average** | | | |
| Very poor, poor | 1 | 0 | 1 |
| Fair | 1 | 2 | 3 |
| Good or Fair | 2 | 2 | 4 |
| Very good or Good | 4 | 5 | 9 |
| **Living Situation** | | | |
| Family home with spouse | 3 | 1 | 4 |
| Family home with child/carer | 1 | 0 | 1 |
| Home alone | 3 | 4 | 7 |
| Downsized home | 0 | 1 | 1 |
| Downsized flat | 1 | 3 | 4 |
| **Local Family and Support** | | | |
| Family within 25 miles | 6 | 5 | 11 |
| No children/grandchildren | 0 | 3 | 3 |
| Help: cleaner (included below) | 4 | 6 | 10 |
| Help: cleaner and gardener | 2 | 4 | 6 |
| **Length of time in the community (average = 56 years)** | | | |
| Less than 2 years | 1 | 0 | 1 |
| 20 to 50 years | 2 | 4 | 6 |
| Over 50 years | 5 | 5 | 10 |

## 4.4 Ethical dimensions

Ethics approval was granted by the University of Southampton Ethics and Research Governance Online in 2018 (See ERGO II 42609 approval and interview guide in Appendix A). The ethical challenges of sensitive research, e.g. ensuring consent and preserving anonymity, are exacerbated in longitudinal research because the length of the project means that the relationship between participants and researcher builds over time, leading to more identifying details being shared. In this sense, QLR is similar to ethnography in that the role of the researcher shifts, possibly changing the dynamics of the research relationship (Dickson-Swift *et al.*, 2008; Neale, 2019). The ensuing possible blurring of boundaries between researcher and participant can be confusing for both parties (Attuyer *et al.*, 2018; Calman *et al.*, 2013; Dickson-Swift *et al.*, 2008; Fahie, 2014; Ross, 2017), risking emotional enmeshment, i.e. feeling emotionally engaged with participants (Possick, 2009) or emotional exhaustion, leading to a need to create professional boundaries in the research (Dickson-Swift *et al.*, 2008). The long-term nature of QLR means that researchers will establish a working relationship with participants, built on trust and respect (*ibid.*). Research relationships can become problematic if they encroach on private life, blurring the divide between the work and private lives of researchers (Dickson-Swift *et al.*, 2008; Lisiak and Kryzowski, 2018). As researchers become more involved in their participants' lives, empathy and greater rapport may develop, creating an emotional bond which may be confused with friendship or counselling

(Dickson-Swift, 2008; Ross, 2017). These issues must be negotiated individually as with many issues involved in QLR, "There is no prescriptive approach that works in all research contexts" (Neale, 2019, p83). These three issues, sensitive topics, anonymity, and emotional enmeshment were experienced in the research.

**Vulnerable populations and sensitive topics.**

People aged 85 and above may be considered a vulnerable population by ethics boards (Attuyer *et al.*, 2018) despite the fact that recruitment criteria required community-dwelling participants. The research topic, decision-making in late-life, can prompt discussions of some of the challenges of late-life: bereavement, the possibility of one's own death, and decline in mental and/or physical health, or increasing dependence, all sensitive topics. The topics to be covered and the possibility of having a supporter present during the interview were clarified in the information sheet. Additionally, informed consent was reviewed at the start of each data collection interview.

As participants didn't spontaneously raise the topic of end-of-life in the interviews, I sought ethics approval to discuss decision-making around end-of-life in the final interview round. Participants were alerted to this novel topic and given the option not to discuss it; in the event, all participants agreed to discuss end-of-life, and none considered it a particularly difficult topic or showed signs of distress (See ERGO II 42609.A1 approval and revised interview guide in Appendix A)

**Consent, Confidentiality and Anonymity.** Preserving confidentiality throughout research is increasingly difficulty in QLR. Consent needs to be an ongoing process as opposed to a single event at the beginning of data collection (Attuyer *et al.*, 2018; Neale, 2019; Saldaña, 2003) and anonymity needs to be balanced with maintaining meaning in the data (Neale, 2019). To address consent issues, the consent statement was repeated and discussed at the beginning of each interview. This also helped to re-establish the boundaries of the research relationship at each data collection point. On occasion, we also discussed issues of confidentiality and anonymity. Over the course of four interviews, details about participants' lives build over time, meaning that the level of detail about identity, circumstances and situations makes it difficult to thoroughly anonymise data without losing the value and meaning of the data (*ibid.*). In many cases, specific details are central to the decision-making, yet it also impacts the ability to respect anonymity. In all cases, however, identifying details have been blurred to protect participants' identity whilst retaining as much descriptive depth as possible.

**Emotion in Research.** Throughout the data collection process, there are incidents when a participant's story may evoke emotions, either in the participant or the researcher. Emotion is a significant marker of meaning, in that the display of it is an indication that the incident under

discussion is important in some way (Dickson-Swift *et al.*, 2009). Engaging emotion with intellect in analysis, becomes a valuable tool for informing the research (Blakely, 2007). Given the nature of QLR and the build-up of relationships as mentioned above, however, it is necessary to balance sensitivity and empathy whilst maintaining a professional relationship. There should be a clear protocol in place for referring participants for support (Calman *et al.*, 2013). For the researcher experiencing emotional enmeshment, this should be documented through reflexive diaries supported by supervisory and peer debriefing sessions (Attuyer *et al.*, 2018; Calman *et al.*, 2013; Dickson-Swift *et al.*, 2009; Fahie, 2014; Lisiak and Kryzowski, 2018), which was done throughout the data collection process.

The impact of emotion occurred occasionally during the data collection, usually when discussing bereavement or loneliness. In a second interview, one participant described how he may never see his best friend again, which made him very sad, reminding him not only of his inability to see this friend, but of the other friends and relatives who had died. He also noted his limited mobility and inability to walk in the neighbourhood in order to meet people and make friends. By the time that interview closed, we had worked through his sadness by focussing on events he had to look forward to. Whilst I didn't show it at the interview, I, too, felt sad but also concerned that I might have caused distress to one of my participants, feelings addressed by reflexivity and debriefing with my supervisors.

This experience exemplifies ethical concerns about 'doing harm' by having participants recall painful issues (Attuyer *et al.*, 2018). The interview space provides a safe place to express previously unarticulated feelings which can be beneficial for the participant; however, the weight of witnessing emotion can also impact the researcher (*ibid.*). In a study of care home practices, older researchers had a harder time maintaining boundaries when working with older participants as they shared understandings of age and the narratives had more direct personal application (*ibid.*). I noticed that after the interview referenced above that I was able to apply the learning when other men also mentioned a lack of friends. The experience increased my awareness of the difficulty older men have in making new friends and how this makes them feel. This became an emerging theme in my data.

## 4.5 Data generation

In line with a qualitative research paradigm, data collection needs to be participant-led and flexible to allow the participants' thinking to emerge (Willig, 2013). For this reason, semi-structured interviews were used although participants also had the option of recording thoughts in a diary or saving items of meaning e.g. newspaper articles in a folder. The challenge to semi-

structured interviews is that they take careful planning to ensure the research questions are being addressed. Additionally, a balance needs to be struck between controlling the interview and allowing participants to interpret and speak about the questions in their own way (Arthur and Nazroo, 2003). A practical challenge was how to record their soft voices without the recording equipment becoming a focus. For this reason, all interviews were recorded using iPhones which could be positioned near the participant; an extra iPhone was used for backup recording.

### 4.5.1 Interview guides

Interview guides typically begin with general questions before proceeding to more in-depth open-ended questions about the topic (Willig, 2013); each subsequent round builds on the previous (Neale, 2019). As seen in Appendix A, the first interview guide began with background and demographic information, leading onto a discussion of previous life decisions before progressing to questions about future decisions. After the first interview round in September-December 2018 and in preparation for the second round in January-March 2019, preliminary analysis of interview data fed into preparing a timeline and summarising the decisions discussed in the interview. Based on this work, a new interview guide was used, tailored to each participant in order to revisit and further explore previously discussed issues, seeking elaboration on salient points and capturing data relating emerging themes. This formed a pattern for the data collection as a similar process was followed for each data collection round. There were generally five parts to each interview: the five-point self-rated health, events and decisions since the last data collection round, follow-up questions from the previous data collection both from their individual interviews and emerging overarching themes, and an open-ended final question, about any other aspects of decision-making.

Academic literature notes that aspects of QLR data collection require special attention. First, the recurring cycles of data collection necessitate a different approach to research practice as noted above in relation to ethics, data generation and analysis (Neale, 2019; Saldaña, 2003). Second, because change is a central aspect of QLR, the changing perceptions, insights, interpretations and developments of both participants and research can be documented. As part of the data collection, participants were encouraged to look prospectively and retrospectively to understand how perceptions of important issues may change over time. In this way we were able to revisit previous comments for further exploration as the research relationship developed.

One of the adaptations made from the second round of interviews concerned self-rated health. In R1, this was a general question which meant there was no consistency about how they reported their health. For this reason, in R2 and all subsequent rounds, the five-point self-rated

measure (very good, good, fair, poor, very poor) was used. This permitted a consistent comparison throughout data collection, but also prompted participants to think about how their health may have changed from the previous interview. From the second interview round forward, the first main question concerned events which had occurred since the previous interview. For example, in the second interview session, held in January-March 2019, participants experienced the following events: a fall and subsequent broken arm; hospital admission for health issues, major surgery for a spouse, another for a child; travel to the Middle East, another to Asia; heart surgery, joint surgery and a car accident. Even those without major life events, experienced Christmas and New Year celebrations which helped to elicit information about family and social contexts.

Interviewing in QLR is recursive, revisiting and revising thinking and updating changes in events and thinking. This means that the information from previous interviews should be brought into subsequent interviews to see whether thinking has changed and if so, why (Neale, 2019). For example, the process of driving cessation seemed to progress along increasing self-limitations, which was initially mentioned in passing by a few participants, but was subsequently queried in later interviews with all participants to understand their thinking about driving if it hadn't been mentioned previously.

Participants were given diaries and folders to capture any thoughts or concerns or to serve as an *aide memoire* between data collection rounds. There was no requirement that they use or record their thinking in the diaries, although for the three participants who used diaries, on one occasion for each, it seemed as if they thought this was an academic requirement that they needed to fulfil. For the two female participants who wrote information (one on the back of an envelope because she didn't want to 'spoil' the diary), they documented specific decisions which we discussed in the second interview. One male participant sent 16 pages of typed diary entries which we discussed at the subsequent interview.

All transcripts were transcribed verbatim by the researcher. Additionally, after the interviews, reflective diary notes were made and an acknowledgement was sent to each participant, thanking them for their time and making reference to the next interview.

### 4.5.2 The last interview: departing the field

As a research relationship built over the course of fifteen months, the last interview was always going to be more difficult in that it would signal the end of the research relationship. Closure in such relationships is difficult and needs to be handled carefully (Calman *et al.*, 2013; Cameron *et al.*, 2019). Throughout the course of data collection, thank-you notes were sent to participants

after each interview and Christmas cards were sent at the holiday season. Prior to the last interview, information was sent regarding the intention to discuss end-of-life issues, as specified by the ERGO amendment. As it was the last interview, I also sent a copy of an academic poster prepared on the project in order to discuss preliminary findings and capture their thinking about the issues and possible results. The final question at the last interview concerned why they decided to participate and whether they found any aspect of the interview, or any of the interviews distressing. None found any aspect distressing and all found the process enjoyable. At the close of the interview, I presented each participant with a box of chocolates and a thank you note which served to signal closure. This gesture was helpful in signifying the end of the research relationship, although I sent them notes at the start of the first COVID lockdown and a summary of findings was sent after PhD submission and I have offered to meet with them to discuss the research further.

## 4.6 Analytical approach

Four data collection rounds resulted in 68 separate interviews, each lasting over 80 minutes, for a total of 93.5 hours of interviews capturing participants' thinking about past, present and future events, and decisions. To synthesise and analyse this information, case study analysis was used to understand each participant's situation and decisions in the context of their thinking and life-history. The purpose of a case study is to understand a phenomenon within a bounded context (Miles and Huberman, 1994). Use of a case study approach allows many different perspectives to be applied in the analysis (Lewis, 2003; Miles and Huberman, 1994; Willig 2013). Cases can be studied from single or multiple perspectives to understand the range and diversity of the phenomenon studied (Lewis, 2003). Cases can be individual people in a specific context, a small group or a specific community, or cases may have many different cases embedded within them (Miles and Huberman, 1994). Ultimately, case study approach is designed to understand the complexity of the topic being studied, seeking both what is common and what is peculiar in the case (Hyett *et al.*, 2014). The OurTown research sought to examine the phenomenon of late-life decision-making from the perspective of people experiencing it, those aged 85 and above living in OurTown. In order to understand the phenomenon, cases were approached in different ways: the individual case; gender specific; women who self-identified as housewives as opposed to those who had careers outside the home; as well as the OurTown Participants considered as a single case.

After the first interview, a preliminary analysis was made of each participant. I drew a timeline of the participant's decisions and major life events for two reasons. First to serve as a mind map, but more importantly because none of the participants spoke of their decisions chronologically.

Once I had a better idea of their chronology, I summarised the major decision episodes in their lives, noting any salient details or points for future follow-up. In this way, I was able to identify possible items for follow-up in subsequent interviews, but also to understand what was similar and what was peculiar in each case, applying this analysis not just on the individual but across the entire OurTown Participants. As noted above, this was helpful in developing individual interview guides, as well as in beginning to formulate trends across the OurTown Participants which could be explored consistently in subsequent rounds. For instance, after the first round, it became apparent that this cohort benefitted from economic growth – bank lending was easier and more available for purchasing houses or cars and there was a great availability of jobs so it was possible to leave a job and try another easily. It also became apparent after the first interview that they seemed comfortable discussing 'easy' decisions, like future travel plans, but the major decisions of life had not yet unfolded. This prompted cohort-generated questions for R2 as well as questions about the hardest decisions they had to make, the most important decisions, and those which didn't turn out as expected, in order to probe deeper into experience. There were also prompts about decision domains: health, social activities, driving, financial matters and domicile, whether they were considering any future moves. This process of case and overall OurTown Participants analysis after each round was also responsible for prompting the decision to discuss end-of-life issues at the last data collection round. It had also been noted that emotion was not readily discussed by the participants, so this became a topic in R3.

At completion of the four interview rounds and individual analyses, a preliminary analysis of the female participants was written, followed by a similar investigation of the male participants. There were many approaches taken. Guided by the literature, I attempted to categorise lifecourse decision domains as suggested by the Kornadt *et al.* but found this was not applicable to the OurTown Participants. As noted in Table 2.1 (page 19), the Kornadt *et al.* research suggests there are discrete decision domains, e.g. "looks and appearance", "leisure activities and lifestyle" and "social relationships". For the OurTown Participants, however, individual decisions often encompassed several domains. For example, an exercise decision may involve finances (a cost consideration), social relationships (by involving a friend), health maintenance, and leisure. The research also distinguished between earlier and later-life decision domains, but the OurTown Participants continued to engage in all domains throughout their lives. The most recent research (Kornadt *et al.*, 2020) added the category of "personality and life management" which suggested decision domains about identity, a single category considering personality and life management in terms of whether older people were stressed about 'finding the right solution' in making life decisions (Kornadt *et al.,* 2020).

Having studied and considered the decisions of the OurTown Participants and attempted to categorise them using the Kornadt *et al.* research, it was found that the Kornadt *et al.* domains portrayed aspects of the decisions OurTown Participants made, but because of the greater depth provided by qualitative research, these domains were insufficient. The OurTown Participant domains concerned more than one domain and involved decision domains made throughout life. For example, the personality and life management domain considered only stress and concern about finding the 'right solution' to later-life decisions. In contrast, the OurTown Participant decisions were broader: how will I maintain my independence when challenged by a variety of concerns: protective attitudes, limited capacity of healthcare professionals, and decreasing financial, social and health resources, decisions which impact many domains. Finally, for the OurTown Participants, the greatest concern in considering later-life decisions, was mental incapacity, which they viewed as a loss of self. This aspect, dementia equated to loss of self, stimulated the realisation that its opposite, sense of self, or identity, is possibly the greatest concern in later-life and one which they will protect through the deployment of all their resources. Once this was recognised, I returned to the raw data and reconsidered the types of decisions made and the decision domains, regrouped the decisions and domains to better accommodate the OurTown Participants' actual decisions. As will be seen in Chapter Five, the OurTown Participants appeared to have four over-arching decision domains throughout the lifecourse, of which identity is the most critical.

In analysing the male and female participants separately, it also became apparent that there were different approaches and processes in decision-making, including the female participants making greater use of social networks. This led to a greater investigation of social networks and social network typology and use of the Practitioner Assessment of Network Type (PANT) instrument (Wenger, 1991). This research helped me consider different types of social networks and types of support provided, even though it was conducted prior to changes brought about by greater global mobility or changes in social networks brought about by the internet. Despite this concern, the application of the Wenger social network types helped to broaden and better interpret the data.

## 4.7 Summary

This chapter has discussed the methodology for my research project, progressing from the research design to specific details about the recruitment, ethics, data generation and analytical approach. A qualitative longitudinal methodology was chosen to study the impact of change over time and to understand their thinking about matters of importance to them. Purposive sampling was conducted to recruit community-dwelling participants over the age of 85 in OurTown. Ethics approval was granted for the project and amended for the final data collection round to include

the topic of end-of-life preparations. The data was analysed using case study analysis and applying different lenses to understand individual cases, gender differences, the differences between women who self-identified as housewives in contrast with career women, as well as the similarities and differences of the OurTown Participants as a whole. Chapters Five through Seven will present the results of this research, focussing on lifecourse decisions, late-life decisions and heterogeneity in decision-making.

# Chapter 5 Decisions throughout the lifecourse

## 5.1 Introduction

The purpose of this research is to understand how people aged 85 and above think about and make late-life decisions. This chapter addresses the first sub-question: how has decision-making changed throughout the lifecourse? This chapter will survey the types of decisions over the lifecourse and seek to ascertain the decision domains, goals and motivations, and the value of experience and emotion. The chapter begins with a section on how thinking about earlier-life decisions is different from those in later-life.

## 5.2 Reduction of earlier-life decisions

In line with the participant-led, semi-structured interviews, the participants themselves defined what comprised earlier versus later-life decisions and how this fit into the lifecourse. In the process, earlier-life decisions appeared to have been resolved so that they became less dilemmas and decisions, and more established facts in the progression of the lifecourse. This reductive process could be due to the process of reflection, but it could also be due to the layering of intervening life experience to the event. For example, Gladys recounted her first independent decision, to be confirmed.

> *"[The decision] to be confirmed when I was about, I don't know, 11, 13 years old, I don't know why. Ours was not a religious household and neither my mother nor stepfather were church goers. I don't think I had any pressure from friends…. I don't know quite where I went and I don't know why…. I don't think anybody went [to her confirmation]. I think I was the only one. They [her family] never went … I thought when I was confirmed, something would happen. And nothing did." Gladys, R2*

This shows an earlier-life religious decision made almost out of curiosity, to try something new. Yet despite her initial disappointment that there was no recognition or dramatic spiritual awakening, it was an important decision that shaped her subsequent life. This example demonstrates two aspects of earlier and later-life decisions. First, how the initial decision itself is presented as a simple binary decision, to be confirmed or not. Once made, it becomes a marker on her timeline involving little more than curiosity with much of the inner debate forgotten in the processing of the decision into a lifecourse 'fact'. The second aspect is that the intervening years have layered greater meaning to decisions about religion. A typical discussion about her weekly volunteering at the church (activity) involved a discussion of the difficulty of walking there and the

lamp posts she leaned against on the way (health resource), the people she met there and spoke with (relationships), the memories of her marriage there, her husband's funeral, or her children's christenings (identity). As will be seen, these are the four main decision-domains of the OurTown Participants.

This is a common pattern in the decisions. Earlier-life decisions were presented as binary choices with the decision reduced to timeline markers in the expected trajectory of education, family, career and achieving financial stability. This reductive process is possibly due to the passage of time and the filtering of detail, but it also points to the layering of intervening experience so that much more is considered in every decision. There appeared to be an extra step in the process, of reflection, where the initial decision was reconsidered and resolved to experience, forming the foundation for future decisions.

> *"You learn from your mistakes in the sense that looking back you can see decisions that in the long run, because of the way things worked out, were not very good. But was it because they were mistakes, or was it because circumstances changed? I mean you try to make excuses yourself. … [It] increases understanding." Mildred, R3*

In this, Mildred described the extra step required of decisions, that of time and reflection to transform the decision and subsequent results into experience that informs future decisions.

## 5.3 Goals and motivations throughout the lifecourse

Decisions appeared to fall into a distinct life stages: earlier-life, retirement age, later-life and very-late-life. Earlier-life decisions laid the foundations of their future lives. The next stage occurred at about retirement age. This was not a specific age number but referred to the thinking prompted around what is 'normally' considered retirement age, which has been described as freedom from external constraints (Wahl and Ehni, 2020). Some participants retired early; others retired then continued in new employment. At the retirement life stage, participants recognised that whilst they had health and resources to pursue a variety of interests and activities, they were, in fact, entering a different life stage, different from earlier-life and what they considered their current life stage, later-life. Five of the female participants self-identified as housewives even though four of them worked part-time outside the home as well. Using their terminology, their thinking as housewives about 'retirement age' was impacted by their children's increasing independence and their husbands' retirement or death. The OurTown Participants recognised that they were currently in 'later-life' which is different from 'very-late-life', a period of possible decline and incapacity. The marker for very-late-life decisions appeared to be the point at which participants recognised that declining health impacts their lives. Later-life decisions concerned

balancing and conserving the resources built in earlier-life to accommodate a comfortable and purposeful later-life, whilst very-late-life decisions concern decisions about ensuring autonomy and safety towards the end-of-life. Results also suggested that these different life stages impact the focus of the OurTown Participants' goals and decision-domains, the way they think about their decisions, and how they make, or defer, future decisions.

Earlier-life decisions generally concerned building lives: establishing careers and families and working towards financial stability, fulfilling an accepted societal expectation. A first step was generally the decision to marry, a major life decision at the time, recounted as accomplished fact.

> *"In those days people married probably rather earlier than they do today. So that by that time my friends were getting married also, so it was a natural thing to be getting on with. And you see, I met a woman and one thing led to another." Norman, R1*

Whilst all participants agreed marriage was an important earlier-life decision, the circumstances were described briefly, in the context of another decision, e.g. buying a house (Ernest), purchasing the ring with money reimbursed from passing banking exams (Glenn), being 'dumped' by others (Clarence) or simply that it was the most important life decision (Albert).

The women spoke in terms of fulfilling societal expectations.

> *"I suppose it was expected that I would get married, which I did, obviously." Judith, R2*

> *"By that time, we were both 25 when we got married. So we weren't youngsters. ... That was an easy decision." Winifred, R1*

In the few instances when earlier-life relationship decisions were discussed, however, it was because the decision involved a conflict requiring resolution or transition which will be discussed in section 5.4.3.

The other main earlier-life goal was to make money to support their families, buy homes and to build financial security for later-life.

> *"Your first job is to make enough money to be comfortable and then you can do the good you want to do in the world. And that was my statement right through life." Clarence, R2*

There were additional goals in their earlier-life career decisions. Five participants sought careers which allowed them to travel (3M, 2F). Other goals included doing something intellectually challenging. One participant specifically moved to countries where he could practice his faith.

For the five housewives, their goals were shaped by societal and familial expectations. In earlier lives, their parents made decisions; after marriage, husbands did.

*"Wives did what their husbands wanted in those days." Judith, R3*

This began to change as children needed less of their attention and care, their 'retirement' from raising children. Increasingly, they sought meaningful engagement in their activities, whether through participation in music and drama productions, travel, pursuing a university degree, expanding their social circles by learning to play bridge or volunteering in local community organisations.

In the retirement life stage, there were two additional trajectories, either continuing in paid employment or focussing on voluntary activities. The participants continuing in new careers sought remuneration, but also something interesting and purposeful. Others sought interest and purpose through their voluntary activities as part of the motivation.

*"It's a mixture of all the things we've been talking about. But when we talked about keeping me involved and active, it is really … intellectual activity and the social interaction. Those are the particular things, as well as the service aspects of it." Norman, R3*

With homes paid for, savings and pensions accumulated, participants focussed more on 'giving back' as a goal to find activities which replaced the personal fulfilment goals and occupation they found in work. Four participants were guided by their religious beliefs.

*"The community has been very good to me and therefore I should try and do something for the community, for other people…So, I suppose in a sense, it's based partly on my faith, you feel like doing something in the community where you're helping … that's a very clear instruction coming out of the Christian faith." Norman, R3*

In this quote, Norman encapsulated the main goals of voluntary work cited in later-life: intellectual stimulation, a way of staying actively engaged and interacting with people as well as the faith and community-driven service aspects. These goals were generally the motivations and goals for all the participants in their later-life activities.

In their current later-life stage, all of the participants continued to provide support in their communities, whether informally by supporting their friends and family including one participant who was a carer for her adult child, or by volunteering for their local community governance, religious communities, Women's Institute and other community organisations. In these and other activities, the goals were to do something providing intellectual challenge and enjoyment, whilst maintaining social connections and 'giving back' to the community.

In very-late-life, as activities became more localised due to declining energy and health, the goal shifted to maintaining autonomy.

*"My family's philosophy and [my partner's] family philosophy, is always make sure you are self-sufficient." Clarence, R4*

To sum, the OurTown Participants' goals and motivations changed throughout the lifecourse. Earlier-life goals concerned building resources for later-life whilst at retirement age and in later-life, the goals shifted to protecting those assets whilst focussing on meaningful engagement. As will be discussed more completely in Chapter Six, the main later-life goal is to continue engagement with the people and activities which are personally meaningful, strategically deploying resources as necessary to retain autonomy.

## 5.4 Decision domains throughout the lifecourse

The OurTown research suggests consistency in the four main areas that people make decisions about throughout the lifecourse. As is seen in the following table, these four overarching domains are: identity, activities, relationships, and resources. Essentially these decisions are about who you are, what you do that gives your life meaning, who is important in your life, and the resources that support your goals. They can be summarised as follows:

- **Identity decisions.** This decision-domain focuses on issues around identity, developing goals, values, ethics, and a sense of what is important in life and who you are. For example, in earlier-life, the participants identified with their occupations: banker, accountant, butcher, housewife, secretary. In later-life, however, identity is refocussed to address changing needs, e.g. whether you are the type of person who attends a balance class, uses a stick or moves into a care home. Each transition requires a readjustment of identity.
- **Activity decisions.** Activity decisions concern meaningful engagement: education, work/community service, cultural pursuits, and travel.
- **Relationship/social network decisions.** This is perhaps the broadest domain, encompassing not just a spouse or partner, but also close friends or confidants; family (parents, siblings, children and grandchildren, nieces and nephews); friends, neighbours and affiliation contacts (alumni groups, colleagues, religious or community volunteering associates); and weak ties[1]. Social Networks and what they provide will be discussed more fully in Chapter Seven on heterogeneity. In this chapter, the focus is on how the

[1] Weak or peripheral ties are less emotionally close social acquaintances that require little time to sustain but can provide novelty and access to novel information sources, e.g. club or activity contacts or casual acquaintances (Huxhold, 2020). Weak tie theory is based on Granovetter's network theory of weak ties in which he noted the bridging importance of weak ties in securing employment and for community organising purposes (Granovetter, 1973).

composition changes throughout the lifecourse. These are referred to as relationship decisions because that is how the participants talked about them.

- **Resource decisions.** These decisions include everything that supports the above, mainly financial resources, housing and health, although relationships and how they are used can also be a resource.

Table 5-1 below charts the types of decisions OurTown Participants made, within the lifecourse stage and domain.

Table 5.1 Decision domains throughout the lifecourse *(Source: author's own)*

| Earlier-life | Retirement Age | Later-life | Very-late-life |
|---|---|---|---|
| **Identity Decisions** | | | |
| Goal and value development. | Reconsideration of self as identity changes in the retirement transition. | Coherence: bringing together the past and present selves to form a coherent whole. | Maintaining independence and identity whilst negotiating possible increased care needs. Self-acceptance. |
| **Activity Decisions** | | | |
| Education supporting work. | University study, language, music and art classes. | Education: language, music and art classes. | Education: language, music and art classes. |
| Work: Career and voluntary community activities.* | Post-retirement career: work and voluntary community pursuits. | Leaving work (closing businesses and retiring). Geographically narrowing voluntary and community pursuits. | Further limiting voluntary and community pursuits given health and driving ability. |
| Cultural: participating in and organising local and regional cultural events.* | Cultural: performing in and attending cultural events at home and abroad. | Cultural activities: attending concerts locally and throughout the UK. | Cultural activities: attending concerts but paying more for personalised transport and arrangements. |
| Travel for work or family holidays. | Travel for pleasure, voluntary activities or cultural trips. | Travel: paying for more service and paying for family to travel distances for family visits. | Travel: Paying more for better/personalised service; having family travel distances. More localised travel. |
| *Activities pursued by women who did not have full-time careers | | | |
| **Relationship Decisions** | | | |
| Partnering: Marriage. | Remarriage and/or reaction to bereavement. | Developing live-apart-together (LAT) relationships and/or confidants. | Developing live-apart-together (LAT) relationships and/or confidants. |
| Family, parents, siblings, and children. | Family, siblings, children, and grandchildren; fictive kin. | Family: children, siblings, grandchildren, nieces, and nephews; fictive kin. | Family: children, siblings, grandchildren, nieces, and nephews; fictive kin. |
| Caring: raising children. | Caring: spouse or other relative. | Caring: adult child; friends. | Caring: spouse, friends, adult child. |
| Maintaining contacts with friends and neighbours. | Maintaining contacts with friends and neighbours. | Maintaining contacts with friends and neighbours. | Maintaining contacts with friends and neighbours. |

| Earlier-life | Retirement Age | Later-life | Very-late-life |
|---|---|---|---|
| Affiliation (colleagues and associates from alumni, church, etc). | Affiliation (associates from voluntary activities, former colleagues, alumni, church members). | Associates from voluntary activities, church, former colleagues. | Associates from voluntary activities, church, former colleagues. |
| | | Weak tie development. | Weak tie development. |
| **Resource Decisions: Finances and Housing** | | | |
| Building financial capital. | Preserving capital. | Balancing current versus future life goals, including monetising assets, e.g. house. | Costing future care options, including monetising assets, e.g. house. |
| Buying a house for family, convenient for commuting. | Mortgage paid. | Downsizing and/or accommodations for age-friendly housing. | Changes to accommodate health changes (wet room instead of bath, stairlifts). Care Home or live-in care. |
| | EOL admin: wills. | EOL admin: wills, LPAs, funeral, and burial plans. | Reviewing EOL admin and anticipating future care. |
| **Resource Decisions: Health** | | | |
| Health emergencies resolved. | Health promotion (exercise classes, swimming). | Recognising health as a limiting factor. Walking (with sticks) for exercise; preventative exercise. | Balance or chair yoga classes or acceptance of declining health. Increasing use of mobility aids. |
| Fitness: tennis, lacrosse, hockey, bicycling. | Fitness: tennis, bicycling, walking. | Fitness: walking and exercise classes. | Fitness: chair yoga. |
| | | Vigilance of prescriptions, medications. | Ongoing vigilance, e.g. prescriptions, medical tests. |
| | | Medical conditions: cancer, encephalitis, sprains. | Continuing medical issues: melanomas, fainting, sprains, heart and lung problems. |
| | | Decisions about medical procedures. | Medical emergencies: falls, heart problems. Increasing health problems as health crisis becomes ongoing vulnerability. |
| | | Macular degeneration and driving reduction. | Accommodating eye problems and consequent driving cessation. |

The major implication from Table 5-1 is that the domains remain consistent, but the focus within them changes throughout the lifecourse, with increasing focus on accommodating declining health. The identity, activity and social networks have greater stability in the types of decisions made, but the resource domain involves more and different types of decisions as life progresses, and as greater resources are required to support and maintain the other three domains.

### 5.4.1 Identity decisions

Identity is inextricably linked with the other domains as decisions about education, work, career, finances, health, and social networks impact identity. Identity was expressed indirectly as the participants spoke about their earlier-life education, career and relationship decisions and the

values developed as part of those decisions. For example, in earlier-life, Judith noted the type of person she was as a housewife, caring for her children and supporting her husband in his career. She felt this was largely socially-constructed, that there were expectations of women that shaped how they thought of themselves and their roles in life.

*"I think I just conformed, there was a certain way that you were supposed to behave." Judith, R2*

As life progressed, with changes in circumstances, political environment, and personal goals, participants changed the ways they thought of themselves. Shirley changed from being a 'yes-wife' to an independent woman. Winifred began thinking of herself as a student; Mildred began thinking of herself as an artist, and Judith changed with bereavement when she no longer had a spouse who made the decisions.

*"I've got more bossy as I've got older." Judith, R2*

Over the course of four interviews, Dolores chronicled her many changes of identity: a loved child in a happy family, refugee, 'Cinderella' or 'skivvy' living with distant relatives, 'daughter' the old ladies never had, wife, widow, second-wife, carer for her husband with dementia, and most recently, her transformation to someone who employed lifelong frugality, prioritising her own goals even if it meant spending more money to continue doing things she enjoys.

For those starting new work careers in later-life (3M, 2F) their decision meant redefining work and how they rejected the societal retirement expectation, instead becoming more independent by changing their sense of control.

*"I made one rule (for post-retirement work): I wasn't going to work for anybody. I'd done that for a long time." Glenn, R3*

Post-retirement, Glenn worked as a consultant and bought his own companies meaning that he determined how much and when he would work.

Having established greater independence, later-life decisions were more about maintaining independence, with identity defined by the key value of maintaining autonomy.

*"I can ask people, but I don't like to. I'd much rather be independent. I think I'm of an independent nature perhaps." Winifred, R2*

*"[My neighbour] said, 'do you need any help?' And I said, 'no'. He was anxious to help, but I said, 'no, no, no, coping well, thank you.'" Eugene, R4*

Few speak specifically of independence as the key value of later-life, but discuss it more in its opposite, losing independence or control through dementia, which is viewed as the loss of self, of the essential person they are, and the ability to make decisions. This is discussed more fully in

Section 6.3.5.3 on dementia in later life decisions, and how dementia is thought of as the precipitation event which will compel them to make major later-life decisions.

> *"You've got to make your decisions before you have dementia because once you've got dementia, you're not going to listen to anybody." Wanda, R4*

All are aware that except for dementia, most future situations can be controlled, generally by spending money, but that all resources will be deployed to protect their independence.

> *"You want to control your own life." Wanda, R1*

A change which a few participants noted in their later-life identity was in their self-perception, that they are more relaxed, possibly because they have resolved earlier-life expectations and decisions in later-life.

> *"I don't have business things to worry about, I don't have my wife to worry about, So, I can just take a more relaxed attitude to everybody. I'm much more able to let things go." Frank, R1*

> *"I think being old, you are more contented in everything…Things don't worry you so much." Wanda, R2*

Later-life health issues also begin to impact identity, requiring a consequent re-orientation of identity to being someone who accepts, or rejects, help.

> *"And of course, you probably find the same thing, half of you is, 'I can do it myself!' But I, you know I think, no, come on, be gracious, accept help." Gladys, R4*

### 5.4.2 Activity decisions

There are three main areas within the activity decisions encompassing education, work and culture and travel activities, all of which are consistent throughout the lifecourse, although the focus changes.

#### 5.4.2.1 Education Decisions

As will be discussed further in Chapter Seven on heterogeneity, there are gender differences in early education decisions as men's education generally supported subsequent career decisions whilst women were focussed towards secretarial or teaching occupations, occupations that would be secondary to marrying and raising children. Education, however, remained a constant activity in women's lives as they continued with education through evening classes or Women's Institute summer courses, studying languages, cooking, history, or creative writing, a pattern which continues into later-life with seven of the women remaining involved in some educational pursuit.

> *"I've been going to literature groups for ages. … I always found where there was one going on and joined it. So, probably for ten years I've been going, usually, one or two." Winifred, R1*

> *"One thing which I see as a characteristic, is the desire to learn. I decided I had time to learn another language, so I started going to Italian classes locally and at the Italian Institute … And I then found a course for A-level and I thought I'll have a go. And I did the exam. That really was a challenge, going in and actually doing exams. Anyway, I did pass, I got a grade C which I thought wasn't bad." Mildred, R1*

> *"We have a writing group, there's about eight of us, and [you are given] a subject and you have to write about it. Two weeks ago, the subject was, what would you change if you ruled the world, can you imagine? It took me, I made lots of notes, then I left it, then I went back to it. And we had it last week, … and you have to stand up and read what you've written." Bonnie, R2*

For the female participants, education is an activity pursued throughout life both for enjoyment and as a way of meeting other people. Conversely, for the majority of the men, education seems to have been a tool for furthering a career, not pursued out of interest later in life. Only Glenn and Albert continued education after launching their careers, in both cases to further their careers. In later-life, only Clarence continues an educational pursuit in that he is now learning his partner's language.

