NAVIGATING DEMENTIA AND SOCIETY

Exploring How People Affected by Dementia Negotiate and Reshape Popular Discourses

Emma Putland

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For my family, friends and everyone who took part in this project
and welcomed me, even if briefly, into their lives.

In honour of my wonderful grandparents, whose love, kindness,
resilience and humour will always inspire me.

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A note on terminology

Since this book's central argument is that our communicative choices hold great power, I would be remiss not to outline the rationale behind the linguistic choices made here to refer to relevant social groups and dementia as a condition. Recognizing that people's responses to language choices are personal and nuanced, that there are cultural and regional differences and that accepted norms may shift over time, this book follows the recommendations of communication guidelines at the time of writing that are produced by or in consultation with people with dementia and their supporters (see Alzheimer Europe, 2022; Alzheimer's Society, 2018; Bould, 2018; DEEP, 2014; KYN et al., 2023).

As such, this book tries to use more neutral language to avoid assuming someone's experience. In the context of discussing people with a diagnosis of dementia, this includes referring to 'people with dementia', 'people diagnosed with dementia' and 'people living with dementia' as opposed to more evaluative terms like people 'suffering' or 'living well' with dementia (see Chapter 5 for participants' reflections on such terms). I recognize that 'living with dementia' can sometimes be used in a broad sense to include anyone with direct personal experience, as exemplified by Dementia UK's campaign tagline: 'We live with dementia: If you love someone living with dementia, you're living with it too' (Dementia UK, 2024a). However, for clarity, in this book I only use the phrase 'person/people living with dementia' to refer to people living with a dementia diagnosis. Likewise, when I discuss 'lived experience' of dementia, this refers to the lived experience of people with a dementia diagnosis, although I also discuss 'lived experiences' in a broader sense, too, and hope that I make the distinction sufficiently clear throughout.

This work uses 'people affected by dementia' or 'people with direct personal experience of dementia' to refer to both people diagnosed with dementia and those close to them, which here includes supporters, carers, family and friends. Recognizing that there are different types of relationships, this book uses the term 'supporter' to refer to someone who offers support to someone (generally to someone with dementia in the context of my participants), and the terms 'family' and 'friends' to refer to individuals who are close to someone with dementia but who do not necessarily identify with a 'supporter' role. As well as ‘supporter’, I use ‘carer’ to refer to someone who identifies with a caring role, which can and does also include people with dementia (see Chapter 3), and I use ‘care worker’ to refer to people employed in the care sector. Where relevant and known, familial terms such as ‘partner’ or ‘daughter’ are also used. I recognize the lack of consensus regarding the best terms of reference for people who take on caring roles, and here, ‘carer’ is grounded in participants’ language. Alternative terms to those used in this book include ‘care partner’ (not used here to avoid confusion about non-partners providing care) or ‘care giver’ (KYN et al., 2023).

As Chapter 2 will outline, to anonymize participants, this book uses letters to refer to participants with a form of dementia (e.g. Participant A, which is shortened to PA), and numbers for participants without dementia (e.g. P1). While certainly not perfect, this system was chosen to facilitate transparency about who is being cited throughout the book, both in relation to a person’s general experience with dementia (i.e. lived experience or otherwise) and the unique individuals within these two broad groupings. The exceptions for this system are Sheila (PS) and Nancy (PN), since Chapter 3 is dedicated to getting to know these two interviewees. I reached out to both participants about this following our interviews, and the person who is named ‘Sheila’ in this book chose this name herself.

As is demonstrated throughout, ‘dementia’ is an umbrella term for a range of neurological conditions, of which Alzheimer’s disease is the most common type. The present work tries to avoid the common mistake of conflating dementia with Alzheimer’s disease by using ‘dementia’ as an overall term and where relevant specifying a subtype, such as Alzheimer’s disease or vascular dementia. When referring to dementia that occurs before the age of sixty-five, I use the terms ‘young onset’ and ‘working age’ dementia interchangeably since, while my participants tend to use the phrase ‘working age’ dementia, ‘young onset’ dementia is the norm elsewhere (Dementia UK, 2024b). Although I use the singular form of ‘dementia’ to refer to multiple subtypes in accordance with present social norms, Chapter 4 briefly considers that the plural, ‘dementias’, may help clarify the plurality incorporated within ‘dementia’. It is worth noting that the term ‘dementia’ is subject to change. For instance, the fifth edition of the American Psychiatric Association’s (2013) *Diagnostic and Statistical Manual of Mental Disorders* replaces the term dementia with the diagnostic categories of major and mild neurocognitive disorders. However, since at the time of writing ‘dementia’ remains the most recognizable term, this book uses the term ‘dementia’ alongside ‘syndrome’ and ‘condition’ to provide stylistic variation where appropriate.

Dementia is 'an umbrella term […] there are different forms of disease, so everything's different'.
We also 'need to look at it as an umbrella of people' who have dementia.
—Participant N (Nancy) and Participant 29, respectively

Figure 1.1 'Umbrella term' illustration (Josh Mallalieu, artist).

1

Navigating dementia and discourse

1.1 Introduction

In response to a question about communicative choices, a very kind and witty gentleman with dementia (known as Participant C in this book) brought up a popular saying that stems from William Shakespeare's play *Romeo and Juliet*: 'A rose by any other name would smell as sweet' (see Chapter 5). Implicit in this saying is the concept that language does not have the power to change an experience of the world, here the smell of a rose. But this book argues the exact opposite: that how we represent aspects of the world (here, regarding dementia) can greatly impact how we experience it. Indeed, the same gentleman noted his hurt at words such as 'loony' to describe people with dementia, exemplifying that words (and the meanings with which they are imbued) hold very real consequences, some of which can be 'catastrophic' for people diagnosed with or otherwise affected by dementia (Mason et al., 2024: 53).

Of course, communication goes far beyond the words that we use. As such, this book focuses on another important aspect of communication: visual language, in particular images. Considering this book's emphasis on visual choices and people's responses to these, choosing the cover image was especially important to me. Following feedback from family and friends, I opted for an image of a flower colloquially known to many as a 'forget-me-not'. I have since learnt that the scientific name that unites forget-me-not flower species is *Myosotis*, which itself comes from 'mouse ears' in Ancient Greek. Take another look at the cover image and see what you think. While I cannot predict how you will respond to the cover image (or any other images for that matter), I can share with you why I made this choice. As you will see if you continue reading, a not-insignificant number of images examined in this book orient around degeneration, isolation and decay, and so I wanted to provide an alternative that could instead acknowledge growth and interconnectedness in life, without necessarily ignoring some of the more difficult aspects of dementia. In many countries, including my context of the UK, the forget-me-not flower is a symbol of dementia and so it became, in that sense, an obvious choice. Yet, beyond this, forget-me-nots can be associated with love and connection (whether romantic or between family and friends), with humility and resilience (these small flowers often bloom in mountainous regions), and with remembrance, all of which are associations that I feel appropriately recognize the people whose contributions have made this book possible.

This book is built on the premise that how we represent dementia both reflects and helps to shape how we experience the syndrome, individually and collectively; thus, attending to communicative choices is vital in better understanding and responding to dementia moving forward. The representational choices that are made – including in media, politics and the conversations we have with one another – each help to reinforce or resist particular ways of thinking about, acting in and organizing society. This work emerges from a society that is 'marked by both hypercognition (an excessive emphasis on intellect and cognition) and hypermemory (an excessive emphasis on memory)' which, as will be explored, has far-reaching consequences for dementia (Swinton, 2012: 110). Notably, this book is set against a backdrop whereby mainstream representations of people with dementia tend to be reductive, exclusionary and have been linked to the stigma faced by people living with dementia (Putland and Brookes, 2024a, 2024b). This is a global issue, with a recent international survey finding that 88 per cent of people living with dementia report experiencing discrimination (Alzheimer's Disease International, 2024). While dementia has biological aspects, then, it is also culturally constructed in a multitude of ways, and a better understanding of how dementia is – and could be – constructed 'contributes to the fight against stigma and can improve the wellbeing of people with dementia and their caregivers' (Swinnen and Schweda, 2015: 11). This book has been years in the making, and in that time, advocacy for the rights of people living with dementia has continued, as have efforts to garner better support for everyone affected by dementia (including carers, supporters, family and friends). Sustained change, however, requires a widespread reframing of dementia – in large part achieved through critically reflecting on, and shifting, the communicative choices associated with the syndrome. Of course, discussions of dementia are not *just* about 'dementia'. Dementia is incredibly complex, with countless intersections with the social world – as such, this book about dementia is also a book about human experiences, identities and inequalities.

At first glance, this book is focused on the micro aspects of dementia: it explores how a group of fifty-one people in the Midlands (England, UK) discuss their experiences of dementia and respond to examples of mainstream media representations. It is interested in the potential implications of particular linguistic and visual choices and in the variety inherent to even this specific group regarding what it can mean to experience life with dementia and with the meaning-making resources (words, images, etc.) that are chosen to communicate this to others. Nonetheless, a micro focus such as this can in turn facilitate important reflections on much larger, macro issues. For instance, what might it mean to experience dementia and to communicate that to others? What role does (and could) society play in how dementia is experienced? What is the gap like between individuals' representations of their lived experiences and prominent social messages about dementia? How might the two be bridged? What role do communicative choices play in perpetuating or challenging the status quo, which has for too long normalized structural and interpersonal injustices? Where does research come into all of this, and what about the researcher's role, too? Where could we go from here?

This book sits at the intersection of multiple research paradigms. In the dementia sphere, it arguably aligns with critical dementia studies through its recognition of dementia as socially constructed, its commitment to self-reflective practice and its goal of contributing to social justice (see Ward and Sandberg, 2023). Perhaps unsurprisingly for an author with an applied linguistics background, this book draws on the (in many ways related) approach of multimodal critical discourse analysis (alongside thematic discourse analysis; see Chapter 2). Namely, I examine how different ways of positioning dementia – and people experiencing dementia – can be realized through particular visual or linguistic choices, which in turn help to foreground and naturalize certain ideologies and actions (or inactions) above others. This book is concerned with how these different positionings can be interpreted, reinforced, resisted or reframed, here in conversations with people directly affected by dementia, whether that is through having a diagnosis, a caring role and/or being close family and friends.

Although a range of communication guidelines consult people affected by dementia on representations, individual voices are generally accumulated into a collective stance on what is good or bad practice. Equally, at the time of writing, the focus remains largely on language choices, ignoring a central resource for making meaning: the visual sphere (for a guideline that does attend to images, see KYN et al., 2023). While some studies have recently begun to attend to the multimodal nature of dementia discourse, far more work is needed to better understand the ideological implications of different social texts (news articles, campaigns, stock images, etc.). This book therefore contributes to a limited but growing body of research that explores how individuals from different social groups, such as people with dementia, supporters, the general public and not-for-profit representatives, respond to varying representations of dementia (Ang, Yeo and Koran, 2023; van Gorp, Vercruysse, and Van den Bulck, 2012; Mason et al., 2024; Slocombe, 2024; Vermeer, Higgs and Charlesworth, 2022). This book aims to interrogate some of the common assumptions made about dementia and people living with the syndrome and to consider how these might be reproduced, resisted or reframed through conversations with people affected by dementia. Some of the key discussion points within this include the diversity of both dementia and people with the syndrome, alongside the transformative change that dementia can bring. Equally, the tensions and interrelationships between medical, personal and media spheres are explored, as are changing relationships with popular portrayals (and the stereotypes they often reinforce) and the subjectivity of both experience and communicative choices.

1.2 This book's structure

This book is organized into seven chapters. The rest of this introductory chapter is dedicated to outlining the key concepts and research that inform this book, beginning with an overview of dementia that incorporates biomedical, psychological, structural/rights-based, embodied and integrative perspectives. Another central yet often debated concept is then defined – that of 'discourse'. Within this, I discuss the impact of discourses, including their role in the stigmatization of dementia and people affected. I also outline the distinguishing features and (sometimes conflicting) interests of three groups that are key to the (re)production of dementia discourses – the news media, not-for-profits and people affected by dementia – and consider factors that contribute to an issue being deemed 'newsworthy'. Following this, I chart influential (and often intersecting) dementia discourses and consider the implications of each for how life with dementia is organized and experienced.