#### 5.4.2.2 Voluntary, career or cultural activities

Most participants with careers worked in intermediate or higher management or professional careers. Earlier-life careers were described as interesting and challenging. At retirement, those who had had careers, mainly the men, sought a variety of activities to substitute for previous levels of activity as well as intellectual stimulation and challenge. As noted previously, there were essentially three trajectories: through voluntary work, a new post-retirement career, or involvement in cultural activities.

**Voluntary Activities.** For some of the OurTown Participants, later-life voluntary activities substituted for their work careers.

> *"The difference in my mind, is between paid and unpaid work, not whether or not you work." Norman, R1*

Norman posits that the goals and motivations will be different, but it is still work which most of participants (6M, 7F) continue to pursue in later-life. Whilst voluntary community or religious activities provide intellectual challenge, purposeful activity, and social connections, the additional motivation is service.

*"Service to the community at large, what can I do for the community. What can I offer back? I've taken from this world enough. It's time for me to give back, for nothing." Albert, R1*

Mildred became a trainer for the Citizen's Advice Bureau (CAB), retiring aged 70 to assume the editorship of the church magazine.

*"[The CAB] was part time. It was two sessions a week. It was pretty demanding … I was looking at something to learn…. and for something outside life here. I was going to meet, apart from colleagues who were interesting, I was going to meet a cross-section of people. … I suppose [the motivation] goes back again, to this ideal of making a difference in the community. And that links up with my Christian faith." Mildred, R1*

Earlier-life activity goals largely focussed on building careers and creating future financial stability. The goal of post-retirement voluntary activities was to remain involved intellectually and socially, whilst also 'giving back' to the community. This remained a goal in very-late-life as most of the participants continued to participate in voluntary activities.

**Post-Retirement Careers.** Five participants (3M, 2F) chose not to retire, choosing to remain in paid employment supplemented with outside activities, not retiring from paid employment until later-life.

*"I saw the effect [of retirement] on people who had retired before me, who were older. I mean they were bored stiff, half of them.… people aged too quickly in my view." Glenn, R3*

Ernest, whose wife was still working, retired early and took a part-time job, citing practical reasons.

*"It was fun, fairly unstressful. I paid my mortgage off, it was [an] easy drive, I liked the people. If I earnt more, I'd be paying higher rate tax, and what's the point of working when you're paying 40% tax?" Ernest, R1*

Clarence, who had built a successful consulting career continued consulting, whilst pursuing voluntary activities. After retirement from her first employer, Virginia was offered a job in a new organisation.

*"I was attracted to the idea of joining a new organisation, to be in at the ground floor, so you could make it what you want to make of it, instead of having to take over from somebody….[Additionally the Chairman} was quite a pioneer sort of man." Virginia, R3*

After her contract expired, she moved to another part-time job.

The final participant with a post retirement career, Bonnie, retired early from the civil service, then continued in employment until the company she worked for ceased operations, after which she combined part-time paid work with voluntary activities, ultimately retiring at age 73.

> *"Because I can't just sit at home, I went to [a local park trust] as a volunteer and I got to know [a woman] who ran the restaurant. And I started to help, you know, do little things. And she said to me one day, 'would you consider doing this?' To cut a long story short, I went on an environmental health course … so I worked for her, not full time, and it was brilliant. I loved it."*
> *Bonnie, R1*

Post-retirement careers allowed the participants to continue earning money, develop social connections, and work at their own pace. Eventually, all retired from paid employment, but most participants continued engaging in voluntary activities.

**Cultural Activities.** None of the men, but six of the women have been interested in music and arts activities, an interest which began in earlier-life and has continued throughout their lives. All of the women continued to attend concerts, and participated in cultural breaks, paying more for a higher level of service, frequently using it as a way of socialising with a friend.

> *"She and I have booked up to go to Cardiff with [a professional events organiser], the end of February, just four nights including Carmen at the opera and it's a door-to-door service. Everything's included, insurance and everything. Not cheap." Dolores, R4*

#### 5.4.2.3 Travel activities

Most OurTown Participants continued to travel to socialise with friends and family, to pursue activities like birdwatching or their cultural interests; for enjoyment and exploration of new cultures; to escape winter weather in the UK; distant travel to family; and one explored the UK in his camper van. The difference in later-life was that the participants paid for a higher level of service, setting aside the earlier-life habit of thrift, to allow them to pursue their travel interests in later-life. They spent extra because they need greater support, but also because they were more confident that their financial resources will be sufficient for their future needs.

For Gladys, travel had been important throughout the lifecourse as a way of learning about the world.

> *"I left school. I didn't like school, I left at 16. So I know, well my own parents never did any travelling. But we have, but yes, well, I did my big trip and that's just that I happened to see it and I wanted to do it. I don't know quite why."*
> *Gladys, R4*

Gladys referred to a long trip she took in her fifties, travelling on a bus with just a backpack. She continued to travel, having taken her adult child on an organised trip abroad.

An avid traveller throughout his life, Frank decided not to travel in later-life, although he took a trip abroad before moving to The Manor and has not travelled since.

> *"I'd probably have to go with family now. It's just arranging. When you're doing that, you need to have the right person, sort of leading. And some of the people I've been with in the past have moved on or died … it's sort of a bit too many unknowns for an old fella." Frank, R3*

This was in contrast to Wanda who after she was diagnosed with a life-limiting condition, made decisions about travel in order to travel more whilst she is still capable.

> *"First of all, you think is my money going to last out until I'm 100 because my genes said that I could live to 100. And now I know that isn't so therefore, I've booked a couple of extra cruises [with a cruise operator offering a high level of service] because again, until I'm not able to walk around, I can keep doing that, and that's what I enjoy." Wanda, R3*

Activities provide intellectual challenge, socialising opportunities, occupation, and something which makes life interesting. Throughout their lives, the OurTown Participants consistently pursued a variety of activities which they will continue to enjoy into very-late-life. Activity decisions generally have a discrete and repetitive nature with patterns of similar activities pursued throughout the lifecourse. The difference is that increasing resources are deployed to support them.

### 5.4.3 Relationship Decisions

Relationships provide more than companionship and support; they also spark participation in new activities and pursuits which enliven later-life. Relationship decisions will be discussed more extensively in Chapter Seven, the purpose of this section is to explore decisions about relationships throughout the lifecourse. Table 5-1 shows that the OurTown Participants maintained different types of relationships consistently throughout the lifecourse comprising a close relationship (spouse, partner or confidant), family relationships, caring relationships, and relationships with friends, neighbours, and activity associates.

Relationships progress throughout the lifecourse. In earlier-life, social networks expand as people marry, have children and develop connections with friends, neighbours and associates. In later-life, however, networks may shrink due to relocation or bereavement. Peripheral relationships may assume greater importance as a source for replacement relationships or providing access to information and contacts, and occasional emergency support.

All participants were married at some point in their lives. Partnering and close relationships proceeded from the earlier-life marriage decisions to later-life re-partnering or, for many of the women, the development of close female confidants. After the deaths of their wives, two of the men formed live-apart-together (LAT) relationships. This later-life partnering decision impacted identity as was demonstrated by Ronald whose life was transformed by his new 'lady friend'.

> *"I socialise more since she (his wife) died than ever I have during my life. But that was probably because of the sheltered life we both led." Ronald, R1*

Gladys, too, spoke of the difference her marriage made to her.

> *"I always think, it was the first time somebody wanted **me**. My father certainly didn't. My mother really wasn't worried about me, I don't think, although I don't know, I mustn't be too hard on her because he left her two children." Gladys, R2*

By her marriage, she transformed from someone who was not wanted and had no place in her home, to someone who was valued by having a role in family life.

Throughout the lifecourse, especially later in life, a close relationship, either with a spouse or partner or a close friend, was important for its associated counsel and companionship, the loss of which makes decision-making more challenging.

> *"When you're a widow on your own, making decisions is much harder, than if you've got a sort of resident person, husband, to talk to." Mildred, R1*

Family relations showed a similar progression in that parents, aunts and uncles died, making children and grandchildren, nieces and nephews more important relationships, although not with the same level of confidence and possible advice-seeking. For most participants, support or companionship from children, grandchildren or more distal relatives appeared to be one-sided in that the participants continued to provide support, usually financial, even in later-life. Participants generally did not want to burden their children, but they also do not want to cede independence by depending on their children.

Friends, neighbours and affiliation associates remained relatively stable throughout the lifecourse which was possibly due to long-term residence in the area. The purpose of non-family relationships was generally for companionship, to do things with and to have fun, as noted by Shirley in explaining the transition in her later-life relationship.

> *"We [she and her later-life partner] made each other really happy. And it was fun! Everything was just fun, you know, we felt so young, we thought we were going to live forever." Shirley, R1*

The importance of fun and doing new things is little explored in academic literature, but it appears to be a primary motivation for both activities and ongoing friendships and relationships in later-life.

As seen in Table 5.1, weak tie relationships are not mentioned during earlier-life, possibly because individuals have either become closer friends or the contact was not maintained. In later-life, participants chose to seek and develop these more peripheral contacts as they provided variety, positive interactions, other sources of information and possibly fulfilled a bridging connection in introducing new people into the social network.

> *"I know more and more people here and you go out into the street and if you walk, … you speak to people, maybe you just say hello, because you recognise them and I sometimes chat with the concierge [of The Manor], when I go down. The cleaners are here today, sometimes I chat to them. The gardener, I chat to, and I told you I was a director, so I'm in that group, too. And somehow, you just get to know more and more people, and go for a little drink or something." Wanda, R3*

As will be explored in Chapter Seven, this is a pattern more common to the female participants.

#### 5.4.3.1 Evolving relationship decisions

In contrast to activity decisions which may have had a discrete repetitive nature, relationship decisions, predominantly discussed by women, required a different approach. For women, especially for the five housewives, marriages impacted their decision-making. The housewives repeatedly protested that they did not make decisions and yet all of them negotiated their limited agency to make or influence decisions impacting the lives of their families. In the process, experience taught them a different type of decision-making, one which required balancing ongoing vigilance of changing situations with values and variables, possibly consulting and influencing others, implementing small steps whilst reacting to changing circumstances. A decision for them was not so much a single event, but an ongoing process extending over time.

This type of decision-making was especially notable with Dolores and Shirley who both had problematic first marriages. Perhaps because of the difficulties, they continued to remember, reflect, and revise their thinking of these earlier experiences, a process which continued even late in life.

> *"We went through some terribly difficult times. … I told you my younger son was freaking out and there were such rows, that my son said, age 16, 'I've got to get out or I'll murder him' [his father]. Can you imagine the situation? So he went into digs, age 16 and it was just ghastly. And one day I visited him and he was ill, so I paid off the landlady, I packed him up, took him to a doctor and home to bed. And I said to my husband, this is the situation, you've just got to*

> *put up with it. … The vision you want is to have love and peace and kindness in your home. And if your son and husband don't get on, it's pretty distressing … On one occasion, he'd gone to work, my sons had gone to school and I'm standing in the middle of the kitchen saying to myself, 'I can't go on. I can't go on.' And then you know, your upbringing, there was the washing up to do, the beds to make, you get on with your work. I always listen to the radio, switched on the radio. Wonderful music. I said to myself, if they could compose music like that with what they had to put up with, you can go on." Dolores, R1*

She made the decision to remain in the marriage, by adapting herself and the family life around her husband.

> *"I was right in the middle of it and I had to stand up for them and not alienate him. It was all very delicate, but somehow, somehow I managed." Dolores, R1*

In the fourth interview round, Dolores elaborated on this decision.

> *"First of all, we weren't well off. So what do you do? We lived in a nice house a bit like here, but we were struggling financially. I was very, very thrifty. So I have to take the children out of their nice schools, give up the house and go into some grotty flat maybe? And you can't leave a man with heart problems, it might have killed him. I couldn't do it. So I struggled on and I'm glad I did because then he had his final heart attack [and died] and we managed to carry on. And I was still in my nice house, surrounded by lovely friends. So I'm glad I did. I didn't have mum that I could leave the children with while I went to work, you see, so I struggled on." Dolores, R4*

This ongoing situation dominated her earlier-life but also demonstrated many aspects of her decision-making process. In the first instance, she was forced to side with either her husband or her son, and showed her shifting allegiances depending on the situation. It also set out her values – love, peace and kindness in her home – and her distress at not being able achieve it. It also showed her coping strategy and resilience, in that she listened to music she loved, and carried on with the routine of her upbringing. Dolores was a child refugee who came to England without her family which meant she had few alternatives.

> *"Maybe having had to leave the security of my parents and my home and live alone in an alien country, I've had to learn to be careful and sensible because when you have the backing of unconditional love and backing of your parents, you probably feel more free. Whereas I had to keep safe … if I gave trouble, they might have got rid of me, the family who took me in." Dolores, R3*

From a very early age, Dolores's experiences shaped her behaviour, and taught her strategies she continued to use in later-life. She continued to foster a broad social circle to ensure companionship and support to accomplish her goals. She also continued to use music as a refuge and had started taking piano lessons in late-life.

Shirley, too, had to make difficult decisions in her marriage. She was married for nearly 50 years and during the marriage had to negotiate a path through ongoing decisions about her commitment to her marriage. Despite having lived abroad on an expatriate compound for eight years, watching how men behaved when their wives were away, she entered into marriage and did as her husband, and her family, expected.

> *"The first ten years of my marriage, I would not have argued … whatever he said, we did. And you know, if he didn't like something I was doing, he'd say, I don't like you doing that, and I wouldn't do it. I just fell in. [Until she discovered his affair]. … I mean I used to sit and cry. I'd got three small kids and I was, it was pretty bloody awful, honestly. From being a very contented happy woman, I came to [be] this deserted, lacking in confidence person. He took everything away. And you're very vulnerable like that." Shirley, R2*

Yet she chose to stay with him, both for her children and for herself, a decision which required constant attention of a period of five years.

> *"I think I did it [took him back after the affair ended] because I knew the children would have a happier life if they had their father living with us. I knew I would have a happier life because I'm no good on my own and I need somebody to make my decisions and to lean on. And he would be there for that. It was selfish really. I didn't want to bring up the children on my own." Shirley, R4*

During this time, Shirley returned to work as a school secretary. To help in her marriage deliberations, she consulted widely with friends, including the school headmistress who also served as her mentor. In her family life, she needed to continually rationalise and explain the situation to her children. This shows both the ongoing nature of the decision, as well as the way Shirley consulted with others and continued to reflect and return to the decision. Ultimately, they reconciled and returned to OurTown where they lived for 30 more years. What had changed was her sense of autonomy.

> *"Well, I thought, I've been the 'yes-wife' and that didn't work, so we're going to do it differently this time. I'm going to do what I want. And I did. With his support, mind you, because I do need somebody there with me always." Shirley, R3*

The decisions about her relationship changed over a long period of time and continued to be re-evaluated in later-life. This was a decision thread carried through and returned to in all four rounds of data collection as she also reconsidered the decision to reconcile with her husband in comparison with the experience of her subsequent LAT partner after her husband's death.

> *"[My husband] gave me a good life. But I don't know if it was fair to him 'cause I couldn't love him … I mean … we loved each other, but with [LAT partner], I just adored that man, I respected him, I admired him. I loved*

*everything about him. You can't, once they've treated you badly, you lose the trust. I never completely trusted him [her husband]. And I didn't admire him. When I married him, I did, I thought he was a wonderful man. But he let me down." Shirley, R3*

Shirley and Dolores demonstrate a complex and protracted type of decision-making. Both needed to balance their own goals and their children's needs in response to the situations created by their spouses. The consequent decisions appear to be characterised by the need to weigh fundamental and possibly conflicting values whilst reacting to experiences which played out over time. As will be seen in Chapter Six, this type of decision process is more common in very-late-life decisions.

Gladys, Winifred and Judith, the other housewives, made similar types of decisions, in that their decisions were shaped by societal and familial expectations. During their married lives the housewives had traditional relationships in that they were responsible for the family, whilst their husbands made decisions about everything else, leading them to feel that they never made decisions.

*"I don't think I've ever really made decisions in my life." Gladys, R1*

*"I don't feel I have anything interesting to tell you about decisions." Judith, R1*

*"I can't make decisions. I have to ask somebody else to do it for me. I'm hopeless." Shirley, R2*

Their earlier-life decisions appeared to be more about negotiating or influencing others, such as Judith's influence with her husband to move from the house she disliked. Shirley, too, 'suggested' a weekend home near their sons' boarding school. Winifred viewed her role as peacemaker between difficult people, not advocating for herself in decisions, but in going along with others.

*"I've had to give in. I would say I had to give in…. I don't really like a lot of conflict, so I avoid it if I can, which shows I'm a bit of a wimp, doesn't it?" Winifred, R1*

This changed when the women were widowed and they were required to make decisions on their own, perhaps for the first time. Gladys noted the change that being widowed made in behaviour when her son's father-in-law was widowed and whilst she was talking about him, she ultimately compared it to how she herself felt, gaining autonomy to pursue her interests.

*"They're free in a way, at last. [Her son's father-in-law] is doing this, he's doing that, he's going there. He'll slow down after a while, but he's able to do things. Because for four or five years, he hasn't left her side. And I can imagine this. Perhaps it's why I went off to Alaska [after her husband died]. For the first time in my life, I'd got money. Well, money I suppose was always there, but I never thought about it." Gladys, R3*

As Gladys notes, after being widowed there is greater ability to make independent decisions, with access to financial control which she had not previously experienced.

### 5.4.4 Resource Decisions

The resources built in earlier-life, specifically financial, housing and health resources, provide the foundation for later-life. During this life stage, resources are generally conserved, although they are continually assessed and deployed to accomplish later-life goals which generally centre on maintaining autonomy and continuing participation with people and meaningful activity.

#### 5.4.4.1 Health and Medical Decisions

In earlier-life, there was little discussion of health or medical decisions. Health activities were generally sports done for enjoyment and socialising possibilities, e.g. tennis, lacrosse, hockey, golf, table tennis, sailing, swimming, birdwatching. Physical activities in later-life evolved to accommodate changing fitness levels, such as walking, gardening, swimming, birdwatching, chair yoga and targeted exercise to ease a specific condition or avoid surgery. All of the women decided to participate in regular exercise, attempting to maintain physical capacity. Five women and one man regularly attended fitness, balance or targeted exercise with the goal of maintaining health and physical capacity. Earlier-life physical exercise was taken for enjoyment; later-life exercise was done to stave off incapacity.

In earlier-life, any health or medical situations, such as sporting injuries and earlier-life illnesses, were straightforward and resolved easily. A prime difference in earlier-life health concerns is that they are emergencies resolved with medical care. Later in life, however, health decisions can have unexpected consequences which impact how the participants think about future medical procedures. For example, in the first interview, Frank discussed future heart surgery, a decision which he described as sensible and relatively straightforward. By the second interview, he had had the operation, but there had been subsequent problems requiring hospitalisation for further tests, resulting in different issues by the third interview.

> *"Up to now, I've always been confident that whatever's happened to me, they can make it right. And you know, there'll come a time when that doesn't happen, I'm sure. Well, it's happening to a degree now, in that my heart valve operation hasn't had the result that I would have liked." Frank, R3*

This exemplifies what may happen with health procedures in later-life. Initially, the procedure provides an improvement, which may be followed by consequent problems, so that the procedure does not necessarily deliver a 'cure' but provides an incremental improvement. This provided a jarring realisation for Frank that his health, although improved somewhat, may never

return to its previous level. This experience impacted how he thinks of his current state of health, making him more cautious in considering future interventions.

Winifred's decision regarding knee surgery provided an experience similar to Frank's, but with more serious consequences. It is interesting to compare with Winifred's decision to have a knee replacement and Shirley's decision not to have a knee replacement. Both women had previously had surgery on their other knees – Winifred having a half-knee replacement and Shirley having an operation to repair her broken knee. Winifred had the knee replaced between the first and second interviews. Post-op, she decided to go for private residential rehabilitation.

> *"Quite expensive, but worth it. The people were telling me, don't go for a week, it's not quite long enough, a week. Don't go for two weeks, you'll be bored, so I had ten days and then came home." Winifred, R2*

In the same interview, she expressed regret at the decision to have the surgery. She described how it was still painful three months after surgery. She later noted that she had started walking with sticks, and that two months after her operation, when she resumed driving, she had had a car accident and subsequently stopped driving entirely. She later reflected on the surgery decision.

> *"The knee didn't seem a difficult decision because I was thinking it was the best thing to be done, but I'm not sure it was the right decision." Winifred, R2*

By her third interview, she was consistently using a stick, and frequently also took someone's arm when walking. She had also begun doing chair yoga as opposed to regular yoga. The knee pain had subsided to 'discomfort' and it no longer kept her awake at night. She has discouraged her friend from having a similar operation, giving advice on the issue. Winifred had also experienced a minor fall days before the third interview. In the time between the third and fourth interviews, Winifred experienced another fall, more serious this time, requiring hospitalisation and subsequent live-in care for a month followed by regular care visits three times a day. At the final interview, she was sleeping in the downstairs reception, having home healthcare three times a day, using a rollator (a Zimmer frame with wheels) and planning to install a stairlift. Winifred's experience shows how an initial medical situation can have subsequent complications. In her case, her painful knee and the subsequent surgery then required longer to heal. In the year following the surgery, she experienced increasing incapacity, progressing from driving, walking independently, and taking yoga classes, to having care three times a day, using a rollator, driving cessation and needing to install a stairlift. This didn't prevent her from continuing with activities. During this time, she decided to fly business class to visit her son and his family abroad. She also went on a holiday with her other son, and continued attending concerts, classes, and church, depending on her friends for transportation.

Like Frank, Winifred's initial procedure had unintended consequences, not providing the expected return to greater mobility, but perhaps initiating subsequent health incidents. In both cases, it became clear that recuperation from major surgery in later-life is a long and unpredictable process, where previous levels of health and mobility may not be achieved.

In contrast to making a medical decision, Shirley continued to deliberate about possible knee surgery. Remembering previous surgery to repair a broken knee and having had other more recent operations, Shirley was taking a slower and more deliberate approach to possible surgery, raising the issue twice in the first interview.

> *"I mean, the surgeon told me this knee needed doing now and he didn't want to do it when I was in my late 80s. But I'd just had the gall bladder [operation] and that had all gone wrong and I had to have another operation to clear a blockage. And I had awful problems and I think I probably nearly died then because I really was very poorly." Shirley, R1*

Besides the unintended consequences of previous surgery, she noted that as she was not in pain, she did not want surgery, weighing possible benefit against future life expectancy.

> *"And I said, well it doesn't hurt me. I think probably, in his book, I should have it done. He said it's only going to get worse, it's not going to get better. I said, can we wait 'til it gets worse? He said I don't want to do it when you're in your late 80s. And then I think, why not? I mean I might drop down dead…. I just said, OK I'll see you in a bit. And I haven't been back to him. But, I might fall off my perch in a couple years and this might last a couple of years. Why would I put myself through all of that?" Shirley, R1*

She raised the topic again in the second interview, this time having consulted with her son who had recent knee surgery, reiterating her previous concerns, but seeming to decide against surgery.

> *"The doctor said he didn't want to do it when I was in my late 80s and it was going to get worse and I'll end up not being able to walk. But I said … I might go through all that and I might die the next year, what's the point? I'll fix it when it's broken." Shirley, R2*

By the third interview, she had been to see her doctor again, who again urged her to have knee replacement surgery. This time it sounded like she had made the decision.

> *"I'm not going to have it. I've got a cyst in there, I've got bone-on-bone, and I've got arthritis, but I'm not in any pain! So why have it chopped up? He said I don't want to do it when you're in your late 80s, and I said I am in my late 80s! … I said, what's wrong with late 80s? David Attenborough had his done when he was 92! And so did the Queen Mum! ... And I mean I might go through all this and be dead. And I've put myself through that for nothing. He [the*

*doctor] said you won't be able to walk eventually. So I said I'll meet that when it comes." Shirley, R3*

It was not until the final interview that she reported she had finally told the surgeon. Shirley consistently said she could not make decisions, that she needed someone to make them for her. What is different about her decision-making is that she takes longer and allows her decisions to evolve, deferring the decisions and leaving it open-ended to accommodate changing circumstances.

In comparing the decision-making process and outcomes of these three cases, both Frank and Winifred trusted the medical opinions of their doctors, with Frank also relying on his child's advice, and Winifred consulting her previous experience. The decision was relatively quick and straightforward, similar to decisions they would have made earlier in life. They were presented with a problem, they conferred with trusted experts and consulted their own previous experience. After this period of diagnosis and consultation, the decisions were made relatively quickly and implemented, expecting the procedures would deliver the anticipated return to health. The disappointing results in both cases have caused them to reconsider the wisdom of their decision-making process, as well as learning to accept their more limited health and mobility. The impact for Frank is that he was reducing his activity levels, whilst Winifred was continuing with activities, but mobilising social and financial resources to support them.

In contrast, Shirley's decision-making process may be the one they employ in the future. Having had knee surgery previously and experienced unforeseen problems with her gall bladder surgery, Shirley adopted a multi-step process in this decision. First, she consulted the trusted expert, her surgeon, and weighed his advice against her experience of previous surgeries and the severity of her situation. She subsequently sought the opinions of her sons, including the vicarious experience of her son's recent experience of similar surgery and lengthy recuperation. Shirley also noted news reports of prominent people who had experienced similar surgery in later-life. She gathered information and experience, assessed the possible 'costs' against an uncertain future benefit and decided against surgery. The process played out over many months and whilst at the time of the last interview she had tentatively made the decision, it remained conditional and may be revisited in the future following any change in circumstances. Her decision-making process of assessing a situation and possible options, setting priorities, consulting with others, and allowing the decision to extend over time, is similar to the process she used in managing her husband's infidelity. Shirley consistently says she cannot make decisions, when actually her process is different in that she allows a situation to evolve. It is a process increasingly used in later-life.

The major factor in making health decisions is the recognition that health may be changing in later-life. All were beginning to recognise the need to be more vigilant about their physical health. Albert described returning from the theatre to the station to catch the train home.

> *"Coming back, after a whole three hours in the theatre and so on, my knees were aching from the short distances. OK, I did walk, but there was that flight of steps to [the train] station that I was pushing myself to do it, and at the end, I literally, literally suffered. And I thought, that was pushing it a little too far. … So I told them, sorry, I have to stop for a few minutes before I can go on. So, you know, I learned." Albert, R2*

Likewise, Judith learned from recent experience of cancelling a cultural visit on the hottest day of the year, 2019.

> *"I thought, you know, I don't think that I can do this because the heat does, above a certain heat… I do feel, I begin to feel peculiar and you know, they were saying on the radio, for the elderly and people with heart problems and things, should be very careful. So I decided not to go and I'm sure I've made the right decision." Judith, R3*

She later used vicarious experience to confirm her decision.

> *"They've got a lady in this group … and she is over 100, and she went on this outing, and apparently, she more or less flaked out at some stage." Judith, R3*

She subsequently booked similar future excursions, but kept her health in mind, booking for the spring and autumn in an attempt to avoid the hottest days of the summer or the coldest times in winter when she is prone to chest infections. Likewise, Albert learned to be less ambitious and will possibly take taxis in the future.

To summarise, health and medical decisions earlier in life were made with the expectation that healthcare professionals could cure any problems and that previous levels of activity and fitness would return. Later-life, however, requires a recognition of the changes in health and mobility and consequent capacity and abilities and a greater consideration of the benefits and possible problems with any medical procedures. The process for making health and medical decisions may become a more complex and longer process, involving information gathering, consultation with friends and family, and review of personal or vicarious experience before a decision is made. The decision may remain conditional depending on future changes in circumstances.

#### 5.4.4.2 Finances

A goal common throughout life was to build financial resources and to ensure financial stability. In earlier-life, many noted the easy availability of financing, that bank managers would cover overdrafts for house or car purchase.

*"The better [bank] managers could distinguish …who you could trust. You used to call it character lending." Glenn, R2*

*"The bank manager said, don't worry about that [house deposit]…He said write a cheque out, we'll cover it." Bonnie, R1*

Despite the easy availability of credit, most remembered being 'skint'. Two participants lived with relatives after marriage whilst others lived in 'digs'; one cited the local library as his only form of entertainment, all developed the habit of thrift.

*"We managed. It was difficult on five Monday months because we allowed so much for housekeeping each week." Ernest, R2*

*"I felt I must earn. My parents were hard up and financial matters, I suppose, pressed on me." Mildred, R1*

Perhaps because of the contrast between early deprivation and their current situations, for the OurTown Participants, finance seems a taboo subject. This could be because all participants are comfortable in that they have pensions, savings and homes owned outright. Another explanation mooted is this could be a cohort issue from an era when religion and money were not generally discussed.

*"In my life, money and religion are always a bit tricky, and particularly money. You know, you have to keep off it. And in a place like OurTown, it really is a prosperous place." Mildred, R1*

There was little discussion of earlier-life financial matters except that most commented that they were 'skint' in earlier-life and that habits of thrift and saving were developed in early-life. Their main priority in their first jobs was to make money. Throughout their lives, however, they built financial stability to the extent that in later-life, it is not a major concern, except when considering future care costs. The more common decision regarding finances in later-life is whether to put aside the lifetime's habit of thrift in order to continue enjoying the activities of later-life.

*"A lot of my friends are saying, now I'm just going to spend it." Dolores, R4*

#### 5.4.4.3 Domicile

A major part of this financial stability experienced by OurTown Participants is vested in the value of the home. In earlier-life, housing decisions were made to accommodate growing families, and, in some cases, career moves or relationship changes. By retirement age, there seemed to be a period of stability. In later-life, however, housing decisions concerned downsizing, decluttering, and ageing-in-place, including adaptations for an age-friendly home and future care.

Six participants (3M, 3F) lived in the same family home in OurTown for most of their lives. Four male participants moved frequently to accommodate international or regional career postings,

before settling in late middle age to their current homes. The final male participant moved frequently because he enjoyed buying property, upgrading, and moving, ultimately settling in his current home 20 years ago, choosing to be within walking distance of shops and amenities given his and his wife's health. Two women changed homes after being widowed and remarried. One moved to accommodate her children's education and her husband's career and two moved to accommodate lifestyle changes anticipating retirement. The only female participant with sole control over her housing decisions was divorced in her late twenties, becoming a single mother also employed full time outside the home. She was able to purchase her council flat due to the Housing Act of 1980. After her son left home, she sold that flat to move to a detached home within walking distance of OurTown and finally, at age 80, moved to The Manor. Only one participant has lived in OurTown for less than 20 years, Frank, who downsized and moved to OurTown a little over a year ago to be closer to his children.

In earlier-life, the men were more active in selecting homes. Women were commonly asked to approve the property or review the final few options. Gladys, who lived in a flat above the family's High Street business as a child and after her marriage when her husband assumed control of the business, remembered the decision to buy the house when she was pregnant with their fifth child. Her husband selected the house where his mother had been in service.

> *"I think [my husband] just said 'that house will do us'. He always decided things. I suppose he was bossy. I don't know. I don't think of him as being bossy. Oh, I came round and looked at it, waddled around and looked over the house. Been here ever since." Gladys, R1*

The house is near the family business and continues to provide the venue for family gatherings.

A frequent mover due to his job, Glenn recalled doing the initial work on selecting houses, allowing his wife to choose between his final two options, always ensuring the less favoured option was shown first so the second, his choice, was better in comparison. Even reviewing the options, did not guarantee that a woman's opinion would be regarded. Winifred noted that in buying her first house,

> *"I chose one and we bought the other one. So I thought that showed me where I stood. My father had come down and looked at both and he thought the one my husband had chosen was better anyway. Two men to one [woman]." Winifred, R1*

In later-life, however, women were more involved in housing decisions. After many years in a house she disliked, Judith influenced her husband to move.

> *"I didn't feel it expressed my personality, not that that should be particularly important, but somehow it is" Judith, R3*

This demonstrates two aspects of earlier-life housing decisions. First, that women do not feel they have agency in the house selection; they can influence, but not select the house. The second aspect concerns the importance of the personal and emotional aspects of home, that a home is an expression of identity and that there is pleasure derived from home, especially for women who work in the home. These aspects carry into later-life in that women have gained greater independence with widowhood, making housing decisions to suit their needs.

A total of five participants (4F, 1M) downsized, moving from a larger home into a smaller home or flat. Three of the women moved due to ill health or bereavement and the recognition that they would be solely responsible for the upkeep of the home. In one case, the decision was taken over a number of years after being widowed; in another, the decision was made within months and in the final case, the participant's husband made the downsizing decision, helping his wife make the move prior to his death. The one male downsizer moved many years after his wife's death due to his declining health and to be closer to his children. This necessitated not just acclimatising to a new home in The Manor, but also adapting to a new community and making new friends, without the benefit of contacts or an identity established through a lifetime in the community. One of the attractions of The Manor is that it provides an immediate social venue of people of the same age, but it also requires a reframing of identity. The final participant had considered moving to The Manor many years previously, but felt she was too young. In her eighties, her detached home required a substantial capital investment, at which point she decided to downsize, release equity and move into The Manor. Even then, she wondered if she had done the right thing as she felt her identity did not match that of the other residents.

> *"I haven't found it always easy, a couple of times, I've sat here and thought, mmmm, did I do the right thing? Because the other people here are elderly, not all of them are elderly, and a lot of them are younger than me." Bonnie, R1*

Six further participants (3M, 3F) considered downsizing, ultimately deciding their current homes could accommodate ageing with minor revisions, allowing them to continue to enjoy their gardens and retain family homes for family gatherings without having to consider disbandment, which the participants labelled 'getting rid of stuff'. Disbandment is a substantial barrier for people who have been living in the same home for many years. Two participants were concerned about disposing of letters and documents which may have considerable historical value or intellectual property value. Yet in both cases, they were reluctant to part with or sort the documents, preferring to leave this responsibility to their children. Even for those whose possessions have only sentimental value, found it a difficult process.

> *"A big problem is deciding what you want and what you don't want, out of all the stuff you've accumulated for twenty, thirty, forty years, whatever it is. So I*

*think you need to be quite decisive. … I think I had about three and a half thousand square feet and here I've got about 700 or something." Frank, R2*

Wanda who also downsized to The Manor noted one additional challenge, the need to be physically able to make the move.

*"That was one of the things that decided me to come here, whilst I was fit, able to do a move." Wanda, R1*

At this point in their lives, it is questionable whether any of the OurTown Participants would consider further downsizing, as they all planned to age-in-place in their current abode. In considering possible physical barriers to ageing-in-place, women appeared to be more proactive in making their homes age-friendly by installing stairlifts (2F), wet rooms or showers in place of baths (2F), grab rails and key-safes (4F). In addition, one female participant improved her home through better exterior lighting, another purchased new seating to accommodate arthritis and one installed a new kitchen and conservatory to better enjoy her home. None of the men had made alterations, although two considered it, but decided it was not worth the cost.

## 5.5 Experience and emotion

It could be inferred from the OurTown Participants' responses that their current wellbeing was largely due to earlier decision-making. All owned their own homes, lived independently in the community, managed their own affairs, were in relatively good health, and remained involved with people and meaningful activities. Whilst their current situation must be related to past decisions, the OurTown Participants only commented generally about the role of experience in their decision-making, as if it was obvious that experience is a foundation for decision-making.

*"Every stage of your life is part of your life." Bonnie, R4*

*"I did not have university education of any sort, but I learnt with life." Virginia, R1*

Both comments hint at the value of experience in making decisions, that you learn from experience and that that learning becomes an embedded part of decision-making. It was also recognised that luck or chance was also a factor.

*"I think [experience helps]. Yeah, definitely…and also I've been lucky… I just feel enormously lucky, enormously lucky in my life and in my experiences and my family." (Frank, R3)*

The participants, however, were unwilling to discuss the value of experience in greater detail, similar to their reluctance to discuss the role of emotion in decisions, even on such emotional topics as marriage, family or bereavement. In participants' responses, they largely considered

emotional restraint characteristic of their generation, although Norman considered emotion an individual trait.

> *"I don't think that I'm a very emotional person and I don't think that my emotions play a very strong part in my decisions. They tend to be a bit pushed below the surface." Norman, R4*

Glenn noted the generational aspects, that his generation did not have the 'luxury' of emotion.

> *"Our generation…I think there was a stoicism. …This new generation has no idea how tough it was for people. I think it had a long effect. …I think the younger generation are more emotional anyway, but it's a luxury they can have." Glenn, R4*

Theirs was a generation impacted by war and subsequent deprivation and rationing. For most of them, the war had a direct impact on their childhoods. For most, their fathers were away, but amongst the participants were also a child refugee who lost her entire family, a participant who spent her teenage years in an internment camp, and two child evacuees. Most lived with rationing and the experiences of war from an early age.

> *"I think it was involved in my character, growing up quickly, because of the circumstances. And being more responsible I think, not so childlike. I think that's how it was." Virginia, R4*

> *"I've never actually gone to pieces…tragedies happen all around, all the time." Dolores, R1*

> *"You just get on with it." Bonnie, R1*

The very fact that they have lived long lives means they have all also weathered loss and challenging life events. Two women and one man lost their spouses in earlier-life. Three men and four women cared for their spouses through terminal illness. Three participants lost children in mid-life and thirteen participants have been widowed, three of them are twice widowed. All have made the decision to 'get on with it.' This determination developed in early life may lead to a more muted expression of emotion throughout the lifecourse.

In discussing the impact of emotion and experience on their decision-making, their responses generally conflated experience with logic, and emotion with feeling. Whilst they trusted the logic or experience of their lives, emotion was generally distrusted as the basis for decisions, but served an important indicator and ultimately, the emotions of want or fear may be decisive.

### 5.5.1 Experience

The participants' educational attainment, families and marital situations, previous employment, religious participation, health, and domicile were the result of previous decisions which provided

a foundation for later-life decisions. As noted above, the participants found it difficult to detail how their experience impacted decision-making, yet they spoke about and demonstrated how their personal and vicarious experience shaped thinking, behaviour, and their planning for the future.

For the men and the four women who all had full-time careers, their earlier-life career experience appears to have shaped how they think about and make decisions.

> *"[The sense of logic and responsibility] you never lose over the years from being in business, you don't lose that." Bonnie, R4*

Bonnie's varied career in business, government and the voluntary sector instilled logic and sense of responsibility that she continued to employ as a director of The Manor.

Wanda also recognised that her training was integral to her decision-making.

> *"I think as an analyst, you do. You're more likely to think things out…. I don't think you know you're doing it, but you look at all points of view and something that excites, the reasons must be that you've worked out that's the one." Wanda, R1*

This hints at the role of emotion, the 'something that excites' when a decision is made. This points to how work experience is embedded in decision-making, but that it is also linked with emotion.

Glenn's training and business experience was critical to his management career and used in his post-retirement career as well.

> *"I got to the stage where I could walk through the front door of a branch, and in five or ten minutes, could tell you whether it was well managed or not. It's the detail. The way people react, and so on." Glenn, R2*

His experience taught him how to assess a situation quickly which guided subsequent decisions. This suggests another aspect of decision-making, its repetitive nature, that at some point, decisions become an embedded heuristic for straightforward decisions.

> *"Everything as you get older, is habit, automatic. I don't actually do very much, that I haven't done before. So I'm just perpetuating things." Shirley, R3*

Similar to Glenn, Albert also used his experience to quickly assess a situation in order to make critical decisions. As a newly hired surgeon in an overseas hospital, Albert noticed a pattern he had experienced during a period of social unrest in a previous foreign posting.

> *"I got my team, the anaesthetist and the assistant nurses, and I said, look, there's something going on here. I've been through it before in my life. I know what to expect. We have to sit here day and night to treat all these people as*

*they come in. And that's exactly what we did. And then there was sort of an avalanche of people … I wasn't thinking of myself as much as I was thinking of the situation that I knew, because of my experience, that there is 'something' there, that it's my duty to face that something until settles and then we know where we stand." Albert, R1*

This quote distinguished between training, the skills Albert needed as a surgeon, from the experience that helped him anticipate what was needed in that situation. This exemplifies a different type of decision-making common to people who work in emergency situations. Recognition-primed decision-making allows them to act quickly based on previous experience of similar situations so that such decisions seem like intuition (Bond and Cooper, 2004).

For some participants, the skills learned in their trades, appeared to have shaped character so that it is hard to separate their intrinsic nature from their training and experience. Eugene noted how his training shaped the decisions he made throughout life to ensure his estate and financial matters were always current.

*"In accountancy, we get involved in handling money on death… When I first married, we did an ante-nuptial contract, and in that, I put a rough arrangement for a funeral if either party died. Then when the children arrived… and when we bought property, whoever died first, how we'd managed the property and divide the estate." Eugene, R4*

This shows Eugene's progression from a young man who even before marriage used his accountancy training to settle estate matters and continued this discipline throughout his life. He was accustomed to working dispassionately with matters around money and death, and in later-life, he continued to assist neighbours in their estates and revise his own affairs. He revised his will between R3 and R4, contacted the local hospice due to his increasing frailty and in the last interview, was preparing for the future.

*"We're trying to get the house looking good for resale … as soon as I go. It's long term planning" (Eugene, R4).*

This embedded nature of experience into character and the habits developed, could explain why the participants found it challenging to delineate the role of experience in their decision-making. Five of the participants recognised that they may not have always made the right decisions, but the learning process was part of the value of the experience.

*"You learn from your mistakes in the sense that looking back you can see decisions that in the long run, because of the way things worked out, were not very good. But was it because they were mistakes, or was it because circumstances changed? I mean you try to make excuses for yourself." Mildred, R3*

This implies that perspective and reflection are necessary in order to recognise faulty decisions and convert the learned experience into knowledge for possible future decisions. That they were still thinking about and reflecting on decisions sometimes made many years previously, points to the possibility that the impact and success of decisions change as perspective changes. Part of this revisiting of past decisions may also indicate a need to reflect, reaffirm or discount, the experience in considering whether to apply it to current or future decisions.

### 5.5.2 Emotion in decisions

Subsequent to the cumulative second round analysis, it became apparent that participants were not forthcoming about the role emotion in decisions. This then became a topic in R3, to query the role of emotion in decisions. Some of the participants noticed being more aware of their emotions in later-life, that this may be something new in this life stage.

> *"I'm quite emotional now, actually, I'm much more emotional than I used to be…. I mean I can shed tears on an advert here. If it's like a couple who are really happy and they're going off to do things, I think, God, I don't have that anymore, that sort of thing. And I'm quite emotional about my children and my grandchildren, you know. I could be emotional with happiness. I'm much more emotional than I used to be, certainly ... I think I'm just more emotional because I've got more time to be emotional." Frank, R4*

Gladys also noticed emotion after the death of her husband.

> *"I have found that since [my husband] died I'm not afraid to shed tears in all sorts of places. … I don't particularly think of anything that makes me shed a tear, but there are things that I think are emotionally involving. You know, the British Legion Remembrance at Albert Hall. There will be a few tears. There's nothing to do with anybody specific." Gladys, R4*

Formerly both participants might have ignored the emotions, whilst in later-life, they recognised that they find themselves moved to tears easily. Clarence and Ronald commented similarly about responding to emotion. Clarence realised that by engaging emotions, he found himself more susceptible to charity appeals and cold calls, making him vulnerable to scams. To counter this, he discussed possible investment and charitable donations with his LAT partner.

> *"So she's stopped me doing silly things." Clarence, R4*

This demonstrated a common approach of balancing emotion with logic.

For OurTown Participants, emotion played a role in decision-making, serving as an indicator of importance, as noted previously with Wanda's decision that "can excite". For her, this indicated that she had found the right answer, the correct decision. Bonnie provided a specific example of

how emotion alerted her of the need for a decision. Bonnie served as a Manor director for many years. At an AGM, however, she began feeling angry, which was unusual for her.

> *"I particularly got frustrated at that meeting, because they attacked us, or he did. And you feel like saying, okay you do it, sorry. And that is not how I am really." Bonnie, R4*

She recognised that the emotion she felt about this experience and her initial response, to quit as a director, did not fit with her identity, "that is not how I am really". In this case, logic prevailed, although it did indicate to her that she did not want to continue in this role indefinitely and was planning her departure. For her, this experience exemplified the role of emotion as an indicator of importance, that something was wrong which needed addressing. She countered her initial emotional response, thinking through the situation, to make her decision.

Like Bonnie, many suggested that emotion and logic must be balanced for a proper decision. Gladys noted the need to delay the decision in order to transcend emotion and ensure balance.

> *"I tend to think, don't make decisions with emotion because you won't make the right ones. You know, really think it over. I'm a great one for – I do lay in bed and think things through." Gladys, R4*

Judith used a similar process, waiting until the decision 'feels' right, that she 'sits' with a decision. Gradually, after possibly discussing with family and friends, she will make the decision, again combining her feeling with her process of thinking things through.

Albert and Frank also raised the issue of context around the decision, whether making the decision for personal or professional reasons, that family decisions generally required a different approach to business decisions. As a surgeon, Albert's medical decisions were professional and clinical, without emotion, but with family matters, he and his wife "think rationally as well as emotionally" (Albert, R4). Frank also noticed the challenge of making business decisions if other people were impacted.

> *"I think with finances, it might be more clinical, but when you're dealing with people, it can be something that affects their lives, so, yeah, it's more emotional, but also requires more thought." Frank, R4*

In thinking about how emotion impacts decisions, many distrust it.

> *"You don't have any control over that [emotions], do you. It takes over." Shirley, R4*

Wanda noted the role of emotion in marriage, but also noted that emotion was part of the reason people marry the wrong person. She also blamed emotion for past career decisions which did not turn out well, specifically she noted that the decision to go into sales was emotional.

*"It was an irrational decision I think, just because of my love of travel." Wanda, R4*

Virginia made a recent decision based on emotion, then thought about it and rescinded the decision. After the death of their much-loved cat, they considered the options.

*"Well, we both said yes, it would be nice to get [a new cat], in fact, we really looked at two baby kittens that we thought we'd get. We went and looked at them, we decided we'd have them. And then we came back, and we talked it through, and said, look, I'm 88 and he's 80. And you know, we're never going to last as long as these kittens. So, is it fair on them, what's going to happen? I mean we could still be alive, but not able to look after them. So we went back to the phone, in fact we sent them some money, to say sorry, we thought of them and she quite understood." Virginia, R3*

Ultimately, they chose a five-year-old rescue cat similar to their previous cat. This example shows the process of the decision in the transition from the initial emotional response, followed by reflection and thinking through the implications of the decision, which ultimately changed the initial 'emotional' decision.

Mildred noticed how emotion may also guide thinking in the decision, in considering 'want' or desire.

*"I suppose, well, if it's something you really want, you are more likely to sort of bend things a bit, and decide what to do what you want, rather than what you ought to do. And that's one emotion." Mildred, R4*

Despite the protestations about logic ruling, or distrusting emotion, ultimately, later-life decisions may be made by emotion, in this case, 'want'. Like Virginia's cat, the emotion of 'want' appeared to be tempered with practical considerations. Other participants talked about 'want' in their travel decisions, 'wanting' to do things they enjoy, which was tempered by a realistic assessment of physical capacity. In deciding how much they 'want' something, they may also decide to deploy resources to secure it. Recognising the need for more support, Dolores, Mildred, Wanda, and Winifred all made travel decisions, paying more for higher levels of service, because they 'wanted' it.

One final emotion was mentioned which involved thinking about future later-life existential decisions. Fear was mentioned specifically by Mildred, Shirley, and Winifred.

*"The older you get, the more you fear… You've got to protect yourself because for me, I'm on my own. Nobody else is going to help me." Mildred, R4*

*"If I'm fearful of something, I'll tell them [her children]. I won't make the decision I help them to make the decision, but fear – I'm afraid of quite a lot of things. And I've always been afraid of dying on my own." Shirley, R4*

Winifred discussed her fear, which she experienced recently.

> *"I think I've come as close as you can [to end-of-life], falling in the house. And everybody asked me, what I've done, where did you fall? And they are all thinking the same thing: it could happen to me." Winifred, R4*

The male participants were not forthcoming about their emotions including fear, but all who still had spouses or LAT partners expressed concern regarding what will happen should their spouse or partner predecease them. Overall, fear served as an indicator, a constant reminder of possible perils ahead, including the fear of what Norman called 'the great unknown'.

> *"I mean this really goes back doesn't it, to what I've said before, is that, you know, we don't know. We just hope that the end when it comes, will be fairly to quick and sudden. But if it lingers, then alas…At that point at which you actually know that you've only got one, two, three, four, five weeks, I didn't think I would be so concerned. But it's the uncertainty…. the uncertainty, I think is the problem." Norman, R4*

Whilst emotion was rarely cited in earlier-life decisions, these two emotions, 'want' and 'fear', were frequently cited in later-life decisions. In earlier-life decisions, emotion served as an indicator of importance, as a 'feeling' about a decision, but that emotion was to be distrusted unless you really 'wanted' something. In later-life, 'want' and 'fear' were balanced, mediated by logic. For example, 'fear' entered Virginia's cat decision. She initially 'wanted' a kitten, but 'feared' that she might not live long enough to care for a kitten throughout its lifetime, thus 'fear' caused her to reconsider her initial 'want' and use logic to find an acceptable solution.

The ultimate later-life existential decision is about balancing independence with safety. The consideration of future care requires considering what is wanted – independence – with what is feared – the possible incapacity of later-life. Whilst participants distrusted emotion in decision-making, decisions about ageing-in-place and future care were dominated by both 'fear' and 'want'. They had an attachment to place, they wanted to stay, but they also experienced fear, the fear of a fall, incapacity, or a care home. These two emotions, 'want' and 'fear', are possibly causing them to delay a decision until one may be forced upon them.

## 5.6 Summary

This chapter sought to answer the question about how decision-making has changed throughout the lifecourse and how the experiences of earlier-life have impacted later-life decisions. Results from the OurTown research suggested that there are four main decision domains throughout the lifecourse involving identity, activities, relationships and resources. From the vantage point of later-life, the research also suggested that earlier-life decisions have been reconsidered and

processed to become relatively discrete and straightforward decisions to achieve clear goals, mainly the building of resources and relationships for the future.

Later-life decisions benefitted from a lifetime of both personal and vicarious experience and knowledge to inform decisions, but that decisions were more complex, needing to balance the four decision domains, whilst accommodating changing circumstances, motivations, and goals. In very-late-life, as health depredations increasingly impact decisions, the emotions of want – what is wanted by the decision – and 'fear' – fear of a possible adverse outcome – drive decisions.

Throughout the lifecourse, however, some decisions required a different type of decision-making process to adapt to changing circumstances, such as relationship or health-procedure decisions. In such decisions, fundamental values were weighed, perhaps involving a period of consultation and advice-seeking which continued as incremental changes were made to adapt to changing circumstances, as the decision itself extended over time. As will be seen in the next chapter, this type of decision-making is used increasingly in late and very-late-life.

# Chapter 6 Late and very-late-life decisions

## 6.1 Introduction

This chapter addresses the second research question: what future decisions are anticipated and how will they be made? This chapter suggests that the main goal of late and very-late-life is to continue meaningful engagement in activities and with people, deploying resources strategically in the process, whilst safeguarding the core identity value of autonomy. Yet this is a time of life when the OurTown Participants recognised that health concerns were an increasing factor in the decisions they made, requiring resource deployment to ameliorate challenges, balancing health and financial resources with activity and relationship goals. Many of the participants had harbinger events which provided a foretaste of possible future incapacity. Such events, either personal or vicarious, challenged them to confront a main concern of very-late-life, the need for possible future care. All had made end-of-life decisions which most considered administrative concerns. Additional late-life decisions concerned driving cessation and euthanasia considerations.

## 6.2 Death and end-of-life

As noted in the previous chapter, the OurTown Participants made a distinction between late-life, their current life stage, and very-late-life, a future life stage defined by increasing incapacity and death. This section provides the foundation for how the participants thought about very-late-life, including how they thought and spoke about death, possible incapacity, and the need for future care. For the participants, death was different from end-of-life. Death was a clinical fact requiring administrative decisions about wills, bequests, and funeral plans. In contrast, end-of-life signified incapacity, the end of *living* life which may come about in very-late-life.

### 6.2.1 Thinking about dying

As was discussed in the Chapter Four, an amendment was made to the ERGO application to allow specific questions about end-of-life. All participants agreed to discuss matters around death. None thought death a sensitive topic but considered it an open topic for discussion.

> *"I think we always talked about death. My mother died on my Silver Wedding. The people who came for my Silver Wedding stayed for the funeral." Gladys, R4*

This could reflect a cohort difference in that death and dying were more a part of life for these participants who lived through a world war and the deaths of many friends and family members.

> *"I think a lot of elderly people never think about anything like that [death]. But then … I don't know what they think. But you know it's going to happen to all of us. We know that." Bonnie, R4*

Bonnie's quote illustrates two things, first that death is an expected part of life, but also that 'a lot of elderly people' don't think about it. This statement 'others' elderly people and suggests she does not consider herself elderly, and that she considers herself to have a more straightforward outlook, able to discuss difficult topics.

Clarence, however, notes the cultural difference in talking about death, that for his well-educated Asian partner who has lived in OurTown for over twenty years, death remains a taboo subject.

> *"[With my partner], one of those sorts of things in [her country] is that you don't talk about death. So if I start to talk about it, beep-beep-beep-beep-beep." Clarence R4*

For the OurTown Participants, death, except for the administrative matters, is not the issue. A more complex and difficult topic is considering a possible state of incapacity prior to death.

### 6.2.2 Death versus end-of-life

Prior to the ERGO end-of-life letter sent before the final round of data collection, none of the participants used the term "end-of-life" to mean death. They were clear in what they meant about death and all hoped it would be quick and peacefully in their sleep.

> *"People say, somebody had a heart attack or whatever, and suddenly died, and I think, yes, it is very sad, but actually it's far better in my view to die suddenly than to sort of fade gently away." Norman, R3*

This quote shows the straightforward way the participants spoke about death, and that they preferred death than a transition from life into a limbo state that exists with incapacity, a time when life can no longer be *lived.*

> *"People don't always die, but they just become completely non compos mentis." Gladys, R4*

All had examples of this spectre of incapacity, people who were resuscitated from a cardiac arrest, and subsequently needing full time care, or of friends and relatives 'lost' to them. Glenn mentions friends 'lost' to dementia.

> *"I was hoping I wouldn't have to deal with dementia 'cause it must be dreadful. And we've had two or three friends who had it to various degrees, including an*

*uncle of mine who had Alzheimer's, and he only lasted four years, he was just a shell. … [he] was a tennis player, a footballer at university and all that. He just disappeared virtually." Glenn, R4*

Although Glenn's uncle remained alive physically, his essence, the person he was, disappeared.

Shirley commented on a friend who was resuscitated from a stroke to live the rest of her life incapacitated.

*"I had a friend who was a doctor and she had don't resuscitate and she had a stroke on Waterloo Station. She was unconscious and the daughters came … and they said 'Your mother needs an operation. There's a 50/50 chance that she'll survive it, but otherwise she's going to be in this vegetative state.' So they said, do it. Well, she's been unable to feed herself and, in a wheelchair, ever since. … It's not what she said she wanted, and they overruled her." Shirley, R4*

Virginia described a friend who stopped engaging with life, quitting her book group and giving up walking for pleasure.

*"She then became 90 and she started to say, 'oh, I've grown old'. And she started to stoop. And she stopped driving her car, which she was perfectly OK with before that. Her mental picture of herself became old. And that really shocked me." Virginia, R3*

As well as providing their definition of "end-of-life", these vicarious experiences demonstrated what they don't want, and provide an exhortation to continue living as fully as possible. They spoke of "soldiering on" or "keeping going for as long as I can." The goal for later-life was to continue meaningful engagement, even as health possibly became a limiting factor, to continue *living,* but in an ever decreasing and more localised space. Albert drew this distinction in noting decreasing capacity, whilst continuing to contribute to life.

*"You get to gradually appreciate that you're not firing on all cylinders as you used to in the past. But I'm not unhappy, because there's more to do than one can ever think of." Albert, R3*

This distinction may also explain the change in late-life decision-making. If their goal was to continue living as fully as possible until they 'drop down dead' (Shirley, R1), their decisions, then, supported maintaining the status quo of continuing with meaningful engagement without tipping over into the feared state of incapacity. As noted above, most of the participants have had vicarious experience of reduced capacity in very-late-life, but many also had personal experiences which foreshadowed what this could mean for them.

### 6.2.3 Harbinger events

Eleven of the participants had harbinger events, experiences which made them think through the implications of incapacity, either for themselves or their spouses. Ernest and his wife were in a road accident where both sustained injuries. Ernest's wife spent a week in hospital and although he had a cracked pelvis, he was sent home. As he was still in pain, his son booked him into a convalescent home where, after a week, his wife joined him. Upon discharge, they moved back home, depending on assistance from relatives and friends.

> *"That gave us some pause for thought. And we were able to cope here quite well actually. We had a bed brought downstairs where that sofa is … We realised in fact, we can live here quite well, even as a couple of invalids, particularly if we put a stairlift in … So, some decision-making had to be taken there, but effectively the decision-making was that we can manage here, with the odd friend dropping in and the odd friend doing some shopping for us."*
> *Ernest, R1*

The experience taught them many things: that they could adapt to incapacity and that they could navigate a different path that recognised limitations whilst controlling the necessary support. Because of this, Ernest and his wife continued to pay for cleaners and gardeners to ensure they have established relationships with support personnel, should they need future assistance. This experience, however, revealed how their house could be adapted to support possible future needs and confirmed their decision to age-in-place.

Norman had a harbinger experience when he wrenched his back, making dressing and getting out of bed challenging.

> *"Several weeks ago, I stumbled a bit and in making sure I didn't fall over, I managed to hurt my back and for a couple of weeks it really was quite bad. It got to the point where I was beginning to have difficulty, particularly in dressing myself … It is a foretaste of the fact that the time may come when … getting on clothes, getting on socks, are really quite difficult, and even getting out of bed was really very difficult … There was a week or so when these sorts of issues were quite prominent, a bit of a foretaste of what could happen."*
> *Norman, R4*

After the experience, Norman considered installing a toilet and shower facilities on the ground floor and moving his bedroom into his ground floor office. Whilst he talked about making changes, he did not progress the plan and it was not clear what might prompt him to do so.

Ronald also considered changes to his home. Reacting to his increasing health problems, he contacted the community health team for an assessment to understand what might make his house more suitable for increasing incapacity. Ultimately, he, like Norman, decided "it would involve more than it's worth" (Ronald, R4). In these situations, Norman and Ronald have

considered the cost, both financial and the impact of the construction, and decided against changes.

Some participants, however, learned from harbinger experiences and made changes. Frank's cancer and heart problems prompted his downsizing move. Clarence's near-death experience impelled him to name his partner in his lasting powers of attorney, instead of his estranged children. After Bonnie's recent fall which resulted in a broken hip necessitating care, she changed her bath to a wet room.

> *"I'd been thinking about it for ages, but until this happened. So, I said to [my son], I am going to have a walk-in shower put in and he said, that's fine. So I rang my [construction] bloke, and he came and gave me a quote and … it took him a week. He started on a Monday, it was finished Friday at lunchtime. And everybody's been. [My friends], all of them, all came in to see it and think it's wonderful." Bonnie, R3*

Mildred had previously installed a shower, replacing her bath, the last accommodation she felt necessary for her bungalow. Two women installed stairlifts, Winifred was prompted by her recent falls. With these changes, these participants responded to harbinger events by adapting their homes to continue ageing-in-place.

## 6.3 Major very-late-life decisions

The main later-life decisions concerned how to maintain the status quo in continuing meaningful engagement and ageing-in-place. The OurTown Participants were realistic in recognising that their trajectory to death may not go as planned, and consequently developed strategies to accommodate declining health that could be deployed in very-late-life. The administrative matters of death, e.g. wills, bequests, and funeral arrangements, was considered a straightforward administrative matter. This section discusses death administration, followed by sections on ageing-in-place, the possible need for future care, very-late-life decisions making and contingent strategies.

### 6.3.1 Death administration

The OurTown Participants were practical in the approach to the administrative aspects of death in that making a will and settling one's affairs didn't seem to be a decision, but an expectation. Lasting powers of attorney (LPAs), too, appeared to be part of the expected administrative preparation for death, perhaps because they are offered within the same estate-planning service commonly offered by solicitors. When it came to considering health directives, however, there appeared to be hesitation, perhaps because it required considering unknown and potentially

unpleasant health trajectories but also because some of the participants have cared for loved ones and have noticed the lack of consistency in the implementation. One of the participants additionally prepared a list of people who need to be informed of her death, as well as a list of computer passwords. This organisation was informed by her own experience of serving as an executor for friends and 'proving' her husband's will.

#### 6.3.1.1 Wills and bequests

All OurTown Participants made wills. This is unsurprising as the majority of people aged 75 and above in the UK have made wills, especially if there are assets to be dispersed. Many male participants had career experience regarding the importance of settling death matters.

> *"You can't leave yourself intestate because then the courts take over and they decide, which we certainly wouldn't want." Norman, R4*

> *"With a legal background, the one thing I know is, it's fatal to die without a will." Clarence, R4*

For them, reviewing and changing their wills in response to changes in financial and personal circumstances, seemed an extension of their previous careers and was something done regularly. Many male participants and one female participant had direct experience serving as executor for others. Based on this experience, Ernest and his wife reworked their wills to ensure they are easy to administer without the assistance of solicitors, thus less costly for their beneficiaries. Two male participants made new wills to reflect estrangement from their children. Only one female participant mentioned updating her will. The female participants were less willing to discuss their wills, only to confirm that they had them. Talking about wills appeared to be in the category of financial matters which women felt uncomfortable addressing, except in the most general terms.

#### 6.3.1.2 Lasting powers of attorney (LPAs)

Broadly, an LPA designates one or more representative (attorney(s)) to make decisions about health and welfare (LPAHW) or property and financial affairs (LPAPFA) if a person becomes incapable of making decisions for themselves. The documents are registered with the Office of the Public Guardian before use. Whilst all participants made wills, only 12 (5M, 7F) created LPAs for property and finance, and 11 (4M, 7F) for health and wellbeing. For those who made LPAs recently, participants observed that the documents were part of a standard estates planning package. Two participants already had Enduring Powers of Attorney in place (EPAs, which are now superseded by LPAPFAs, but which remain valid), and two were revisiting them, in one case to reflect family estrangement.

The participant who chose not to create a LPAHW decided that he trusted that his family and the medical team would act in his best interests anyway and considered it unnecessary to make one. Four participants learned the value of LPAs through vicarious experience. The Manor participants recounted a situation with a fellow resident, Patsy, who had not created a LPAHW. Her family had to apply to the Court of Protection to act as her Deputy to be given the power to make the decision for Patsy to be admitted to a care home after she developed dementia. This served as a cautionary warning to The Manor residents who witnessed their fellow resident's loss of dignity as well as the difficulties experienced by her family in not being able to manage health decisions for her. The three Manor participants (1M, 2F) have both types of LPA in place, as does another female participant with a similar vicarious experience.

The main barriers mentioned were the cost in having a solicitor write and file them, although LPAs can be filed directly. Another participant noted that she did not have children and was unwilling to burden distant nieces and nephews with making decisions on her behalf.

#### 6.3.1.3 Health directives

The only health directive mentioned by participants was a do-not-attempt-resuscitation (DNAR), yet only one of the participants has a signed DNAR, whilst seven have thought about it. This reluctance was based on vicarious experience, in that they had friends or relations whose DNARs were either ignored or overridden. Ernest did not believe they are legally binding, whilst Wanda reported inconsistent experience whenever her husband was admitted to hospital.

> *"Every time he went into hospital, they would lose it and so we'd have to have to have another one. In hospitals, nothing seems to stick, they all fall into the waste bin." Wanda, R4*

These experiences suggest three important barriers to completion of a DNAR. First, there is no clear and uniform method of filing them and for ensuring that communication regarding preferences moves with the patient across all care settings. The second problem is that those wishes could be overridden by well-meaning family members. The greatest barrier for most, however, was that this was considered an end-of-life decision and they were not yet at end-of-life.

> *"I'm not at the stage to even consider it. As I say I don't like the idea … I think most of us would rather drop dead with a heart attack than anything else." Wanda, R4*

With his recent health problems, Frank considered the decision with each of his four operations over the last six years and decided that in the case of incapacity, his daughters is his attorney and he has placed a DNAR in his medical records.

*"I mean I don't know what the circumstances would be, but they're [his daughters] both sensible. They both understand. We've been through it with my wife, we had to make a decision about letting her fade away, so, I'm happy that they'll do whatever's necessary if I'm incapable of making decisions." Frank, R4*

#### 6.3.1.4 Funerals

Only three participants did not mention their funerals (2M, 1F), the rest had considered and planned the arrangements to varying degrees. One participant donated his body to science to avoid funeral costs and fees, whilst three (2M, 1F) had prepaid the costs. Nine (3M, 6F) had drawn up specific plans including hymns, because they realised their executors were not religious and would appreciate guidance. One childless participant had also written autobiographical notes, knowing that her niece and nephew were less familiar with her life, most of her friends had died, and the new vicar didn't know her well. Glenn and his wife were debating whether to be buried or cremated and where to be buried, in their current community or with their relatives in the North. Virginia kept a file of funeral programmes to inform her future thinking, but as she did not have children, she was not settled on who it would be for.

*"I don't want a complicated service. I did think I'd just have a crematorium service, then I think a small church service might be nice … I haven't quite made my mind up yet. See, it depends on how old you are, really. If I live another five, ten years, there's hardly anybody of my era left. There'd be younger people I know, but it might be best just to go to the crematorium, [if] the few remaining relations are younger than you are … It doesn't bother me, it's just deciding if it's going to happen unexpectedly, in the next year or two, then you know, there's still a lot of people that know me. If I end up in a home or something, then, what's the point? So, it's good to decide different contingencies." Virginia, R4*

In this quote, besides discussing her possible funeral, Virginia demonstrates thinking about very-late-life decisions. Such decision-making depends on imponderables such as unknown life expectancy, requiring the exploration of contingencies; thus ultimately, postponing the decision.

Gladys, who had the deepest roots in the community through her family, the family's business and her extensive volunteer work, already communicated her wishes to her family: "they know no expense spared. I want a send-off" (Gladys, R4). As 400-500 people came to her husband's funeral, it is likely that hers would be similar. She has specified songs, but also knows that her family will organise it.

*"I think the thing is [the family] make a production of it. This is what we do, somehow. We did it [with her husband's funeral] and we did it again with [her brother's funeral]." Gladys, R4*

At the time of her husband's death, she also pre-purchased 12 burial plots for the family. This is the same cemetery where her husband's father wheeled two, week-old children in homemade wooden boxes in a wheelbarrow to bury them on top of his father's coffin, because they could not afford another plot. Having a 'send-off' for her funeral represents more than just a ceremony. For Gladys, and Albert who also has more explicit instructions guided by his faith, funerals provide continuity of their families within their communities, and both participants have ensured this extends to their final ceremonies.

This thinking also includes considering specific legacy issues. Both Gladys and Albert have considered their legacies. One of Albert's later-life projects was a biography of his father, co-authored with his brother which charts his family's involvement in their religion's development. On a more personal level, Albert also wrote occasional letters to his grandchildren.

> *"What I'm trying to give them, is a snapshot of certain aspects of my life, my circumstances and my past within literally 1,000 words, 1,200 words, not more because I don't want to burden them…. And I've just given them little snippets of things that, one or two things that happened in my life. And that's a little story, a letter from Grandad ... I think this is my legacy now." Albert, R3*

Gladys, too, wrote letters to her children which will be left for them after her death. In thinking about death, Frank considered his regrets about words left unsaid.

> *"I mean one of the things I did regret, especially soon after my wife died, that we'd never had a conversation about dying. Well, not about dying, but just lay it on the line, how much I loved her, how great she was, and you sort of can't have that conversation unless the person is dying. So, I did bitterly regret that for a long time. But when I moved, [she] had an old desk that had been in the family for ages, and I was cleaning it out, and suddenly I'd found this letter which I'd written to her the day we retired and basically I said all the things that I'd wanted to say. So that made me feel better." Frank, R2*

### 6.3.2 Home and ageing-in-place

> *"I suppose the nearer you get to the end-of-life, the more you will want to die in a nice place, to be at home. I dread the idea of dying in hospital, with people [who don't know you]. I mean, I shouldn't say that, but I feel that they're all too busy to look after you or be with you. I mean you die alone, probably." Mildred, R4*

The major decisions of late-life concern ageing-in-place and the possible need for future care. In discussing the decision, the participants talked about home whether that home was the family home or their retirement flat, as more than a structure; it was the store of identity, memories, and value. It was a venue for socialising, and it was adaptable to their changing needs. Home impacts all the domains of decision-making: identity, relationships and activities and resources.

The aim during the interviews was to probe the participants' thinking, to understand what resources and strategies might be employed and the process involved in progressing a strategy to a decision about possible action. To address this issue, participants were asked about future decisions which inevitably led to discussions of home and the emotional salience of home. This section explores the value and meaning of home which is at the base of this decision, before looking at the process, personal and vicarious experience of needing care, strategies developed and, finally, what might precipitate a decision.

As noted previously, only six of the participants downsized from the family home, and all planned to age-in-place, whether it be in the family home (6M, 5F), in a flat (1M, 3F) or their downsized home (1M, 1F). In thinking towards the future, the concept of home was inextricably linked to consideration of future care needs and where to age. The multi-faceted nature of home impacted the types of decisions participants made and understanding the meaning of home is central to understanding why the OurTown Participants were committed to ageing-in-place.

#### 6.3.2.1 Home as identity

Home represents freedom and independence, security, the hub of daily activities and identity. Gladys exemplified how her home is part of her identity. She has lived her life in two homes – the flat above the family business and the family home situated near the business. Gladys married a man who worked for her stepfather in the family business and who eventually acquired and continued to run the business. For the first 13 years of marriage, with four children and pregnant with her fifth, Gladys lived in the flat about the shop with bedrooms above and bath and washing facilities below. The flat now houses professional services, so that when she visited the chiropractor, she had a different sense of place.

> *"Of course, I'm walking into my bedroom of my home, the one that I put my wedding dress on, to get married in. But of course, it's really just a consulting room now." Gladys, R3*

The home her husband selected was a substantial detached home where his mother had formerly been in service. Family life was dictated by the early morning hours required by the business. Every day, her husband returned home for lunch and a rest before returning to close the shop in the evening. Her son, who now runs the business, continues this tradition. Another brother who has a neurodegenerative disease also joins them for lunch. In late-life, Gladys continued to cook and provide for her sons, a role she values.

> *"I thank my lucky stars that I've got all the inconvenience of dirty cups on the draining board." Gladys, R4*

Gladys was a central pillar of the community. She was confirmed in the local church where she still volunteers and was a founder member and active participant in numerous community activities. Her home stored family photographs, trophies and awards which attested to her extensive volunteer work. It remained the venue for family Christmases and an annual Guy Fawkes bonfire. She has lived in OurTown for over 80 years, is recognised and feels safe in the community.

> *"I went down the alleyway yesterday and I thought, people are so kind, I find. You know this chap with a small dog, and in fact he said, 'You all right?' And indeed, he sort of slowed with me all the way down the alleyway. He said, 'Are you going to cross the road?' I said yes. And he saw me across. And of course, you probably find the same thing, half of you is, 'I can do it myself!' But I, you think, no, come on, be gracious, accept help ... It's very nice." Gladys, R4*

As she and the family contemplated the future, they continued to support her ageing-in-place and considered centralising care for both Gladys and her son.

> *"…the family talked about it…. I will stay here. It can be altered. I could have carers, but at the moment I know what they're thinking of, whether I can look after [my son]. Now I've said yes…." Gladys, R4*

And whilst the home is a holder of identity, it is also a store of value.

> *"All I have is the house. I can get £1.25 million for it. That's to keep me. And I've decided I'm going to stay here." Gladys, R1*

Gladys and her home exemplified most of the values older people place in home. It provided continuity with her identity as a mother and her family's identity in the community. Home provided security and convenience in that she could walk to shops and medical appointments, and it stored memories and served as a gathering place for family. Ultimately, her home was a store of value.

#### 6.3.2.2 Home as a family gathering place and store of memories

Gladys was not alone in maintaining home as a family gathering place. Four participants (2M, 2F) had families living abroad who used the home when they returned to this country. Norman, whose family lived in the North of England and abroad, intentionally decided to keep the home for family as opposed to downsizing.

> *"I came to the conclusion that I wanted a house to which the family could always return.... So I stayed here. I now have my granddaughter living with me and they come and go ... The amount of stuff I'm storing is enormous. And there's much more that's in this house that doesn't belong to me, than does! So, I mean, that's my granddaughter's piano. To that extent, one can*

*say, yes, it's been a success staying here because this is the house that members of the family know they can always come to." Norman, R1*

Other participants also noted the importance of items stored in the home, which was part of their identity, as with Ernest and his lathe.