Chapter 2 outlines and reflects upon the theories, research decisions and contexts that underpin this book. It begins by defining my theoretical position, with a particular focus on thematic discourse analysis and multimodal critical discourse analysis, and on multimodality, metaphor, criticality and subjectivity within this. I then examine the rationale and practicalities of the study design, including the running of focus groups and interviews, stimuli, the recruitment process, participants, ethical practice and data analysis. I also reflect on the research context and on my role as the researcher.

Chapters 3 to 6 orient around the analysis of different facets of the focus groups and interviews. These chapters are structured to help balance 'an idiographic focus on the individual voice' with 'making claims for the larger group' (Smith, Larkin and Flowers, 2009: 107). As such, Chapter 3 provides an in-depth exploration of interviews with two women with dementia, Sheila and Nancy (pseudonyms). The chapter explores how these two individuals differently represent dementia in their interviews and how their distinct discursive focuses inform their responses to the same visual representations. Chapters 4, 5 and 6 then draw upon the whole focus group and interview dataset. These chapters are organized around prevalent themes that occur across participants' contributions. In its examination of different meanings of dementia, Chapter 4 explores the diversity of both people with dementia and of dementia as a condition. Diversity is also explored in relation to participants' varying interpretations of two close-up photographs of hands, for which particular visual choices (such as the participants shown and the camera angle) intersect with viewers' personal experiences and worldviews. Chapter 5 focuses on how life with dementia can be differently represented, focusing first on participants' accounts of past, present and future experiences and then on participants' discussions of linguistic and visual choices, paying particular attention to metaphors surrounding 'living (well)', 'suffering', 'battling' and 'journeying', alongside visualizations of loss and decline. Chapter 6 ties the analysis together by exploring both medical and social spheres in relation to life with dementia, which includes a consideration of biomedical technologies and figures, social support systems and shared understanding among peers. It concludes by exploring how participants draw on their personal experiences of dementia to critique media representations and recommend ways to improve such representations moving forward.

Chapter 7 concludes this book by asking: how might the findings and questions raised throughout this book inform potential routes for change? The chapter begins by summarizing this book's main conclusions and contributions, which are organized around some central themes, namely regarding the diversity of dementia and associated discourses, navigating identity and transformation with dementia and the (re)shaping potential of semiotic resources (i.e. the communicative resources that we use to make meaning; see Chapter 2). From there, the focus shifts to this book's recommendations and potential routes for change, with a particular focus on how the concept of 'news values' (introduced in Chapter 1) might be reimagined and repurposed with the aim of promoting more nuanced and supportive media representations. The chapter then concludes by reflecting upon some of this book's key limitations and proposing avenues for future research.

1.3 Defining dementia

The contemporary term used in this book, 'dementia', is derived from the Latin *de* (out of) + *mens* (mind) + *ia* (state of), making its literal translation 'to be out of or to have lost one's mind' (Herskovits, 1995: 148). It is important to recognize that there are multiple ways of conceptualizing what is currently referred to as 'dementia', and that the dominant conceptualizations fluctuate over time and across societies. This includes situating dementia as a natural part of older age, associating dementia with a personal character flaw, with sin or witchcraft and defining it as a form of insanity, stupidity, an 'insufficiency of Qi, a flowing energy' and as a neurological disorder (see Boller and Forbes, 1998; Koncul, George Onyedikachi and Bartlett, 2024; Liu, Wang and Tian, 2012: 2948). Such variation reflects that 'what we conceive of as "diseases" are the products of the society in which they emerge – not merely an outgrowth of the science of the day but constructs forged by particular historical and political-economic circumstances and the dominant technologies, institutions, ideologies, and beliefs of an era' (George and Whitehouse, 2021: 35). In this section, I therefore present from a UK perspective an overview of some of the most influential contemporary approaches to dementia, namely biomedical, psychosocial, structural/rights-based, embodied and integrative (these 'approaches' can also be regarded as 'discourses'; see Section 1.4).

At the time of writing, a biomedical approach to dementia is dominant, and this is reflected in dementia definitions, which overwhelmingly position dementia as a pathology caused by physical processes. Notably, the World Health Organization (WHO, 2023) defines dementia as a syndrome (a group of associated symptoms) caused by a range of diseases that damage the brain, resulting in a progressive decline in brain functioning beyond what might be expected from biological ageing. The umbrella term 'dementia' incorporates a range of neurodegenerative conditions, the most common of which are Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia and mixed dementia. Dementia can affect someone's memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgement, social behaviour and motivation, but consciousness is not impacted. Although age is the biggest known risk factor for dementia, the syndrome is *not* an inevitable consequence of ageing. Indeed, most older people do not have dementia, and young-onset dementia, whereby symptoms occur before the age of sixty-five, accounts for up to 9 per cent of diagnoses worldwide (World Health Organization, 2023). Viewing dementia through the lens of biomedicine focuses on physical disease pathways, which can be used to inform diagnoses (i.e. by using brain scans alongside clinical assessments of symptoms) and research into preventing and treating dementia. In recent years, numerous potentially modifiable risk factors have been identified, including depression, smoking, social isolation, physical inactivity, low education and air pollution (see Livingston et al., 2024).

The 'socially perceived authority' of the biomedical perspective (Zimmermann, 2017: 86) means that a dementia diagnosis can legitimize people's experience, both for themselves and others, by validating their symptoms as being 'real', with a physical cause, and as recognized by medical experts. Indeed, Gerritsen and colleagues (2018: 598) have suggested that distinguishing dementia from psychiatric conditions and ageing can give patients a degree of 'respectability' by attributing symptoms to 'abnormal' brain damage. Positioning dementia as abnormal can justify helping and treating people with dementia wherever possible, thus mitigating the 'therapeutic nihilism' that often accompanies complaints attributed to 'normal' ageing (Hughes, 2014: 39). In theory, then, medicalizing dementia can help to 'shed much of the shame and stigma associated' with the syndrome, yet this tends not to be the case (Lock, 2013: 14). Indeed, the opposite has been argued: that the medicalization of dementia has been accompanied by a range of demeaning representational choices (often to justify continued funding for biomedical research) that perpetuate, rather than alleviate, dementia-related stigma (George and Whitehouse, 2021). This is an issue that the chapter returns to in Sections 1.4 and 1.5.

Clearly, the contemporary biomedical conceptualization of dementia is not without controversy, nor is it apolitical. In fact, Fletcher (2024) suggests that 'biopolitics' is a more apt term than 'biomedicine', in acknowledgement of the political decisions that underpin much of dementia's existence as a biomedical entity. This 'biopolitics' is perhaps best exemplified by dementia's most common subtype, Alzheimer's disease, which has received the most attention from society and researchers alike (for a more comprehensive discussion, see George and Whitehouse, 2021; Fletcher, 2024; Lock, 2013). Throughout much of the twentieth century, dementia was distinguished according to age, as either 'senile dementia' (a normalized outcome of older age) or as 'presenile dementia', a rare disease that was pathological if it occurred before people were sixty-five.

In the early twentieth century, Alois Alzheimer experienced his first two cases that would later become key exemplars of Alzheimer's disease, Auguste D. and Johann F., both in their fifties. Notably, whereas each individual exhibited similar clinical symptoms, post-mortem examinations found differences in their brain pathologies (both had atrophied cells and plaques, but neurofibrillary tangles were only identified for Auguste), and Alzheimer expressed uncertainty about whether this counted as a medically discrete disease. Nonetheless, in 1910, the term 'Alzheimer's disease' was introduced by his colleague, the well-known Emil Kraepelin, in the latest edition of his influential textbook *Psychiatry*. While some scholars have emphasized the exploratory nature of many of Kraepelin's categories (Keuck, 2018), others have argued that the addition of Alzheimer's disease may have been as much a tactical decision (when competing against other schools to lead in describing and explaining specific brain diseases) as a scientific one (George and Whitehouse, 2021: 40).

Following decades of relative obscurity, interest in Alzheimer's disease soared in the 1970s (for a more comprehensive history of the eras in between, see Ballenger, 2000; Lock, 2013). This surge of interest was due in part to technological advances (e.g. in electron microscopes), an ageing population, structural changes (such as the growth of National Institutes for Health and Ageing) and the politicization of dementia as a disease to improve funding, public support and care networks (Fox, 1989; Herskovits, 1995). At this point, a historical (although not rigid; see Keuck, 2018) separation between dementia that was related to older age (senile dementia) and not (presenile dementia) was removed, establishing a 'unifying construct' that pathologized senility into a disease with specific characteristics and symptoms (Fox, 1989: 59). This heightened the numbers of 'potential victims' so that, across about twelve years, Alzheimer's disease was converted from a rare and obscure diagnosis into a major cause of death, being dubbed the 'disease of the century' by some (Fox, 1989: 58–9). Now, Alzheimer's disease has become cemented in both research and popular culture, but to this day, scientific and clinical communities must navigate the still-blurry boundaries both between diagnostic categories (e.g. between ageing and dementia) and the extent to which dementia symptoms can be connected to changes in the brain (notably, people can exhibit the pathological signs of Alzheimer's disease in their brains but *not* exhibit its symptoms, and vice versa; Lock, 2013; Whitehouse and George, 2008).

Excessive faith in the validity and reliability of clinical and neurobiological constructs has significant ethical ramifications. Misdiagnosis is common and difficult for people to deal with, as is the disbelief many people face from others if they do not exhibit expected dementia symptoms according to the biomedical framework (Swaffer, 2016). Equally, assessment rubrics tend to overly rely on a 'hypercognitive' ideal of a person, which prioritizes cognitive abilities above other facets, such as emotionality and empathy (Post, 2000a, 2000b) and thus insufficiently considers the many abilities that people use and display in the everyday social world (Sabat, 2018). Another ethical concern is that the biomedical approach positions people living with dementia as patients with increasing deficiencies and as 'damaged brains' rather than people with social relationships, interests, desires, identities and agency (Gerritsen, Oyebode and Gove, 2018: 598). Through this focus, a biomedical approach risks overly focusing on dysfunction and inaccurately attributing the actions of people with dementia to their syndrome, thus individualizing and depoliticizing people's behaviour rather than considering broader social and environmental factors that can be changed to better support people.

In contrast, a psychosocial approach situates dementia as a subjective experience that is 'relational and co-created' (Latimer, 2018: 839) and thus reasons that many of the behaviours and losses that have been associated with pathology are greatly determined by people's social environment. It shifts the emphasis from 'person-with-DEMENTIA' to 'PERSON-with-dementia' by focusing more holistically on individuals' lives, personalities, histories and relationships (Kitwood, 1997: 7, original emphasis). Particular focus is thus on how social interactions can maintain and/or undermine the 'personhood' (Kitwood, 1997) or 'selfhood' (Sabat, 2002, 2018) of people with dementia. In his seminal work, Tom Kitwood (1997: 8) explicitly ties personhood to social relationships, defining personhood as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust'. Relatedly, Steven Sabat (2002, 2018) draws on social constructionist theory to consider how dementia does – and does not – affect a person's selfhood, referring to three different aspects of self: (1) the experience and emotion-based personal identity (a sense of 'I'/'me' that can be expressed throughout dementia), (2) the self of mental and physical attributes, and a person's attitudes towards these (e.g. being proud of your kindness) and (3) social personae, which vary according to our social relationships with others, and in turn rely on the cooperation of others and are thus particularly vulnerable for people with dementia (e.g. to be a respected member of the community requires continued respect from others).

As these definitions demonstrate, the psychosocial approach emphasizes that ‘being a person is something that we do together’; thus, with appropriate relational conditions and opportunities, people with dementia can live lives full of value, meaning, dignity and purpose (Swinton, 2021: 174). Supportive environments tend to appreciate people with dementia for who they are, consulting and actively listening to their individual stories and needs (Sabat, 2018), being open to not only verbal but also emotional and sensory meaning-making (Hughes, 2014) and acknowledging the contributions of the person with dementia rather than assuming a one-way relationship (Kitwood, 1997; Taylor, 2008). The psychosocial approach highlights that even well-intentioned individuals can undermine personhood/selfhood through their interactions, with Kitwood (1997) presenting six psychological needs that all people require from interactions with others: love, inclusion, identity, occupation, comfort and attachment. These can be violated for people diagnosed with dementia through social interactions, including through infantalization, labelling, stigmatization, invalidation, exclusion and disparagement (Kitwood, 1997; Sabat, 2002, 2018, 2019). Such actions undermine selves 2 and 3; for instance, positioning someone with dementia as a defective burden (rather than recognizing other more admirable traits and social personae) restricts their identity to a dysfunctional, passive patient (Sabat, 2002).