*"[The lathe] is a bit of a symbol. I hardly ever use the lathe to be honest. So really, it is more symbolic than real … I may almost use the 'where would I put my lathe if I move over the road', as a sort of paradigm. But I have my work room, where would I put that, and that does get used … The bench drill gets used a lot. And more, all my other equipment, electric drills and hand drills and vices and chain saw." Ernest, R2*

In Ernest's context, the lathe also represented continuity because "…disposing of that is disposing of a bit of me [sic] dad" (Ernest, R1). It was also his identity of someone who continued to repair things and work with his hands.

For Dolores, home was where she lived happily with her second husband. The pictures on the walls and the house itself represent one of the happiest times of her life. As a child refugee, her possessions and secure home may have additional significance.

*"I've got stuff from my background, you see, and I can't, I don't know what my children will do about it, but I'm leaving instructions, if you don't want them, take them to a museum, because they will want them for their archives." Dolores, R3*

There may also be perspective involved in that items may not have personal salience with descendants until after the death of a beloved relative. There was also the logistical aspect inhibiting action.

*"I would hate the logistics of shutting down all this and throwing away all this stuff … [it] is frightening and I would like to avoid it." Glenn, R1*

#### 6.3.2.3 Home as a venue for activity and ageing

Home can also provide a site for activities important for maintaining physical fitness. Many of the participants (4M, 4F) cited their gardens as a site for valued activity (gardening) and something that gives them joy.

*"I love gardens, a garden to walk around in. I love pottering in the garden, it's great. Even now, I still potter around. It keeps me active." Eugene, R2*

Clarence's home also had a table tennis table and swimming pool which he and his partner used for regular exercise.

*"The swimming pool, 'cause it's got heating, it's been running at 30 degrees all the way through, and [partner] … just gets in and swims round for 40*

*minutes…. I get dragged in more or less, but, nevertheless, of course, when I get in there, I just do a few short bits up and down… So that's been quite important in terms of going on." Clarence, R4*

In thinking about possible future care and changes in physical capacity, home must also be adaptable to support physical capabilities, but also to create a space for healthcare delivery. Six participants (2M, 4F) adapted their homes to accommodate assistive devices in the care of their spouses at end-of-life, accommodations which may be helpful as they consider their future ageing.

An additional factor in the decisions of those who moved to The Manor was the need for adapting to a new situation in late-life. This was especially noticeable for Frank who, unlike the others, moved from outside of the OurTown district, requiring an adaptation both to a new home and a new community. Frank made the decision to make it easier for his daughters. He also recognised that the community where he and his wife had run successful businesses and brought up their family was changing. His friends were dying, and many were moving to be closer to their children. He needed increasing medical care and his daughters were travelling over 100 miles each way to be with him. Whilst Frank thought it was the right decision, he alluded to the adaptations this required in getting to know a new community, finding new friends and activities, reconsidering his identity in a new different context.

*"I was chairman of the day centre, so, I was sort of really involved in that, in raising money and whatever. And I miss that. I thought that I might go to the day centre here, but I went over there, and I thought, well, it's not the same. So, I'm pretty involved in [The Manor]. I'm on the entertainments committee, I do the film night. I'm now a Director of the Limited Company. These things and my family pretty well fill up my time." Frank, R3*

Frank contrasted these two time periods, pre- and post-relocation to The Manor. His previous activities with the village hall in his former community, "that was good, I enjoyed that" (R1), whilst his current activities with The Manor "fill up my time" (R3). Frank considered his downsizing decision a good one, but he was clear that part of the reason this has been successful was that "I get on with most people" (R2).

Another issue which was not mentioned in the consideration of ageing-in-place, was emotion. Although house and home are inanimate structures, over time, emotion develops which is beyond attachment. This makes it difficult to consider anything other than ageing-in-place for the future. Home provides a powerful emotional anchor which weighs on the decision to change.

*"If we moved over to The Manor, this house, almost inevitably, will be sold for development. So, we would be looking out the window, metaphorically, looking out the window from [The Manor], seeing the bulldozers knocking this*

*place down. That I think would be a bit of an emotional strain, to put it mildly."*
*Ernest, R4*

### 6.3.3 Future care

Whilst home represented identity, security, freedom and activity, the prospect of future care, especially a care home, represented end-of-*life*, with increasing incapacity, and the spectre of dementia. Future care was an issue that the participants had been considering for a very long time. All OurTown Participants wished to continue living as fully as possible for as long as possible, but they were aware that at some point, they may need to consider receiving care. Their goal was to remain independent and in control, which included not burdening their families.

*"You want to control your own life … You want to be independent for as long as you can." Wanda, R1*

*"I wouldn't go and live with any of my daughters, I want them to have the freedom to lead their own lives." Frank, R2*

Most participants had experience of care, either personally in caring for siblings, parents or spouses (4M, 6F) or watching friends (2M, 3F). These experiences informed their thinking for the future.

Ernest and his wife noticed the importance of living within walking distance of shops and medical facilities, having watched their mothers' late-life progressions. This prompted them to buy a home within walking distance of OurTown High Street, an advantage also cited by The Manor residents and Shirley who also lived nearby. Winifred noted the problem with living a distance from conveniences.

*"I had to give up driving, and without the car, I'm using taxis of course, and kind friends. But it is a consideration. I've got a birthday card I want to send to Australia, and I can't get to the post office unless I get the taxi. And it seems ridiculous to get a taxi from the station to take me back to the station and post it." Winifred, R3*

Mildred also noted her prescience in purchasing a bungalow as this meant that she need not consider moving. She mentioned this in three of the four interviews, also noting that she had anticipated future health issues by installing a shower.

*"I feel I can, in a bungalow without stairs, I'm quite happy. I've had my bathroom, my bath taken out and a shower put it. I mean that was a good decision, to have a shower." Mildred, R1*

Even though they all considered that they will stay in their homes for the foreseeable future, they still considered alternatives with most commenting on the new retirement flats on OurTown High Street. Winifred considered this alternative, recalling a previous conversation with her husband.

> *"I don't think I want to move, certainly not to the flats in the centre of OurTown. I wouldn't live there. We did talk about it. I said to [my husband], 'would you like to live there?' 'Oh God, no,' he said. Right in the centre of OurTown." Winifred, R1*

In her final interview, she had reconsidered.

> *"We've got one [retirement flats development] in the centre of OurTown, as you see, but they don't do food. I mean to have a look at it with my neighbour. Nice, yes, but they thought that food was essential, you didn't have to go out and find a café all the time. There aren't many of those amazingly." Winifred, R4*

Winifred was typical in her level of awareness of residential alternatives in OurTown. Winifred also noted that her niece had investigated local care homes, including sending her the ratings, none of which she decided to pursue. At that point, the investigation of alternatives confirmed her decision to age-in-place.

The most complete discussion of the process behind thinking about and eventually moving into care was provided by Judith, who had a multi-generational perspective. As a child, her father's mother lived with them. She described the interplay between her mother and grandmother.

> *"She [her grandmother] didn't keep herself to herself. She didn't make any attempt to, and … my mother, I remember writing a card when they'd gone away, and they'd found someone to look after my grandmother. And mother put on it something about, 'if only we could be on our own a bit more.' I mean she was a very sweet old lady, my grandmother, … but she was a totally different personality to my mother. I mean they got on all right." Judith, R4*

It was largely because of this experience that Judith's mother refused to live with her. Instead, she lived in an OurTown care home, eventually celebrating her 100th birthday there. The care home remains in operation and in the first interview, Judith mentioned this as a possibility for her own future care should it become necessary. In the second interview, Judith described the circumstances around another care situation she negotiated. As executrix of her husband's will, she assumed responsibility for the care of her sister-in-law, Beryl [pseudonym] after her husband's death. She and another sister-in-law had noted changes in Beryl's activities and monitored the situation for many months.

> *"She wasn't looking after herself properly, that she hardly stayed in her flat at all. She didn't do anything in it, she didn't clean, she didn't you know, well, there was hardly any food in the fridge when we went." Judith, R2*

Additionally, in the winter she frequently walked the local High Street, not wearing warm clothes. Yet Beryl was an extremely private person who didn't allow people to care for her. Instead of a confrontation, Judith monitored the situation for a few months, knowing it would eventually become a health issue. Judith assisted her regularly, inviting her for meals, ensuring there was food in the refrigerator and taking her to medical appointments. Nonetheless, in due course, Beryl was admitted to hospital with pneumonia. Whilst in the hospital, Beryl was diagnosed with dementia and a care home was suggested. Judith and her other sister-in-law found a care home and managed the subsequent sale of Beryl's flat and the move, suggesting the move was to temporary respite accommodation. Eventually Beryl settled into her new home and stopped asking when she was going home. This demonstrates the lengthy and ongoing process of initially recognising a situation, providing ongoing monitoring and support, allowing the situation to develop until circumstances changed to the extent that a decision needed to be taken. Judith attempted to balance ongoing monitoring with supporting Beryl's independence, until care home placement became necessary.

As she considered possibilities for her own future care, Judith would like to age-in-place, hiring private care as necessary. In her initial interview, citing her mother's experience, she said she would never live with a child, presumably her daughter who lives nearby and provides occasional support. After a friend of hers successfully moved-in with her child, Judith reconsidered.

> *"I mean, if it can be somewhere completely separate with their own front door and everything, then that might be a possibility, but I don't think it would be fair otherwise." Judith, R3*

Judith's thinking demonstrated two aspects of late-life thinking. First, although people may not be aware of it at the time, they are storing lifecourse experiences which may inform future decisions. It also shows the impact of perspective. Initially, she relied on the previous two generations to inform her thinking about where to age. In late-life, however, when she may be feeling more vulnerable, she reconsidered her options and the future, and considered what circumstances might make it possible for her to live with her daughter. This shows late-life decision-making to be a process where the situation is explored and contingencies considered, but decisions are postponed, using a 'wait and see' strategy or deciding not to think about it except in very general terms, in the hope a decision is never needed.

#### 6.3.3.1 Variables: cost

Cost was usually the first consideration, although it was mentioned only in the most general terms, that cost of care was approximately the same whether provided by a care home or brought-in for ageing-in-place.

*"I reckon it wouldn't be much different, the costs wouldn't be much different, having a live-in carer, than going into a home." Mildred, R4*

Although participants were aware of the costs of care, they were also aware of the limitations on their resources.

*"I mean one of the main things, in every old person's mind is, have I got enough money to see me out?" Mildred, R4*

To this end, participants protected their capital to prepare for an uncertain future.

*"There's quite a lot of things in the press about, because the price of housing, people are trying to help their children to buy a house and so on … My view on that is that you don't know what your financial needs are going to be … If you give a lot of money away, it's a risk. You might regret it … [Your future needs] are not calculable. That's the problem. If you live to 102 or 103 whatever, it's very difficult." Glenn, R4*

All participants considered the equity in their homes as a financial backstop which could be monetised to pay for possible future care. They were aware that their homes may need to be sold to pay care home fees. One Manor resident who hoped to age-in-place, realised the challenge of using housing equity to pay for care.

*"It takes a long time to sell these flats for some reason or other. I think there are beginning to become too many of them in OurTown." Wanda, R3*

Whilst cost was the first consideration, few discussed it more than to comment that it costs a lot.

*"If you have living-in carers, that costs a bomb, but so does a home. But then on the other hand, if you go into a home which is very expensive, you don't have the upkeep of the house, council tax, gas, electricity, insurances, so I'd probably have to end up in the home." Dolores, R4*

Whilst the participants were aware of the costs, the comfort of having a home which is a substantial financial asset possibly means that they were not overly concerned about the financial implications of longevity. To put their concerns into context, in 2020 the average property price in Our Town was £1.1 million, 83% above the average London housing price (Foxtons, January 2020), and the average cost of a one-bedroom retirement property was £350,000 (Rightmove, 2020). To compare this with the costs of care, a nursing home in the borough averaged £68,000 per annum, while bringing care into the home started at £21/hour (Which?, 2020) which would make a low level of care, e.g. one hour per day, cost close to £8,000 per annum. Costs of brought-in care for up to eight hours per day were still less than a care home. These costs may be part of the reason OurTown Participants were considering bringing care into the home; costs are containable, and provision can be tailored to need. Additionally, in paying for care, control is maintained.

*"Cash is king. You get decent care and some of [his wife's] friends have done that." Glenn, R1*

Former civil servant Norman, whilst not willing to discuss his personal situation, was concerned about who pays for care.

*"I thought the Dilnot report was pretty good and provided a really solid base for a government to do something. So now I don't know. I mean I suppose now all one can say is that anybody who hasn't got any money, the state will look after them. But the problem is there are people with sort of smallish amounts of money who will be losing almost everything they've got … I will lose a lot, but I think I'd have to be in long term care for ten years or something before it really began to run out." Norman, R4*

#### 6.3.3.2 Variables: care home or brought-in care

Cost was not the only concern when thinking about care, whether brought in or via a nursing home.

*"The alternatives if I become infirm, to me, are either residential care, or more help here … and financially, that's about the same. I would visualise if necessary, getting help here. Agency help, or possibly residential help. I've got a large spare bedroom. I mean to me and most of my friends, the idea of the care home, is very depressing, vastly expensive, and you're completely losing your independence. But it depends on health." Mildred, R1*

Three participants noted issues with brought-in care. Mildred had friends who found cultural and language differences challenging in negotiating personal care. Judith was concerned about privacy.

*"It must be awful having somebody strange coming into your house and having to look for things in your drawers." Judith, R4*

Wanda had extensive experience with brought-in carers during her husband's lengthy demise with dementia. She paid £1000/week for live-in care and found it difficult to have other people living in her house, citing bullying and uncomfortable comments.

*"You've no idea how awful it is living with them … So having had that experience, I think if it comes to that bit I shall have to go into a nursing home." Wanda, R1*

Further, she noted that she might be more independent in a care home.

*"You'd have your own room and you could choose, if you were able to make that choice, if you were to go and socialise." Wanda, R1*

Conversely, Winifred had positive experiences with care. During her final interview, she had private carers visiting, having done errands for her; it was clear she was on good terms with them. After her fall, she had a live-in carer.

> *"Yes, she was lovely, but they're all a bit like that, you know. And [name] was wonderful, this Japanese lady. We sat and did exercises every day when she discovered I was a lot better." Winifred, R4*

Bonnie and Ronald also had brought-in care, supplied by the community nursing team. They had very different experiences. After her fall where she broke her hip, Bonnie needed assistance with washing for six weeks. Care was arranged by the hospital.

> *"I met some lovely, lovely carers. And every one is different. Every day, you'd have a different person. I think out of the six weeks, I only saw the same person three times. So, you've always got a stranger coming in. And that's how it was. But it's very funny, you accept it. Well, I had to. You have no choice." Bonnie, R3*

Conversely, the district nursing team attended Ronald twice daily, an experience he found difficult. He needed care in bandaging his legs and subsequent bathing. He described a difficult process with inconsistencies in types of services provided from day-to-day, requiring him to contact the local office to advocate for his nursing care. The differences in treatment could be attributed to different personnel, but it could also be due to the attitudes of care recipients. In considering possible future care, part of the concern for Ronald is the treatment he might receive. In the first interview, Ronald said he would be a 'nightmare' in a care home, that it 'wouldn't suit my peculiar temperament'. Given his subsequent experience with community care, it is hard to disentangle his 'peculiar temperament' from how his expectations become self-fulfilling prophecies.

> *"I don't want to go into care, because I feel I would be, well, treated like a piece of dirt, whether that's fact or fiction, I don't know, but that's my opinion." Ronald, R3*

Yet he, Wanda and Dolores also noticed how people quickly adapted to a care home environment.

> *"Patsy, a few months before, would have gone screaming and kicking to the nursing home. And then they took her to see it and she went there the following week. … She seemed reasonably content, although every morning she packs her bags. So all her things are still packed in a suitcase, a big bag. I suppose when she goes out for lunch, they take the things out of this bag." Wanda, R4*

In considering a care home, Mildred summarised the typical concerns.

> *"I don't like the idea of being surrounded by a lot of old people, putting it rather bluntly, a lot of people of my own age. You know, I think that's a bit depressing because there's no stimulus at all. Well, that's not quite fair, because some of them might be pretty bright, but that's how it seems … of course, around here, the care homes or the nursing homes or whatever you'd like to call them, are fantastically expensive. I've had friends in several of them, I know quite a bit about them." Mildred, R1*

In this quote, Mildred noted her experience, but also 'othered' the residents, emphasising the difference between her independence and vitality as opposed to those in a care home. As noted above, a care home represents physical or mental incapacity which none of them want to consider. The most common strategy for considering the options was expressed by Norman.

> *"I mean these are the awful things [going into a home or needing future care] that one prefers not to think about except in the most general terms." Norman, R3*

They mostly preferred not to think about the possibility of incapacity or future care, but when they did, they mentally distanced themselves from the 'others' in the care homes.

#### 6.3.3.3 Variables: location and the impact of children

Most participants had children living within 50 miles (5M, 4F), four had children living at a greater distance (2M, 2F), three women had no children and one man was estranged from his children. The participants without children and estranged from their families had no family resources for future care. For those with family living at a distance, however, the decision was whether to move closer to them or to remain in OurTown. All decided to remain. Glenn considered moving near one of his children but realised that the distance to the closest health facilities made the location prohibitive. Shirley's son recently moved from living a short walk away to the town where she grew-up. Asked if she would move there, she said that she planned to remain in OurTown.

> *"I think I'd be mad. I've lived here for sixty years all my friends are here. How crazy would that be?... I couldn't move from OurTown. I've got all my contacts, my friends, my bridge friends, my life's here. You know, I go into the paper shop and he says hello Mrs. [Surname]. It's lovely. I don't want to start all over again. It's too late." Shirley, R4*

Dolores made the decision to move near her son who lives over 200 miles away only if necessary.

> *"I shall go up there when I'm no longer independent. When I have to go into a home, then I might as well go up there…. My son, who's a doctor, and my daughter-in-law who's a physio, they can keep an eye on me in this old people's home if I'm near them. I think it will be the right decision." Dolores, R2*

For participants with children living nearby, the decision was to continue ageing-in-place with increasing amounts of care. As seen previously, Shirley was the only participant who would consider living with her child (only with a separate entrance). Shirley was also the only participant whose child had provided care.

> *"I do tend to get nasty chest infections. I have twice, I think now. [My daughter] could tell that I wasn't feeling at all well and she said why don't you come and stay. And I'd go and stay with them for two-three days and be taken care of. I'm so lucky, lots of people don't have anybody, do they?" Judith, R1*

The few participants (1M, 2F) who wanted care beyond what the council would provide, either paid privately to stay at a nursing home or had care brought-in. In such cases, the children helped to find and arrange the carers. Two participants (1M, 1F) needed care at home which was provided through community nursing teams. One participant (male) had care provided by his partner. As mentioned previously, one participant and his child had a reciprocal relationship where housing and financial support was provided for the child in exchange for occasional caring and another participant provided some care for her child. The others with children received visits from their children and support in liaising with medical professionals. If higher levels of support were needed in the future, it is anticipated that all would pay for this, both because the participants did not want to burden their children and because they wanted to maintain control of decisions.

### 6.3.4 Very-late-life decision-making process and contingent planning

As noted in Chapter Five, some decisions benefitted from experience, becoming almost heuristics, but decisions necessitating adaptation to changing circumstances required a different decision-making process. In earlier life, participants made decisions, lived with the consequences, and learned from experience. Similar to how resources of wealth, housing, and relationships were built, decision-making patterns developed.

For the more complex late-life decisions, however, where possible conflicting goals must be weighed and considered, a different process was developed. Late-life decisions require an evolving process where values and goals are re-assessed and balanced, interim goals reset to adapt to changing circumstances, various strategies developed and interim interventions implemented, whilst waiting for a precipitating event forcing the decision. Until a decision is needed, however, the decision remains open-ended allowing interim steps to be taken. For example, ageing-in-place is a goal for all OurTown Participants, but in the future, this goal may need to be adjusted by bringing in care. There may be a need for respite care or selecting a future care home. A redefinition of identity may be made to accommodate a care home move, thus

sacrificing the ageing-in-place goal for the over-riding goal of preserving self-identity as an autonomous and independent person.

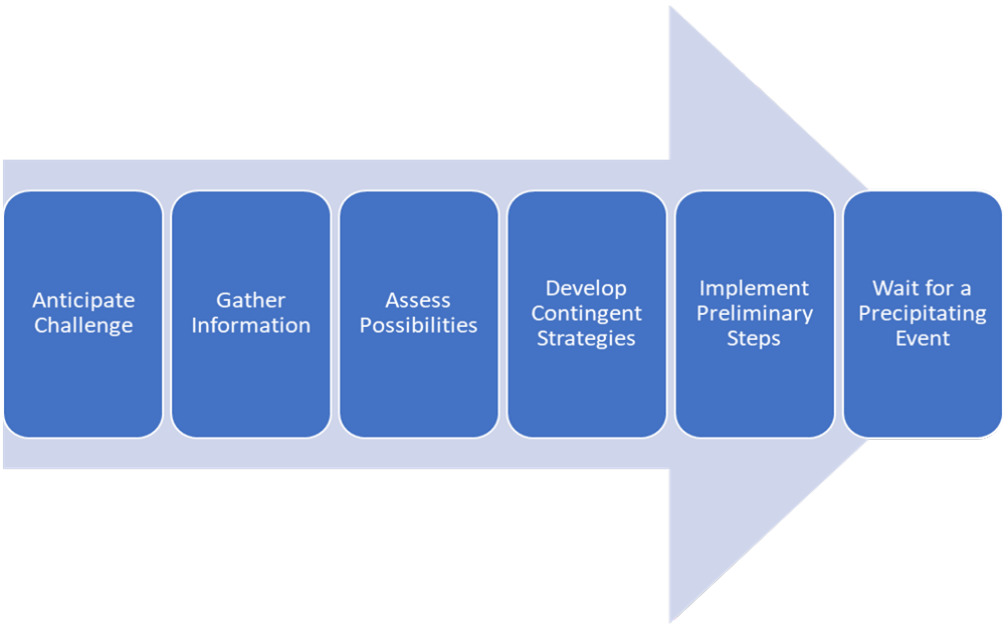



Figure 6-1 Later-Life decision-making process (*source: author's own*)

In later-life, not only has the complexity and the process of decision-making changed, but the people who might previously have provided assistance may have died. For the female participants who were widowed, the loss of their husband also meant that there was no one to discuss decisions with or who perhaps made most decisions.

> *"When you're a widow on your own, making decisions is much harder, than if you've got a sort of resident person, husband, to talk to." Mildred, R1*

> *"I think the ones [decisions] I've had to do in the past are easier than these [late-life ones] actually. And now it's just me making the decision. I think these are the hardest." Winifred, R1*

Those with surviving spouses or LAT partners (5M, 1F), discussed decisions with them. Five participants (2M, 3F) discussed decisions with their children, although Bonnie notes limitations in conferring with children.

> *"They've got their own lives and they're you know, as close as we are, I never talk to [my son] about any of this. … It's not his life and yet he'll say, 'Oh fine, mum.'" Bonnie, R4*

Three female participants, two of whom had children, conferred with close confidants, although one of the childless participants realised the impact of her friends' deaths.

> *"I mean I would only say that I might have three friends I would trust not to gossip or speak…. I mean quite a few of my old friends are gone. That's another hazard." Mildred, R3*

Finally, three participants (1M, 2F) had no one to discuss decisions with. For two of them (1M, 1F), this did not present a problem as they had made decisions throughout their lives. The final participant began using professional legal and financial services as her husband had previously managed their affairs.

The process may also progress to delegating responsibility to others, medical people, God, or family. Frank, who early in life delegated financial and family decisions to his wife, delegated his late-life decisions to his children, one of whom is a solicitor and the other a medical professional, whilst others noted that 'it's in God's hands'. Ultimately, they may not decide, but wait for circumstances to change.

> *"I think most of us just, use it [death] as a sort of excuse. You know when things happen, that are going to happen in the future, you think well I'm not going to bother about that I shan't be there." Mildred, R4*

This thinking extended to justification for not making decisions, whilst also recognising that life is finite.

### 6.3.5 Contingent strategies

> *"I'm hoping that I'll be one of the lucky ones who will just drop dead, like my first husband did. But if not, I accept that I'll have to go to a nursing home because I don't have anybody to look after me. So. Full Stop. I'm a realistic person." Wanda, R1*

In this, Wanda expressed the thinking of most, that they hope for a quick death, but that they also were realistic. All participants tried to anticipate possible future situations, e.g. future care, possible incapacity, bereavement, and how they would address the situation. Each developed contingent strategies that included employing preliminary interventions and considering the impact of possible precipitating events.

#### 6.3.5.1 Preliminary interventions

In thinking about or perhaps experiencing increasing infirmity, a first step (2M, 2F) may be to arrange for wearable alarms. A next step may be installing a keysafe, followed by a stairlift and changing a bathroom into a shower or wet room. Simultaneously, cleaners or gardeners may be repurposed to provide transport for shopping or medical appointments, progressively experimenting with occasional or live-in care or residential respite care.

> *"I took my husband for a respite at [local care home]. And that's a beautiful place, but that's not a nursing home, it's only a care home. But they had lovely lounges with dining room with nice tablecloths. I had meals with him there, it was beautiful. I know they're not all like that." Wanda, R1*

Some participants used harbinger events to make changes, whilst others used the experience to confirm their current thinking, as Ernest and his wife did in thinking towards adapting their home to accommodate future care. In her recent recuperation from knee surgery and subsequent fall, Winifred tried residential and brought-in care, deciding that she preferred carers to a care home. In response to her children's concerns, she also considered downsizing to a flat and possible local care homes.

> *"And I can't bear the thought of moving into one of those and sitting in a room on my own, you know. I like to go out and do things so this [ageing-in-place] is much better for me. That's a decision I've made on my own. And they've [her children] agreed with me because I do go out a lot. I mean I'm going out tomorrow to the Wine Group in the morning and then going to a concert at lunchtime. Friday, what am I doing? Hoping to go shopping with [the cleaner]. Yesterday I was somewhere. So I like to go, if I possibly can. You know friends, kind friends sometimes say, would you like a lift? Otherwise I use a taxi."*
> *Winifred, R4*

In this, Winifred has expressed the decision process of most of the participants. With the goal continuing with her activities and friends, she considered alternatives and decided to repurpose her cleaner for errands, accept lifts from friends or hire taxis as necessary. In the process, she conferred with her children, perhaps as much to inform them that she was considering alternatives. Whilst she discounted other options, the investigations provided information for the future. If it should prove necessary in the future, she has contingent care home options, having viewed the local ones.

Characteristics of later-life decisions included that they progressed over time and that resources were balanced to achieve the desired goal. The goal for Winifred was continuing activities, thus maintaining her current lifestyle. As her health began to fail, she employed other resources – the support of her social network in supplying lifts, or financial resources in paying for taxis. Whether the participants have experienced actual harbinger events or gained vicarious experience, all participants have developed progressive strategies and weighed resources in order to continue, as much as possible, their current lifestyles.

For these unresolved late-life decisions, each has considered them and created contingency plans, although none of the male participants have implemented proactive interventions. It was unclear what might prompt moving facilities downstairs for Ernest and Norman, or at what point any of the men would investigate bringing in private nursing care. More likely, the participants will cycle through various types of informal support, gradually employing private care as the need develops.

#### 6.3.5.2 Precipitating event: possible bereavement

Four participants (3M, 1F) still have living spouses and two men have LAT partners. For two participants (1M, 1F), the fact that their spouse/partner is considerably younger means that they were not seriously considering the impact of bereavement.

> *"If anything should happen to [my husband], then of course, I'll have different decisions to make. I would probably go into a flat where you have a communal place, where you can meet people and do things with. But I don't find that necessary at the moment." Virginia, R1*

Those whose spouses and partners were of a similar age were more concerned about the prospect of bereavement.

> *"I think, and if it comes to that [bereavement], that it's a very difficult one, because you don't know who's going to go first. You could die in your sleep, which two of my friends have. … So, to get back to the point, these things are not very predictable. … I work on the basis of I might not be here tomorrow." Glenn, R4*

Glenn, Ernest, and Albert realised there would be very different considerations if their wives pre-deceased them. It was an uncomfortable thought which all three mentioned in passing but didn't wish to pursue.

> *"I think the sad thing is, we have to think if I get severely ill, or [my wife] gets severely ill, or I die, god forbid, I don't want her to die of course. I mean these are thoughts that come at this stage of our life, of course. To be honest, I have no plans. I'll just wait and see." Albert, R3*

In this, Albert expressed the discomfort that those still married felt about reflecting on the possible demise of their spouse or partner, as well as the most common strategy for coping with it: wait and see.

Eugene's experience, however, provided a cautionary warning. At the last interview, he explained the unexpected challenge to his late-life plans. The oldest of the participants, Eugene thought that he had made all necessary decisions. His son lived with him in the family home as his carer, driving him to medical appointments, cooking and shopping for him. Eugene had settled his financial and legal affairs, given up driving, and stopped participating in outside activities. He and his son had cared for and nursed his wife/son's mother at home until her death, creating the model he wanted for his own demise. He thought he had made all his decisions until, prior to the last interview, his son was taken to hospital for 18 days, and was not expected to live another year. Throughout the last interview, Eugene repeatedly returned to his dependency on his son.

> *"If something happens to [my son], I'm in trouble." Eugene, R4*

This example demonstrated that even with a great deal of planning and end-of-life preparation, uncontrollable circumstances can force the need for new strategies and decisions.

#### 6.3.5.3 Precipitating event: dementia

> *"You've got to make your decisions before you have dementia because once you've got dementia, you're not going to listen to anybody." Wanda, R4*

Wanda's second husband died with vascular dementia. She cared for him through a series of strokes and his illness, supported by private care. Wanda had also been the local family contact for Patsy, and was beginning to recognise the signs in another Manor resident. She recognised the importance of quick response to the signs, because she also recognised how quickly dementia alters decision-making capacity.

The one point of agreement by all participants who mentioned it (2M, 5F) was that a diagnosis of dementia would be a precipitating event to moving into care.

> *"If I was all there mentally, if I kept my brain going, you can manage a lot if you can do that … But if you get dementia, it's a totally different ball park and you've got to, at the first signs of that, you have to really make big decisions, before you get past it, you know. So I keep a close eye on my brain." Virginia, R3*

Referred to as 'doolally' or 'losing marbles' or 'gaga', all had seen the impact on friends and acquaintances.

> *"And we've had two or three friends who had it to various degrees, including an uncle of mine who had really, Alzheimer's is one kind of dementia. He only lasted four years, he was just a shell, you know. … He just disappeared virtually. I used to have to force myself to go and see him because he didn't know who you were." Glenn, R4*

Shirley, whose sister had dementia and whom she no longer visited because she found it too distressing, found the possibility of being a burden, of being a [she used her sister's name as a pejorative[2]] to her family, an anathema. It would only be in such a situation that participants would agree to move closer to their family, or to a care home, although they also realised that should that happen, decisions would be controlled by others. Independence and agency were valued and fundamental aspects of their identity. Dementia was viewed as the greatest threat and most uncomfortable consideration.

[2] In this instance she used her sister's name, but the way it was referenced, her sister has lost meaning as a sister to her and represented a burdensome person with dementia, e.g. if the sister's name were Zara, she said, "I don't want to end up being a Zara to my sons."

Instead of discussing the situation as it could impact him, Norman switched the issue to governmental policy inconsistency, a way of diverting the conversation from the uncomfortable topic of incapacity. This tactic was employed in three of his four interviews which suggests how disturbing he found the topic; his only solace was reverting to his previous civil service identity.

> *"Well, there's the great unknown of care. I mean … that is the big decision and who knows? Where in the ridiculous decision, that if you have cancer of the brain, you will be well looked after, but if your brain just deteriorates with age and you get dementia, you don't get looked after. I mean what is the distinction that justifies this great [policy] difference?" Norman, R1*

Norman was not alone in preferring not to think about the possibility. In terms of decision-making, the participants hoped to avoid mental decline altogether or at minimum, recognise dementia in its early stages.

#### 6.3.5.4 Future care strategies

The most common strategy for thinking about future care was to 'wait and see' or only think about it superficially. This was unlikely to change without a specific precipitating event, as in Eugene's situation. A testament to his experience and resilience, however, was that in the last interview, he was already considering other relatives or possible support solutions.

Only one participant considered a long-range strategy should ageing-in-place prove impossible. Having been twice bereaved, Shirley recognised that few people "drop down dead like her mother and [partner]" (R1). To anticipate what may be necessary, she followed the development of a luxury continuing care project in OurTown. In the summer before data collection began, the developer bought a plot of land which had belonged to friend on the road where she had her first house. In her second interview, after the developer filed for planning permission, she again referred to the subject:

> *"I'm now starting to think that when I can't look after myself, what will I do? … There is no place for a carer and … I don't want to be a burden to my family. So I have started investigating the next step in my life. And I've done quite a lot associated with that. … I like to be able to see the way forward … And I don't want to end up being a [sister's name] to my sons." Shirley, R2*

By the third interview her thinking had progressed further:

> *"I've told the boys [her sons], I know I couldn't have anybody living in here with me … I don't want somebody banging about in my kitchen, into all my bits and pieces in the kitchen … That's my domain and I don't want anybody trespassing on it. So I've said to the boys, when I can't drive, when I can't make my bed, when I can't bath myself or wash myself, when I can't cook for myself, I'm going into a home. And I'll need you to find me a very nice one. There's two I*

> *have in mind, because I have done a bit of research. If I can afford it, I'll go to one of those. Because I don't want anybody living in, and I don't want you living in, and I don't want to live with you, either, because that won't work, that will destroy our friendship. I love to be with them, but I couldn't bear to live with them." Shirley, R3*

She agreed with her sons that when she can no longer drive, that would be the time to consider a move, although she also countered this by noting she had Uber on her phone which possibly means she has already implemented strategies in advance of driving cessation, indicating her priority for ageing-in-place for as long as possible.

By the last interview, the developer was weeks away from receiving planning permission which was granted in November 2019. Based on the developer's reports, it appears it will be 2022-23 before Shirley could consider relocating. The report also noted that up to 95% of the properties were bought off-plan, meaning Shirley was wise to anticipate this decision. Her main concern was affordability. To this end, Shirley contacted her son, a former banker, and had him audit her finances to ensure that she would be able to afford her proposed development.

> *"I'm looking at my finances. Okay I can afford to buy it if I sell this, but can I afford the upkeep? It's a thousand pounds a month before you start on anything, just for the care they give you and for the use of their facilities. So you've bought the house … then you've got the community charge, then you've got your electric and gas…. so that's when they said 'you can afford [it] mum, you can afford all this, so rest easy'." Shirley, R4*

At the end of over 90 hours of interviews, it was clear a diagnosis of dementia would be the precipitating event prompting the participants to make concrete decisions future care, but it was a possibility they were unwilling to consider in greater detail. It also remained unclear what level of physical decline would prompt increasing care or move to a care home. Having made what they considered to be sensible precautions, they saw no reason to give future care decisions further attention.

> *"I mean it's like so many things, it's like Brexit, everything's in the future and we don't know. That's what your life is. It could be different tomorrow. So, it's hard to prepare for the unexpected or the unknown." Frank, R4*

Ultimately, Mildred elaborated on the disincentive in making future plans.

> *"As I get older I think I'm less decisive because everyday pressures take your energy and you don't really look that far ahead, perhaps. …[Besides,] you might be dead anyway." Mildred, R4*

## 6.4 Other late-life considerations

Whilst the main decision of very-late-life concerned future care, driving cessation was another evolving decision. Additionally, some of the participants raised the topic of euthanasia. Whilst this may not be a decision *per se*, it was an indication of very-late-life thinking.

### 6.4.1 Driving cessation

Decisions about driving were made throughout the lifecourse. As noted in the literature review, driving is a part of identity, as well as a symbol of continued independence and control. In very-late-life, driving may also impact control, in that participants may quit before their children or circumstances force them. Although objectively a minor decision of later-life, driving cessation impacts decisions about activities, relationships, resources, and identity in progressing from a person who gave other people lifts to someone needing to ask for them. It was viewed as a harbinger of very-late-life. At the start of research, all but two of the OurTown participants were still driving.

Table 6.1 OurTown Driving Status *(Source: author's own)*

| Driving | Men | Women | Total |
|---|---|---|---|
| Driving, no modifications | 5 | 3 | 8 |
| Driving, some modifications | 1 | 5 | 6 |
| Driving cessation prior to data collection | 2 | 0 | 2 |
| Driving cessation during data collection | 0 | 1 | 1 |

Only Winifred ceased driving during the course of research. At the first interview, she mentioned driving as an indicator of wellbeing, that she could still drive. After an accident before the second interview, she gave up driving which she accommodated by repurposing her cleaner, asking friends for lifts and hiring a regular taxi driver. Whilst she recognised that she could have killed people with her car accident, she still regretted the decision.

> *"It's just that I miss the car more than anything, so I wish I'd carried on because I keep meeting people who are much older than me, still driving. So, yes. That's a real regret." Winifred, R3*

Driving cessation generally progressed in incremental reductive steps such as deciding to drive during the day only, no longer driving on motorways, or only driving locally.

> *"I'm quite comfortable when I'm in roads I know. I don't really go anywhere strange. I don't go out after dark. I don't go that far … It would be a complete change of lifestyle [which] I've got to face up to sooner or later." Mildred, R4*

This may progress to repurposing cleaners and gardeners as drivers and downloading the Uber cell phone application. By using taxis more frequently or accepting lifts from others, identity and

values shift. Initially, driving was considered a sign of independence and control. By shifting the focus to cost considerations, however, driving cessation becomes a sensible financial decision, whilst maintaining decision control.

> *"When you take away insurance and the cost of running it and all the rest of it, you can go quite a long way in car hires, taxis and so on. In fact, it balances without much difference." Glenn, R3*

Three participants recognised that their vision problems would be the deciding factor. Ultimately, the participants recognised there would come a time when they were no longer safe to drive, a decision they intended to manage by allocating more resources, whether paying more for taxis or higher levels of service in travel, or depending on friends or spouses for driving.

### 6.4.2 Euthanasia

Five participants (2M, 3F) raised the issue of euthanasia. One participant had attended meetings of the Euthanasia Society and two had friends or relatives who ended their lives at Dignitas. For them, the criteria for considering euthanasia should be clear, based on suffering with a progressive illness like motor neurone disease, and that there should be safeguards to ensure mental capacity and free will, with no outside forces impacting the decision.

> *"It is absolutely right when you have these people who have these really significant diseases that are overtaking their lives, and if they reach a point that they really don't want to go on, … I can see that they ought to be able to have the right to say … that their lives have just got to the point that they would like to die … On the other hand, … there is a great deal of concern about how that can be misused. … It would need to be so very carefully controlled, so that [it was] a person's own choice and not something that been put in their minds by the people who are around them. So that is a great moral issue which over the next 10 years probably will get resolved." Norman, R4*

They also recognised that it is more humane to allow someone to die in their own homes, as opposed to needing to leave the country.

> *"I've followed that quite a lot in the press. The law is so inconclusive. They have hardly ever taken anybody to court for doing that [assisting someone to travel to Dignitas]. But, if a threat is there … it's much more dangerous. But why somebody has, who is seriously ill, and the last few weeks, you have to go to a foreign country to some horrible room, when they could be in the comfort of their own home, with their own things around them, and their loved ones and just say goodbye." Virginia, R4*

Even if the law changed, with appropriate safeguards to allow people to end their own lives in their own homes, actually doing it might be very different.

*"You could well see something as major as that, taking it to the actual act of swallowing that. It must need a great deal of resolve." Norman, R4*

For the participants, the main issue was not sanctity of life, but control, whether it was the individual or the state which had ultimate control over life. They noted that people may just want to be able to determine their own death, in their own way when they felt the time was right. In this sense, it was as much about having alternatives and exercising control in the manner of death. Whilst none of the participants admitted to considering euthanasia as a possible strategy, the fact that it was in their thoughts was indicative. Throughout their lives, the OurTown Participants had sought control over their affairs which could be one of the reasons why the prospect of incapacity and a lingering period of dying was so painful for them to consider. Likewise, euthanasia and the possibility of control the timing and manner of death, had appeal.

## 6.5 Summary

This chapter set out to understand the decisions of very-late-life and how they would be made. Throughout later-life the OurTown Participants sought to continue meaningful engagement with people and activities, deploying resources strategically to accomplish this. If and when declining health impacted these plans, a more extended and evolving decision-making process would be used. Like the medical and relationship decisions cited in Chapter Five, compensating for declining health required a process of constant resource monitoring, advice seeking, information gathering, strategy development and possible implementation of interim steps, then waiting for a precipitating event which may force a decision. The overriding goal was to maintain autonomy and control.

Examples of this decision-making process included driving cessation or responses to harbinger events. The participants who were still driving constantly monitored their abilities, implementing modifications such as in not driving at night or long distances. Cleaners or gardeners were repurposed, and Uber downloaded. In the process, the focus shifted from the freedom that driving provides, to considering the costs involved, that it might be more expensive to maintain and drive a car than to hire taxis. In this way, the final driving cessation decision could be based on financial considerations.

Considering future care involves a similar process. Many participants have had harbinger events, providing a foretaste of possible incapacity. In response, some have implemented interventions, e.g. wearing a personal alarm, or installing grab rails, wet rooms or stairlifts. They may begin to experiment with brought-in care, conferring with their friends about possible providers. Some of the participants have investigated local care homes. Having progressed their thinking to the

consideration of possible future options and strategies, they are content to wait, reluctant to allocate too much time or energy developing plans which may never needed. The next chapter explores heterogeneity in decision-making and how social networks support decision-making.

# Chapter 7 Patterns of Heterogeneity in Decision-Making

## 7.1 Introduction

This chapter addresses the third research sub-question: What heterogeneity exists in later-life decision-making? The aim was to ascertain the individual and structural differences in earlier-life that may shape circumstances and patterns of decision-making and, further, how those differences impact later-life. As will be seen in this chapter, gender, employment patterns, and how social networks are used, impact decision goals, the types of decisions made, and the process for making the decisions. As was shown in Chapter Six, a central goal of later-life is to remain independent and to continue meaningful engagement with activities and people. This involves both the social networks and the activities of later-life. Social networks provide emotional and instrumental support; they are a resource for continuing the salient activities of life, and they are part of what gives life meaning, the relationships and people who provide affection and companionship in very-late-life. Decisions made about social networks impact all decision-making domains. This chapter will first consider gender differences in earlier-life decisions and how those differences shaped decision-making in later-life. A section on social networks follows to explain how men and women use social networks and how this impacts later-life decisions and resources.

## 7.2 How gender and earlier-life situations impact decisions

The earliest decisions OurTown Participants discussed were decisions about education, career, and family. In these discussions, it was apparent that familial and societal expectations impacted the types of decisions and how decisions were made. All were a product of their time in their more traditional gender roles and in their experience of living through the war and post war experience.

> *"I think the Second World War was, you were sort of thrown into it. One minute you were leading a life and all of a sudden, you are at war … But people just got on with it. The men had to go to War and a lot of women … for the first time went to work. … It opened up a whole world, particularly to women." Bonnie, R2*

This quote encapsulates the impact of the war for this cohort, that they just 'got on with it', but also that the world had changed, especially for women. Their earlier-life trajectories were framed

by traditional gender roles and expectations, but society was transitioning to a time where there was wider acceptance of women in employment whilst also raising families. As noted previously, four of the five female participants self-identified as housewives, despite the fact they also worked outside the home. For the male participants, five had wives who worked outside the home and most commented on it because it was in opposition to the societal norm of the time.

> *"When I got married and I told my grandfather that she was going to continue teaching, he said 'no [Surname] woman ever worked.' And what he meant, 'no [Surname] wife ever worked.' … A woman only worked if her husband was unemployed, or she was widowed." Glenn, R4*

This transition to greater acceptance of women working outside the home impacted the participants and their families. Nonetheless, in their earlier lives, there was an expected trajectory. At its most basic, young people were expected to marry and have families, but the prescribed marital roles expected men to find employment and support their families, whilst women were permitted jobs as teachers, nurses or secretaries until they married and had families, at which point they should stop working. Thus, in their earlier lives, men made decisions about their education and future careers based on their interests and goals, supported by their families, whilst women were constrained by familial and societal expectations, factors outside their control. This set a pattern in women's decision-making of considering factors other than personal goals or desires in decision-making. In earlier life, their parents guided them and after marriage, decision-making was delegated to their husbands, a pattern which evolved in later-life. This section will first discuss men's decisions in education, career, and families, followed by a similar section focussing on women's decisions.

### 7.2.1 Men's decisions

The first decision male participants discussed concerned education and how that impacted their future careers. Their decisions were self-directed, usually influenced by their fathers or other male family members. For most, the choice of education was determined by career intentions, whether that education was through university, medical school or professional training in accounting, finance, or trade.

#### 7.2.1.1 International relocation

Two participants who were born outside the UK made an additional early life decision to leave their home countries. As Eugene lived in a Commonwealth country and had professional accountancy training, he was easily employable in the UK. Eugene also noted the importance of his education not only for the training itself, but the friends he made during his accountancy

training. He and his friends decided to move to England together which also provides an example of how a social network can be a powerful resource in supporting decisions. In this quote, Eugene described how his friends arranged accommodation and when he was disappointed in his initial job offer, suggested another. This is a pattern and resource he used throughout his life.

> *"We'd all studied accountancy together and we'd all known each other for many, many years and we came two of us in one trip and one chap came two weeks earlier and arranged accommodation … I had a job to come to and I went down on my second day and I wasn't impressed, but we were all accountants and the chap who came two weeks early said, 'when I was enquiring, there's this firm called [company name]' and he was already committed to another firm and he said, 'go and see them.' And they offered me a job straightaway within an hour of talking and offered me a salary of over £100 a year more than the other one so, it was £600 to £700 just by two days. I stayed with them for years and through them I joined [my ultimate employer]." Eugene, R1*

Albert's situation was more complicated in that he needed a more circuitous route due to political and visa restrictions at the time. Once he and his wife came to England, his wife's salary as a trainee midwife supported them whilst he pursued further medical training as a surgeon, until she became pregnant. At the time, it was illegal for a pregnant woman to work on a maternity ward, so they lost that income.

> *"We couldn't cope with my salary. … We were literally in a bedsit at that time. So we had to make a decision, where do we go from here? The decision was made for us in that I had a friend, a doctor I was working with, … he said 'I have a friend' … And he gave him a call, and … I went there and I must have impressed that consultant, but it wasn't a proper interview. To cut a long story short, … they took me, it meant many things. A, that my future is secured. … B, I was having the right training because I was training under two consultants, not just one. Third, I had more money because I was a registrar, and fourth, but not least important, was the fact that part of the job was a cottage within the hospital, with hot water running and free coal for heating." Albert, R1*

For both Eugene and Albert relocation to a new country meant focussing on their own career and life goals and using their social networks to achieve them.

#### 7.2.1.2 Familial career influence

In determining their future careers, six of the eight male participants had direct career influence from their fathers. Glenn was given his first banking opportunity through a conversation his father had with his banker. Ernest's first job was in the company where his father worked (although with a first-class maths degree, he was well qualified). Norman followed his father into the civil service. Ronald worked in the family news agent and post office. Eugene's father suggested bookkeeping and accounting for his career and encouraged him to leave his home

country to relocate to England. Frank became a master butcher like his father. Albert noted that both of his parents, despite having 'meagre' educations themselves, had a major impact on the lives of their children. Clarence noted the direct influence of his uncle who stayed with his family regularly.

> *"[My uncle] was a very big influence on me, and he treated me almost like a little brother… he influenced just about every decision, in a way, because he built in me, you know, strengthened [my decision] that I wanted to go to university." Clarence, R3*

For the men, the families provided positive guidance and connections to support the men's formative career decisions.

#### 7.2.1.3 National Service

The other main influence on the early careers of the male participants who were born in the UK was National Service. Most felt that it gave them time outside of education and employment to consider their options. Most recognised the social education it provided.

> *"We had such a sheltered life up to 18 … I then did my National Service which was certainly not something I enjoyed, although it was very pleasant, but that was an enormous shock to the system." Norman, R2*

Ernest's electronics work whilst in the service transferred to his subsequent employment. Glenn considered National Service as like university in that there was a good library and time in the evening which he used for study.

> *"[During National Service] I'd finished my banking exams, I'd finished the associates, and I started into the members. And I was lucky enough to get promoted, there was nothing else to do during the week. I got 84% in accountancy. Anyway. When I came back, I could do 50-words-a-minute in typing." Glenn, R2*

Clarence also found National Service beneficial in that he studied for and earned a law degree. Additionally, in his role as an education officer, he learned how to structure and provide training, skills he used in his subsequent teaching career and industry training consultancy. Only Ronald, one of the older male participants, did not experience National Service as he was conscripted prior to the implementation of National Service.

#### 7.2.1.4 Career progression

After completing National Service, Ernest, Clarence, and Norman had a straightforward trajectory from university to their careers, as did Glenn who trained in banking. Frank trained and joined his father in business. Clarence entered teaching as Deputy Head, then Head of Languages at two

independent schools. He subsequently used and developed his teaching experience to switch focus and take a position as a corporate trainer, ultimately starting his own consultancy business. Clarence viewed his career decisions as opportunities to try new experiences.

> *"I'd say that my theory of career development, you can either be on a tramline, in which case you like being a schoolteacher, then a headship, or you can be on a raft sailing on an ocean and you see another raft passing by and they say, 'would you like to come aboard?' And what you should do is, if you can learn something new by doing that, you don't want to go on another one where you'd be doing the same thing, you go on where it develops your skills a bit further. Jump on that raft." Clarence, R2*

This quote shows both his sense of agency but also the value of his social networks. When his path to a headship was not forthcoming, Clarence redirected his career by pursuing an industry offer made by the father of one of his students. Clarence continued to use and expand his social networks throughout his career, a pattern which continued in later-life.

Albert described his career decision-making as having an overall sense of direction.

> *"I had a vision. I wasn't aimless … Everything I dreamt of happened, but not because I knew how to do it… just making use of any opportunity ... anything that sounded OK, it's just like driving before the SatNav days, you look at something, that's a good sign, let's go this way." Albert, R1*

Four of the male participants took a narrower approach to their careers, seeking stability in their employment, working with the same organisations most of their lives.

> *"In those days, people were looking for a job for life … so it was important to find somewhere which would be a good fit for me, as well as a good fit for them." Norman, R1*

In making his decision about that important first job, Norman was seeking his 'job for life', a priority voiced by three others who worked for the same organisations throughout their careers. In this decision, however, they traded security for a loss of independence as the companies had stringent terms of employment. Norman worked with the civil service for the rest of his working life, retiring at age 60, a decision over which he had no control.

> *"I retired in 1994. I was slightly disappointed about that because when I joined the Civil Service, it was understood on both sides, that you could retire at 60 or anytime after 65 depending on both the department and yourself. But it was quite some time before I was told that in my position, that I would definitely have to retire at 60. … Now, left to myself, if the choice had been entirely mine, I certainly would have stayed." Norman, R1*

His was a 'normal' cliff-edge retirement in that he worked until the very end.

> *"I can honestly say that until that last week, I was working those sorts of hours [12-hour days and weekend work]. And then on the Wednesday, nothing. And you know, it's difficult to prepare." Norman, R3*

Glenn also remained with the same company all his working life, starting with the bank at age 16.

> *"It [banking] was seen as a very, very secure position. If you weren't dishonest and so on, you might not progress very much, but you wouldn't be fired." Glenn, R1*

This security came with stringent conditions in that the bank dictated the terms of employment concerning frequent relocations and that bank employees were not allowed to marry until after age 24.

> *"As I wasn't married, I was sent [on a distant posting] and I got engaged there when I passed the exams. And I was immediately sent to [a different distant posting] at the beginning of the summer and I thought it was a permanent shift. I had a landlady there and all the rest of it. And I was still quite hard-up and I was saving to get married and at the end of the season in September … I got shifted to [a third posting], a real tough area." Glenn, R1*

The lack of agency was compensated for by the fact that Glenn was promoted with each move. He also found the work interesting and he liked working and "feeling he's doing something important" (R1). Glenn's career progression required frequent moves, something mentioned only in passing. He was fortunate in that his wife was willing to manage the frequent moves and disruption to her career and the children's schooling, in order to support his career.

> *"Some of my contemporaries couldn't get on with [banking] because their wives wouldn't accept a transfer or move, but [my wife] was always up for it." Glenn, R1*

Although it was not mentioned as part of the initial decision, an advantage to the job for life, was that they retired with full pensions.

Whilst not on a corporate trajectory, Frank, too, had a job for life in deciding to become a butcher. In addition to training him as a butcher, Frank's father involved him in all the decisions regarding their shops, purchases of businesses and the running of the shops, gradually giving him more control.

> *"My father was really good to me. … He would leave me alone and would let me make mistakes. And he would be good about it, but he wouldn't be happy if I made the same mistake twice, but he would often just leave me and let me get on with it." Frank, R1*

Ultimately, Frank's wife joined him and together they ran a successful butchery business until they took early retirement in their 60s. This pattern of decision-making, of being allowed to make

decisions with background guidance is one that Frank used throughout his life. He delegated the family finances to his wife, but the running of shops they determined together. As seen in Chapter Six, Frank delegated decisions about future care to his daughters.

The majority of the male participants had an overall vision of what they wanted in their careers and pursued it, supported by their families. They recognised both limitations and advantages and were decisive in their choices. The exception to this career focus was Ronald. His discussion of decision-making was different in that his education or career decisions were not described as choices, but as 'drifting': he 'drifted' into the shop to help his parents, he 'drifted' into a job at the post office and later 'drifted off the marital line' by having an affair, as if such events were more a matter of 'drifting' than making decisions. Ronald's decisions seemed to be less goal-focussed and more based on reacting to circumstances as they developed. Whilst he recognised that he had a quick mind that helped him in his work career, Ronald returned many times to career paths he regretted not pursuing. Ronald's career focus seemed to lack the overall vision and goal direction of the others which left him 'drifting' as opposed to choosing.

#### 7.2.1.5 Family decisions

Whilst it was clear that all the men cared deeply about their families, it was also apparent that their careers occasionally took precedence over family concerns. Norman, whose wife died in a road accident when their children were in their early teens, described eleven-hour days at the office with an hour each way in travelling, with additional work on the weekend. Yet this didn't change after his wife's death.

> *"[The children] were in their teens, 15 and 13 I think. So there wasn't so much emphasis on the practical issues, as it would have been if it had been ten years earlier. If they'd been three and five, it would have been very very different and difficult practically as well as. I mean the practical support for my children, wasn't so difficult. My mother-in-law was still alive and came over a bit. I mean she lived [two hours via public transport], but she came over from time-to-time and helped look after them." Norman, R1*

This suggests that his children and his mother-in-law supported his employment focus and that it was expected he would continue to work long hours.

Ernest, Eugene, and Albert all had international careers which necessitated either taking their children with them or placing them in boarding schools. Ernest moved approximately every three years when his children were younger, placing them in international schools in each country. Initially this worked well for Ernest and his family, until his English children began having problems with the American-curriculum international school.

> *"We decided that this was causing too much stress…. So, we had a family conference and decided this was when the kids would start boarding school. So, this would have been when our children were 9 and 10 probably. So that summer they came home, and we got them into a prep school." Ernest, R1*

In this situation, Ernest consulted with his family as the decision impacted, not just his career but his children and their education. This is similar to Albert's decision-making in balancing career aspirations with family concerns. Albert placed his children in boarding school whilst he and his wife lived abroad. For them, a decision needed to be made when his children entered their teens.

> *"They were coming to the age of about 12 or 13 and we had to make a decision whether we were going to keep them in boarding school for the rest of their lives, and of course being separated, although they came three times a year, but they weren't part of the family, in the normal sense. Or, I come back to England and bring the family together. It took an agonising period of time … and then at the end, we decided we would come back to England. We didn't have a job, but I decided this is what I have to do. The family must not be dispersed." Albert, R1*

Whilst Albert's family would have supported retaining his career abroad, he decided even though he didn't have a job, that family togetherness was more important. For Eugene, Ernest, and Albert, it is notable that the decision-making changed from a total career focus to greater consideration of family goals at a time when the children were entering their teen years. It is difficult to determine the cause of the change from career focus towards a more family-centred approach. There are possibly three interlinking explanations. First, the men would have been more established in their careers and possibly had greater workplace agency. Another reason could be that children entering teenage years benefit from familial and education stability. Finally, this change occurred in the 1960s, a time of wider societal change.

#### 7.2.1.6 Summary

What is common in the men's experience is their individual focus and agency to pursue their goals, allowing them to seek jobs they liked, that paid well and that were interesting. The men largely shaped their education and career trajectories through their own interests and work, supported by their families. The men's career trajectories were mostly self-directed, supported by their wives and families until their children reached the teen years when there seemed to have been a more collaborative approach to decisions about how career impacted the family. The exception to the self-directed goal-oriented career decision-making was Ronald who seemed to have less focus on career goals or a belief that he could achieve goals, which left him reacting and making decisions about circumstances as they developed, which is more similar to the experience of most of the women.

### 7.2.2 Women's decisions

As noted above, women were expected to marry and have families, with concerns about education and careers subsidiary to this expected trajectory. In discussing education and careers, it was apparent that most of the women were constrained by a combination of societal and family expectations and financial need in making their decisions. Their education decisions were not necessarily their own, but an extension of parental control. Female education decisions generally also considered family circumstances and parental and societal expectations. Whilst their parents and societal pressure may have shaped their earlier-life decisions, the pattern of control and consideration of other factors, continued after marriage as family concerns and their husbands' careers shaped their decisions. The expectation was that they delegated decision-making to their husbands and that they raised the children, kept house, and supported their husband's careers.

An additional challenge for women trying to support themselves and their families, was the expectation that women would be paid less.

> *"There was not equal pay before 1956. And one of the changes then made was that it should be introduced over seven years, so that the gap was narrowed by a seventh every year until 1963, seven years after '56, then we had equal pay in the Civil Service." Norman, R2*

At about this time, equal pay was also introduced for teachers.

> *"I remember when equal pay came in, you know, we were all just very pleased. I didn't sort of start thinking, well, it's all been very unfair." Mildred, R2*

#### 7.2.2.1 Women's education and careers

Only Wanda had an educational and career trajectory like the trajectories experienced by the men. After doing well in her qualifying exams and securing a place in a competitive girls' secondary school, Wanda determined her future path.

> *"Once I'd started there [her girls' school] the first thing that I realised, that first year, that science was something that was going to take a big part of my life. That was my first decision, that I can make, that I made, not my parents." Wanda, R1*

The selection of science in those days was unusual for a female, but it put her into a 'male' environment where she could compete and succeed based on ability. After leaving school, Wanda had an interview at a university and was offered a place as a student which she rejected.

> *"I decided that I wanted to work which may not have been the sort of decision I would have made today, but I didn't want to go to university because I thought that I would like to earn some money and be independent." Wanda, R1*

Instead, she worked full time for five years, continuing with night school to achieve the university equivalent in her subject.

> *"And when I got my [qualification], I looked for other jobs and one came up to go to [African country]. So, I was lucky enough to be accepted.... And I went to [Africa] for four years." Wanda, R1*

Wanda was the only one of the nine women who from an early age determined both her education and her future career. The factors behind her ability to make these decisions were that her parents were ambitious for her education and, because Wanda was top in her qualifying exams, she was sent to a top girls' school that allowed girls to pursue their interests.

The other eight female participants were expected to train as secretaries, teachers, or nurses until marriage, in line with societal norms.

> *"Unless you were going to teach or be a nurse, you go to secretarial school." Gladys, R1*

Six of the nine female participants attended secretarial school. Dolores, Virginia, and Winifred all achieved well at secondary school, but when considering further education, their choices were limited. Winifred, who had attended a competitive girls' school on scholarship, wanted to attend university and live at home, but her father was not prepared to pay tuition unless she undertook teacher training. Dolores, who was an immigrant living with distant relatives and dependent on their kindness, also did well at her girls' school.

> *"I did brilliantly well. Nobody from the family came to my last speech day. They didn't see that I won all the prizes. I came top of my year. There was a Latin competition between all the girls' public schools and I won it … [Instead of university] I did a crash course in shorthand typing and got a job… I thought I'd better get on with it. I didn't go on to study." Dolores, R4*

Virginia completed her school certificate a year early, despite having much of her secondary education in an internment camp school taught by fellow internees, without textbooks. There was no choice regarding further education, however, she needed to work as soon as possible to pay her brother's school fees.

> *"[I] came back to England with my parents and my father died after the rigours of the camp. So we were a bit stuck for money. My brother had to continue school because he was only 12 or 13. But I went to learn shorthand and typing and by the time I was 17, I was working. My first job. So education, I did not have university education of any sort, but I learnt with life." Virginia, R1*

Gladys and Bonnie also learned secretarial skills. Gladys had always worked in the family business, but on completing secretarial training, worked outside the home until she was married, then continued the rest of her life working in the family business.

> *"I never thought about getting paid for it [the work she did for the family business which included the payroll, bookkeeping, and inventory]. Never asked, actually. [My husband] said oh I'm not bothering to pay you …. If you want any money, ask for it." Gladys, R3*

These examples illustrate the expectations of the time, that a woman's ultimate vocation was as mother and housewife, supporting her husband's career.

Bonnie left her grammar school to attend secretarial college, although she seemed to follow her own choices.

> *"I decided I really wanted to do secretarial, so I left the grammar school and went to a college to learn shorthand typing, bookkeeping. I did English and law, that was it. I did very well at shorthand and typing and I became a secretary at 17 to a solicitor in Whitehall and yes, it was fine. I've never been out of work." Bonnie, R1*

She quit work after she was married but returned to work when their son was three years of age, divorcing her husband shortly thereafter. Bonnie was the only one of the participants to divorce, a decision which impacted her confidence and finances initially, but gave her greater independence in decision-making. As a single mother, Bonnie had limited finances as she was the sole support for herself and child. Through contacts in an evening course, she applied early for a council flat in a new complex and subsequently learned about the Housing Act of 1980 which allowed tenants to buy their council flats. This use of her social network allowed Bonnie to build housing equity in her flat which she used when she decided to purchase a home in OurTown.

After completing secretarial training, Shirley benefitted from family connections to travel abroad for a job. This allowed her to pursue her goal to travel. In this way, Shirley was able to combine societal expectations (become a secretary) with her goal of travel, but it only deferred societal expectations that she would ultimately settle down and marry.

> *"I think my parents wanted me to be married. You know, all my friends, we didn't go to university. You found a husband, you got married and you had kids. Well, I didn't want to do that, I wanted to travel. And that's when I took off to [country]. I was out there for eight years, so I was quite old when I got back. I went out when I was 19." Shirley, R2*

Two female participants pursued university educations. Judith attended and graduated with a degree in music, yet she never considered having a career or finding employment in music. Shortly after graduation, she married, focussing on supporting her husband's career and raising their children. She continued to participate in music organisations and attend music performances, an interest maintained in later-life.

*"I suppose it was expected that I would get married, which I did, obviously. So that I didn't have a career as such, because I'd studied singing, but I think perhaps if I'd been more outgoing, more competitive, I might have tried to make something of that, but I wanted to have children." Judith, R3*

Mildred's university experience had a more direct application. Her father was a teacher, and she was brought up in a school, so teaching was her expected career. She completed a four-year university course in French and German at a Scottish university, after which she secured employment as a teacher at the same school where she had been a boarder. Her main goal was to earn money to help her parents.

*"With hindsight what I didn't see, teaching restricts your social life because it's rather intensive. But still being in the boarding set up, was even more restricting." Mildred, R1*

An additional restriction on her social life was her mother's death, at which point she became responsible for her father.

*"When my mother died, I remember after the funeral, they [her two older brothers] more or less said, well, take father with you." Mildred, R2*

Whilst her accommodation was usually provided by her school, her father lived in a hotel near to her, which is how she met her husband as his mother lived in the same hotel.

*"I really wanted to get married. I was 35 or so. … And also I suppose that various friends influenced me, they all encouraged me to get married. At that point, people do influence you. … Married friends." Mildred, R3*

Shortly after her father's death, she married her fiancé and left her teaching job to move to OurTown to be near her husband's job.

*"At that point, there were plenty of jobs for teachers, I didn't worry about another job. I took a year off and then looked around." Mildred, R1*

Mildred continued teaching until her husband retired, at which point she took early retirement to care for him.

The only other female participant to attend university was Winifred. She had wanted to attend after Sixth Form, but her father refused to pay. Winifred attended university 40 years later, after her retirement when her children were grown, and her husband was still employed. Her husband was supportive until his retirement.

*"So the only difficulty was the last year when my husband had retired … And he wanted me to go out and do things with him. Whereas I had got all my things arranged, you know, I didn't have time for this and didn't have time for that, so I had to be very tactful that year. But once I'd got the degree, it was all right." Winifred, R1*

For these three women who pursued university education, whilst the education was important for them, all three women found their educations and jobs subsidiary to the needs of their families.

#### 7.2.2.2 Family decisions

The one area where women had greater latitude concerned their children's education. Whilst the women may have felt their educational ambitions prescribed by their upbringing, they became advocates for their children's educations. Shirley and her husband disagreed over the education of their sons. Shirley, having grown up in her father's prep school, determined that they would go to boarding school at age eight, over her husband's wishes.

> *"I always trusted him implicitly with the decisions we made in our lives. Except, sending the boys to public school. He didn't want to do that. He hadn't been to public schools, he didn't think it was necessary and it was hugely expensive … But I took the reins then. And I said, [husband's name] I really want them to do this." Shirley, R1*

Over the course of the four interviews, this is the only decision Shirley said she made, protesting frequently that she could not make decisions.

Bonnie's most difficult decision was deciding to divorce her husband, something that was not common at that time and came with a stigma.

> *"I went through a stage where I couldn't have walked into a restaurant without perhaps passing out with nerves because I had been rejected in a way, and I thought it was the rejection that was making me ill. And it took me a long time." Bonnie, R2*

In the third interview, she returned to this lack of confidence after the divorce, yet despite this, she advocated for her son's education. She opposed the education authority's placement of her son in a comprehensive and successfully secured his placement in a grammar school because she felt that as the child of a divorced single mother, he needed greater support.

Dolores insisted on independent schools for her sons. Judith recognised that sending her daughter to the boarding school she had attended, was a mistake, withdrawing her and placing her in a school closer to home which was a better match for her daughter. Winifred persuaded her husband to move to a home with better schools for their sons, and Gladys was persuaded to send the last of her five children to a fee-paying school because he was considered academically gifted. Child-rearing decisions were generally the only decisions women could make. It is notable that the female participants with children were more determined in the decisions they made for their children, than they felt they could be for themselves. Gladys noted the problem, that they had little control over family finances.

*"When I did get involved more with WI, some of us got a bit, yes, yes, we wanted our own chequebooks even if we didn't use it. I can remember us talking about that. And that was something, things were changing, I suppose." Gladys, R1*

#### 7.2.2.3 Women and work outside the home

The main aspect of decision-making difference amongst the OurTown female participants concerned not whether they worked outside the home because most of the women did, but how they talked about work. As noted above, Mildred and Wanda both worked outside the home, making decisions about their lives and careers which changed when they married in their mid-thirties. Both marriages meant making choices between their marriages and their careers, but both continued working outside the home after marriage. Bonnie, too, continued working outside the home to support herself and her child.

Virginia was the one participant who identified herself as a career woman. At the first interview, she submitted a copy of her curriculum vitae.

*"It's just to give you a soupçon of my life, so I don't have to tell you every word." Virginia, R1*

By focussing initially on her career, it points to how she perceived herself and her life, although initially, this was possibly not the life she anticipated. Virginia expected to marry and have children. She was working for a large multinational company when she married at age 30. They planned to have a family, but her husband died within two years of their marriage. During this time, she found work a solace and was largely supported by her female boss who also became a friend, helping Virginia personally and professionally. After her husband's death, Virginia decided to buy a flat and continue working. With the encouragement of her boss, she took a promotion and moved abroad, to enhance her career prospects. She subsequently remarried a man eight years younger but continued working and was promoted into her boss's job. She continued working for the multinational until she took early retirement to care for her mother, prioritising family concerns over her career. After her mother's death, and because she and her husband had no children, her career was self-directed and a main priority in her decisions, continuing in other management roles until she retired at age 76. These four women who had careers spoke easily about their life decisions and how they made them.

In contrast, the five women who considered themselves as housewives, rarely mentioned their jobs. Additionally, they were reluctant to say they made decisions.

*"I don't feel I have anything interesting to tell you about decisions." Judith, R1*

> *"I can't make decisions. I have to ask somebody else to do it for me. I'm hopeless, I say, should I do this? And [son] will say, 'well only you know that, mum'. I say, help me darling, I can't do this. Why is [decision-making]t so hard? I think it's because you've always discussed things. Is it the lack of confidence in making important decisions?" Shirley, R1*

Whilst during the course of research it became clear that these women had made decisions, these comments appear to address the lack of confidence they felt in decision-making, except, as noted above, about their children's education. There almost appeared to be a stigma, as if it was unfeminine to make decisions. Whilst this was queried in interviews, the participants chose not to answer. In earlier-life, they made decisions, as long as they had their parents' or their husbands' support to make them. In midlife, with grown children or after the deaths of their spouses, these women became more decisive, making autonomous decisions.

Delores decided to re-marry. Previously her decisions had involved ensuring peace between her husband and sons. About five years after her first husband's death, however, she made a decision about her future.

> *"I was lying in my bath. I was 57 and I was still, I had a very nice figure and I looked young. So I was lying there and thinking to myself, I don't want to be alone for the rest of my life. I need another man." Dolores, R4*

The decision was both a mental shift, recognising that she could re-marry, and a resolve to meet eligible men.

Gladys decided to travel more after her husband's death. Judith decided to downsize and relocate; noting that she had become 'more bossy', meaning decisive, in later-life. As noted previously, Winifred decided to go to university, although she needed to fit this around her husband's interests. These women recognised that they had begun to make their own decisions. Only Shirley continued to protest that she didn't make decisions. When queried about her reluctance to admit to decisions, she passed them off as 'common sense' or 'because the alternative is so awful' or again repeated that she cannot make decisions. When pressed, she cited societal and familial expectation.

> *"I don't know whether it's a lack of confidence, we had a very, you know, what you should do and what you shouldn't do. Nowadays they've got freedom that we didn't have … We didn't have freedom of what we decided, our parents decided what we would do, and where we would go … and even the type of friends we had." Shirley, R3*

What is notable about Shirley is that although she continued to protest that she didn't make decisions, as will be seen later in this chapter, she was clear and proactive in her decisions, but she was reluctant to call them decisions.

### 7.2.3 Summary

*"There used to be a joke about [decisions]. The husband declares wars, and the wife tells him what kind of car they're going to have, and where the children will be educated." Glenn, R4*

From the first independent decisions cited by the OurTown Participants which generally concerned education, careers and family, there were gender differences in the process, considerations, and influences on decision-making. In general, men made their decisions based on their own goals with the support of their families and colleagues, whilst women were constrained by societal and familial expectations that their careers were secondary to their husbands'. Consequently, their decisions were not necessarily goal-focussed but a reaction to circumstances as they developed. In midlife, however, men began to incorporate a more collaborative approach, considering familial factors, whilst women were able to become more self-directed in their decisions. As will be seen in the next section, social networks and how they are used also impact decision-making.

## 7.3 Social networks and decision-making

As was seen in Chapter Five, the main decision-domains concern identity, activities, relationships, and resources and as was noted in Chapter Six, the main goal of later-life is to continue meaningful engagement with people and activities. In most cases, this goal involves social networks, either as the focus in the companionship they provide or in how they help sustain or support meaningful activities. In both situations, participants made decisions about people, activities, and resource deployment. The decisions also involved identity, e.g. whether they were the type of person who takes exercise classes to stave off physical decline or whether they were the type of person who pays for higher levels of service to accomplish goals. As will be seen, there is heterogeneity in how people maintained and used social networks.

As was explained in Chapter Three, social networks provide instrumental support, companionship, emotional, and informational support (Wenger, 1991; Cornwell and Schafer, 2016). They also help to mediate behaviour, maintain identity (Wenger, 1991), and provide a monitoring function (Cornwell and Schafer, 2016). The OurTown Participants' social networks provided companionship and support in helping sustain the types of activities they like doing, and also in helping maintain identity and their roles in the community. This section will look at the types of social networks the OurTown Participants have and how those networks supported decisions about activities, focussing on how gender differences impact both the networks themselves and the goals and activities of later-life.

### 7.3.1 OurTown social networks

The purpose of the OurTown research is to understand how participants make decisions about their lives, not to study social networks and social network typologies. Social networks provide different types of support and decisions are made about them (their composition, purpose, contact frequency and activity participation). Thus, it is important to understand the social networks, the types of support provided and the decisions, especially as this chapter concerns heterogeneity, as men and women appear to approach them in different ways. Nearly all the participants had diverse networks which included many different types of contacts:

- Family (spouses or LAT partners, children and grandchildren, siblings and/or nieces and nephews)
- Friends of varying degrees of closeness
- Neighbours
- Organisation contacts from alumni associations, former business colleagues, service clubs
- Voluntary organisation contacts
- Contacts from classes, cultural organisations, book clubs, cruises
- Church members
- Weak Ties such as a cleaner or gardener, The Manor concierge, check-out people at Waitrose, or a frequent taxi driver. Throughout the course of data collection none had regular carers, except for Eugene whose son provided instrumental support.