Focusing on social and psychological factors challenges the trend of attributing a person’s experiences and behaviours to their diagnosis. For example, someone with dementia may act aggressively not because of their dementia but because of their frustration with their poor treatment by others (Sabat, 2018). As Swaffer (2016: 209) declares, ‘Of course we will display “challenging behaviours” if no-one bothers to understand our frustrations, or our needs.’ While the psychosocial approach has heralded better recognition of people with dementia as fully rounded individuals who need respect and support to thrive, this approach also has its weaknesses. Notably, an overemphasis on the role of *other* people in maintaining or undermining people’s personhood risks unduly passivizing people with dementia and blaming supporters for ill-being by ignoring other factors, including larger systemic issues and the suffering, losses and grief that dementia itself entails (Bartlett et al., 2017; Higgs and Gilleard, 2016). Moreover, as Dewing (2019: 20) rightly asks, ‘Can, and should, anyone of us bestow personhood on another person? What happens to others and to our own being, should we withhold it?’ If our relationships are what makes up our personhood, then without such relationships, the implication is that it is ‘possible to be human and not be a person’ (Swinton, 2012: 145).

A structural or rights-based approach to dementia focuses instead on the citizenship of people with dementia and the fundamental rights each individual citizen has in society. This extends the psychosocial conceptualization of personhood by focusing on people with dementia as social citizens, with social citizenship being popularly defined as

> a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level. (Bartlett and O’Connor, 2010: 37)

Here, Kitwood’s (1997) psychological *needs* (for love, comfort, identity, occupation, inclusion and attachment) are recast as fundamental *rights*, namely to freedom from discrimination, growth, recognition of social positions, purpose, participation and solidarity (Bartlett and O’Connor, 2010). Focusing on fundamental ‘rights’ is significant, since such rights are universal, objective, reciprocal and absolute, with not only moral but also legal backing (Cahill, 2018). The structural approach builds on the central argument of the social model of disability: that if a person has an impairment (as a result of a condition), they are disabled not by their impairment but by a range of social, attitudinal, physical, economic, architectural and environmental factors (Mental Health Foundation, 2015: 15). For instance, the right to freedom from discrimination (and freedom more broadly) is commonly violated for people with dementia through involuntary surveillance measures and physical or pharmacological restraints, with even residents in low-care facilities unable to go outside of their own free will (Cahill, 2018; Steele et al., 2023; Swaffer, 2016). More subtly, doctors frequently promote what Swaffer (2016) terms ‘Prescribed Disengagement®’, whereby people with dementia are encouraged to disengage from their role as active citizens in society and become passive, including through giving up driving and work before it is necessary.

A structural approach recognizes the intersectionality inherent within dementia, namely that people tend to experience dementia within the context of an ableist, ageist, sexist, classist, racist and heteronormative (and often homophobic) society, meaning that individual citizens can be privileged or marginalized in multiple ways *beyond* having dementia, which significantly affects lived experience (Hulko, 2009; Watchman et al., 2019). It also foregrounds that dementia is experienced within the context of intersecting (inter)national structures and issues, such as hyper-capitalism, the climate crisis, precarity and poverty (George and Whitehouse, 2021). Dementia research is likewise situated within this social context, necessitating critical reflection on the perspectives that are elevated and supressed when defining dementia, including the 'systemic silencing of black voices and promotion of white culture as absolute truth' (Fletcher, 2021a: 1820). The heterogeneity of society must be accounted for, with Parveen and colleagues (2014) highlighting that although dementia is stigmatized across cultural groups, age is not itself a social barrier in some British minority ethnic communities due to a greater cultural respect for elders, which notably contrasts the ageism associated with the UK more broadly.

The structural approach has heralded the recognition of individuals with lived experience as advocates who are integral to progressing the rights and experiences of people with dementia by bringing experience-led expertise. This is acknowledged by the popularization of the disability rights' slogan 'nothing about us, without us' within a dementia context (Bryden, 2016). While valuable, applying the social model of disability to dementia through the structural approach is limited, since, it being designed for people with static physical impairments, it does not adequately contextualize impairments that are associated with cognitive impairments, mental health conditions, frailty, pain and degeneration (Shakespeare, Zeilig and Mittler, 2019). As such, a structural/rights-based approach that is unduly oriented around the social model of disability risks ignoring people with more severe cognitive impairments who cannot engage as actively in society. Indeed, advocates are often younger, well-educated people who are not living with the most challenging aspects of this syndrome (McParland, Kelly and Innes, 2017).

Dementia is also increasingly being conceptualized in relation to (non-)human interconnectedness and the creativity, intentionality and communicative attributes of the body through what this book refers to as an embodied approach (Hughes, 2014; Katz and Leibing, 2023; Kontos, 2004, 2006). Rather than privileging the brain, an embodied approach recognizes the *whole* body as a site of expression and engagement with the world; as such, personhood and selfhood (often subconsciously) manifest in both the body and in relations with other people, animals and artefacts, such as art, clothing and furniture (Downs, 2013; Hughes, 2014; Katz and Leibing, 2023). This includes more natural bodily responses (for instance, laughing and crying) and socialized ones, such as hairstyles, which are reflective of sociohistorical discourses surrounding gender, race, ethnicity and class (Kontos, 2004; Kontos and Grigorovich, 2018). An embodied approach to dementia is inherently relational, as we are 'always intertwined with a shared world' and interconnected through our bodies which, having both intentional and creative capacity, continue to express agency and personality throughout the progression of dementia (Kontos and Grigorovich, 2018: 41).

This embodied-relational association provides the basis for an alternative and more inclusive model of citizenship: relational citizenship (Kontos and Grigorovich, 2018; Kontos, Miller and Kontos, 2017). This model builds on the central tenets of relationship-centred care (interdependence, reciprocity and supporting people with dementia as active partners in their own care) and embodied selfhood theory (which focuses on natural and socialized bodily expressions as a source of agentive interactions and communications; Kontos, Miller and Kontos, 2017: 184). Relational citizenship prioritizes cultivating 'a relational environment that supports the capacity of individuals living with dementia for creativity, imagination, and other positive human potentialities' (Kontos and Grigorovich, 2018: 41). By recognizing and supporting a person's citizenship status through their embodied and relational agency, relational citizenship can thus involve everyone, unconditionally, including people with more advanced dementia (Kontos, Miller and Kontos, 2017).

Aligning with an increasing body of scholarship, this book recognizes dementia as a multifaceted social phenomenon that is entangled with various biological, psychological, interpersonal, social, environmental and structural factors. It recognizes that dementia can be a site of significant suffering, existential crisis and losses, but that simultaneously people can have positive experiences, including of hope, humour, creativity, wisdom, resilience, spirituality and growth with dementia, and that a person's social environment (at all levels) can help to facilitate this (see Clarke and Wolverson, 2016 for more on the positive psychology movement for dementia). Accordingly, this book advocates for an integrative approach that combines multiple focuses in order to better engage with the diversity, instability and complexity of dementia. Particularly pertinent here is the relational disability model of dementia proposed by Shakespeare, Zeilig and Mittler (2019). This prioritizes nuance and multiplicity, as it attends to the personal experience of disability (which arises from the interaction between a health condition and environmental and personal factors) alongside larger sociopolitical contexts. The approach thus incorporates a biomedical focus on impairments and treatment, alongside a concern with overcoming social, attitudinal and architectural barriers. It also strives to empower people with dementia while acknowledging that people with dementia need 'support and protection when their disease makes it impossible for them to be active' (Shakespeare, Zeilig and Mittler, 2019: 1082).

1.4 Looking at 'discourse' in this book

Defining discourse

The above approaches that were drawn on to define dementia can be understood another way, as being examples of *discourses*. Since 'discourse' is an enigmatic term that is used in often inconsistent and intersecting ways, it is important to define how this book understands the concept (for useful overviews of how 'discourse(s)' can be conceptualized and analysed, see Baker, 2023; Brookes and Collins, 2024; Mills, 1997; Tannen, Hamilton and Schiffrin, 2015). In this book, a discourse essentially refers to a particular way of representing the world that both reflects and contributes to the social context that it occurs in. By 'representation', I refer to 'the process by which members of a culture use language [and other forms of communication …] to produce meaning' (Hall, 1997: 61). It can be useful to think about discourses as being 'scripts', with discursive scripts entailing different participant identities (e.g. 'a dementia patient' or 'a person living with dementia'), actions, causalities, priorities and evaluations (van Leeuwen, 2008; Machin and Mayr, 2023). Discourses can be considered in both a 'micro' and 'macro' sense (Gwyn, 2002). At a micro level, focus is on the particular communicative choices (e.g. word choice, grammar) that are made to express meaning in interactions or when producing texts (Gwyn, 2002). At a macro level, the focus broadens to 'a generic style of representation' – namely, 'constrained ways of thinking and talking within a given sociocultural orbit' (Gwyn, 2002: 31). In reality, as Brookes and Collins (2024) note, distinctions between micro and macro approaches are blurry, and many works, this book included, combine these two approaches when exploring discourse.

It is worth unpacking some of these points about discourse(s) further. This work accepts that our understandings and ways of being in the world are shaped by how we use the semiotic resources (i.e. meaning-making resources, such as words or camera angle) that are available to us in both verbal and non-verbal communication, making much of our reality *discursively constructed* (Cameron, 2001: 15), since discourses establish 'parameters of a cognitive "window"' through which people and events can be '"seen"' (Pan and Kosicki, 1993: 58–9).

In this sense, discourses are social practices with plural and often competing possibilities (Cameron, 2001) since 'surrounding any one object, event, person, etc. there may be a variety of different discourses, each with a different story to tell about the object in question, a different way of representing it to the world' (Burr, 2015: 75). This is perhaps best exemplified by the different ways of approaching dementia discussed in Section 1.3; each of these can be understood as one of many discourses on dementia that offer competing explanations and encourage different social actions (e.g. a biomedical discourse promotes focusing on the pathology and finding a cure, whereas the psychosocial discourse foregrounds the person and the role of their social context).

Discourses can be usefully conceptualized (and analysed) as being manifest in a 'set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events' (Burr, 2015: 74–5). However, although discourses are manifest in the choices that are made in concrete instances of communication, such as conversations and images, they cannot be reduced to such tangible entities (Fairclough, 2010: 3). This is inspired by a post-structuralist, Foucauldian view that discourses are not just 'groups of signs (signifying elements referring to contents or representations) but […] practices that systematically form the objects of which they speak. Of course, discourses are composed of signs; but what they do is more than use these signs to designate things. It is this more that renders them irreducible to the language (langue) and to speech' (Foucault, 1972: 54).

When analysing and discussing discourses, it is important to recognize their fluid and subjective nature. Semantically, an instance of discourse is like an iceberg, as only a small proportion of its meaning is actually expressed – most remains implicit and must be inferred from explicit features and the broader context (van Dijk, 2009). As Sunderland (2004) reminds us, analysing discourses is a wholly interpretive project; there is no agreed, finite set of discourses to identify, since they are unbounded, interrelated and invisible, continually being produced and reproduced. There is therefore no 'right' discourse label, meaning that labels vary significantly, including from very general (e.g. 'tragedy discourse') to specific ('people with dementia are the living dead'; these labels will be explored further in Section 1.5). How I label something as a discourse will likely differ from another person and will inevitably, and often unconsciously, be impacted by the discourses that each of us live with. As Foucault (1972: 146) observes, 'it is not possible for us to describe our own archive [of discourses], since it is from within these rules that we speak'. It must be emphasized that due to their fluid nature, the discourses identified throughout this book cannot be considered authoritative or concrete. To increase this work's relevance, I give preference to discourses that have regularly been identified across different contexts in the broader literature. As well as indicating a certain level of reproducibility, this facilitates discussion through utilizing a shared discourse repertoire.

Discourses as reflecting and shaping society

Critically engaging with discourses is vital, since discourses have a dialectical relationship with the situations, stakeholders and structures that frame them – in other words, they are 'socially constitutive as well as socially conditioned', as discourses help to *create* situations, objects of knowledge, social identities and relationships as well as express them (Fairclough, Mulderrig and Wodak, 2011: 394). At an individual level, people's discursive representations of dementia are informed by prior discourses that they have encountered, including in conversation and the media (socially conditioned). Individuals' discursive representations function to reiterate and/or challenge existing discourses and subsequently can influence understandings, interactions, identities and social structures in a multitude of ways (socially constitutive).