As important as the diversity in the network, however, was frequency of contact amongst these groups and the focus of the network. The network focus, whether diverse networks focussing on friends (as might be the case for participants whose children live at a distance or abroad or have no children), or family-focussed (for those who have high frequency contact with their families and whose main social life centres on family) is the other consideration in network typology. The majority of the OurTown Participants would be in either of these two categories. A third type, restricted networks, is for those who have small networks and little contact with others. As only one OurTown participant is in a restricted network, this will be considered first, before progressing to discussion of family-focussed and diverse networks.

#### 7.3.1.1 Restricted social networks

Eugene was the only participant in a restricted network. He was also one of the oldest participants. He lived at home with his son who was his carer. Most of his friends had died. Eugene had the smallest social network as he rarely left home. His only other contacts were by Skype to a friend abroad, and by telephone to his sister with dementia who also lived abroad.

*"It makes me a little bit sad, thinking of the past. Wonderful days. Yes. I'm sorry I never got to visit Australia and New Zealand. The only one of my best friends who's still alive is out there." Eugene, R2*

Five years previously, Eugene would have had a diverse network. His wife was still alive, his two daughters lived locally, he was active in the local community and had many friends he could contact for companionship and support. In the intervening five years, he ceased voluntary activity and participation in outside organisations to care for his wife. After her death, both of his daughters moved away, and one became estranged. Athletic in his youth and into later-life, at the start of data collection, Eugene still walked about the neighbourhood and to the local public house. By the end of data collection, however, his walking was restricted to what he called 'furniture walking', walking from one strategically placed chair or table to another within the house, or around his back garden. Eugene previously made the decision to engage his son as his carer, as opposed to moving into a retirement complex or care home. His son became his only source of support and companionship. By being so dependent on one source of support, Eugene became vulnerable late in life due to his son's ill health and given Eugene's restricted social networks, he had limited social resources for assistance.

#### 7.3.1.2 Family-focussed social networks

For those in family networks, family was their main source of companionship and support. Their main source of socialisation was attending family meals, events, and celebrations, occasionally still supporting family with financial loans or gifts of money. This group was primarily male (5M, 1F). All of the married men were in this group and all agreed that their wives were the organisers of their social lives. Without their input, it is possible they would have been in the restricted group. During the course of research, all curtailed their outside voluntary activities to a narrower geographic spread.

Gladys was the only female in this category. For her, family and the family's position in the community were an important part of her identity. She and the family were staunch volunteers in every aspect of OurTown life. She spoke of the sense of responsibility that older families had towards the community, contributing to the community betterment. Whilst she recognised that that way of life was gone, she carried on volunteering, maintaining in a lesser way that role and identity. Her social network included people she met on her travels, through her extensive volunteer work, and her extended family, but increasingly focused only on family and the church. She still had friends for socialising, but contact was increasingly by telephone. Whilst she was no longer involved directly with the family business, two of her sons still came to the family home for lunch every day. This maintained her family connections and allowed them to look after each

other (one of her sons had a neurodegenerative disease), whilst also maintaining her sense of identity as a mother and her connection with the family business.

> *"I always thank my lucky stars that I've got all the inconvenience of dirty cups on the draining board." Gladys, R4*

Although Norman still volunteered for some local organisations, he discounted the importance of his activities in providing social interactions. Norman described his social network as follows.

> *"A lot of my friendship groups centre on the church as you might expect. … You don't go to church to meet people, but that is one of the things that happens … Apart from that, I mean obviously I've got family. I have one group of former colleagues who meet occasionally, and we started out as a group of nine and we're now a group of four … I don't really have any friendships from school or even university." Norman, R1*

Norman's wife and daughter died many years ago and his son lived abroad. His main social interaction was with two grandchildren who lived with him, although he expected this to end when his granddaughter secured a job and his grandson a place at university. What was notable was that although he met people through church and with his voluntary work, Norman did not consider any as friends, nor did he make efforts to convert contacts into friends.

Frank's social networks reduced after his wife's death, and due to the death and relocation of old friends. This change was exacerbated by his subsequent decision to downsize and move closer to his daughters. Whilst Frank served on the entertainment committee and the board of directors of The Manor, his main social contacts were with his daughters and their families. His move to the retirement community was successful in that there were socialising opportunities within The Manor.

> *"I go down in the lounge every morning which nobody used to, and so, quite a few people come in and have a chat and what not, so I'm beginning to make that more of a social thing." Frank, R3*

Like Norman, Frank did not seem to convert contacts to friends. This inability may be why some of the men's networks progressed from family-focussed to restricted, which may happen for Norman when his grandchildren move on. For the men who were still married, their wives were responsible for organising social contacts, meaning they were dependent on family for social engagement and support. The men's networks narrowed due to bereavement and relocation, but also the inability or disinterest in converting contacts or acquaintances into friends.

> *"I've lost people I was quite close to, and I'm not good at making new friends, at my age, it's not so easy." Glenn, R2*

The disadvantage to family networks is that the only source of support and companionship is from family, thus restricting outside sources of information, making people vulnerable to a decreasing range of activities, companionship, and sources of possible support. For men in family networks whose wives were still alive, they were also more vulnerable to their wives' ill health.

#### 7.3.1.3 Diverse social networks

Diverse networks are characterised by regular contact with family and friends and with participation in the community. Academic research tends to divide these networks into those who have children and those who don't which may be appropriate for younger people, but in later-life, the OurTown Participants derive as much social support and connection from their friends and neighbours as they may from children who may live at a distance or in another country.

This network type is predominantly female (2M, 8F), despite the fact that the female participants, on average, are a year older than their male counterparts. Academic literature suggests that social networks retain their internal structure over time (Cornwell *et al.,* 2020) and this is true for the OurTown Participants, except the two men who have live-apart-together (LAT) partners, the impact of which is discussed below. Even within the diverse networks, however, there was heterogeneity in terms of network breadth, frequency of contact, and types of activities.

Dolores's diverse network was typical of the female participants. She had regular virtual contact with her children as the closest lived over 200 miles away. She met people through her cultural activities, through language lessons and classes she has taken, through bridge games, even attending medical appointments where she described meeting a nurse who helped her to the car. Learning that they have similar backgrounds, they had begun attending cultural and religious events together and her new friend took her shopping for a dress for her grandson's wedding. This demonstrates a major difference in that the women seem more capable of converting a contact into a friend who can provide companionship and instrumental support.

Dolores described the participants at a recent bridge party.

> *"Well two of them are very very old friends from when I used to live in [her home with her first husband], but we've kept in touch all the way through. I mean they came to my ninetieth birthday party. We're… going to the theatre in January. ... In fact she was my French teacher at one stage. I went to classes and she was the teacher and then we played golf together. They'd learned bridge, they'd learned golf, and with [my second husband], they're very very old friends. And the other one I've known about 12 years. She… played [bridge] yesterday at this Monday group I've introduced her to. So she's making up the fourth. [She came from abroad]. I don't know how long she's been in England,*

*35 years? But I still don't understand a word, it's as if she came yesterday. Extraordinary." Dolores, R4*

This extract captures the interconnections of Dolores's network and diverse networks in general. Dolores maintained friends through relocations and relationships. She actively cultivated her friends by suggesting different types of activities and socialising which they, in turn, also suggested for her. These connecting opportunities provided new activities and sources of potential new friends. She was adept at converting new contacts into friends. Finally, she noted that even though there were language issues, they still enjoyed each other's company and played bridge together.

Dolores's network also provided encouragement and advice for her decision-making. She was apprehensive about travelling to visit her son abroad, but her friends encouraged her to set aside a lifetime's thrift and fly business class which gave her the extra level of service she needed to accommodate her decreasing mobility. Whilst these connections may appear to be formed from a gregarious personality, they are built from a long chain of decisions – decisions to foster and retain friendships, decisions to learn and take courses, and decisions to overcome possible physical limitations to continue doing those things which give life meaning. Her goal was to continue living as fully as possible and her network helped her achieve this.

Diverse networks included family members, although as Dolores's family lived at a distance, they were unlikely to provide support in an emergency. Even with nearby family, friends may be a first point of contact. When Bonnie had a minor health emergency, she depended on her Manor friends. Winifred and Shirley reacted similarly when they had accidents. There appeared to be a reluctance to contact children. The reasons given were that they don't want to bother them or to become a burden. An underlying reason may be that they wish to maintain control. By depending on a child in an emergency, that child may wish to limit future activities citing safety concerns. Friends are more likely to maintain reciprocal relationships, helping each other without seeking to control. In these situations, family members were usually informed after the event.

The women who were widowed and/or without children developed relationships with friends or neighbours whom they could contact in emergencies. Wanda had a friend whom she considered next-of-kin. The two became close because her friend's husband died of similar causes to Wanda's second husband.

*"Her husband died just slightly before my husband started on his four-year thing [cognitive decline due to dementia], so she had four years with the same sort of thing, and she would tell me who to call, who to go to and how to do everything….who to ring for this nurse, who to ring for a wheelchair, who to ring for whatever." Wanda, R3*

Wanda benefitted from her friend's experience in caring for her husband. The two remained close and provided instrumental help for each other. Even though her friend had a new partner, they continued to go on cruises together and to look after each other. Wanda also noted the benefit of living in The Manor with social connections on the doorstep.

> *"It's there for people to mix, but everybody, when you meet them, whether they are mixers or not, they'll always pass the time of day." Wanda, R3*

Like Dolores, she had a diverse set of friends, including people she met on cruises and a variety of weak tie contacts.

> *"I know more and more people here and you go out into the street. And if you walk, you speak to people, maybe you just say hello, because you recognise them. I sometimes chat with the concierge, when I go down. The cleaners are here today, sometimes I chat to them. The gardener, I chat to, and I told you I was a director, so I'm in that group, too. And somehow, you just get to know more and more people, and go for a little drink or something." Wanda, R3*

In this description, she noted one of the advantages of weak ties mentioned by Huxhold *et al.* (2020), that by having a large group of weak ties, they can be cultivated into a closer connection, replenishing or rejuvenating the social network. Wanda also noted the value of the vicarious experience of others at The Manor. A woman who lived on her corridor had the same disease that Wanda was recently diagnosed with, so she was following the progression of the disease by watching her friend, learning by her example.

> *"I have a friend along the corridor, who is quite far down the line with, you know, oxygen and morphine, so it has made me think, right, I'm not going to live to 100, so I'll be booking more Saga tours." Wanda, R3*

Mildred who was one of the oldest participants, had few living relatives and many of her close friends had died. She had been an active volunteer in OurTown, however, and was known in the community.

> *"Whenever I go to Waitrose, I nearly always meet someone. I wouldn't say I've got many close friends. But then, that's a different story, isn't it? I've got, say, I've got a couple of close friends in Our Town and one in [nearby town] … I rather regret that I haven't got more friends. I've got lots of acquaintances at the church and lots of people I meet in Our Town who seem to know me." Mildred, R4*

Despite her lack of relatives and old friends, Mildred seemed to thrive on her weak ties. In her neighbourhood, she cultivated her neighbours through playing Scrabble, comparing scores on University Challenge, taking each other shopping, and, as a volunteer at a local landscape gardens, taking her neighbour with children to the gardens.

*"I've had dozens, well not dozens, but it must be six or seven neighbours I'm joined onto. And in a way they're more important because if something goes wrong [there's someone to call]." Mildred, R4*

Given her narrower social networks, Mildred realised that she would have to work harder to cultivate and replenish her social networks.

*"I tend to be the person who takes the initiative socially. I don't wait for people to contact me." Mildred, R4*

These situations demonstrate why people need different types of contacts in their social networks and how the OurTown Participants adapted their social networks to answer their needs. Mildred and Wanda both took the initiative in cultivating weak ties for these purposes. Other widows who may have family nearby, appreciated the need for friends who are available for companionship, instrumental support, and emergencies. Three of the female participants formed confidant relationships with other women and another cultivated her gardener who assists with technology and transportation. In very-late-life, many of the OurTown female participants made conscious decisions to expand network contacts in anticipation of future needs.

#### 7.3.1.3.1 Live-apart-together (LAT) relationships

A LAT relationship is a monogamous partnership between unmarried people living apart but considering themselves as a committed couple (Benson and Coleman, 2016). The two male participants with diverse social networks, Ronald and Clarence, had LAT partners. Ronald's and Clarence's LAT partners transformed their social networks and provided different types of support: instrumental, informational, companionship and emotional. Clarence's and Ronald's partners encouraged them in positive health behaviours, and their partners expanded their social networks and the types of activities and experiences they pursued. Both partners were also the first point of contact in emergencies.

Ronald's social life was invigorated after his wife's death when a neighbour invited him to the local British Legion. He became an active member and his neighbour became his 'lady friend'.

*"We've struck up a relationship. She does all the shopping for me, or most of the shopping for me, and I treat her to the odd thing now and then. We go out, I go up, she's only at the top of the hill. And I go up there and have a cup of tea, you know, most days, that sort of thing. So, there we are." Ronald, R1*

He noted that this pattern was different from his previous relationship with his wife as they rarely socialised or participated in community activities.

*"I socialise more since she died than ever I have during my life." Ronald, R1*

Clarence's LAT relationship provided similar network re-invigoration. His Asian LAT partner introduced him to a broad international social network, joined him in travel opportunities both as a couple and with her family, and promoted linguistic skills, as he began learning her language. He attributed his improving health to her encouragement to undertake health and exercise behaviours. During his emergency admission to hospital with meningitis, she drew on her Asian medical contacts to assist in his treatment and recovery. Both were devout Christians and assisted their local vicar whose adopted daughters were from the same Asian country. One of Clarence's unresolved decisions was whether to marry her, which exemplified one of the differences between a LAT relationship and a marriage. A LAT relationship is a lifestyle choice and an end in itself, not necessarily leading to marriage and where the partners maintain financial independence (Benson and Coleman, 2016).

> *"I mean we certainly like the arrangement when we're not always living together because I think we'd kill each other if we did. On the other hand, we're very close, and the other thing is death duty. But with death duty, we're just trying to work out because she would lose provisions from her late husband, which I could supplement, no problem, but she would lose that. And all her life, she's lived on a principle, which [is] always make sure that you can make your own living … Never be dependent on anybody." Clarence, R4*

Ronald also maintained a sense of separation in financial matters based on his definition of reciprocity, that he paid for groceries, but she cooked for him, which became more frequent during a period of ill health.

> *"She's been a brick, 'cause she's come down and cooked me meals and that sort of thing, done shopping for me … I mean she's been a brick in this past month … She's been using my oven, to cook us both a meal. And I square with her, by paying her for doing it. And you know, that's the only way I think it will work." Ronald, R3*

Shirley was the only woman who had a LAT partner, but he died a year before research began. Hers was a relatively short relationship, only four years, but in that time, they travelled extensively, shared activities, learned from each other and supported each other through health problems. The only problem in the relationship was that he had traditional ideas about relationships until Shirley addressed the issue directly.

> *"I said to him, I need to just wipe the slate clean. I don't want to marry you, I don't need your money, and I'm not going to live with you … I don't want to be married to anybody. It isn't that I don't love you, I do love you, but I've waited a long time to do what I want to do in my life. And I'm not going to surrender that." Shirley, R3*

This was an example of Shirley, who said she never made decisions, clarifying a situation (which she would not call a decision), and yet, by deciding to confront the issue, she possibly secured the

relationship. From that time, they socialised and travelled together frequently and whilst he would pay for the trip, she would pay supplements to upgrade the class of travel and pay for extra luxuries.

For these three participants, their LAT relationships reinvigorated their lives but also made them redefine later-life relationships, not just with the LAT partner, but also with family. Clarence's children disapproved of his LAT partner which forced him to choose between his children and his partner. In choosing his partner, he became estranged from his children and all but one of his grandchildren. This necessitated changes in his end-of-life preparations. Clarence increasingly found support from younger people whom he formerly mentored and formalised this somewhat in making the decision to make them executors of his will. In all three situations, the LAT partners were initially peripheral contacts or weak ties and whilst there may not have been a conscious decision to cultivate the partnership, the relationships transformed lives, introducing new people, activities, experience and knowledge which supported decisions about the future.

### 7.3.2 Activities and social networks

Social network decisions involve more than deciding the composition of the networks, there are also decisions about how to use the network. As important as the network members themselves, is what the social networks provide. Whilst traditional academic research focusses on the support provided by social networks, for the majority of OurTown Participants, the primary purpose of social networks was to provide companionship, social engagement, and the ability to explore and continue with meaningful engagement. People make conscious decisions about how they want to spend their lives. The social networks and the diversity within allowed them to pick and choose which network members best supported the desired activity. Choices were made about network members and the types of things they do with them.

Compared with the six men who did not have LAT partners, the women continued to explore a wide variety of cultural activities, clubs, educational classes, exercise classes, and social events like bridge games, teas, lunch or dinner parties. It exemplified a symbiotic relationship, as diverse activities resulted in a broad and varied social network, but also required broad and diverse social networks to support them. Certain social network members might be bridge players, others enjoyed educational or cultural events, whilst others served as confidantes or cocktail party companions. This demonstrated the value of broad social networks, as participants select which social network members are best suited for which activity.

On average, the OurTown female participants were actively involved with four different organisations, attending meetings or events regularly. The men, typically, were only involved in

one or perhaps two activities. The women's involvement required them to curate or proactively manage their networks, organise events and looking after their friends.

> *"I think you have to cultivate, sounds rather calculating, but cultivate friends who are helpful." Mildred, R3*

The women were more strategic in ensuring they had appropriate people in their networks to support their activities and that they had different types activities to choose from. They organised regular social gatherings to remain in contact, they selected amongst people to accomplish their goals, be it for a specific activity or companionship. Whilst men may have used colleagues earlier in life to help them in their employment, women used broader social networks throughout their lives. Throughout their lives, the female participants were more proactive in maintaining and nurturing social networks, as well as encouraging each other to maintain and try new activities.

An example of the different approach to social networks can be seen with Bonnie and Frank. Both lived in The Manor. Both were Directors and involved in the Entertainment Committee. Other than family, these activities formed the basis for Frank's social network. Bonnie used these same contacts to learn about and join a writing group; another told her about an exercise class which they attended together. Outside of her Manor activities, she also volunteered for the local library and the OurTown Hospice, occasionally meeting-up afterwards for lunch. She formed an occasional relationship with the woman who bought her house and lived nearby. In all these different ways, Bonnie explored relationships and new experiences.

This approach to meeting and making new friends was enunciated by Virginia.

> *"I still make new friends now. Not many, but I mean I bumped into somebody at a party for about 50, lived around here, but was never a friend, just an acquaintance, and we started talking and we discovered we had a lot in common. So we're sort of not close friends, but we're developing a closer relationship than we ever had before, much later on in life." Virginia, R4*

The male participants tended to view their volunteer activities as an extension of work, that the purpose was intellectual and service, not social. Conversely, the female participants enjoyed activities not just for positive feelings of involvement but also for the social engagement possibilities, frequently meeting afterwards for lunch or arranging subsequent social events with their new friends.

#### 7.3.2.1 Curating social networks

Shirley, who had one of the broadest and most diverse social networks, provided an example of how she selected and cultivated her network and how it met her needs. Shirley liked to travel

and explore. She still drove and was curious about a historical site. She drove with a new friend who was a neighbour and a Blue Badge Guide, assuming they shared a common interest in history. Instead, she had a different experience.

> *"She [her friend] is **soooo** negative. I felt so depressed when I got back. She didn't like the places we'd stayed in. I'd chosen B&Bs. She didn't like those. She didn't like the food that they had up there. She didn't like **anything.** There was nothing right, but she tells everybody she had a lovely time. I came back so depressed." Shirley, R1*

Instead of addressing the discomfort directly after the trip, Shirley continued to socialise with her as a neighbour, until the friend suggested they take another trip together, at which point Shirley addressed the previous trip directly.

> *"I said actually it didn't work very well last year, darling, did it. So she said, that was the weather. I said, it wasn't only the weather, was it? I think she's got the message. She's coming in to have a drink with me tonight because I feel so sorry for her. She's got no friends and nobody in the world." Shirley, R3*

Shirley continued to invite her for drinks occasionally but decided even this has its limits.

> *"I've got one [friend] that lives here, I've told you about her, she's my negative friend. And she drags me down into her miserable world. And she was getting too close to me - always wanting to go away and do this and the other and I can't do it anymore. I said to the boys [her sons], I can't with her, and they said don't be so unkind. Don't be unkind? I said it's not unkind, it's self-preservation. I'm tired of people like her. I'm forever having her in for a drink. Does she ever entertain me? It's not a one-way thing. She said I like to get out of the house. I said so do I sometimes. And she never asked me back." Shirley, R4*

Shirley was the most direct of all the participants in curating her social network. This example shows how she selected someone, a neighbour who has particular attributes as being available and a Blue Badge Guide so they might possibly share an interest in history. In a sense she promoted a contact from being just a 'neighbour' to becoming a closer travelling companion, testing the arrangement by travelling with her and sharing an activity experience. Whilst she didn't risk unpleasantness during the trip itself, upon the return home, she continued to occasionally invite the neighbour for drinks, until the neighbour proposed another excursion. Shirley had already determined the boundaries of her relationship with this neighbour and made those clear, although she continued to have drinks with her. In a sense, she categorised this friend as an occasional drinks friend, yet even in the end, the lack of reciprocity or shared values of the relationship, meant that Shirley considered less contact, but it was still an open decision. This ongoing process shows the advantages of an evolving decision. Ultimately, Shirley may keep her as a friend to have the occasional drink with, on Shirley's terms. This demonstrates the types

of decisions made in relationships and the activities supported by the relationships. In one progression, she demonstrated the process of intermediary steps of a possible peripheral contact becoming a closer contact, experience of the relationship over time, and the subsequent decision to relegate the travelling companion to a more peripheral place. The decision was still open, as Shirley retained the option of inviting this person for drinks. The fact there was no final decision, that there were levels of friendships with boundaries and criteria, means this social contact is open to reconsideration depending on need.

Of the men, only Clarence similarly curated his social networks. Clarence maintained contacts from all areas of his life. He still had school and alumni friends, contacts from National Service, his career as a teacher and housemaster, his subsequent career in industry and European consulting, his relief work and subsequent community development work with aid agencies, as well as his local community social and volunteer contacts. His friends and contacts receded and reappeared, in a sense, as he needed them in his life, either to support his activities, or because his friends needed his assistance. He was generous with his time and money and helped support many young people to achieve their career goals. He continued to tutor one student and regularly socialised with two young people, one of whom he trained during his consultancy and the other whom he met during his aid work. As noted previously, these two became fictive kin and in the absence of his own children who 'divorced' him, he appointed these two young people as executors of his will.

#### 7.3.2.2 Emergencies

Social networks also provide support during emergencies, but again, men and women react differently. Shirley, Bonnie, Dolores, and Winifred all experienced falls during the course of research. Shirley contacted a friend, only telephoning her sons when she was out of the hospital and back home. Dolores was with a friend who took her to the hospital, and only latterly did she contact her son who helped her arrange care. Bonnie contacted neighbours and friends in The Manor whilst Winifred contacted the service using her emergency alarm. When the emergency services failed to discover Winifred's broken ribs which were the source of her increasing pain, her friend took her to the hospital, waiting with her for an extended period in the accident and emergency department. In all cases, friends provided the necessary support, including after care. The women were reluctant to 'bother' their children, even though they lived locally (for Shirley, Bonnie, and Winifred). This was also the case for the men with LAT partners, as their partners were the first point of contact.

When Ernest, Norman, Eugene and Frank experienced emergencies, family members were the first point of contact. These men did not seem to have close enough relationships with any

friends to be able to contact them in an emergency. It is unclear what could happen in the future or in a longer-term situation. This experience suggests, however, that as much as possible, the women will depend on their friends, seeking to maintain independence, not burdening their children, and paying for care as needed.

#### 7.3.2.3 Social networks in very-late-life

As seen in Chapter Six, it is challenging to predict how the participants might respond to declining health, emergencies, and the need for future care. The four participants over age 90 (2M, 2F) could provide an indication of how social networks and activity levels change in very-late-life, and how the participants make decisions. Again, there appeared to be a gender difference.

As noted above, Eugene had the most restricted network which shrank from a diverse network to a network encompassing his son and a friend whom he occasionally Skyped abroad. During the course of data collection, Eugene progressed from being independent and steady enough to walk around the neighbourhood, walking his dog, chatting with neighbours and monitoring the progress of local construction, to being essentially housebound, but still protective of his autonomy. His neighbour who knew of Eugene's son's illness enquired if he needed help.

> *"Then he said, do you need any help? And I said, no. He was anxious to help, but I said, no, no, no, coping well, thank you." Eugene, R4*

Instead of trying to cultivate the neighbour, should he need help in the future, Eugene did the opposite.

Ronald, too, found his network narrowing as his friends were dying. He continued to socialise in his service club, but he ceased his voluntary activities with them. His social network essentially encompassed his LAT partner, his son, and the neighbours who were available for emergencies.

The networks and activity levels of these two men contrasted with Dolores and Mildred, who were in their same age group. Dolores and Mildred also reduced their volunteer responsibilities. Mildred recognised that for the good of the organisation she worked for, it was time to curtail her activities.

> *"I know I shall miss it [the volunteering]. But you know I don't think it's fair because at 91 you have a risk of some health problems exacerbating, sort of suddenly, and then it will be terrible mess for the [organisation]." Mildred, R3*

Yet although both women curtailed their volunteer activities, they continued to cultivate a wide circle of friends and neighbours and plan for future cultural trips. Both continued to pursue other interests: Dolores was taking piano lessons and Mildred an art course. They both exerted

themselves physically, considering this a way of promoting continued mobility. Both women, although they used sticks, continued to walk in the community.

> *"I try to walk a bit every day. I'm not really fit enough for an exercise class, I used to go, but I can't keep up. But walking is the thing." Mildred, R3*

During the course of the research, Dolores fell which impacted her physically and mentally in the way she thought about physical capacity. She stopped playing tennis, but still walked around the neighbourhood, using a stick. Mildred challenged herself similarly. Dolores and Mildred were still involved in activities, attending concerts and cultural events, and organising social get-togethers with friends. Both continued to travel but paid more for higher levels of service. Both maintained diverse social networks. Neither had local relatives to depend on. Dolores's closest child was over 200 miles away and she stated that her life was in OurTown, she would only move near her child if she were incapacitated. Mildred had no children. Both depended on neighbours, friends, or paid help for assistance.

> *"Because for me, I'm on my own. Nobody else is going to help me. Well, that's a bit that's a bit strong, but there's nobody. It's not like having a husband or companion … who is around." Mildred, R4*

The women overall seemed to take a more proactive stance in thinking about the future. Both women (as were all the female participants) tried to balance maintaining meaningful engagement with a concern for safety, deploying social and financial resources as necessary. They wore personal alarms, pushed themselves to continue walking or taking exercise classes. Many had already installed stairlifts and transformed baths to showers or wet rooms. Except for Clarence who was organised by his LAT, none of the men have. The reason for this could extend back to the decision-making of earlier-life when women had to work within constraints to achieve their goals and this left them with the practice of working around limitations.

## 7.4 Summary

This chapter set out to explore heterogeneity as it impacts decision-making which for the OurTown Participants mainly concerned gender differences. What is suggested by these results is that from the first decisions the participants made, which centred on education, there were gender differences. The male participants made self-directed decisions, supported by family and social norms, whereas the female participants' early decisions were constrained by family and society. This meant from the beginning, women's decisions, including the women who were career women, needed to anticipate and negotiate circumstances and family and societal expectations. For women this early pattern of decision-making, of considering it a process where divergent considerations needed to be balanced, became the subsequent pattern for their

decision-making. Even in later-life, whilst the women became more decisive, they also retained the need to balance other considerations which in later-life means balancing safety with independence.

These findings also noted the importance of and difference in the social networks and activities of later-life. The OurTown Participants recognised they were beginning to experience declining health and narrowing of social networks due to bereavement and relocation. In response, the men appeared to accept this as the natural progression of life. Conversely, the women continued to maintain and develop their diverse networks and participate in nearly four times as many activities as the men. Women continued to explore new activities proactively and strategically use their networks to achieve their later-life goals.

# Chapter 8 Discussion and conclusion

*"I've waited a long time to do what I want to do in my life and I'm not going to surrender that." Shirley, R3*

The main question addressed in this research concerns how people aged 85 and above think about and make late-life decisions. Academic theory and empirical research were presented in Chapters Two and Three. The sub-questions queried decision-making over the lifecourse, anticipated future decisions and the process for making them, and heterogeneity in decision-making, which were addressed in Chapters Five, Six, and Seven, respectively. Bringing these findings together provides an answer to the main question, how do people aged 85 and above think about and make late-life decisions.

This Chapter will first review briefly the theoretical and empirical research underpinning the project before proceeding to sections which answer the research questions. The Chapter continues with suggestions for future research and policy recommendations before closing with limitations and final conclusion.

## 8.1 Theoretical and empirical foundation

The lifecourse paradigm informs this research, providing a framework for understanding how personal development is shaped by the interaction between external factors and individual agency. The external societal systems include social networks, schools and other organisations, and historical and cultural contexts; life history and its impact e.g. on health, socioeconomic status and cumulative advantage; and on social roles (Zacher and Froidevaux, 2021). Additionally, using a lifecourse approach for decision-making permits the examination of an individual's decisions throughout their lives from their biological, historical, social, cultural perspectives (Alwin, 2016; Bengtson *et al.*, 2005; Milne, 2020) as well as the cumulative impact of previous life decisions and the choices people make (agency) (Bengtson, 2005; Milne, 2020).

The historical time of the OurTown Participants was especially salient in shaping their lives. In living through World War II and subsequent deprivation, they developed the habit of thrift, but also a general stoicism in emotional response, of 'just getting on with it'. They also benefitted from a rising post-war economy and a change in housing laws impacting home ownership, which affected their current financial situation. These cumulative factors and their historical and societal contexts impact the way the OurTown Participants think about and make their later-life

decisions in that they have a dispassionate and well-developed sense of caution and thrift, which in later-life they are balancing with a growing awareness of the impact of advancing age, declining capabilities and a limited future time horizon. They are increasingly aware that to prioritise what they want to do, that they may need to deploy greater resources, for instance, by altering their views on thrift.

Inherent in lifecourse theory is the idea that there are different life stages and different developmental tasks dependent on lifecourse stage. This idea underpinned the analysis of decision domains, framing decisions by lifecourse stages, showing the commonality in decision domains, but how the focus, goals and resources change throughout the lifecourse. Erikson's conceptualisation of eighth stage focuses on resolution and re-evaluation of identity and continuous development (Erikson *et al.,* 1989) which is similar to Tornstam's (1989) focus on identity and coherence of past and present selves in later-life. The common factor in the conceptualisations of ageing is that identity continues to develop throughout life. In very-late-life, there may come a period when possible health declines prompt a redefinition of autonomy and hence, identity. Maintaining the identity, the sense of self in control of decisions, may mean that autonomy is redefined to encompass choosing to accept limits on independence, e.g. by hiring domiciliary care or moving to a care home, in order to make an anticipatory decision of protecting health and not burdening family.

Other theories impacting ageing and decision-making are:

1. Selective optimisation with compensation (SOC) is a strategy to manage health-related decline by optimising what can be done, to maintain competence and achieve goals (Baltes and Carstensen, 1996).
2. Consistent decision-domains exist throughout the life course, but their dominance changes depending on the lifecourse stage with decisions about safety and security increasing in importance given SRLE (Kornadt and Rothermund, 2014; Kornadt *et al.,* 2018 and 2020). This will be discussed in greater detail in Section 8.2.1.
3. Continuity theory proposes adult development continues throughout the lifecourse and people learn from previous experiences to adapt to new situations. In making these adaptive choices, there is continuity in maintaining levels of activity, living and social arrangements (Atchley, 1989; Atchley, 1999).
4. Prospect theory anticipates that people will change their minds as their reference point changes and that their perception of future and past decisions changes over time depending on the reference point (Bern-Klug, 2017; Kahneman and Tversky, 1979).
5. Social networks, or relationships, support decision-making throughout the lifecourse, but men and women negotiate relationships differently (Cornwell and Schafer, 2016; Cornwell *et al.,* 2020; Wenger, 1999; Jerrome and Wenger, 1999),
6. Complex decision-making requires evolving development including prioritising values and re-evaluating goals, in a process which involves information seeking, assessment, strategy development, and contingency planning, all of which may evolve over time with intermediary steps explored (Heiss, 2018; Löckenhoff, 2018).

Whilst theory suggests how people may react, empirical research demonstrates how people actually respond and the results of changes in health capacities. The empirical research suggests there are three health trajectories of later-life with some people maintaining high levels of cognition and functioning until death whilst others have a precipitous decline into fourth age. The third trajectory is a more gradual decline suggesting increasing frailty and the need for greater support (Cosco *et al.,* 2016; Johnson and Barer, 1997; Stephan *et al.,* 2018). In accommodating later-life, people re-order priorities so that activity is congruent with capabilities and that in the process, goals may be redefined, as suggested by SOC. The hope for later-life is that people can continue living at home, dying peacefully in their sleep, but the overarching goal is to maintain independence and control. This means that independence is redefined so that control is maintained by 'choosing' greater support or moving into care, thus maintaining the identity of a person in control (Cosco *et al.,* 2016; Lloyd, A. 2016). Research also suggests that maintaining social connection and meaningful activity support health (Rantakokko *et al.,* 2020). For those experiencing a gradual or precipitous decline, falls and increasing frailty may indicate the need for more care or a care home (Fleming, 2008).

Specific later-life decisions concern relationships and social networks, health and advance-care-planning (ACP), residential decisions and driving cessation. As noted above, social networks are important for later-life decision-making because they provide support for activities, companionship, and information. Women tend to be more proactive in maintaining their networks whilst men's networks tend to be more activity-related which means in later-life as activity decreases, social connection may decline. By later-life, people generally have made wills, but remain reluctant to commit to further ACP until there is a need to do so (Lloyd-Williams, 2007; NPEOLCP, 2017). Most people wish to remain ageing at home until death and those with higher socioeconomic status will generally contract for private care in the home (Krout and Wethington). Regarding driving cessation, women are generally more proactive, gradually weaning themselves from driving over a lengthy time. Men generally found the decision more difficult as it required a loss of role identity (Musselwhite and Shergold, 2014).

To summarise, these theories and empirical research provide an academic framework for the OurTown findings.

## 8.2 Answering the research sub-questions

This section aims to summarise the results from the data collection, comparing it to academic literature in order to answer the research sub-questions. The main question, regarding how

people aged 85 and above think about and make late-life decisions will be addressed in section 8.3.

### 8.2.1 Decision-making change throughout the lifecourse

The first sub-question is how has decision-making changed throughout the lifecourse?

This section brings together the literature about decision-domains and the impact of emotion and experience in lifecourse decision-making.

#### 8.2.1.1 Decision-domains and the lifecourse

Academic literature theorises that there are discrete decision-making domains including housing, finances, emergencies, health, leisure, physical appearance, fitness, social relationships, and personality, and that the domains and goals change throughout the lifecourse. Specifically, it is argued that people with less SRLE prioritise maintaining safety and security, loss prevention and sparing their relatives from decision-making on their behalf (Kornadt and Rothermund, 2014; Kornadt *et al.,* 2018; Kornadt *et al.,* 2020). This suggests a shift in goals and focus as resources are deployed to achieve the changed goals. Whilst the Kornadt *et al.* domains do not specify an identity domain, the addition of a personality and life management domain (Kornadt *et al.,* 2020) suggests decisions about identity. Additionally, Tornstam and Erikson postulate that later-life identity coherence is concerned with the integration of past and present selves (Erikson *et al.* 1994; Tornstam, 1989). Drawing together the personality and life management domain with the integration of past and present selves, it follows that the OurTown Participants would seek to form links amongst various domains from throughout their lives, rationalising many domains into essential ones, in order to find later-life coherence.

As was noted in section 4.6, an attempt was made to use the distinct Kornadt *et al.* (2020) decision domains for the OurTown participant decision domains, but that this was unsuccessful as OurTown decisions encompassed many domains simultaneously. Additionally, contrary to the Kornadt *et al.* (2020) research, the OurTown Participants continued to make decisions in most domains in later-life, but all within the four over-arching domains of identity, meaningful engagement in activities, relationships, and resources. Whilst many of the Kornadt *et al.* domains could be aggregated within the last three domains, the main difference concerned the identity domain. As theorised by Erikson and Tornstam, and found in empirical research (Johnson and Barer, 1997; Lloyd, A. *et al.*, 2016) and the OurTown data, identity is continually adjusted throughout the lifecourse to accommodate change. Erikson and Tornstam, however, focus mainly on the individual and personal factors impacting identity, whilst more recent research considers

external factors, such as gender, sexuality, kinship, institutional and cultural factors on identity (Hockey and James, 2003; Heinrichsmeier, 2020; Twigg and Martin, 2015). Additionally, intersectionality, the combining of two or more aspects of identity (Calasanti and King, 2015; Gilleard and Higgs, 2020) and performative aspects of identity, that people decide what narratives they choose to present (Phoenix and Sparkes, 2009), also impact identity. This implies that decisions are being made continually about identity. The OurTown Participants were aware of the personal and socially-constructed lifecourse factors impacting their identities, in that they recognised the effect of their historical time, how the social changes of the 60s and 70s impacted them as opposed to their children, as well as the cumulative effect of the strong post-war economy and changes in housing law that are relevant to their current financial standing. They also recognised the importance of social connections in providing instrumental support, companionship, emotional and informational support, and the value of their individual agency in continuing to make decisions. Whilst aware of the influences, however, it should be noted that throughout the interview process, the participants chose which selves and identities to present, responding to questions, but also changing identities throughout the course of interviews as trust and confidence built.

As noted, the OurTown main decision domains remained consistent throughout the lifecourse. In common with the Kornadt *et al.* research, however, the OurTown evidence suggests that SRLE changes how they focus on the domains. For example, earlier life decisions focussed on building resources and relationships and developing their main activity whether a career or voluntary activities. The retirement age focus shifted to enjoying and redefining life goals. In later-life, what OurTown Participants consider their current life phase, they are balancing and conserving resources, but also enjoying as much as possible the activities they still wish to pursue. In very-late-life, their future, they expect to balance safety with autonomy, employing resources to support this. For the OurTown Participants, earlier-life decisions were relatively simple decisions to achieve the main goal of building resources in all domains: resources, relationships, and the types of activities they do, whether work, voluntary, cultural or social activities. With the progression of life, however, decisions become more complex requiring redefinition of goals and balancing of resources in considering future decisions. Later-life decisions benefit from a lifetime of personal and vicarious experience and knowledge to inform them. The decisions are more complex, needing to balance the four decision domains, and taking into consideration changing circumstances, motivations, and goals. That these domains remain relatively constant and consistent throughout the lifecourse and that earlier-life decisions form the foundation for later-life is consistent with Atchley's continuity theory (Atchley, 1989).

The difference between the more discrete decision-making domains of Kornadt *et al.'*s research, as opposed to the over-arching domains suggested by OurTown research, can be partially attributed to different research samples and methodologies. Kornadt *et al.*'s quantitative research is based on a large research sample with a wide range of younger and older people, with an average age in the early fifties and the oldest participants in the early 80s. Additionally, the research employed a questionnaire using prescribed domains and a Likert scale to understand the types of decisions made during different times in the lifespan. In contrast, the OurTown inductive qualitative research involved only people aged 85 and above and allowed participants to think about and define their decisions in their own ways. By talking about their lives, they defined the narrative for the types of decisions, their goals and processes, and their life stages. Additionally, as older people looking back on life, the OurTown Participants were contemplating and shaping their decisions through conscious reflection which would give a different perception in line with prospect theory that proposes that the reference point is key to understanding phenomena. The perspective of an older person making sense of a decision in the past would be very different from the perspective of a younger person considering the same decision and projecting to how to react in the future. For instance, the decision to marry and subsequently stay in that marriage, may be considered as having been a good decision, for the sake of children involved and for reasons of building resources for a more secure future. Much later in life, however, after experience in a different, happier, and conflict-free relationship, the same decision may be viewed as problematic as it meant that neither partner was happy in the previous relationship.

viewed as problematic as it meant that neither partner was happy in the previous relationship.

#### 8.2.1.2 Emotion and experience in lifecourse decision-making

Chapter Five also considered the impact of experience and emotion in decisions. The impact of the OurTown Participants' earlier-life decisions was evident in their current situations, in that their previous life decisions were at least partially responsible for their current health, housing and financial stability. They continued to draw on this experience, their own and vicarious experience, in making decisions about the future, consistent with Atchley's continuity theory. The participants' earlier life experience and their historical context, specifically the cautiousness engendered by their experience of the war and deprivation, shaped their values, forming the framework for their current decision-making. Similar to Atchley, OurTown results showed that people learn from experience, processing the learning, revising the initial framework and thinking as necessary, then applying it to future decisions (Atchley, 1999). Both the OurTown and Atchley's research showed that people have consistent decision-making patterns which are revised through experience, as learning from previous decisions is incorporated into their thinking

and values (*ibid.*). What is not addressed in Atchley's continuity theory is the value of emotion in making decisions and yet the OurTown Participants utilised both emotion and logic in their decisions. For them, whilst logic guided their decisions, emotion was an indicator of importance. Yet they distrusted emotion and used strategies to integrate emotion and logic by thinking about a decision overnight, or by talking it over with a trusted confidant. This is consistent with the findings countering Socioemotional Selectivity Theory, that instead of a positivity effect, when a decision directly impacts an older person, experience-based strategies will be employed to reduce emotional reactions, in order to respond logically and find a solution that balances emotional concerns with practical solutions (Lerner *et al.,* 2015; Raposo and Carstensen, 2015; Schweizer, 2019). Decision-making theory also suggests that emotion provides motivation (how much you want something) and indicates importance by shaping the depth of thought (Lerner *et al.,* 2015).

As noted in Chapter Five, the OurTown Participants cited want, but also fear as being critical emotions in later-life decision-making. Despite the participants' assertion that logic and experience were most important in the decision-making process and that logic over emotion was to be trusted, if want was involved – how much they wanted something, or if fear was involved, that they were afraid of consequences, those emotions became the deciding factor. Academic research is increasingly recognising the importance of emotion and other human factors in decision-making (Lerner *et al.*, 2015), which is borne out in the OurTown Participants' responses.

To answer how decision-making has changed throughout the lifecourse, it hasn't so much changed as developed. The participants have learned from experience and incorporated that experience into their subsequent decision-making, developing their capacity throughout their lives. They recognise the importance of balancing logic and emotion in decision-making, recognising that emotion is an important indicator, but that it needs the foundation of logic.

A further consideration in their lives is the importance of time in later-life decisions. An additional aspect of SST posits that in later-life, with a more limited life expectancy, people balance how much they want something, against the expected time they have left to experience the benefit of the decision (Carstensen, 1992). In essence, an aspect of decisions for later-life involves a cost-benefit analysis regarding whether the expected outcome justifies the cost. In considering their subjective remaining life expectancy (SRLE), older people will balance their emotions – either want, about how much they want something or fear, what they need to do to stave-off what they fear – against the SRLE and whether the deployment of resources is worth the expected benefit.

Finally, the major goal in the decisions is to maintain their identity as someone in control of the decisions.

### 8.2.2 Later-life decisions and decision-making process

The second sub-question, what future decisions are anticipated and how will they be made, was addressed in Chapter Six. The OurTown Participants' definition of this life period is later-life. As noted, the goal was to continue meaningful engagement with people and activity for as long as possible. All hoped they will be lucky and die peacefully in their sleep at some point in the future, having maintained independence and control to the end. The main decision of later-life, then, is how to maintain this. In thinking towards the future, an important aspect is managing the administrative matters around death, which was approached dispassionately. As set out in the Chapter Six, the OurTown Participants had little difficulty in thinking about, discussing, and making decisions concerning death. All were well-prepared with wills and had decided whether to have lasting powers of attorney and/or health directives. This was similar to research on older people's discussions of end-of-life which noted that death and dying is a major issue in later-life; they speak openly about it and they want to control death and the manner of death as much as possible (Lloyd-Williams *et al*., 2007). The ultimate control of life and death, euthanasia, was mentioned by five OurTown Participants, commenting on the need for clarity on the subject, without suggesting they would consider it. Academic research suggests that older people with more traditional values and who are more religious reject physician-assisted euthanasia, but younger people with higher educational levels are supportive in that they wish a self-determined death without becoming a burden in the case of a prolonged or degenerative illness (Poli, 2018). Although research tends to explain this as a generational difference, it could also be due to prospect theory, in that a younger person considering possible future compromised health might view euthanasia differently from an older person realising it is possible to live well, even with compromised health (Bern-Klug, 2017).

The more challenging and evolving decision of later-life was how to address the possibility of needing future care. This is the quintessential late-life decision and one which requires balancing priorities and resources in anticipating the possible loss of capacity. Similar to the decision-making framework suggested by Löckenhoff (2018), the OurTown Participants used a multi-stage process of anticipation, information gathering and assessment, development of contingent strategies and possible implementation of preliminary steps, but, unlike Löckenhoff, there the process stalled. As opposed to Löckenhoff's framework where a decision is considered and made, the OurTown Participants extended the process, perhaps implementing small interventions, reconsidering, and devising new strategies. Ultimately, they wait for circumstances to change before progressing a decision. In this sense, their decision-making process was more like the anthropological decision-making process in that the decision is not a single event, but an evolving process over time reacting to changes in circumstances and goals (Heiss, 2018).

The Our Town participants had a clear idea of what they don't want – to be dependent, whether in a care home or having care brought-in to their own homes, although both of these options had typically been investigated in a preliminary manner based on vicarious experience and remained fallback positions. None wanted to be dependent on their children or anyone else. Through vicarious experience, however, they understood the impact of a dementia diagnosis and how quickly that changes decision-making capacity. To them, a dementia diagnosis was framed in the loss of self, that you lose your identity, not only as a person, but as someone capable of making independent decisions, a status that must be protected. In this, and in the ongoing vigilance of their health, they recognised that mental and/or physical decline was possible, and, in such cases, they would act quickly to make future care arrangements, in order to maintain decision-control for as long as possible. None of the participants have had to address this possibility. Until they do, they are unlikely to do more than they already have, which is to investigate possibilities in the most general terms whilst continuing to live as fully as possible, protecting and strategically deploying resources.

This approach demonstrates the OurTown Participants' distinction between an agentic late-life and incapacity, similar to, but not the same as the distinction between third and fourth age suggested in academic literature. Laslett's original description of fourth age focussed on the physical aspects, describing fourth age as "final dependence, decrepitude and death" (Laslett, 1994, p439). The first of these, final dependence, is what the OurTown Participants consider the dividing line, the point at which they would have to make a decision, but in their thinking, despite the fact that some of the participants were declining physically, as long as they retained independence and control by arranging their own care, they were still agentic and in control. In this redefinition, the dividing line becomes less of a line and more of a sliding scale, moving towards greater care, but never crossing the line. Until such time, they planned to continue living their lives as fully and independently as possible, without making explicit plans for future care.

In some senses, the later-life decision about driving cessation was a similar model to thinking about care. Of the 14 OurTown participants still driving, six had implemented modifications. All had considered the impact of driving cessation; most noted the cost and had experimented with local transportation possibilities. Until such time as there is an inciting incident, such as the accident experienced by one participant, they planned to continue driving for as long as possible.

To answer the research question, what future decisions are anticipated and how will they be made, it depends on the types of decision. Their future decisions about continuing meaningful engagement will be made so as to balance their goals with the circumstances of health, deploying resources as necessary to achieve their goals. Regarding the main very-late-life decision of how to

manage possible decline and the need for greater care, they believe that they have made the important decisions in settling the administrative matters of death. The decision about possible decline will be taken if and when it occurs. In the interim, they will continue vigilance, implement intermediary steps and strategies as necessary and wait for a precipitating event.

### 8.2.3 Heterogeneity in decision-making

Chapter Seven addressed the final sub-question regarding heterogeneity in later-life decision-making. Heterogeneity amongst the OurTown Participants emerged around gender differences in the decision-making process as well as how the decision-making resources were used. As was discussed in Chapter Six, women's decisions in early life were constrained by societal and familial expectations, necessitating a decision-making pattern of considering other people's expectations and circumstances, a pattern for most of the female OurTown Participants. The consequence of these constraints was that women learned a different pattern of decision-making: they learned to consider societal restrictions, how to work around them and adapt their goals accordingly. In the process, they built resources, mostly in their social relationships and activity patterns, throughout the lifecourse. Whilst they may not have had the career focus their husbands had, they have been active in their communities through religious, community, and voluntary activities throughout their lives. The impact of this pattern was that women arrived at later-life with broad and deep social networks and an adaptive decision-making pattern. These outward, more social activities meant that the OurTown women had active social networks. They made active choices about the types of activities they pursued and in this, their social networks became resources in providing information about activities, companionship in pursuing them, and possible support in providing driving. Additionally, because of the active fostering of relationships, women also had people other than family they could contact in emergencies. In considering future decisions, women also consulted with their friends and learned vicariously about options, e.g. around care or changing their environment to support possible physical decline.

Academic literature supports these findings. Gender differences have been noted in later-life social networks and patterns of activities in important ways. Women's participation is fairly consistent over the lifecourse (Atchley, 1999; Finkel, 2018), and women consistently participate in more and a broader range of activities throughout the lifecourse (Finkel *et al.*, 2018). Women also tend to have more social activities in later-life than men (Cornwell and Schafer, 2016; Finkel *et al.*, 2018). This was also noted as part of the Newcastle 85+ study in that women participate in more outward-directed and social activities such as playing cards or other games, visiting or being visited by friends or family and participating in religious activities (Rantakokko *et al.,* 2020).

The OurTown male participants generally made more self-directed decisions throughout the lifecourse, focussing on their careers, supported by their families. Consistent with academic literature, their social networks (outside of work colleagues) were generally managed and developed by their wives (Finkel *et al.*, 2018). Empirical research also found that men tended more towards self-directed activities in late-life, doing more walking, driving for pleasure, DIY and gardening, mainly maintaining contact through email, as opposed to social activities (Rantakokko *et al.*, 2020). This meant that they have narrower and less diverse social networks which are more family-focussed. Few of the male participants had close friendships which meant in later-life they were dependent on their wives or partners to initiate social activities and connections which may provide diverse activities and information which support later-life. This is consistent with academic research that notes men's smaller support networks which means that widowhood impacts men more than women (Finkel *et al.*, 2018).

Finally, two other factors common with the OurTown Participants, education and socioeconomic status, were important resources for their decision-making. The Newcastle 85+ research found that education impacts activity participation in that those with higher education participate more broadly and frequently in all activities, card and board games, visiting friends and family, attending religious activities, and club and cultural activities. Activity participation has psychological and cognitive benefits (Finkel *et al.*, 2018), but also provides instrumental, emotional, and informational support as well as companionship (Cornwell and Schafer, 2016). In comparison, those with lower levels of education spend more time watching television and visiting friends (Rantakokko *et al.,* 2020). Higher socioeconomic status also impacts activity participation in that those with higher socio-economic status in older age also participate more in activities, possibly because they have better health and cognitive function (*ibid.*). Given the higher education levels and SES of the OurTown Participants, it was not surprising that they were still involved with a large number of activities, although, as has been noted, this was beginning to decrease with age, consistent with the Newcastle 85+ research (*ibid.*).

To answer the third research sub-question, heterogeneity in decision-making stems from gender differences and how decisions have been made from early life. Women have always needed to consider societal constraints as well as their own goals, whilst men's goals have been self-directed. Additionally, men and women develop and use social networks differently which also impacts later-life activities and resources. Activities are more than just keeping busy, they provide support and companionship and help in emergency situations. Perhaps because of their need to negotiate societal constraints earlier in life, in later-life, women have the advantage in their lifetime of adaptive decision-making and their large and well-developed social networks.

## 8.3 How older people think about and make later-life decisions

This thesis addressed three key questions in order to answer the overall question, how do people aged 85 and above think about and make later-life decisions? The first sub-question sought to understand how decision-making changes throughout the lifecourse. This research suggests that four main domains, identity, activities, relationships, and resources impact decision-making throughout the lifecourse and that earlier life was a time of building resources, relationships, and experience whilst later-life focuses on maintaining status quo by balancing activities, relationships and resources. Identity constantly evolves as sense of self is redefined to accommodate changing circumstances. Later-life decision-making has one clear goal, to maintain independence and to continue doing whatever gives life meaning. Decisions become a process of balancing and deploying the domains in order to achieve that goal. To make this decision, considerations of SRLE, will be balanced with the emotions of want – what is wanted in the decision – and fear, the fear of a possible adverse outcome. Additionally, the findings suggest that people are consistent throughout the lifecourse in making decisions about four main domains: identity, activities, relationships, and resources. Earlier life goals focused on developing all domains, whilst later-life goals focus on balancing domains and deploying resources to maintain status quo.

The second sub-question explored what types of future decisions are anticipated and how they will be made. The OurTown Participants considered that they had made the necessary decisions. They have settled their wills and lasting powers of attorney. Those who chose to move to a retirement community have done so. The rest have considered it to some degree and have decided to continue ageing-in-place. The major late-life decision was how to remain independent in the face of changing circumstances and declining health. To accomplish this, the decision-making process must change from the more discrete process of earlier life, where there are relatively few variables, a decision is made, and life moves on. For example, the decision to buy a house concerns cost, size, location, and possibly schools and other family considerations. Options are investigated, resources allocated, and the house purchased.

In later-life, however, the process changes. The goals must be clarified, possible options researched and explored, which perhaps necessitates revising strategies and modifying goals and priorities. At this point, the decision may stall, waiting for a precipitating event which may mean implementing another interim step or strategy, as opposed to a major decision. The process changes for many reasons. Part of the reason the process changes is that there are fewer pressing matters needing their direct attention, giving them more time to consider the decision. Additionally, the decision-making requires balancing resources, as, ultimately, there is less time to recover from a harmful decision. Later-life decisions become more complex as fundamental

values are weighed and the decision isn't so much a single event but a step onto a continuum. For example, the major later-life goal is to remain independent and living at home. A decision about installing a wet room to accommodate greater difficulty in getting in and out of a bathtub, then, is anticipating a challenge and a possible adverse situation, e.g. a fall which may then necessitate hospitalisation and bringing in care or moving into a care home. The decision about the wet room, then is more than just a construction problem. It involves recognising and addressing decreasing mobility and assessing if additional accommodations are also necessary. If so, is this the precipitating event to investigating more care or a care home? Then, once these choices are investigated, does the wet room appear the better option as this staves-off moving to a home or bringing in care. The wet room may be delayed whilst balance and exercise classes are attempted.

Inherent in these decisions are considerations of want and fear, but also time and experience. In considering the need for future care, none wants to move into care, yet vicarious experience (and empirical research) suggests that there are possible very-late-life trajectories: sudden demise, gradual decline and more precipitous decline and move into care (Cosco *et al.,* 2016; Johnson and Barer, 1997; Lloyd, A. *et al,* 2016). The first of these would not require a decision; the second requires a gradual move towards more care at home, perhaps avoiding a move into a care home, whilst the third requires addressing care swiftly and taking a decision regarding moving into care. Given their lifecourse habits of caution and thrift and their personal goals to remain independent, they will avoid bringing-in care or moving into care for as long as possible. Additionally, because SRLE is subjective, until such time as a decision must be taken, it will not be made.

Thus a 'simple' decision becomes a lengthy process of information gathering, assessment and exploration of possibilities, development of contingent strategies and possible implementation of intermediary steps. The result is that all options are explored – exercise and balance classes, the impact of installing a wet room and whether a stairlift may also be needed or whether care needs to be contracted or care homes investigated. In this way, not only are all possibilities investigated, strategies developed, and preliminary interventions made, but control has been retained. Thus, if a move to a care home is necessary, having explored all options, it can be reframed in terms of choosing to make that decision, thus maintaining control.

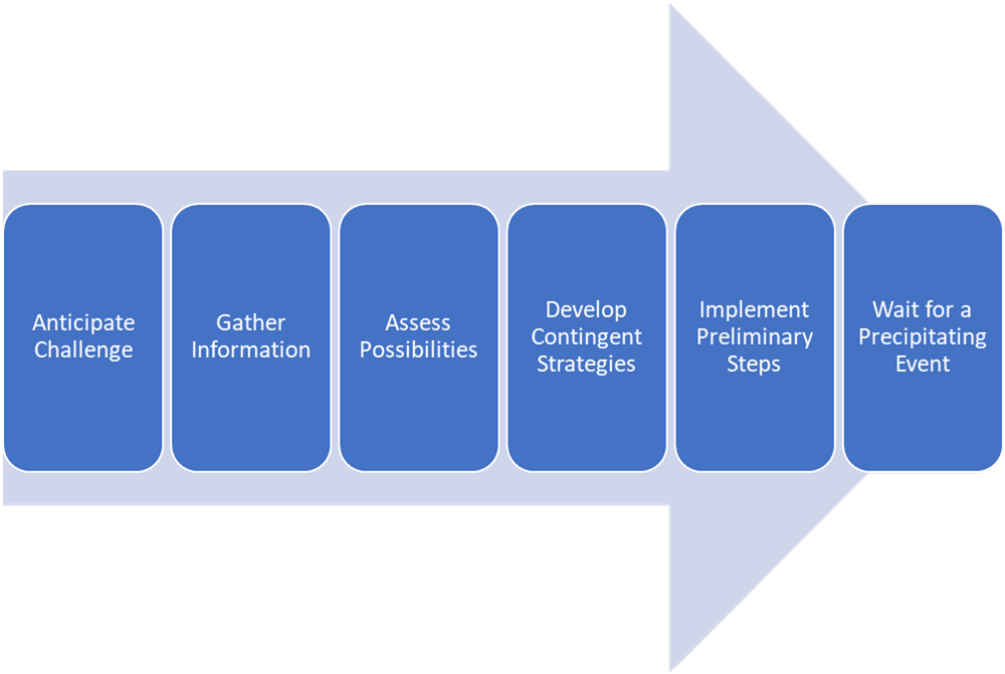



Figure 8-1 Later-life decision-making process (*source: author's own*)

As demonstrated in Bonnie's installation of the wet room, the later-life decision-making process evolved to a lengthy process where values and goals were re-assessed and balanced, interim goals reset to adapt to changing circumstances, various strategies developed and interim interventions implemented, whilst waiting for a precipitating event forcing the decision. Until a decision was needed, however, the decision remained open-ended allowing interim steps to be taken. In Bonnie's situation, she had debated installing a wet room, but instead decided to take exercise classes, feeling that a wet room was not necessary. In her case, her fall was the precipitating event and after recovering, the wet room decision was a quick and easy one.

The final sub-question queries the heterogeneity in late-life decision-making. The main OurTown differences concern gendered approaches to later-life decision-making. Women continue to build and maintain social relationships in late-life to support their goals and to assist them in emergencies. Conversely, men accept that their social networks will become narrower and less diverse, focussing more on family, which they consider a natural part of ageing. This makes them more vulnerable to bereavement and later-life emergencies as their main support is family. This essential difference, that women continue to build and maintain relationships and activity levels despite changing circumstances, as opposed to men's acceptance of changed circumstances as an expected part of ageing, means that women have broader sources of information and experience informing later-life. They watch and talk about changes and strategies; they tend to be more proactive. The OurTown female participants anticipated and implemented changes which may prevent or delay a more extreme decision. This was possibly due to two factors: most of the women were widows who became accustomed to making their own decisions, and because of

their broad networks, they had friends whose knowledge and experience they could draw upon. This difference was demonstrated in the harbinger events experienced by many of the participants. The men consistently used family or LAT partners for support. The women, with broader networks, used a variety of sources, sharing information and strategies, both in the pre-decision conversations and post-decisions results, as was noted in Bonnie's installation of a wet room which became a focal point for her friends who were considering installing their own. In her proactive decision, she was making a conscious effort to redefine incapacity. The process was also seen in Dolores's falls experience. For transport to the hospital, she repurposed her gardener to take her. She had a lengthy visit, feeling vulnerable and in pain, yet as the nurse was taking her to the taxi for home, she continued talking with her, seeking to establish a connection so that by the end of the encounter, she had made a friend of the nurse who subsequently provided companionship and instrumental support. She redefined the experience of incapacity, to one of control and of making new connections and sources of future information and support.

In synthesising these results to answer the main research question, the sub-question findings point towards the conclusion. As has been seen, the goal of later-life is to continue meaningful engagement with people who are important to you for as long as possible, strategically deploying and developing resources in the process. This partially explains how people think about and make late-life decisions, that they are continually vigilant regarding their resources and that they deploy them carefully, drawing on their social networks for information and vicarious experience, by narrowing the level of participation, and by employing greater financial resources as necessary to support them. As they think about future decisions, many consider they have made the important ones, in that they have settled the administrative matters of death. The remaining decisions concern reacting to circumstances to achieve their goals.

They know from vicarious experience that it is possible that they will die peacefully in their sleep. They also know it is possible that they may experience physical or cognitive decline and may need to consider more care or a care home. They have the experience and perspective to understand that even though they have made reasonable plans for later-life, that in the case of increasing incapacity they will have to make more difficult decisions. As they currently do with their decisions, this will proceed over time. Their activities and social connections will continue in ever smaller circles. As noted, they will continue to try to maintain the status quo, deploying all resources to achieve the main goal of retaining agency and control, even if it means redefining their identity to being the person who chooses to enter residential care. This is consistent with academic literature addressing the importance of autonomy, the reluctance to accept assistance except from friends and the redefinition of self to re-interpret capabilities and to avoid thinking of

themselves as 'old' and incapable (Pirhonen *et al*., 2016). At this point, this remains theoretical, as none of the participants were approaching a time when they might need to progress strategies.

The remaining decision of very-late-life is how to maintain that independence and control in the face of declining health and what will happen if declining health forces a decision. Given that the one point of agreement amongst all OurTown Participants is the concern over dementia, which they view as a loss of self, it is expected that should decisions about dementia need to be made, that they will act quickly, gathering appropriate information, anticipating future needs and making arrangements for future incapacity, even if that means designating a proxy to make decisions on their behalf. In this way, they will maintain their essential identity as someone who makes independent decisions for as long as possible.

The unanswered question from this research remains, what will force the OurTown Participants to make a decision about more care or a care home and what will they actually ***do?*** All are committed to ageing-in-place with care brought-in as necessary. Bringing in and managing care requires both energy and organisational skills. For the married participants or those with LAT partners, they are hoping and depending on their younger partners to help, but as has been shown, spouses, partners, or children may experience ill health or adversity, meaning that assistance may not be forthcoming. The most common strategy is to wait and see, in the hope that they will 'drop down dead' (Shirley, R1) and avoid a drawn out and lingering trajectory. Empirical evidence suggests otherwise; very-late-life health trajectories may mean they need to employ other strategies. It could be theorised that, given the high priority people in late-life place on remaining independent and agentic, this will become the ultimate goal, with all other goals and resources sacrificed to maintain it. In other words, the goal of ageing-in-place may be sacrificed in order to remain in control, by choosing to move to a care home. This provides possibilities for future research.

## 8.4 Recommendations for further research and policy

The results and limitations of this thesis suggest opportunities for further research as well as policy recommendations impacting health guidelines for older people and future care and housing policy.

### 8.4.1 Further research

Following on from the conclusions above, an additional avenue for research would be to continue this research, with as many of the participants as possible, to follow their decisions over the next three to five years. In this way, it might be possible to understand how they will either continue

to defer or will make future care decisions. This subsequent research could also provide an interesting perspective regarding COVID effects with older people, how they reacted, the effect, and how it might have changed their thinking about the future. In this future research, because one of the limitations of the research sample was its relative wealth, it would be interesting to work with the contacts made in the intervening four years to recruit participation from the OurTown churches, community centre, council-supported sheltered housing centre and the local almshouse charity, perhaps through focus groups or participatory action research, to work with a wider range of older people to understand the types of programmes that would help them make informed decisions about the future. One of the barriers to making the future care decisions seems to be a lack of complete knowledge of late-life health trajectories and how that might impact their physical and cognitive abilities. Participatory action research could be conducted to understand the types of information older people need in order to make late-life decisions, e.g. material about preventative health exercise, late-life health trajectories, options for bringing care into the home, respite care and care home availability, the costs involved and how the local healthcare and council supports this. Once the range and scope of information is understood, a pilot education programme could be produced to deliver the information and guidance, ultimately researching whether this helped people to make more informed decisions. This additional research could be combined with the policy recommendations below.

### 8.4.2 Policy recommendations: health and housing

The literature review and findings of this research point towards policy recommendations in areas of health and housing.

#### 8.4.2.1 Health-related policy recommendations

As has been noted in Chapter Six, there is confusion around health directives such as do-not-attempt-resuscitation (DNAR) orders. The OurTown Participants were familiar with them, some had vicarious experience through their spouses or friends. The problem is that there doesn't seem to be consistency in how they are applied, that DNAR forms are not carried across all care settings and that they can be overridden by well-meaning family members. The most important barrier is that people realise their preferences may change depending on the circumstances. National guidelines recommend that the same DNAR form should be used in all healthcare settings so that it is easily recognisable, but there are differences in the forms and contents and the forms do not automatically transfer across health settings (Compassion in Dying, 2020). There is little research on the benefits, but US research found fewer aggressive medical interventions for those with advance directives (Mullick *et al*., 2013). There needs to be consistency and clarity around the issue and completion of forms, if people are interested. More broadly, an open

discussion of end-of-life matters, currently considered taboo, could widen understanding and prompt open and realistic discussion. An example of a positive approach to considering health directives was taken by the town of LaCrosse, Wisconsin, which implemented required questions regarding end-of-life with every hospital admission, regardless of age or medical condition. They found that the responses to the questions were not as important as the discussion itself, that people of all ages began developing end-of-life literacy and opened discussion amongst family members (Gawande, 2014).

Another health-related policy consideration concerns the extent of falls prevention. Six of the participants (2M, 4F) had falls or near-falls ('stumbles') during the course of research, all of which required subsequent medical attention, yet none of the participants were aware of falls prevention or physiotherapy services before or after their falls. Falls impact people psychologically as well as physically, making them less confident about regaining and improving gait and balance. Given that as people age, they are less likely to recognise the need for more help or ask for help (Pirhonen *et al.*, 2016), implementation of regular health checks and falls assessments could ensure that potential mobility problems and possible needs for greater care could be identified earlier and interventions implemented (Zhao *et al.,* 2010). For example, because falls are a leading cause of accident-related death for older people as well as a precipitator of greater healthcare needs, falls preventions should be a priority for older people (Finnegan *et al.,* 2018; Finnegan *et al.,* 2019; Mackenzie and McIntyre, 2019; Zhao *et al.,* 2010). NICE guidelines (2013) specify multifactorial risk assessments for people who have fallen or have had repeated falls in the community, or who are in the hospital or receiving inpatient services. This means that the first time people receive assessment could be in the hospital after having experienced a serious fall. Half of people aged 80 and above fall with 5% ending with a fracture. This alone costs the UK NHS $2 billion annually (Finnegan *et al.,* 2018). Exercise programmes have been shown to improve balance and gait and overall functioning and should be delivered by all NHS trusts (*ibid.*). This will possibly become a greater concern due to the isolation and enforced lack of exercise during the extended COVID lockdown which makes such proactive assessment and subsequent interventions critical.

#### 8.4.2.2 Housing and Future Care Policy Recommendations

Chapter Six set out the research regarding planning for future care completed by the OurTown Participants. All of the participants have vicarious experience of the general costs and availability of care options in the area, but only two have explored options in the most general terms, the rest are willing to wait and see how circumstances develop before committing to further investigations. This leaves them vulnerable to possibly needing care in response to an emergency, yet the most successful moves are those in which the older person controls the decision and it is

done in a reasonable and progressive fashion (Ewen and Chahal, 2013; Golant, 2015; Gottlieb *et al.*, 2009; Scheibl, 2019b). The decision depends both on the availability of housing, but also on knowledge of options (Gottlieb *et al.,* 2009).

Regarding the availability of a range of appropriate housing options, in the housing report conducted in North England (Robinson *et al.*, 2020), only age-exclusive housing was in oversupply. There were no enhanced sheltered housing options, and a need for sheltered (88% more needed), extra care (53% more needed) and care homes (22%) (*ibid.*). In comparison to other boroughs in the county, OurTown is at the higher provision of options with number of both housing with support and housing with care (Elderly Accommodation Council [EAC], 2015), but OurTown Participants may not be aware of the range of housing available. Two participants have explored options and found them unsatisfactory, as both are seeking self-contained flats, meals, and the possibility of increasing care provision onsite. One of the participants had identified that planning had been given for such a facility and it was currently under development in the area, although not expected in the near future. Despite the lack of such specialist housing options in the area, the local borough council turned down an application for a retirement and care complex in a town centre on the basis that it would "undermine the vitality and viability of town centre." (OurTown Borough Council, 2020 p1). The proposed new housing would be developed on an Australian model incorporating continuing care and facilities onsite, allowing residents to progress from care brought into their residential apartments, to 24/7 care in a special facility onsite. Additionally, onsite dining and recreational facilities were proposed and access to the town centre was a short walk away. There has been little consultation on the future of housing for older people in the borough, except for the decision by the planning board to deny the proposal and to keep older people and care out of the centre of town.

At this point, the choice for OurTown residents is mainly in age-exclusive housing or care homes with no intermediary options. The challenges with obtaining planning permissions for specialist housing for older people is noted as one of the reasons for an undersupply of the type of housing needed (Robinson *et al.*, 2020). In comparison with other countries, UK provision for housing-with-care is relatively low at 0.7% for those aged 65+, as compared with Australia (5.4%), New Zealand (5.2%) and the US (6.1%) despite the fact that the UK has the highest percentage of people aged 65 and above of all these countries (Beach, 2018). There needs to be a detailed assessment of current and future needs and provision in the borough to inform planning departments.

The decision about future care is at the intersection of health and housing where knowledge and options are required about both. People need knowledge about health trajectories and the

consequences and implications for care. They also need information about, and appropriate, flexible housing and care options. Such knowledge will help older people anticipate, prepare for, and manage decreasing health whilst adjusting their living space to accommodate their needs, either through changing their current home to support infirmity or move to a care home. In order to make informed decisions, older people need to understand both the health trajectories and their implications, as well as the options for care, housing adaptation, and future residential care options. Yet there also seems to be a lack of knowledge about health trajectories and implications for housing adaptation and future care. Whilst the OurTown Participants were more inclined to be in the higher functioning trajectory given their current status, the results of this research suggest specific possibilities for further academic research and policy change.

The 2014 Care Act specifies that local authorities must provide information and advice relating to housing and care (Robinson *et al.*, 2020). The OurTown Council does have a website to help people remain independent either in their current home or advice on other housing options, but the information and advice is mainly generic, although connected to local borough housing information. FirstStop, an independent national advice service, provides the information which includes a factsheet on helping older people age-in-place whilst anticipating problems, with the goal of helping people remain independent for as long as possible (EAC FirstStop, 2020). This service also offers a Housing Options for Older People (HOOP) questionnaire linked to the local borough options in order to encourage people to consider how their home supports ageing and provides links to options in the area (EAC, 2020). Additionally, OurTown has a Care and Repair England (CARE) service which conducts home assessments and provides repair and project management services to ensure homes support ageing. The HOOP questionnaire is administered online, but there is also a paper copy available and a free telephone service for consultation. There needs to be greater dissemination of the information as only one of the OurTown Participants was aware of the CARE service. This policy recommendation could be combined with the possible future research cited above, where part of the project could be to ascertain the types of information and housing needed to help people make informed decisions about their future.

## 8.5 Limitations and conclusion

A main limitation of this research is that the time period, fifteen months, is not enough to witness substantial change in the participants' lives. By the end of data collection, three participants (2M, 1F) were beginning to experience health changes either in themselves or their carers, which might precipitate decisions about future care. This limitation has prompted thinking about future research. The other limitation, which has also prompted thinking about future research, is the relative economic security of the participants. All own their own homes which gives them a

cushion against possible future care needs. It should be noted that the majority of participants also started with very little financially, but all worked hard, planned for the future and were fortunate in the rising post-war economy. Efforts were made to recruit 'seldom-heard' participants in the OurTown community but were unsuccessful. This has been noted in the possibilities for future research, that given contacts made in the past four years and a possible change in research design, that there could be a wider range of socioeconomic situations in the research population for future research. Finally, as qualitative research, this would not have statistical generalisability, but in the detail, breadth and depth of description provided, it can perhaps provide analytical generalisation (Smith, 2018) which may provide greater conceptual understanding of late-life decision-making.

Despite the limitations, however, this research adds to the growing body of literature about decision-making in later and very-late-life. The research points to the value of qualitative longitudinal research in capturing the voices and reflections of older people themselves about their lifecourse decisions, as well as their thinking about later-life and planning for the future. The research demonstrates a lifetime of decision-making development and how earlier life decisions and decision-making lay the foundation for later-life. The findings suggest the differences in the ways men versus women deploy resources and react to changing circumstances, but also shows continuity in the decision domains, and that people learn from experience to adapt to new situations whilst recognising that the reference point changes perceptions of decisions. Very-late-life appears to be a balance between continuing involvement with meaningful engagement and relationships, whilst strategically deploying available resources to accomplish this in the face of possible challenges, always supporting the overarching goal of retaining autonomy and decision-making control.