To provide a more concrete example of the socially constitutive role of discourses, Heap and Wolverson (2020) found that exposing care workers with a background in a biomedical discourse to discourses of embodied communication and personhood (see Section 1.3) could change how the care workers positioned people with dementia. Initially, care workers focused on loss, non-communication and non-personhood, presenting the act of 'being with' people with dementia as separate to paid work. Here, 'being with' refers to activities that affect someone's psychosocial needs, like holding hands and talking, rather than the tasks typically recorded and prioritized in paid care settings, like eating and dressing. Following exposure to alternative discourses, the care workers instead drew on discourses of communication and personhood, reframing 'being with' people with dementia as *part* of their role. While acknowledging the institutional barriers to more sustained change, the shift observed in this study demonstrates the potential impact being exposed to different discourses can have on perceptions and the treatment of people with dementia. Relatedly, it can be argued that the dominance of the biomedical discourse as a supposedly 'value-free' 'medical fact' naturalizes and upholds a society whereby 'cure remains the dominant goal, not care', which influences the allocation of money and other resources accordingly (Ward and Sandberg, 2023: 2).

Discourses are underpinned by ideologies, which can be defined simply as 'sets of beliefs and values belonging to particular social groups' (Flowerdew and Richardson, 2018: 23). Since discourses are socially constructed forms of knowledge, they inevitably serve or undermine the interests of particular social actors, whether these are institutions (e.g. news organizations, corporations) or more informal groups (e.g. researchers, people with dementia and carers; Kress and van Leeuwen, 2001). It has been widely noted that dominant ideologies, and the discourses that convey them, disproportionately benefit groups with more power and are deeply entwined with normalizing and validating particular social structures (Fairclough, 2010). Yet, discourses can always be challenged and changed to better represent the realities people experience and to denaturalize harmful social practices, such as the stigmatization of both dementia as a syndrome and people affected by dementia (Putland and Brookes, 2024a, 2024b).

Stigma is an international priority for the dementia community, and it is an important example of discourses' role in reflecting and shaping society. This book defines stigma as a social process whereby members of (marginalized) social groups are positioned as undesirable according to socially constructed criteria – here, that of having dementia (Jones and Corrigan, 2014). Goffman (1963) famously discusses stigma in terms of a spoiled social identity, whereby people are regarded not as 'a whole and normal person' but as a 'tainted, discounted one' (31, 12). While there are a range of theories, stigma is often discussed in relation to negative ideas and assumptions (stereotypes) that are associated with negative feelings and attitudes towards a social group (prejudice) and unfair treatment as a result (discrimination; Jones and Corrigan, 2014). Stigma can be discussed in relation to:

1. *public stigma:* prejudice and discrimination from the general public;
2. *self-stigma:* internalised stigma directed at the self;
3. *courtesy stigma*: experiencing stigma through being associated with the stigmatised person, which may affect family, carers and professionals;
4. *affiliate stigma*: self-stigma felt by people close to the stigmatised person;
5. *structural stigma*: whereby a stigmatised person is surrounded by social structures that discriminate against them, whether through laws, policies or practice. (Alzheimer's Disease International, 2024: 16–17)

Stigma is a significant barrier to the physical, psychological and social well-being of people with dementia and their supporters, being, among other things, associated with social isolation, avoiding a diagnosis, not seeking help and having a lower quality of life (Alzheimer's Disease International, 2024; Nguyen and Li, 2020). For instance, stereotype embodiment theory posits that when negative stereotypes are internalized (self-stigma), they negatively influence a person's abilities and health, whereas the opposite can be said for positive stereotypes (Levy, 2009). This is demonstrated through the findings of Low et al. (2018) that experiencing stigma (from others, anticipated stigma and self-stigma) can impact self-identity and cause people with dementia to socially withdraw and give up activities, as they pre-empt failure and embarrassment, and to accept others unnecessarily taking over (self-discrimination). Equally, supporters may also experience social exclusion (courtesy stigma), internalize negative stereotypes of family and carers (such as being 'neglectful') or socially withdraw (affiliate stigma; Alzheimer's Disease International, 2024: 17).

Stigma can also manifest structurally, including through a lack of support from services, which is felt by both people with dementia and carers (Peel and Harding, 2014; Werner and Heinik, 2008). Structural stigma most acutely affects people with dementia, however, including through the normalization of social practices such as incarceration, neglect, social isolation and violence in institutional care (Steele et al., 2023). Structural stigma was brought into harsh focus in the UK and other countries during the Covid-19 pandemic. Ward and Sandberg (2023: 1) reflect on the question posed during a UK government strategy meeting in March 2020: 'Who do we not save?' In hindsight, they find that the answer is clear; the pandemic disproportionately affected people living with dementia in both the death toll (likely at least in part due to hospital patients being transferred into residential care homes without needing a Covid-19 test) and in their experiences of pandemic policies, ranging from (the lack of) protective equipment to extreme social isolation rules that failed to account for their well-being.

Stigma is inherently intersectional, meaning that someone with dementia may anticipate or experience discrimination as a result of their dementia *and* other stigmatized identity features, which can also impact health. For instance, being a woman and having dementia may exacerbate a person's lack of power and confidence in interactions, such as with healthcare professionals (Proctor, 2001). More structurally, women and transgender people especially face discrimination as both employees and patients in the healthcare system (Shannon et al., 2019), while the gendered expectation for women to be the family caregiver negatively affects women's health, whether as the giver or receiver of care (Erol, Brooker and Peel, 2016; Ward-Griffin, Bol and Oudshoorn, 2006). Likewise, the association of dementia with older age provides a 'combined jeopardy' for people (Milne, 2010: 231), since age discrimination, or ageism, is pernicious at both structural and individual levels (Chang et al., 2020). Since each form of stigma is upheld or resisted through discourses, it is important to explore how this can occur (see Section 1.5) and to consider how different social actors may contribute to this process.

(Re)producing discourses: The news, non-profits and experts-by-experience

Three types of influential social actors this book is especially (but not exclusively) concerned with are the news media, not-for-profit organizations and experts-by-experience, namely people directly affected by dementia. Each is a key player in influencing how dementia is navigated by society, and each has particular interests that can guide the dementia discourses they (re)produce.

The news media is widely regarded as 'a window on the world' (Tuchman, 1978: 1), since it both provides a platform for popularizing knowledge about phenomena and helps determine what is seen and thought about (Harvey and Koteyko, 2013). This 'window' can change according to the type and focus of news media (e.g. print, televised or digital, mainstream, alternative or specialist, rural or metropolitan, local or national, free or paid-for) and is heavily influenced by, and equally able to influence, its economic and sociopolitical context (Bednarek and Caple, 2019). Notably, the news media has the power to influence governments and major social institutions (including non-profits), as well as to shape the ideas and behaviours of individual consumers (Bednarek and Caple, 2019). This is the case with health, where news media is instrumental in shaping public knowledge, opinions and reactions (Walsh-Childers, 2017). However, the media's main interest is to attract and engage readers, not to tackle stigma or disseminate messages from the dementia community (Kelly, 2019). It is therefore important to explore how dementia is communicated in the news media, as certain events, social groups, solutions and courses of action will inevitably be prioritized here over others (Harvey and Koteyko, 2013).

In comparison, not-for-profit organizations are key sources of information, support and advocacy for people with dementia and their supporters, as well as for researchers, the news media and the wider public (Lawless, Augoustinos and LeCouteur, 2018; Taylor and Yardley, 2014). That it is common practice to reference non-profits in the news media or academic texts (this book included) exemplifies non-profits' frequent positioning as expert sources of information for whichever social issues they specialize in – although some types of non-profits are more widely cited than others. By non-profits or charities, I refer to a variety of organizations that are run for the psychological and/or physical benefit of a particular community rather than to make a financial profit – indeed, the word charity is derived from the Latin ‘caritas’, meaning care (Malik, 2008). Non-profit organizations include local not-for-profit groups such as Memory Cafés, as well as national charities like Alzheimer’s Society, and advocacy groups such as the Dementia Engagement and Empowerment Project (DEEP), which is an independent, rights-based UK network consisting of over 100 independent groups of people with dementia aiming to enact change (DEEP, 2024). At an international level, not-for-profits include the World Health Organization (WHO) and international advocacy groups like Dementia Alliance International.

Not-for-profits are key drivers of dementia research, policy changes, advocacy and social interventions such as anti-stigma campaigns (Alzheimer’s Disease International, 2019, 2024; Devlin, MacAskill and Stead, 2007; World Health Organization, 2017). However, not-for-profits have agendas; they must fund and justify their philanthropic work, much of which requires continued public and government support. As such, research has identified an increasing marketization of the non-profit sector, with ever-growing competition for public attention and funding (Nikunen, 2016). In response to this sociopolitical context, many non-profits’ discourses are increasingly resembling the promotional discourses traditionally associated with the private sector, such as the news and advertising (Mautner, 2005). Tensions can thus materialize, notably between garnering public attention and concern to maintain financial sustainability, much like the news media, against improving understanding and supporting people with or otherwise affected by dementia.

Increasingly, the voices of experts-by-experience, who have personal experience of dementia, are also influencing how dementia is represented. This can be seen through memoirs (Mitchell, 2018; Zimmermann, 2017), blogs (Castaño, 2020), social media (Talbot et al., 2020), advocacy work (Bryden, 2016), research (Bryden, 2020; Davies et al., 2022; Swaffer, 2014) and advisory roles, such as on communication guidelines for dementia, which tend to be made in conjunction with non-profit organizations (e.g. Alzheimer’s Society, 2018; Bould, 2018; DEEP, 2014 – for a collaboration between people living with dementia, a non-profit and for-profit organization, see KYN et al., 2023). Although historically the voices of people *without* dementia, such as family and carers, have been prioritized over those of people with dementia, there is an increasingly rich repertoire of work by and with people with dementia, who are being better recognized as experts through experience and emphasizing that there should be 'nothing about us, without us' (Bryden, 2016, 2019).

While there is of course great variation between individuals, the accounts of people with dementia can be particularly multifaceted, drawing on multiple discourses and demonstrating a complex interaction between positive and negative aspects of a person's lived experience (Beard, 2016; Buggins, Clarke and Wolverson, 2021; Hillman et al., 2018). There is often a tension between continuity and change in people's lives and sense of self, which can be related both to dementia (which is often regarded as an existential threat) and to many other factors that can affect an individual's sense of identity and positioning in the world, including gender, class, race, ethnicity and sexuality. Notably, Hulko (2009) argues that the extent to which dementia is viewed as problematic for a person's life and identity is related to the social location of the affected individual, suggesting that people with multiple privileges in gender, race, ethnicity and class are more likely to regard dementia negatively than people who are multiply marginalized, who will more likely dismiss dementia's significance and resist being viewed in relation to their condition.

When discussing people affected by dementia, it is important to balance individual and collective identities. For instance, regarding how visible an individual makes dementia within their presentation of self, Fletcher (2020a) notes a direct conflict of interest between people with dementia and their carers. Whereas people with dementia may be more likely to conceal dementia-related impairments, likely due to a fear of being unfavourably perceived, many carers actively work to increase the visibility of dementia, as it legitimizes their self-presentation as a carer and benefits them through institutional and interpersonal allowances. Such an example foregrounds the importance of distinguishing between carers and people with dementia and attending to conflicts of interest when representing themselves, each other and dementia. Interestingly, Beard et al. (2009a) observe supporters/carers to be generally more medicalized and negative in their expressed views on having dementia, compared to people diagnosed with the syndrome. More recently, van Corven et al. (2021) argue that when considering empowerment for people living with dementia, diagnosed individuals focus on individual needs and wishes, while carers prioritize the wider environment. Of course, carers also vary in their experiences, personalities, approaches and overall self-presentations (García-Castro, Alba and Blanca, 2021; Wawrziczny et al., 2017), so it is important to foreground the heterogeneity of not only people diagnosed with dementia but also carers, supporters and other people who are affected, such as family and friends. Simultaneously, many individuals with dementia cultivate a collective identity rather than focusing on a personal one (Bartlett, 2014; Talbot et al., 2020), and a sense of solidarity can emerge among people affected by dementia (people with lived experience and carers alike) through shared experiences and reciprocal support, which can contrast a sense of social distance from others, such as healthcare professionals (Hillman et al., 2018; Keyes et al., 2016).

News values

Even from a brief overview of non-profits, news organizations and experts-by-experience, it is apparent that there are many often competing interests when it comes to just three of the stakeholders in dementia discourses. Self-interests intersect with cultural interests, making 'news values' (namely what makes an event, person or social phenomenon newsworthy) a useful concept for examining the (re)production of dementia discourses. Galtung and Ruge's (1965) seminal work theorized some of these factors and emphasized that a threshold must be passed in order for something to be deemed sufficiently newsworthy to be recorded. This book draws on Monika Bednarek and Helen Caple's more recent multimodal discursive approach to news values, which builds on research in both linguistics and journalism (Caple and Bednarek, 2013). Here, rather than events or social issues having a fixed or inherent newsworthiness, news values are regarded as existing in and being constructed through discourse(s), which the news media (and other social actors) both draw upon and contribute to when constructing a topic or text's newsworthiness (Caple and Bednarek, 2016). As such, particular aspects of a news story and specific news values can be backgrounded or foregrounded in texts through a range of semiotic resources, including words, format and image features, such as distance or camera angle (Bednarek and Caple, 2012, 2014, 2017). Table 1.1 outlines key news values, which depend to some extent on the target audience's perception; for example, regarding negativity, some may see immigration as negative while others do not (Bednarek and Caple, 2017: 61).

The news values of negativity and positivity map especially well onto the existing dichotomy in dementia representations, with an overall emphasis on portrayals that emphasize the negative aspects of dementia ('tragedy' discourse) that has resulted in a more recent push for portrayals highlighting positive aspects ('living well' discourse; McParland, Kelly and Innes, 2017). This is the focus of the subsequent section, within which I also draw on other news values, such as the role of stereotypes in relation to dementia (consonance) and the

Table 1.1 Summary of Different News Values, with Reference to Bednarek and Caple (2017)

News value	Definition
Negativity	Posited as 'the basic news value' due to its prominence (Bell, 1991: 156), since the news regularly foregrounds 'negative aspects of an event' (Benarek and Caple, 2019: 52), for instance, by framing protests in terms of *conflict*, regardless of whether the newspaper sides with the protestors or authorities.
Positivity	The opposite of negativity, concerning 'the [discursive] construction of events as positive', for example, as a heroic act or scientific breakthrough (Bednarek and Caple, 2017: 55, 61).
Timeliness	Constructing events as 'temporally relevant to the reader', including as new, imminent, recent, ongoing, seasonally relevant or trendy (Bednarek and Caple, 2017: 56, 65).
Proximity	Constructing events 'as happening geographically or culturally near the target audience' (Bednarek and Caple, 2017: 62).
Superlativeness	Constructing an event as 'of high intensity or large scope/scale' (Bednarek and Caple, 2017: 64).
Eliteness	Constructing events (and quoted sources) as 'of high status or fame', including through the people, countries or institutions referenced (Bednarek and Caple, 2017: 60).
Impact	Constructing 'the actual or potential effects/consequences of a reported event […] as significant' (Bednarek and Caple, 2017: 55).
Unexpectedness	Constructing events as 'atypical, unusual, rare, different, that is, out of the ordinary in some way because they conflict with what audiences have come to expect based on their experience of the world' (Bednarek and Caple, 2017: 66).
Personalization	Gives 'a "human" face to the news through references to "ordinary" people, their emotions, views, and experiences' (Bednarek and Caple, 2017: 61).
Consonance	Constructing 'news actors, social groups, organizations, or countries/nations in a way that conforms to stereotypes that members of the target audience hold about them' (Bednarek and Caple, 2017: 57).
Aesthetic appeal	The 'aesthetically pleasing' aspects of an event/issue (visual only). This can be through subject matter (people, places, etc.) culturally recognized as beautiful or through technical qualities (e.g. colour contrast and shutter speed for artistic effect; Bednarek and Caple, 2012, 2017: 67).

imbalance in voices (linked to notions of eliteness). Often, these news values overlap, and below I particularly attend to the interrelationship of negativity and consonance. Namely, if negative portrayals are consistently presented, this contributes to negative stereotypes of dementia and the reinforcement of these by subsequent portrayals that adhere to this narrow stance, since observing these negative expectations can increase newsworthiness (Bednarek and Caple, 2019). The concept of 'newsworthiness' is also something that I will return to in Chapter 7, to consider how these news values might be differently engaged with to shift the current discursive landscape of dementia.

1.5 Competing dementia discourses

Having outlined some of the key approaches to dementia and explored the both socially reflective and shaping role of discourses, it is important to now attend to the dementia discourses that are particularly prominent in the public sphere and to consider how they might manifest in the language and images used to represent both dementia and people affected. As noted above, a biomedical approach remains the primary lens through which dementia is represented in contemporary society, and an associated emphasis on (cognitive) loss, degeneration and death drives what has been broadly labelled as a 'tragedy' discourse (McParland, Kelly and Innes, 2017). There are many facets to this broad discourse, including the positioning of dementia as a threat and the passivization or even dehumanization of people living with dementia. In response to this, a 'living well' with dementia counter-discourse has also emerged, which focuses on people's strengths, agency and opportunities while living with dementia (McParland, Kelly and Innes, 2017). In this section, I briefly summarize existing research on popular representations of dementia, which include, but are not limited to, contexts such as the news, public health campaigns, non-profit websites, blogs, books, stock images, adverts and AI-generated images/text. Here, I focus on key metaphorical, linguistic and visual tropes and broadly relate these to the concept of 'tragedy' and 'living well' discourses while considering the criticisms of each. Of course, this topic can be usefully organized in many other ways, including around the concept of stigma (for comprehensive reviews, see Low and Purwaningrum, 2020; Putland and Brookes, 2024a, 2024b).

Biomedicine and a 'tragedy' discourse

A biomedical discourse dominates many areas of public communication about dementia, including in the news, with coverage often focusing on dementia's pathology, research into treatments/cures and strategies to reduce dementia risk (Bailey, Dening and Harvey, 2021; Clarke, 2006; Šestáková and Plichtová, 2020).

Noticeably, the complexities of the biomedical field are often oversimplified in mainstream communication channels. For instance, the diverse range of dementia symptoms may be reduced to memory loss (Brookes, Putland and Harvey, 2021), while the multifaceted interactions of dementia risk factors may be overlooked in favour of suggesting an overly simplistic causal link between a single risk factor and dementia (Peterson and Schicktanz, 2021). That such communicative choices have ideological implications is exemplified by metaphors that explain pathological processes by linking them to everyday ones. Bailey, Dening and Harvey (2021: 368, 372) convincingly argue that the 'body as a machine' metaphor, which likens increasing plaques and tangles in the brain to waste in a pipe or a faulty computer system, serves to position diagnosed individuals as 'merely a passive vessel within which the syndrome progresses' and encourages the assumption that science can 'fix' what is 'broken'.

Metaphors are powerful framing devices, since they foreground certain aspects of a scenario while downplaying or ignoring others. They thus shape cultural responses to dementia through either naturalizing or challenging specific worldviews and encouraging certain behaviours, often without people being aware of the metaphor's influence (Johnstone, 2013; see Chapter 2 for my approach to metaphor). It is therefore notable that dementia is regularly presented as a threat to individuals, communities and societies, and that metaphors are frequently used to achieve this positioning. Dementia may be presented as a natural disaster (epidemic, tsunami, flood) or a weapon of mass destruction (timebomb); it may also be personified as a malicious agentive being (invader, thief, killer, monster, parasite) and portrayed as a threat to the self (whereby people with dementia lose their selves and enter a zombie-like 'living death'; Putland and Brookes, 2024a). Dementia is often anthropomorphized as a powerful, 'cruel' and 'deadly' enemy that 'ravages', 'strikes', 'kills' and 'robs' its victims, as with the headline 'Dementia is the *cruellest* of diseases. It *robs* you of your faculties, your dignity, your identity' (Brookes, 2023: 220–1, original emphasis). Indeed, headlines frequently feature the fear-inducing metaphors mentioned above, as with 'Brain disease on rise; Alzheimer's epidemic' (Peel, 2014: 890) and 'Dementia becomes Britain's biggest killer' (Brookes et al., 2018: 374). The metaphorical conceptualization of dementia as a threat is so integral to the popular understanding of the syndrome that Zeilig (2014a: 262) argues dementia has itself become a metaphorical device, whereby 'Dementia = a complex, unknowable world of doom, ageing, and a fate worse than death'. Accordingly, surveys indicate that dementia is the most feared condition in the UK (Alzheimer's Research UK, 2023).

Accompanying the metaphorical positioning of dementia as a threat are representations that encourage a metaphorical *fight* against this enemy; this reflects a common yet controversial trend of comparing illnesses to a war to be fought, both individually and collectively (Semino, 2008). At an individual level, the idea of fighting one's dementia symptoms can be useful for people to respond agentively to their condition, as with one message board user who wrote: 'I had dementia, I was not going out like a victim!' (Bös and Schneider, 2022: 222). However, considering that this syndrome is progressive and currently incurable, winning the metaphorical battle is arguably impossible, with one blogger writing 'If it were cancer, I'd have a chance of beating it. Dementia? No chance' (Castaño, 2020: 122). In this sense, embarking upon a metaphorical battle with the chronic syndrome risks evoking feelings of inadequacy or hopelessness (George and Whitehouse, 2014; Lane, McLachlan and Philip, 2013).

Individuals who do not (yet) have dementia are also encouraged to fight dementia through taking actions to manage their risk, exemplified by newspaper headlines such as 'Beetroot can fight dementia' in the UK (Peel, 2014: 894) and 'How We Should Live to Protect Ourselves From Dementia' in Germany (Petersen and Schicktanz, 2021: 2011), alongside non-profit communications such as Dementia Australia's resource titled 'The Diet to Fight Dementia' (Chelberg, 2023: 9). Reflecting the broader neoliberal shift of responsibility for health from the governing state to the individual citizen, this discourse largely downplays the role of other systemic and contextual factors to foreground how the individual should act, according to scientific and medical advice, to prevent (or at least manage and postpone) dementia and thereby remain the 'ideal' person – 'active, productive, fit' (Latimer, 2018: 842; Lawless, Augoustinos and LeCouteur, 2018; Šestáková and Plichtová, 2020). In what Peel (2014) terms a 'panic-blame' framework, dementia is simultaneously presented as an overpowering and disastrous threat, yet also as preventable through following biomedical advice, some of which (at least in the context of the news) is contradictory or overly accusatory in tone (Peel, 2014; Peterson and Schicktanz, 2021). Many scholars have expressed concern that overemphasizing individual responsibility for preventing dementia risks blaming people who do develop the condition by implying that they have failed to take the appropriate preventative measures, which may intensify dementia stigma (see Putland and Brookes, 2024a).

In comparison, at a society-wide level, viewing dementias such as Alzheimer's disease as 'a physical disease, not some mystic curse' that 'will fall to a physical cure' can facilitate optimism by empowering humanity to rationalize and envisage defeating a condition the individual 'can't battle' or be 'a plucky "survivor" of'

(Pratchett, 2008: x). Although the collective fight can sometimes be for awareness and equality (Castaño, 2020), more often scientific advancement is presented as the hope of fighting, and eventually defeating, this enemy, which rationalizes prioritizing a future cure above supporting people with dementia now (Bailey, 2019; Lock, 2013).

Turning to the representation of people diagnosed with dementia, what becomes immediately apparent is the overall *absence* of their voices and perspectives in mainstream media, with other social actors such as carers, relatives, medical professionals and government representatives often speaking on their behalf (Clarke, 2006; O'Malley, Shortt and Carroll, 2022). People with dementia are regularly referred to as 'dementia sufferers' or 'dementia patients', both of which place dementia before the person and conflate the person's identity with either that of suffering or being a medical patient (Putland and Brookes, 2024a). People living with dementia are frequently homogenized, victimized and passivized, as illustrated by the headline 'NEEDLESS emergency admissions have rocketed by 70 per cent in just five years as tens of thousands of dementia sufferers are *dumped* in A&E' (Brookes, 2023: 222, original emphasis). The passivization of people diagnosed with dementia is an enduring trope that can occur both linguistically and visually and in a range of contexts, including newspapers, public health campaign posters, books, stock images and AI-generated outputs (Ang, Yeo and Koran, 2023; Brookes, Putland and Harvey, 2021; Brookes et al., 2018; Caldwell, Falcus and Sako, 2021; Harvey and Brookes, 2019; Putland, Chikodzore-Paterson and Brookes, 2023, in press). Grammatically, people with dementia are often cast in the passive role of object, in which they are acted upon by others, namely doctors, scientists, supporters or a personified dementia (for example, 'Experts will demonstrate how to work with Alzheimer's sufferers'; Bailey, Dening and Harvey, 2021; Šestáková and Plichtová, 2020: 391–3).