# Appendix A Ethics approval and interview guides

As noted in the methodology chapter, the initial approval for the research was granted in August 2018, and an amendment was sought in 2019 to discuss end-of-life. The approval and interview guide for the initial application and subsequent interview guides are shown below.

## A.1 Ethics application approval and interview guide

**Heather Mulkey**

**From:** ERGOII
**Sent:** 31 August 2018 11:14
**To:** Mulkey H.
**Subject:** Approved by Research Integrity and Governance team - ERGO II 42609

Approved by Research Integrity and Governance team - ERGO II 42609

University of Southampton

ERGO II – Ethics and Research Governance Online https://www.ergo2.soton.ac.uk

Submission ID: 42609
Submission Title: Decision-Making by the Oldest-Old
Submitter Name: Heather Mulkey

The Research Integrity and Governance team have reviewed and approved your submission.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external ethics review (e.g. NRES/HRA/MHRA etc).

The following comments have been made:

•
•

*Tid: 23012_Email_to_submitter___Approval_from_RIG id: 74696 hm2e16@soton.ac.uk coordinator*

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# Decision-Making by the Oldest-Old

## Round 1 Interview guide

### Before the interview, ensure participant:

- Understands the purpose of the interview
- Has reviewed the participant information sheet
- Has given consent
- Has arranged a supporter if desired.

### Introduction: Background information

- Age: Actual Age. What do you enjoy about being this age? What are the challenges? Do you feel 'old'?
- Overall health: Can you do most of the things you want to do or are there limiting factors? How do you maintain your current level of health?
- Care: Do you have assistance in any way? Shopping or gardening? Meal preparation? Transportation? Managing finances? Physical care?
- Living situation: How long have you lived in this area? Were you born here (history of any relocations)? With whom do you live? Do you have family nearby? Significant relationships?
- Religion: How important is religion in your life?
- Education: How important was education in your life?
- Previous employment: Tell me about your previous employment. When did you retire?

### Decision-Making

As you know, this project is about decision-making and how your previous experiences have prepared you to make future decisions.

### Previous decisions

- There are many changes and transitions in life, (Prompt if needed: leaving school, getting married, having children, job and career concerns, bereavement, disability). Thinking back, what were some of the major changes or transitions in your life? (Some people might have lived passively letting life happen to them. Thus, if none, had you ever considered... e.g. getting married, moving, changing jobs, further education, travel abroad? Why did you decide not to pursue it?)
- How did you decide what to do? Whom did you confer or consult with? What other resources or sources of information was necessary in the decision-making?
- What was important to you in that decision? (goals/factors)
- Thinking about the problem and decision, what was the process involved (Timeframe? Phases? Revisiting?)
- What was the result? How did it turn out? How did you feel about that? What were the positive aspects of this decision? Negative?
- What would you change if you could do it over again?
- Have any of your friends experienced similar decisions and if so, how did they handle them? What was the result? What are the advantages/disadvantages to that approach?
- What are the other challenges you've faced? Follow this up with each life transition.

### The future

- What are the major types of decisions you are making now, in this stage of life?
- If there are no decisions, have any of your friends needed to make decisions about changes – downsizing or moving to a care home? Tell me about it (query circumstances around it, why they did it that way, how it worked for them, advantages and disadvantages of the decision – has that impacted their thinking)
- What thoughts do you have about possible challenges or changes which may come in the next year or so? (prompts if needed, health, disability, bereavement, downsizing)
- How will you think about this? How will you approach a decision?
- What's important to you in this decision? What factors will you consider in making a decision about it? What would your goals be in this decision?
- How will you ensure those values or goals are preserved in the solution?
- Whom might you consult and what other resources or sources of information will you need?
- What decisions do you think you may need to consider over the next 3-5 years? How will you prepare for them?
- If they can think of none, can you suggest some types of decisions other people or your friends might think about at this stage of life? (health, care, housing, financial, bereavement)
- What might be some connections between how you made decisions in the past and how you make them now? How have you built on experience?
- Is there anything you'd like to add?

### Closure

- Brief summary of discussion and thanks
- Explanation of diary and folder
- Arrangements for making a future appointment.

## Subsequent interview guides

Each subsequent interview will be built on that participant's previous interview(s) as well as any overall trends from the first round of interviews.

### Before each interview:

- Prepare for the interview by re-reading the transcript of the previous interview(s) noting any specific issues to be revisited.
- At the interview, reiterate the purpose of the interview
- Verbally go through the consent issues (unless there may be a reason to re-issue the form)
- Check if the participant arranged a supporter if desired.
- Query whether there are any items in the folder or diary. Discuss them.
- Review some of the major points raised in the last interview.

### Recap of previous interview

- How have things been since we last met? Have you needed to make adjustments to your living arrangements? Refer to things previously discussed and see if there are developments.
- Compare the overall results (framework, resources, priorities) with theirs. Get their thoughts.

## A.2 Ethics amendment approval and modified interview guide

Approved by Research Integrity and Governance team - ERGO II 42609.A1

UNIVERSITY OF Southampton

ERGO II – Ethics and Research Governance Online https://www.ergo2.soton.ac.uk

Submission ID: 42609.A1
Submission Title: Decision-Making by the Oldest-Old (Amendment 1)
Submitter Name: Heather Mulkey

The Research Integrity and Governance team have reviewed and approved your submission.

You can begin your research unless you are still awaiting specific Health and Safety approval (e.g. for a Genetic or Biological Materials Risk Assessment) or external review.

The following comments have been made:

- Dear Heather,

  Thank you very much for providing further information, and for updating your study letter. I am now happy to approve this amendment. Good luck with your research.

-

*Tkt: 23012_Email_to_submitter___Approval_from_RIG Id: 192733 hm2e16@soton.ac.uk coordinator*

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## Round 4 Additional Questions

After a conversation of changes since the last interview and recap of the previous three interviews as detailed above, the participants will be asked if they received my recent letter and if so, would they mind discussing end of life preparations which include wills and advance health directives. They will be reminded that there is no obligation to take part and if, once we begin, they have the right to change their mind and withdraw at any time without giving a reason and without participant rights being affected. During the interview, they are welcome to pause, stop or reschedule the interview. Likewise, they may choose to withdraw from participation at any point even after the last interview, up to 14 days after completion. Interview data will be destroyed and there will be no adverse consequences or repercussions.

## Proposed End of Life Questions

1. Thinking ahead towards the end of your life, have you made any particular plans or decisions around your care and affairs at the end of life?

*Prompts:* What decisions or plans have you made? What aspects do these cover (e.g. advance health directives, care plans, wills)? With whom have you shared these plans? How were these decisions made and implemented? Who initiated the conversations and how did they progress? What facilitated these steps? Was there some compelling incident which prompted your thinking and subsequent action?

If you haven't made any decisions, what are the barriers? Have you discussed these issues with anyone? Who? What effect did that have? What might change your mind about making more concrete plans?

What do you think are the advantages or disadvantages to this course of action?

2. What might prompt you to review your current situation? How might these current choices change over the next five years? Ten years?

After the conversation, they will be thanked and reminded that the letter sent to them contained details about sources of support for any discomfort which includes details for contacting Age UK, Citizen's Advice Bureau, Cruse Bereavement, the Samaritans, Silverline, or Supportline which has an extensive list of support services for older people.

## Close

- I'm interested in why you decided to join this study. Could you tell me about your thoughts when you decided to take part?
- How have you found the experience of being involved in research?
- Is there anything else we haven't discussed which you might like to add?
- Would you like to receive a brief summary of the results?

# Appendix B Literature search

Late-life decision-making is a very broad topic and whilst there is literature on decision-making, there is little on late-life decision-making

Literature searches began in October 2017 and continued periodically through April 2021 prior to final thesis submission. Literature searches were conducted primarily through the University of Southampton's DelphiS Search Directory and Web of Science, although other databases, including Google Scholar were also consulted. The goal was to find articles on the decision-making of community-dwelling people aged 85 and above.

Initial searches conducted in 2017 focussed on broad search terms (decision-making or decision making and older-people or older adults or seniors or elderly) producing over 500 results and just over 400 results when limiting to academic journals. Sifting through these results using title and abstract suitability, it became clear that much of the literature concerned other people (healthcare, social workers, etc.) making decisions ***about*** older people, not decisions being made ***by*** the older people themselves. Additionally, there is a great deal of quantitative literature comparing older and younger people in making consumer-related decisions or testing performance on gaming and gambling tests. Some of this literature concerns financial decision-making which can be pertinent, but frequently the goal is to test performance with various financial instruments which is not the goal of this project. This initial broad search was useful in finding research on specific cohorts, e.g. the CC75C, Life beyond 85 years, Newcastle 85+ study, etc. and in finding specific later-life decision topics such as housing decisions and driving cessation. The main search terms are listed below.

| Decision-making terms | People aged 85 and above | Limiters |
|---|---|---|
| Decision-making or decision making or decision-making process or decision making process | Oldest-old or oldest old or older people or elderly or seniors | NOT cancer, chronic kidney disease, carcinoma, chemotherapy, COVID, renal, statins, cirrhosis, dialysis, hypertension, cardiovascular disease, dementia or Alzheimer's |
| | "age 85 and above" or "age 85+" or "age 85" | |
| | "late life", not petroleum or gas projects | |
| | "4th age" or "fourth age" | |

Searches continued to be conducted throughout the course of research, often suggested by results to investigate specific aspects encountered, e.g. decision domains, decision process, social networks, the role of emotion or experience in decision-making, residential relocation, live-apart-together partners, etc. Results of a typical literature search conducted with DelphiS on 9 February 2021 are shown in Table 2. Suitability was determined by reviewing the title and abstracts. It should be noted that there is a quirk in the DelphiS system in that the tabulation of results does not always equal the actual number of results. For instance, in #8 below, the search history stated 149 results, but in reviewing the results themselves, there were only 80.

| Delphis Search Keyword | Number of results |
|---|---|
| 1. Oldest old or oldest-old | 17,672 |

| | |
|---|---|
| 2. "age 85" or "aged 85+" | 225 |
| 3. "late life" | 61,733 |
| 4. Decision making or decision-making or decision making process or decision-making process (limited to academic journals) | 583,631 |
| 5. Community dwelling older adults or elderly | 15,882 |
| 6. Combining 1 and 4 | 24 |
| 7. Combining 2 and 4 | 0 |
| 8. Combining 3 and 4 | 149 per the search history; only 80 actually. |
| 9. Combining 8 and 5 | 1 |
| 10. Combining 4 and 5 | 49 |

Web of Science is a more difficult system to use but it occasionally generates a few articles each revisit which were not found in DelphiS.

| Decision-making terms | People aged 85 and above | Limiters |
|---|---|---|
| Decision-making or decision making or decision-making process or decision making process | Old* adults, old* people, elder*, lat* life, | NOT cancer, chronic kidney disease, carcinoma, chemotherapy, COVID, renal, statins, cirrhosis, dialysis, hypertension, cardiovascular disease, dementia or Alzheimer's, etc. |

# Appendix C Participant information

Pen portraits follow the list of participant pseudonyms and overview information of the participants. Participant pseudonyms were generated from a list of popular children's names from the 1930s.

| Men | Age | Marital Status | Changes during course of research |
|---|---|---|---|
| Albert | 87-89 | Married | None |
| Clarence | 84-86 | LAT relationship | Health improved due to exercise |
| Ernest | 84-86 | Married | Cataract operations on both eyes |
| Eugene | 90-92 | Widowed | R1 leg scrapes healed by R2; R4 son's ill health |
| Frank | 84-86 | Widowed | Heart operation; blood pressure problems; polypharmacy |
| Glenn | 84-86 | Married | Increasing vision problems |
| Norman | 84-86 | Widowed | R3: broken ankle; R4 wrenched back |
| Ronald | 90-92 | LAT relationship | Angina; oedema |

| Women | Age | Marital Status | Changes during course of research |
|---|---|---|---|
| Bonnie | 84-86 | Divorced | Chest infection; fall & broken hip; heart & vision problems. Wet room installed |
| Dolores | 90-92 | Widowed | Fall necessitating care; stopped playing tennis; using a stick |
| Gladys | 87-89 | Widowed | Atrial fibrillation treated with medication |
| Judith | 87-89 | Widowed | Pre-cancerous skin lesion operation; chair yoga instead of regular yoga |
| Mildred | 90-92 | Widowed | Increasing macular degeneration; using a stick |
| Shirley | 84-86 | Widowed | Broken nose due to a fall; walking with a stick |
| Virginia | 87-89 | Married | Her cat died and she got a new one |
| Wanda | 87-89 | Widowed | Pulmonary fibrosis diagnosed due to her inspection of her CT scan |
| Winifred | 87-89 | Widowed | Knee operation; driving cessation, two falls, broken ribs; driving cessation and stairlift. |

## C.1 Albert

*"I was brought up to discern and to think and be aware of what's going on, to see how I can be of benefit, what good can happen as a result of what I'm going through" (R1).*

Albert was 87 at the start of research. He and his wife had two children (his son is deceased) and grandchildren who live locally. Both are retired healthcare professionals, and both are committed to a religion which has impacted their decisions throughout the lifecourse. Albert has known his wife all his life as they both grew up in the same religious faith in a middle eastern north Africa (MENA) country. Albert's early education was in an English missionary school which shaped his thinking about the future. In making his decisions, he was guided by his goals for himself and his family, but also by his religion in his sense of 'awareness', dedication to service and sharing his faith.

*"I was looking also for a service element. Am I going to be really useful to these people? Do they need my services? And in particular, as a [member of his religion], can I offer the religion to them as well" (R1).*

In making decisions about their moves worldwide, his concern for his family has been 'paramount' as he has changed jobs and career direction to better accommodate his family. His familial concern continues with more recent decisions. In his Brexit decision, he was guided by family in voting against his personal thinking that the EU is a failed concept, having witnessed previous similar efforts fail in the Middle East. He voted to remain:

*"Not because I'm convinced that this is the right decision, but it's to preserve the unity of the family … I told them I'm going to vote remain, even though I don't believe that's the right decision. And I did vote remain. But I said, this is just for the family, maintaining the family unity" (R4).*

In addition to his medical interest, he is also a published economist and poet. As part of his legacy for the future, he is co-authoring a biography of his father and his contributions to their religion.

## C.2 Clarence

Clarence was 86 years old at the start of research. He and his wife had children and grandchildren, all of whom live nearby. He and his wife were married not long after his completion of National Service, when he was working as a housemaster and teacher at a school in the North of England. Sadly, his wife died over ten years ago, having chosen quality of life over chemotherapy in her final year of life.

*"We had one of the best years we'd ever had, simply because we knew what was going to happen" (R1).*

Clarence and his wife were active through the local church in refugee relief programmes. He remains involved in church and relief work. At core, Clarence is a teacher and thinks of former students, and people he has worked with as friends and family.

*"They're your friends, your family. And you don't walk away from that. And this is my philosophy as a schoolteacher … once somebody is my student, they're my student for life." R2*

After his wife's death, Clarence developed a live-apart-together (LAT) relationship with an Asian woman which has caused a rift with his children and grandchildren. A few years before the start of research, he had a life-threatening health event which his LAT partner helped him recover from. Since then, she has encouraged him to maintain his health through exercise and diet.

*"I've been getting increasingly better in health terms…because I'm doing the exercises, my balance is fine. I'm walking." R4*

He maintains contacts with friends from school, his consultancy and work life, former students and people he knows having lived in OurTown for over 55 years. He and his LAT partner still travel widely and he is trying to learn her language.

*"We're still trying to do perky things." R4*

## C.3 Ernest

At the start of research, Ernest was 86 years old. He and Edith (pseudonym) have children, grandchildren and great-grandchildren, none of whom live nearby, but all live in this country. Ernest and Edith both attended university and education is important to them. They married shortly after Edith's graduation. Despite the social expectation of the time that women wouldn't work, Edith continued her teaching career throughout their earlier life, managing her work around raising their children and their many international moves. When decisions needed to be made about career moves which impacted family, the decision was made as a family. In later-life, Ernest and Edith continue to share decision-making equally.

*"I think as far as decisions, it's always been 'we'" (R2).*

Initially, Ernest began work at the same company where his father was employed, but shortly after marriage, he began working for a large multinational company. He chose the company because it was a "company with operations in various parts of the globe; it seemed a bigger and potentially more interesting pond to swim in" (R2). He and Edith were looking for adventure and the chance to learn new languages abroad. Ernest and Edith remain active in church and charitable activities, although this is gradually decreasing.

*"What is sometimes difficult for the older person, is actually knowing when to pass something on. Otherwise you go on stirring the same pot long after you should stop" (R1).*

Ernest continues to enjoy home maintenance and 'doing' things around the house. Both are avid gardeners and bridge players and they continue to travel throughout the UK camping, meeting with friends and providing support to extended family.

## C.4 Eugene

Eugene was aged 90 at the start of research. His early education and accountancy training was in Africa. He subsequently moved to England with school friends, with whom he lived and travelled during holidays from work. He met his wife on one of his travels and after their marriage, they moved back to Africa. His wife also enjoyed travel, so they returned to England to work for a large multinational corporation. Part of the reason he joined the company was that the family was able to make frequent moves throughout the world.

> *"I was interested in seeing the world and I knew that the conditions where I would be living would be excellent, and so I went where I was told." R2*

After retirement, he was involved in many voluntary, political, and sports activities locally and internationally, using his accountancy skills with charitable organisations abroad.

Eugene is estranged from his older daughter and his younger daughter lives nearly two hours away. He lives in the family home with his son who is his carer. He and his son ensured that his wife was able to die at home two years prior to the start of data collection. It is the death he hopes for himself. Unfortunately, his son was taken to hospital over two weeks before the final interview and it was not certain when he would be returning home. Eugene had never had to cook for himself and spent much of the last interview asking frequent food preparation questions.

> *"If anything happens to [my son], I'll have to go through it all [managing his affairs] with somebody else. It's my only worry, if something happens to [my son], I'm in trouble." R4*

## C.5 Frank

Frank was 86 at the start of research. He and his wife married when he was in his early twenties and subsequently had two daughters. He had trained in the family business with his father, expanding it and inheriting the business when his father retired at which point his wife joined the business to run one of the shops. They retired in their early 60s.

> *"We were both healthy, we had loads of friends, we used to have lots of dinner parties, we used to go down to the beach most weekends, we used to walk on the moors. You know, we had a great life. We used to travel abroad, say twice a year, and yeah, there was nothing not to be happy about." R1*

Sadly, about 15 years later his wife developed a neurodegenerative disease, and eventually needed to move into a care home. A few years later, Frank began developing health issues, so he downsized and moved to The Manor, nearer his children. Before moving there, however, he took a trip to the arctic wilderness, something he'd always wanted to do.

Frank felt his move to The Manor was a successful in that he was closer to family. He has become involved with the life of The Manor community, on the entertainment committee and serving as a director.

> *"I go down in the lounge every morning which nobody used to, and so, quite a few people come in and have a chat and what not, so I'm beginning to make that more of a social thing." R3*

## C.6 Glenn

*"The City [of London, the financial capitol of the world] was like a big village or a small town…it was an experience. I mean I wouldn't have missed it for the world. I always thought it was like being in the first division." R3*

Glenn was 84 at the start of research. He and his wife have two children, one who lives in the north of the UK and the other who lives in Australasia. Glenn started work in finance at age 16 and was identified relatively early in his career as having great potential which he fulfilled in his successful business career.

*"I was brought up with a work ethic, very much so … I was taught to work and I can't understand people who don't." R3*

Post retirement, Glenn decided to continue in a business career, with the proviso that he would never work for anyone. He bought two businesses and continued in a successful consultancy until his early 80s, when he sold his businesses. He remains on a business forum, attending semi-annual meetings and continues participation and voluntary involvement with his church.

He continues with regular exercise although he has retired from sailing. Increasingly, his socialising occurs with his extended family at annual get-togethers. Glenn still drove at the end of data collection but recognised that his eye problems could limit driving in the future. He has also recognised that he and his wife may have taken their last trip abroad and instead will be paying for family to visit them.

*"Curiosity. That's one of my strongest traits. I'm really very, you know, I'm very curious about things and I like to know how they work and why people have said [what they've said], and all that sort of stuff." R4*

## C.7 Norman

*"Most of the decisions I took were 'yes'! I mean, if I was asked… I can only immediately think of one [volunteer] job which I was asked to do which I didn't and that was due to the commute." R1*

Norman was 84 years old at start of research. After graduation from an Oxbridge university, he entered the civil service where he worked until his retirement at age 60. Norman married aged 28 and shortly thereafter he and his wife moved to OurTown to the family home where he still lives. He and his wife had two children, but his wife died suddenly when the children were in their early teens.

After retirement, Norman was involved in charitable work in the UK and abroad. He remains active, volunteering for his church and a number of charitable organisations, including a state secondary school. He has scaled down his volunteer work based on geography as he no longer drives distances. His goals in continuing his volunteer work are intellectual stimulation and social interaction, that it keeps him active and interested and that the organisation aligns with his ethical goals. After retirement Norman considered downsizing but decided to keep the house as a gathering place for family. This has worked well as his grandchildren live with him which he enjoys. Other than his grandchildren, the rest of his family lives in the north of England or abroad. After the first interview, Norman flew to Asia to visit family living there, but other than visiting family, he no longer travels.

*"As time passes and there are more health issues and whatever's going to come around the corner, they will determine my life more and more. Inevitably. But quite in what way?" R4*

## C.8 Ronald

Ronald was 90 at the start of research. He was 12 at the start of World War Two and 14 when he left school to help his mother and grandmother run the family shop and post office. Ronald married a woman he knew because her father supplied produce to the family shop. They had one child. He and his wife purchased their first house shortly after their marriage. The house needed work, much of which Ronald did himself. They subsequently bought and developed many houses around OurTown, fixing them up and selling them on. He did the same with cars, although with less success.

> *"I've said many a time, I could have had a row of houses if I'd not spent money on cars, 'cause I always lost." R2*

Ronald worked initially in the post office but moved to successive jobs in multinational companies where he was made redundant in his early 50s. After a heart bypass, Ronald returned to working in the family shop, expanding the shop and redeveloping the flat above the shop for their home. Ronald always expected to die early because of his heart problems. Anticipating this, he and his wife moved to a home within walking distance of OurTown so that it would be easier for his wife. Sadly, her health deteriorated, and she died over a decade ago.

> *"From that date onwards I have lived alone and to this day I am aware of entering an empty house every time I get home."*

A few years ago, Ronald met a neighbour who has since become a close friend. She introduced him to the local serviceman's club which enlivened his social life. He has participated fully in the life of the club, serving on the board for many years, ultimately retiring from his volunteering just before the end of data collection.

> *"You probably say to yourself, well, I don't come across too many like him on this job, but then again, you might turn around and say, he's a bit of a softie, I don't know." R4*

## C.9 Bonnie

*"I've always worked. I've never stopped." R1*

Bonnie was age 85 at the start of research. She is part of a close-knit family and maintains close relationships with her siblings and extended family in the North of England, North America, and Australasia. She married in her twenties and had a child but divorced when her child was young. She remains close to her child's family and sees them weekly for Sunday roast dinner which seems to be a symbol for family cohesion and succession.

Bonnie left school after learning business skills, shorthand typing, bookkeeping, English and law. She has always worked, whether paid or unpaid, and has always taken evening classes both out of interest and as a way of making friends. Her friends and work have provided social networking opportunities which have helped throughout her life. She learned in an evening class about the possibility of securing a council house, and later learned about Thatcher's "Right-to-buy", both of which she took advantage of. When her child left for university, she sold her flat and bought a small home in OurTown, subsequently selling this home to move to The Manor.

During the course of research, Bonnie had a number of health problems which necessitated hospitalisation, including a fall where she broke her hip. She recovered completely from the fall, noting the importance of persevering with the exercises. She participates in writing and exercise classes at The Manor and is a director. She remains an active volunteer, finding "it's good for the brain" and that her Hospice work "puts life into perspective".

*"We know it's [life] going to end. Funnily enough, I just like to leave everything tidy. Now that might sound ridiculous, but when I go away, I leave everything just so, in case I don't come back." R4*

## C.10 Dolores

*"Who lives a normal life? Other people lose their loved ones and all sorts of things happen. So, you know, we've all had our issues." R4*

Dolores was age 91 at the start of research. At the start of World War II, she came to England as a child refugee speaking no English. It was expected her family would follow, but instead were taken to labour camps where they later died. She lived with distant relatives and whilst she appreciates everything these relatives did for her, it was not a loving family. During evacuation, however, she was billeted with three spinster ladies where she felt she was treated like the child they had never had. From these ladies she learned unconditional love which she determined to give her own children. She excelled in school, winning prizes and coming top in her class, but instead of continuing to university, took a secretarial course in order to earn money.

Dolores was twice married. Her first husband was also a refugee and a linguist. It was initially a happy marriage, but after the birth of their children, the relationship became increasingly difficult, forcing her to negotiate a path between her husband and her children. Her first husband died of a sudden heart attack when Dolores was in her early 50s and her children were starting their careers. Dolores met her second husband in a language class and they had a happy life, travelling widely, enjoying a variety of activities and social connections. He died two years before the start of data collection. None of her family live nearby, one child lives in the north of England and the other in America.

Dolores has many friends whom she has met through language classes, cultural events, bridge lessons, clubs, and sports activities. She makes friends easily and maintains them throughout her life. She considers her health as very good and only stopped playing tennis after a fall just before the second round of data collection. The fall has made her more cautious and necessitated the use of a stick. Education and music have always been important to her. In her last interview, she noted that she had begun taking piano lessons with her 80-year-old neighbour, trying to practice a bit every day.

*"I've always been a coper. I've gone through some terrible periods in my life and I've managed somehow to get through it and keep strong." R4*

## C.11 Gladys

*"I can remember being in the shop with my doll's pram … it must have been about 11 o'clock in the morning I suppose, when Chamberlain spoke to the nation, the speech is the one you know … it finishes up, "…and therefore I'm sad to say this country is now at war with Nazi Germany' and then the siren went off, the peculiar noise and we all trooped down to the cellar … which was full of spiders and dusty and dirty and I can remember going down there. And that's it. That was my coming to OurTown." R1*

Gladys's parents divorced when she was four years old. She continued to live with her father, cared for by her paternal grandmother until just before her eighth birthday, Gladys moved from her father's home to live with her mother who had recently remarried. The quote above describes that memorable day when she moved into her stepfather's shop. They lived in the flat above the shop for much of her life.

*"My youth in a way, was spent counting up pennies and making piles every evening, cashing up. And you know, the odd pound note because it was all cash. And I'd done that always." R1*

Gladys was 87 at the start of research. She married her husband in her late teens when he returned from the War. He had worked for her stepfather and he eventually took over the business. They continued to live in the flat above the shop until he found a home for them to raise their five children. Gladys continued working in the shop, doing inventory and the accounting, never being paid for it.

Gladys represents a different kind of England, where families and communities took care of each other and worked together for the common good. She was a founder member of the local theatrical group, an early member of the local Women's Institute, a volunteer and trainer for St John's Ambulance, and volunteer for the parish church. She ran county music festivals, participated in local drama productions, and presented musical evenings for the WI. She and the family have travelled widely. She continues to be community and family focussed, volunteering for the parish church and participating in the WI. Two of her children still come home for lunch every day.

*"I always thank my lucky stars that I've got all the inconvenience of dirty cups on the draining board." R4*

## C.12 Judith

*"I've never been a leader type person … I've got more bossy as I've got older." R2*

Judith was 88 at the start of research. She married shortly after completing a university degree in music. She and her husband had many children whom she raised whilst he pursued a career in the City. She has been widowed for over 20 years. Judith never worked outside the home but was always active in local music societies and choirs and church activities. Her activities have reduced somewhat, but she continues to volunteer for the community transport service and attends concerts and educational weekends frequently. She has downsized from the large family home and she still drives.

Judith has a good relationship with all of her children, but her daughter is the only one living nearby. They have a close relationship and her daughter provides occasional support for her mother by having her stay when she is ill. Her son-in-law also helps with the maintenance of the house. One of her sons accompanied her on a brief holiday.

Judith has good relationships with her neighbours and is very close friends with Winifred, a participant whom she suggested for this research project. Judith and Winifred have been friends for many years, sharing common interests in music, singing, and church activities. They appear to have almost a sisterly relationship in that they provide emotional support and care.

Judith considers her health as good or fair. Her health was stable throughout the course of research, although she has a variety of chronic conditions. At the beginning of research, she attended regular exercise classes locally, but towards the end of research she began doing balance classes, providing a lift for Winifred in the process. She frequently protested that she had made few decisions, despite having raised many children. Part of this was because she felt she didn't need to make many decisions.

*"I've been very fortunate because I've had a happy childhood and loving parents and then I married and was happy with that and my children. So I haven't had a rough time." R4*

## C.13 Mildred

Mildred was aged 91 at the start of research. Her father was a teacher who was ambitious for her education, but his health issues meant that the family had financial problems. She was a scholarship student at an academic girls' school and subsequently completed a four-year degree in languages and secured a job as a teacher in the school she had previously attended.

> *"I had to earn money. And I enjoyed teaching and also I'm a creature of routine … I mean, my father was a teacher. I was brought up more or less in a school, so I just do time-tabling for myself." R1*

She held a number of teaching jobs, including a headship at a school in the north of England. After her mother's death, her father was considered her responsibility which meant that he moved with her to nearby accommodation with every teaching move. Shortly after his death, she married in her mid-thirties to an older man, the newlyweds relocating to OurTown, where they purchased the home where she still lives.

She continued to teach, fitting her work around her husband's career. After his retirement, he developed a neurodegenerative disease, at which point Mildred retired from teaching to care for her husband until his death. Mildred subsequently volunteered for a number of charitable organisations, one an intellectually challenging job for which she had additional training.

> *"I was looking for something to learn…something outside life here and life in OurTown…I suppose it goes again to this ideal of making a difference in the community." R1*

She subsequently worked as a guide for a gardening charity where she still volunteers as an archivist. Additionally, she served as editor for the church magazine for over 20 years, only stopping in her nineties. She volunteers because:

> *"I think [it's] my sort of character. I think it's going back to the way I was brought up…you were educated to think you've got to go out and help society." R1*

## C.14 Shirley

*"Nobody tells you the joy that's just around the corner, do they?" R2*

Shirley was 85 at the start of research. She was married to her husband for 50 years before he died of cancer in 2008. After secondary school she worked abroad for eight years prior to returning to the UK to marry. She and her husband had three children, one of whom died in her late twenties. She is close to her remaining children and all her grandchildren and recently celebrated the birth of her first great-grandchild.

Shirley was active and playing tennis three times a week until age 80, but since then, she has had two major operations, a fall where she broke her knee and another when she broke her hip. Shirley has an active social life built around bridge, travel, and the local parish church. She met a gentleman through her bridge group who subsequently became her LAT partner. They had a very close relationship for four years, travelling widely and enjoying an active later-life. He died in 2017 and she still misses him.

Despite the fact that she says she cannot make decisions, Shirley is the only OurTown participant actively considering options for future care. She may think she doesn't think she makes decisions because she confers widely with family and friends about decisions. This helps her sift through advice, vicarious experience and thinking from which she then determines what she wants to do. She has noted that she makes it a conscious decision to remain positive.

*"I put my shoulders down, I stick my head up and I put a grin on my face, and you feel better. And lately, because I still miss [her LAT partner] horribly, I spend a lot of time alone. I go outside or I sit on my balcony and I listen to the birds and I look around and I think, God, it's all so beautiful, how lucky I am. And you have to think that way." R3*

## C.15 Virginia

*"I suppose I had expectations of life, that life would go on as it was … and all of a sudden, everything changed. You were suddenly, you had two suitcases, and you were in a great group of people waiting to be transported to some unknown place." R3*

Virginia was 88 at the start of research. She is married to a man eight years younger. From the age of five, she lived abroad. Her family was interned during much of World War II, where her education was provided by interned teachers and missionaries, without textbooks. She had one more year of formal education after the war, being placed in a grade a year above to complete the school certificate. Her family returned to England where her father died after the rigours of camp life. Her younger brother needed to continue his education, so Virginia learned shorthand typing and began working as a secretary by age 17. Having never lived in England, she didn't feel she belonged in the country so with the support of friends from her internment camp and over the objections of her mother, she chose to work abroad.

*"I thought maybe going to [country], they were all outsiders there. So that was the reason for my decision, I think. I didn't think of it at the time, but … as I look back on it, I think that was one of the reasons that made me want to go, to change my environment." R1*

When Virginia was 27, she returned to the UK because her mother wanted her to settle down. She worked in a number of temporary jobs until she was hired by the large multinational where she worked for the next 26 years, moving from a junior position to middle management which was unusual for women at the time. In her early 30s, she married a former RAF pilot who subsequently died a few years after their marriage. Her supervisor at work was a great support during this time and encouraged Virginia to take a posting abroad in the Middle East to further her career. She met her future husband there where he was in the army. After returning to England they married when she was near 40 and he in his early 30s. After retirement from the multinational, she worked in two other organisations, eventually retiring at age 76.

She and her husband continue to travel widely, selecting places to explore new civilisations and cultures. They continue to be involved locally in a variety of church, livery, and arts activities. She has made the conscious decision not to tell people how old she is.

*"I don't tell anybody my age, because I don't think it's anybody's business. Let them wonder and guess. That's my decision. Because I think when you tell somebody how old you are, they look at you as an 88-year-old woman. I don't want to be looked at like that. I want to be looked at like a person. As me." R3*

## C.16 Wanda

*"I think as an analyst, you do. You're more likely to think things out…. I don't think you know you're doing it, but you look at all points of view and something that excites, the reasons must be that you've worked out that's the one."*

Wanda was 85 at the start of research. Her education was as a scholarship student in a competitive girls' school in the north of the UK. At school, Wanda determined that she would like to study sciences. After graduating, she was offered a place at university, but decided to work and attend night school to continue her education, achieving higher national certificates in science. She subsequently applied for and accepted a job to work in Africa. She subsequently returned to the UK to work in a scientific company, rising to become chief analyst for the company. After changes in the company, she left and later joined former colleagues in forming a consultancy.

She has been married twice and widowed twice. She married her first husband in her 30s. He died unexpectedly and she became the stepmother to three teenaged children. Ten years after the death of her first husband, she met and married her second, to whom she was married for 35 years. They travelled extensively, but also moved frequently. After his death, she sold their house and moved to The Manor both because she didn't want the responsibility of maintenance and upkeep and she wanted to free the equity for travel. She also likes being within walking distance of shops and the local Day Centre, and having readily available socialising opportunities. She serves as a Director of The Manor.

*"I do feel sorry for people of my age who are still in a house, maybe somewhere in the country and don't see many people, maybe their families, but they're lonely and they don't have enough money to be able to do things … I think I'm lucky." R1*

Over course of research, she investigated a persistent cough. After studying her CT scans, she recognised that she might have a lung disease, a diagnosis which was confirmed between R2 and R3. Her response was to reserve more cruises in order to visit the places she would like to see before the disease limits her mobility.

*"I think being old, you are more contented in everything. You don't, things don't worry you so much." R2*

## C.17 Winifred

*"Age does bring its limitations, definitely…. [decisions] are harder because I'm having to make more, I suppose. And you realise that you can only do so much. So yes, it's sad, but it is age." R2*

Winifred was 88 at the start of research. She was married in her mid-twenties and she and her husband had three children, one of whom died age 20. Of all the participants, Winifred has experienced the most change during the course of research. At the beginning of the research, she was still recovering from the death of her husband of 62 years who had died six months previously: "So it's all a bit sort of lonely since, when you're used to talking to somebody." She was still driving and walking unassisted. She had recently discovered that she was in the early stages of pulmonary fibrosis, but she was living unassisted in the family home where she had lived for 38 years. During the course of research, she stopped driving due to an accident with a stationary vehicle in a car park, had knee replacement surgery which she regrets, stopped two of her activities, visited her son in Australia for 5½ weeks, and taken two falls, the last of which resulted in six broken ribs and the necessity of bringing in care.

And yet she continued to be active in the community, repurposing her cleaner to take her grocery shopping and using taxis, making a friend of one driver, whom she says has "attached himself to me." At the start of research, she was Chairman of a voluntary organisation providing transportation for medical appointments, was taking Italian lessons, and participated in a variety of activities such as a book club, cultural club, concerts at the local Music College, and various church activities including yoga and wine club. At the end of research, she had stopped taking Italian lessons and had switched to chair yoga. She depended on friends to take her to church and her other activities. Before her last interview, she had fallen and broken six ribs. She was now living downstairs on a pull-out sofa where her husband had died. She had carers coming in, but was still living alone and considering a stairlift to maintain her independence.

*"Well I think I've come as close as you can [dying], falling in the house. And everybody asked me, what I've done, where did you fall? And they are all thinking the same thing: it could happen to me. So do be careful, won't you, going home?" R4*

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