Visually, people who (presumably) have dementia are regularly shown as passive, immobile (often being seated alone) and with vacant, unchanging facial expressions; such figures tend to avoid eye contact with viewers or other represented participants, instead they either look down, look vacantly elsewhere, or have their eyes closed (Putland and Brookes, 2024b). This discourages viewers from feeling social affinity with the represented individuals by impersonally 'offering' them as 'items of information, objects of contemplation', much like 'specimens [of people with dementia] in a display case' rather than as people with whom viewers can form relationships (Kress and van Leeuwen, 2021: 118). Further discouraging social affinity, people with dementia are often visualized in ways that may encourage viewers to see manifestations of dementia ‘before and perhaps instead of the person’ (Brookes et al., 2018: 384). Notable visual tropes with the potential to contribute to this foregrounding of dementia above the individual include (1) close-up shots of body parts, namely (frail) hands and (scans of) brains; (2) participants posing in ways that emphasize the presence of dementia, for example, by being post-fall, or by pointing to or otherwise touching the brain area, often with a pained expression; and (3) visual metaphors of degeneration, often showing heads disintegrating or being obscured in some way in the area where the brain is (for instance, a tree-head losing its leaves; Putland and Brookes, 2024b). These disease-first and socially distancing tropes tend to focus on suffering, degeneration, frailty and brain pathology and risk creating a sense of a healthy/normal ‘us’ (people without dementia) and a damaged ‘them’ (people with dementia; Harvey and Brookes, 2019).

The visual emphasis on the (degenerating) brains of people with dementia reflects a wider hypercognitive discourse, whereby the brain ‘harbors all that defines the self’ (Zimmermann, 2017: 81). Here, values of rationality, independence, self-control, economic productivity and cognitive enhancement largely define a person (Post, 2000a: 245). In such a worldview, people with dementia inevitably experience a gradual loss or ‘unbecoming’ of self through cognitive deterioration (Fontana and Smith, 1989). The eventual destination is that of becoming ‘empty shells’ with ‘no identity’ (van Gorp and Vercruysse, 2012: 1276–7) and thus being positioned as socially dead (Sweeting and Gilhooly, 1997). Indeed, people with dementia are often metaphorically positioned as the living dead, both linguistically (notably, a recent controversial Alzheimer’s Society’s (2024) advert asserts, ‘With dementia, you don’t just die once. You die again, and again, and again’) and through visual choices, such as blank expressions and dull, lifeless colour palettes (Putland and Brookes, 2024b). Behuniak (2011: 74) compellingly argues that when aspects of the biomedical discourse (such as a focus on abnormality, degeneration and the disease above the patient) are combined with the zombie metaphor, this ‘infuse[s] stigma with disgust and terror’ and delegitimizes people with dementia as fellow humans. This is particularly stark in a recent dataset of AI-generated character descriptions, which associated people with dementia with death, inhumanity and decay, exemplified by lines such as ‘my own body rotting from the inside out’, ‘We no longer recognized her as a human being’ and ‘There is no fragrance of life, no essence of humanity’ (Putland and Brookes, in press: 8–9). Ageing and death have become embroiled with dementia to the point that dementia has become a ‘metaphor for fears of aging’ (Zimmermann, 2017: 88), and, when combined with an overemphasis on dementia’s terminal stages (van Gorp and Vercruysse, 2012), such representations risk ‘equating all forms of dementia with death’ (Taylor, 2008: 323). As such, bloggers with early-onset dementia frequently portray their diagnosis as a ‘death sentence’ – although notably they often rescind this view after realizing the threat is not as imminent as representations convey (Castaño, 2020).

While it is important to acknowledge dementia as a site of suffering, popular media has been widely criticized for unduly foregrounding loss, degeneration and (social) death above other aspects of life with dementia and for contributing to dementia stigma, including through socially othering people with dementia, catastrophizing the threat that dementia poses and (re)producing delegitimizing stereotypes (Low and Purwaningrum, 2020; Putland and Brookes, 2024a, 2024b). Returning to the news value of consonance, it is concerning that the predominant representation of dementia is so negative; although there are some counter examples, research indicates that dementia is consistently positioned as a catastrophic threat that victimizes and erodes the identities and social status of people with dementia. The accumulative impact of these representations is severe, since positioning people with dementia as lesser (i.e. subhuman or even inhuman) due to their cognitive changes encourages dismissal, fear and repulsion rather than care and respect (Aquilina and Hughes, 2006; Behuniak, 2011). This in turn increases the risk of violations to people’s human rights (Cahill, 2018). In reaction to these issues, various counter-discourses have emerged, the most prominent being that of ‘living well’.

‘Living well’ with dementia

Positive psychology and a related ‘living well’ discourse have become increasingly prominent in dementia non-profit, advocacy, research and policy circles in recent decades (Clarke and Wolverson, 2016; McParland, Kelly and Innes, 2017). The ‘living well’ discourse foregrounds the enduring nature of personhood/selfhood and positions dementia as a manageable disability that people can live ‘well’ with, given appropriate social conditions. Importantly, the ‘living well’ discourse tends to recognize that people with dementia are experts through experience and have much to contribute (Bryden, 2016, 2019). Indeed, the accounts and perspectives of people with lived experience are integral to reinforcing that people with dementia can and do ‘live well’ (Beard, Knauss and Moyer, 2009; Hillman et al., 2018; Talbot et al., 2020).

What it means to ‘live well’ with dementia varies; for instance, the ‘living well’ discourse is often associated with encouraging healthy habits and enhancing cognitive reserve to either reduce the risk of developing dementia or manage the condition. This emphasizes maximizing a person's potential to 'live well' through self-responsible individual behaviours, such as brain training, exercise and staying socially connected. As Castaño (2023: 109) notes, this focus on neural plasticity, resilience and recovery draws on metaphorical conceptualizations of the brain as being '"malleable" and able to "rewire" through "training"'. Alternatively, a 'living well' discourse may emphasize the role of local communities and society more broadly in upholding the rights of people living with dementia and providing a social environment that enables people to 'live well' (Leone, Winterton and Blackberry, 2023).

That the 'living well' discourse emerged to challenge the disempowering implications of the 'tragedy' discourse is exemplified by the explicit attempts to replace overly negative and demeaning communicative practices with more positive alternatives. Guidelines offer a prime example of this practice and tend to occur as a collaboration between people affected by dementia and not-for-profit groups. Multiple 'dos and don'ts' of representing dementia have been published to popularize 'words and descriptions that are accurate, balanced and respectful' (DEEP, 2014: 1) and that focus 'on our remaining abilities, not on our many and increasing deficits' (Bryden, 2016: 222). Terms that appeared throughout the above section are criticized for being depersonalizing and othering, including phrases that are suffering-oriented and passivizing (e.g. 'sufferer' and 'victim'), overly medicalizing (i.e. 'patient' and 'service user' outside of a hospital or care service context), fear-inducing ('epidemic' and 'plague'), ageist ('senile'), undermining of personhood and selfhood ('demented', 'empty shell' and 'living death') and that are otherwise demeaning (as with discussions of people with dementia as a 'burden' or 'dotty'; Alzheimer's Society, 2018; DEEP, 2014; KYN et al., 2023). Person-oriented alternatives are recommended instead, including the unabbreviated terms of people 'with dementia', 'living with dementia' or 'with a diagnosis of dementia', to better value individuals with dementia and reduce stigmatization through language (Alzheimer's Society, 2018). More explicitly positive terms such as 'people living well with dementia' (DEEP, 2014) or 'living beyond dementia' (Swaffer, 2016) may also be used as alternatives to counteract passivizing and negative stereotypes. Representations of 'living well' are deemed important, as they prioritize having meaning, agency, growth, social participation and life satisfaction alongside considering the role of society in supporting this (Morgan, 2018).

While lagging behind language, the importance of visual communication is also increasingly recognized by guidelines, including the potential for images to be damaging if they create or reinforce a generalization of who someone with dementia is and how they behave (Bould, 2018). Problematic visual tropes include a lack of diversity regarding both people living with dementia (with a predominance of older, fairly wealthy white people, oftentimes women; Alzheimer Europe, 2022; Bould, 2018) and experiences of the condition itself (with an emphasis on confusion, suffering and negative depictions, with one particular trope being people holding their head in their hands; Bould, 2018; KYN et al., 2023). Preferred images thus tend to feature a diverse range of (if possible, real) people; show individuals engaged in everyday activities, relationships with others and/or in caring scenarios; and, overall, reflect 'the whole person' rather than, for instance, reducing people to 'a fading face or wrinkled hands' (DEEP, 2014: 4; KYN et al., 2023).

In mainstream media, the 'living well' discourse might manifest by representing people with positive emotions (e.g. smiling) and showing people with dementia experiencing growth, connecting with others, exercising agency and being socially involved, whether by setting up a charitable foundation or by expressing love through words, hugging and other physical signs of affection (Ang, Yeo and Koran, 2023; Kessler and Schwender, 2012; Low and Purwaningrum, 2020). Both visually and linguistically, the person diagnosed tends to be foregrounded above the syndrome, as exemplified by a blogger's statement that 'I am me not the illness. I am not a label' (Castaño, 2023: 8). Metaphors assume enduring personhood through either the continuation or transformation of the self, as with 'I'm still me, or at least a version of me' (Caldwell, Falcus and Sako, 2021; Castaño, 2020: 120). The right to participate meaningfully in society and to be different may also be presented (Leone, Winterton and Blackberry, 2023). Overall, a far more agentive, socially connected and joyful account of life with dementia tends to be presented, as with: 'At Alzheimer's Society, we do everything we can to keep people connected, because *life doesn't end when dementia begins*' (King, 2022: 4, my emphasis).

The 'living well' discourse itself is not without criticism. Notably, the positive focus of 'living well' risks sanitizing negative experiences (Fletcher, 2019a) and thus denying people the ability to express their pain, despair and moments where they do not, or cannot, 'live well' (Bartlett et al., 2017). The pressure of normative expectations of what someone with dementia 'should' be like can be oppressing for individuals with dementia and cause 'dementia-related fatigue' for those advocating for 'living well', who may feel that they are 'putting on a show' (Bartlett, 2014). This is especially problematic if undue emphasis is placed on the individual rather than on existing inequalities and necessary social action to support ‘living well’ (Hillman et al., 2018; Wu et al., 2018). Many people thus risk trying to ‘live well’ with dementia in a disenfranchised way, insufficiently supported by the systems surrounding them (Rahman, 2015: 51). Reflecting on his experience of dementia, activist Keith Oliver highlights that ‘this living well with dementia is very important and it is something we aspire to … but it’s not easy. It can become almost a rod for your own back that you feel you’re failing to live well with dementia therefore you’re a failure’ (Bartlett et al., 2017: 178). As Gilleard (2018) highlights, ignoring suffering is likely to make it worse, and only attending to positive aspects of ageing and dementia may restrict social change by denying the seriousness of the issues. Equally, although a living well discourse better prioritizes the voices of people living with dementia, these are disproportionately younger, well-educated individuals experiencing less challenging stages of their condition (Fletcher, 2019a; Talbot et al., 2020). As a progressive condition, the living well discourse risks dividing people with dementia into those who are living successfully with dementia and those who can no longer maintain society’s notion of living well, perpetuating the rejection of the most cognitively impaired, frail and disadvantaged individuals (McParland, Kelly and Innes, 2017: 89).

Beyond the binary

Increasingly, there are efforts to move beyond the simplistic dichotomy of either sanitizing or catastrophizing dementia and towards more accurately reflecting and supporting dementia’s multiple realities, which include (but also go beyond) facets of both the tragedy and living well discourses (McParland, Kelly and Innes, 2017: 91). Individuals living with or otherwise personally affected by dementia often integrate multiple discourses to describe the condition, which may reinforce, adapt or challenge the more mainstream discourses discussed above (Beard, 2016; Fletcher, 2020b; Hillman et al., 2018). These personal understandings are fluid and can be renegotiated throughout the progression of dementia, as they are both formed by and formative of a person’s experiences and sense of identity (Beard, 2016; Fletcher, 2020b). Communicative tropes thus need to be nuanced, flexible and informed by individuals diagnosed with and otherwise affected by dementia.

Importantly, very few representations can be considered entirely ‘good’ or ‘bad’, and the same metaphor, image or phrase can have different meanings for different people (Gerritsen, Oyebode and Gove, 2018). For instance, the term ‘dementia friendly’ may be celebrated as representing a move towards a more supportive society for people with dementia (Alzheimer's Society, 2021) or be criticized as patronizing and misleading (Shakespeare, Zeilig and Mittler, 2019; Swaffer, 2014). Equally, conceptualizing dementia in terms of a battle may place undue pressure on individuals (George and Whitehouse, 2014) or provide an outlet for expressing agency and communicating the psychological impact of having dementia (Castaño, 2020, 2023). Exemplifying the importance of consulting different social groups regarding dementia discourses, Ang and colleagues (2023: 635) interviewed four employees of the Alzheimer's Disease Foundation Malaysia and found that they had more positive interpretations of metaphorical brain degeneration images (such as a missing jigsaw puzzle piece) than visual analysts, since they evaluated the trope as 'an accessible way to explain these complex abstract processes in the brain to the public'. In small focus groups exploring healthism and ageism in media representations of dementia, Slocombe (2024) found that people with more personal experience of the syndrome (lived or otherwise) were more likely to contest media messages suggesting that dementia can be delayed or prevented, whereas individuals with less personal connection were more likely to position such coverage as educational and empowering. As this small but growing body of research demonstrates, exploring how individuals with different experiences of dementia respond to social texts (e.g. images, news headlines) facilitates more nuanced discussions of dementia representations and broader social discourses.

Throughout this chapter, it has been made clear that discourses play an important role in shaping understandings, experiences and social action in relation to dementia. Discourses can both naturalize and uphold – or challenge and reshape – existing social norms. Acknowledging the need to further interrogate contemporary discourses and to explore potential avenues for change, this book focuses on how people directly affected by dementia might variously reproduce, resist and reshape dominant dementia discourses. Throughout, nuance and multiplicity emerge as key facets of representing dementia, as do points of tension between personal experiences of dementia and social stereotypes surrounding the syndrome.

That's 'what life's all about isn't it […] Different stories'.
Everybody's got a different story to tell.

—Participant J and Participant 23, respectively

Figure 2.1 'Different stories' illustration (Josh Mallalieu, artist).

2

Research approach and process

2.1 Introduction

It is said of Matilda, the eponymous character of the story book imagined by Roald Dahl and illustrated by Quentin Blake, that 'all the reading she had done had given her a view of life they had never seen' (Dahl, [1988] 2016: 20). This book is itself built upon reading the words of many others, alongside the exchange of words during conversations with study participants. As Participant 23 says, everyone has 'a different story to tell' (Figure 2.1), and I am fortunate that many people shared aspects of their stories with me through the interviews and focus groups. Of course, the story of the research itself is also important; so before exploring participants' contributions in the subsequent chapters, this chapter is dedicated to outlining and reflecting on the theories, research decisions and contexts that underpin this book and its arguments. All of these either inform or are informed by the following research questions:

1. How do participants represent dementia for themselves and others?
2. How do people respond to visual and linguistic representations of dementia?
3. How do participants reproduce, resist and/or revise prevalent discourses of dementia?

I begin with my theoretical position, in which I situate myself in relation to thematic discourse analysis and multimodal critical discourse analysis. Following this theoretical discussion, I outline the research project design and processes, including the organization of focus groups and interviews, the participants involved and my approach to ethical practice. Throughout, I reflect on the decisions made, and the chapter concludes with a consideration of how the research context influenced participants' contributions and my interpretation of these.

2.2 Theoretical position

This book draws in particular on two approaches that centre around identifying and critically engaging with aspects of discourse, which I defined in Chapter 1. Firstly, in organizing the chapters, I draw upon *thematic discourse analysis*, since I aim to simultaneously showcase important themes across groups and interviews while also attending to the linguistic details of specific interactions. The explorative nature of this project suits thematic discourse analysis, which, as with any approach with no set formula, requires a definition of its use in this context (Cheek, 2004).

As the name indicates, thematic discourse analysis straddles thematic and discourse-oriented analytical traditions, which enables key themes to be drawn from the data alongside attending to the contexts and implications of communicative choices (Šestáková and Plichtová, 2020). Authors vary in the emphasis placed on each component, with some focusing closely on the structured coding of themes, attending to discursive features as an aid (Taylor, Sims and Haines, 2012), while others prioritize discourse analysis to discuss how issues are constructed and use looser themes to organize findings (Peel and Harding, 2014; Šestáková and Plichtová, 2020). This book ascribes more to the latter tradition, taking a more inductive, fluid approach to theme identification and using such themes to structure discourse-oriented analysis. By 'theme', I refer to a broad topic or issue (such as 'explanation of dementia'), *within which* there are different discourses (e.g. psychosocial versus biomedical discourses), each providing alternative ways of constituting the same topic/theme.

Turning now to the 'discourse' aspect of thematic discourse analysis, this book is concerned with how discourse is used 'to represent, evaluate, argue for and against, and ultimately to legitimate or delegitimate social actions', here surrounding dementia (Cap, 2023: 156). As such, it takes a critical stance that aligns with the tradition of multimodal critical discourse analysis (MCDA). MCDA is a multimodal branch of critical discourse analysis (CDA), also known as critical discourse studies (CDS). Of the diverse multimodal research that exists (for an overview, see Jewitt, 2014), this book is particularly informed by the work of Gunther Kress and Theo van Leeuwen (2001, 2006) and David Machin (2013; Machin and Mayr, 2023). Underpinning their research is a social semiotic theory of communication, which is concerned with how 'language and other communicative modes are used in social contexts and to create and shape identities and social relationships within society' (Brookes, Putland and Harvey, 2021: 243). Here, focus is on how communicators use the semiotic resources available in a particular context to realize their interests, assuming that communicators are working to an extent within a rule-based system (although the nature of these rules can vary greatly) and that they are aware of (at least some of) the potential meanings (or 'affordances') of their communicative choices – for instance, of 'living well' versus 'suffering' with dementia (Machin and Mayr, 2023). By *semiotic resources*, I refer here to communicative devices (such as camera angle or pronouns) that are used within broader meaning-making systems (*semiotic modes*) such as language, images, gestures and architecture (Caple, 2018: 86). Below, I unpack MCDA in more detail, firstly outlining key frameworks and then discussing the notion of criticality.

Multimodal frameworks

Building on Halliday's work in systematic functional linguistics (Halliday, 1985; Halliday and Matthiessen, 2013), MCDA analysts regard communicators as navigating a rule-based system, or 'grammar' (Kress and van Leeuwen, 2006, 2021) when using or interpreting semiotic modes and resources such as images, font, colour and language. Famously, Kress and van Leeuwen (2021: 16–18) propose that visual texts can also fulfil Halliday's (1978) three communicative functions; they can represent the world (ideational), construct social relationships and express attitudes towards what is being represented (interpersonal) and be internally and contextually coherent (textual). For instance, similarly to sentences that begin with familiar information and end on new, Kress and van Leeuwen (2006: 185–90) propose that for cultures that read left to right, horizontally arranged compositions can present elements placed on the left-hand side as 'given' (the already familiar and agreed-upon point of departure for the message) and other elements on the right as 'new' (not yet agreed upon, and so requiring greater attention). Although of course textual, this can also fulfil ideational and interpersonal functions, for instance, through who/what is presented as 'given' versus 'new'. Interpersonally, the authors chart how the camera angle and gaze of represented participants can establish different power dynamics and social closeness. For example, a distant side-shot and/or lack of eye contact from a represented participant can convey greater social distance, while a higher camera angle positions viewers as higher (and thus apparently more powerful) than those depicted. The authors detail each variable at length, making their work a useful framework to provide both a more descriptive account of what is being depicted ('denotation', itself not ideologically neutral, of course) and a more interpretive account of the ideas and values likely being implied and/or interpreted by audiences ('connotation'; Barthes, 1977).

Taking a “visual grammar” approach such as Kress and van Leeuwen’s comes, of course, with limitations. The appropriateness of imposing linguistic frameworks (here, Halliday’s systematic functional linguistics) onto non-linguistic semiotic modes and resources is debatable, as is the balance struck between empirical evidence and the authors’ personal contextual knowledge when informing the framework (Machin, 2014). The authors themselves emphasize that their general theory is hypothetical, provisional, culturally specific and open to development, and that any ‘general theory must look crude by comparison with the richness of the actual semiotic world’ (2006: 266). It is therefore essential to regard this not as a fixed or comprehensive ‘grammar’ but as ‘a flexible set of resources that people use in ever new and ever different’ ways (Kress and van Leeuwen, 2006: 266). Overall, though, this ‘grammar’ of visual design provides a productive and insightful framework for exploring how participants respond to visual representations of dementia, here in a British context.

A more recent and particularly relevant extension of the above work is the Visual Discourses of Disability (ViDD) analytical framework, developed by Ang and Knox (2023) and applied to a dementia context (specifically in Malaysia) by Ang, Yeo and Koran (2023). The framework proposes a quadrant with two axes: one cline charts the extent to which an image focuses on the person (personizing) or the disability (perspectivizing), while the other cline focuses on the construal of emotion and power, considering whether this enables or disables the individual(s) depicted. The authors usefully outline the role of different semiotic resources within this; for instance, a personizing image tends to be (but does not have to be) associated with using a mid-shot or close-up shot of a person, alongside direct gaze (making eye contact with viewers) and a focus on specific individuals rather than generic cultural tropes. In contrast, perspectivizing images may use close-up shots to focus on dementia above the person (e.g. through symptoms, medical devices and body parts) or long-shots that homogenize depicted individuals. Represented participants do not look at viewers and are instead “offered” as ‘specimens’ of dementia (Kress and van Leeuwen, 2021: 118). A more enabling image is understood to carry positive affect (e.g. through someone smiling), be appropriately realistic of a regular person, show someone with dementia in an active role and position them either at eye level (equal power) or looking down at the viewer (lower viewer power). A more disabling image carries negative affect (e.g. by showing pain) and may overly pity or exoticize the represented individual, present them in a passive recipient patient role or even exclude them. The ViDD framework thus provides a useful point of reference when considering images in a dementia context.

As one of the means through which discourses can be expressed and multimodally analysed, my approach to metaphor also merits discussion here. Metaphor can be usefully conceptualized as 'the phenomenon whereby we talk and, potentially, think about something in terms of something else' (Semino, 2008: 1). Of course, metaphors are not restricted to talk, and this book also engages with visual metaphors, a point that I shall return to shortly. Acknowledging the range of metaphor theories (see Semino and Demjén, 2016), this book draws on cognitive and discourse approaches to metaphor which, while having different focuses and levels of generalizability, are each concerned with the concept of framing (for further details, see Semino, Demjén and Demmen, 2018). This book refers to Entman's (1993: 52) definition: 'Framing essentially involves *selection* and *salience*. To frame is to *select some aspects of a perceived reality and make them more salient in a communicating text, in such a way as to promote a particular problem definition, causal interpretation, moral evaluation, and/or treatment recommendation* for the item described' (original emphasis). In other words, metaphors frame social phenomena (such as dementia) in line with associated discourse(s) by foregrounding certain aspects while downplaying or ignoring others – this, in turn, can encourage (and conversely discourage) particular interpretations, appraisals and responses.

A cognitive approach to metaphor focuses primarily on *thought*, namely on conceptual mappings that are involved in metaphor, which is largely inspired by the Cognitive Metaphor Theory initially proposed by Lakoff and Johnson (1980). A cognitive approach highlights that metaphor provides us with the tools to make complex, abstract, unfamiliar, subjective and/or poorly defined phenomena more intelligible and communicable. This is achieved by mapping features of a literal 'source domain', which tends to be a more concrete, familiar, simple, physical and/or well-defined experience (such as a fight or journey), onto a more complex or abstract 'target domain', here, regarding either dementia or aspects of dementia (Semino, 2008). According to a cognitive approach to metaphor, by mapping a source domain onto a target domain like dementia, particular features are foregrounded, while others are hidden, which can in turn bias how people think about dementia. For instance, drawing on what is often referred to as the WAR source domain (Lakoff and Johnson, 1980 – in the cognitive tradition, small capitals are used to indicate a conceptual mapping), Chapters 1 and 5 explore metaphors that orient around fighting or battling with dementia. Notably, envisioning life with dementia as a fight encourages an emphasis on opposition, strategies and winning versus losing. While potentially useful to some individuals (Castaño, 2020), it has been noted that when applied to this progressive and currently incurable syndrome, the metaphor risks evoking feelings of inadequacy for ultimately being unable to 'win' (George and Whitehouse, 2014; Lane, McLachlan and Philip, 2013). Subsequent research has critiqued Lakoff and Johnson's (1980) overly broad approach to the labelling process of 'domains' (e.g. WAR and MONEY) and has instead suggested a less overarching and more multilevel approach to conceptual mappings, for instance, that incorporates subdomains (for an overview, see Semino, Demjén and Demmen, 2018). This is useful for conceptually mapping a range of related yet distinct metaphorical uses – for instance, life with dementia may be referred to as a struggle or fight rather than a war that can be won; the opponent can (and does) vary; and likewise, different attitudes can be expressed through specific applications of otherwise similar concepts, such as fighting (see Chapter 5 for more).

A discourse-based approach to metaphor complements a cognitive one by focusing on how metaphors are used in a range of real-life contexts, such as in conversation, newspapers or healthcare communication. From this perspective, 'the framing power of metaphors does not just depend on the conceptual structures involved, but emerges in the dynamic interaction of people "talking and thinking" in interaction' (Semino, Demjén and Demmen, 2018: 630). This approach can examine both broader metaphorical patterns and more context-specific uses of metaphor within particular communities and situations, which suits this book's exploration of both popular metaphors and more personal, anecdotal uses of metaphor, as seen especially in Chapter 5.

Since much metaphor work orients around language, I find the work of Charles Forceville (1996, 2002, 2008; Forceville and Urios-Aparisi, 2009) particularly helpful when attending to visual metaphors shown to participants. Advocating for greater recognition of multimodal metaphors, Forceville (2002: 12) outlines three key questions for determining the presence of a metaphor: (1) What are the metaphor's two elements, and how do you know? (2) Which element is the metaphor's source domain and which the target domain, and how do you know? (3) Which features can/should be mapped from the source to the target domain, and how is this decided upon? These questions provide a clear and reflective starting point for identifying visual metaphor, which I will return to in the analysis chapters.

'Critical' as more than 'criticism'

Moving onto the second word in multimodal critical discourse analysis (MCDA), this book regards MCDA (and CDA more broadly) as 'critical' in the sense of being problem-oriented, interrogating social phenomena in a way that challenges rather than accepts the status quo (for a more comprehensive discussion of the term 'critical', see Breeze, 2011). Although 'critical' does not necessarily mean negative, this is a common misconception for critical studies (Wodak and Meyer, 2009). (M)CDA works are best known for critically deconstructing semiotic resources that reiterate the unequal distribution of social power, for instance, through (re)producing racism, sexism or class inequalities (Flowerdew and Richardson, 2018b).

When 'critical' is understood in a fuller sense, the CDA umbrella comfortably includes its subdiscipline, positive discourse analysis, which highlights alternative discourses – often produced by marginalized groups – that address social inequalities and hold potential for positive change (Bartlett, 2018). Simply put, analysts study discourses they like rather than wish to criticize (Macgilchrist, 2007). Positive discourse analysis seeks to offer more constructive analysis that engages with an ever-changing and increasingly connected world, rather than continue to deconstruct the same types of texts without considering what can be and is being done to create positive change. Regarding critical discourse studies as too narrowly focused on problematic interactions, researchers are calling to instead examine how different members of society, especially minority and stigmatized groups, (re)interpret and resist mainstream discourses and generate counter-discourses (Breeze, 2011; Luke, 2002). Attending to people's discursive choices is incredibly valuable since, as we adapt and change semiotic resources according to our own lived experiences, identities and contexts, we all hold the potential to *reshape* the semiotic resources (and associated discourses) that are available to us, on both individual and collective levels (Kress, 2000). As Macgilchrist (2007: 75) highlights, counter-discourses do not always remain so, since they change according to what is considered to be 'predominant' versus 'dissenting'. As just one example, once the feminist discourse regarding women's equal right to vote became widely accepted and normalized in the UK and many other countries, it became part of rather than a 'counter' to the mainstream.

This book engages with critique in both a deconstructive and constructive sense. As will be demonstrated in Section 2.3, I have selected stimuli to reflect a spectrum of dementia discourses and used multiple images and phrases in existing (M)CDA studies to explore participants' perspectives on representations that have already been critiqued by analysts other than myself. Many phrases, images and discourses are critiqued and deconstructed in the analysis, which occurs in conversation with people affected by dementia. Equally, through consulting people with their own experiences of dementia (lived, as a supporter and/or loved one), I aim to complement analytical deconstruction with a more "constructive" focus on how particular members of society draw on their lives and discursive repertoires to interpret, align with and resist different ways of representing dementia. This produces both counter-discourses and some recommendations for how popular representations of dementia could improve. Here, critiques of existing discursive practices are grounded in the input of a traditionally disenfranchised group, who are uniquely placed to generate experience-based alternatives in the hope of contributing to positive social change.

A critical lens is also needed when considering the assumptions that underpin this and other research. Notably, (M)CDA works have been criticized as too selective, subjective and qualitative in data selection and analysis (Machin and Mayr, 2023). While these are important issues to reflect upon, I would highlight that researcher subjectivity is an inevitable aspect of any research, whether in the social or natural sciences (Mautner, 2010), including in corpus-based studies working with a vast collection of texts (Baker et al., 2008). Reflexivity is thus an essential component of critical research, which must grapple with the tension that as researchers 'we are socialized into discourses and dispositions produced by the socio-political order we aim to challenge, a socio-political order that we may, therefore, reproduce unconsciously while aiming to do the contrary' (Alejandro, 2021: 154). This is an issue that I return to in the final section of this chapter, where I reflect on the research context and my own role in creating the book you are now reading. Regarding the critique of a qualitative approach, it is worth recognizing that smaller, qualitative samples also hold great value, since the aim here is not to be 'generalizable as descriptions of how things *are*, but as how a phenomenon *can* be seen or interpreted' (Talja, 1999: 472, my emphasis). Equally, as with any research, some selectivity is driven by practical constraints (including, for example, this book's wordcount restrictions). Thus, I focus here on the interpretations of certain examples of images and language use, which necessarily ignore alternative texts and their production, as well as broader discourses despite these, too, being valuable avenues for research (Stubbs, 1997).

Through engaging with people affected by dementia, this book arguably partially addresses another key criticism of (M)CDA: that it tends to ignore real consumers of semiotic resources, which risks overlooking that there is always 'a plurality of possible interpretations' (Machin and Mayr, 2023; Widdowson, 1998: 150). Foregrounding only the analyst's interpretation heightens other critiques of (M)CDA, namely that being politically rather than linguistically motivated, studies risk finding what the analyst expects to find (Stubbs, 1997). Widdowson (1998) argues that, ironically, this practice undermines (M)CDA's goal to expose inequalities and injustice, since imposing the analyst's single view in turn controls audiences' access to the semiotic resource. Of course, in reality, as Kitzinger's (1993) account of different groups responding to media representations of HIV/AIDS illustrates, people draw on a range of existing knowledge and interpretative techniques to produce a spectrum of readings and may accept, reject or ignore discourses (Breeze, 2011). This book therefore contributes to a small but growing body of research that explores how individuals with different experiences of dementia respond to some of its representations (see Ang, Yeo and Koran, 2023; van Gorp, Vercruysse and Van den Bulck, 2012; Slocombe, 2024; Vermeer, Higgs and Charlesworth, 2022). Inevitably, though, this book cannot escape that, as with any discourse analysis the analyst is given great power to impose meaning onto another's text (Cheek, 2004), since, although I consult participants about visual and linguistic representations, ultimately, I am the person collating, analysing and presenting the interview and focus group data. Returning to the need for reflexivity, it is thus vital that I explicitly outline and reflect upon my theoretical and ideological stance throughout, and I direct readers to Section 2.4 for the greatest detail on this issue.

2.3 Research design

Having outlined my theoretical position, I now turn to the design and rationale of the project that this book has developed from. This section begins by outlining the study design, particularly regarding the rationale, structure and content (i.e. stimuli) of the focus groups and interviews. Following this, I discuss participant recruitment, ethical practice and my approach to the data.

Both interviews and focus groups were included in the study design. This decision had multiple motivations: first, to better enable me to meet the individual preferences of participants, who may be more comfortable in a group or one-to-one situation; and second, to draw upon the different strengths of each method of data collection. Both means of data collection provide valuable insights into how participants construct their experiences and position themselves in relation to different discourses surrounding dementia.

Interviews are simultaneously a familiar interaction that we consume via the radio, magazines and television (Dörnyei, 2007) and unusual to participate in within everyday life, since the interviewer shows unrivalled interest in someone's views and experiences for an extended period while simultaneously holding greater power in the context of the interaction, as the interviewer traditionally determines the topic, questions and will report on their personal interpretation of the participant's responses (Brinkmann and Kvale, 2018). In contrast, group discussions are seen to better emulate how people exchange opinions and navigate topics in everyday interactions (Flick, 2018). Of course there are still issues of power asymmetry, with the facilitator initiating and helping to direct the sessions, but researchers maintain that for focus groups of people who share an identity feature or experience, here of dementia, this more informal method can facilitate greater candour and help to discuss more sensitive topics, with a perceived safety in numbers and the stimulus of other group members (Barbour, 2018). It is this group interaction that is central to focus groups, making them invaluable for exploring 'how knowledge, ideas, story-telling, self-presentation and linguistic exchanges operate within a given cultural context' (Kitzinger and Barbour, 1999: 5). More than this, focus groups provide a 'socially legitimated' opportunity for group members to be introspective and to reflect on assumptions and social narratives that are usually taken for granted and rarely articulated in a critical space (Bloor et al., 2001: 5). The same can be said at an individual level for interviews, with both offering the opportunity for participants to probe their perceptions and experiences, allowing the researcher to harness participants' own observations and insights in the process of generating and then analysing and reporting data (Barbour, 2007).

However, in a group context, multiple participants compete to tell their personal stories and viewpoints, which often produces non-chronological and noisy data that is difficult to attribute to individuals (Barbour, 2018). In addition, there is a risk that some participants' voices dominate others, with the latter voices being interrupted or unexpressed in conversation (Smithson, 2000). Here, the key strength of interviews becomes important, as the one-to-one (or sometimes one-to-two) nature better facilitates a detailed and comprehensive account of an individual's experiences and discursive practices. Of course, neither method offers 'the authentic Voice of the People', as that is itself a myth, and these methods are always constrained by processes of recruitment, conduct and analysis (Bloor et al., 2001: 15). Both artificial and naturally occurring data are influenced by discursive norms and perceived audience, here, group members and the researcher (Barbour, 2018). What combining focus groups and interviews offers, then, is a range of insights into how people situate themselves in relation to popular discourses of dementia and choose to represent themselves, their experiences and others.

To make focus group and interview data more consistent, all sessions were semi-structured, using the same stimuli and overall structure throughout. Piloting both a focus group and interview enabled me to test my structure, delivery and stimuli, resulting in the interview schedule shown in Table 2.1, which I adapted to participants' needs during data collection. This is exemplified in Stage 4, where I shift from asking what participants associate with dementia, which, being quite broad, generated uncertainty, to the more specific and interaction-oriented question 'how would you explain dementia to others', which participants more readily engaged with.

As Stages 2 and 8 will be discussed under the 'ethical practice' section, here I focus on my framing of these sessions for participants, before discussing the rationale and organization of the visual and linguistic stimuli. As Table 2.1 shows, in Stage 1, I concisely explained the study for participants, summarizing it as aiming 'to collect your opinions on how we show dementia and talk about it in Britain, and how this affects you personally'. Participants' relationships with newspaper and charity portrayals were noted as especially of interest, but I emphasized that other sources of social portrayals, such as television, were welcome too. This explanation was intended to give participants context about the overall focus while ensuring that I emphasized being interested in people's personal stance and experiences, in the hope of reducing preconceptions of a 'right' or 'wrong' answer. I then discussed the session's overall structure and audio-recording, welcoming any questions.

The session began by gaining information about how participants engage with different sources of social portrayals (e.g. newspapers) and their own discursive practices (Stage 4). This was achieved through first asking what experience participants had of newspapers and charities, and where they got their information about dementia from, which may include examples of specific organizations (often Alzheimer's Society) or other sources, such as the internet, doctors or peers. This was intended as a straightforward starting question to help participants relax into a discussion while providing useful context about their personal information sources. Before influencing participants with stimuli, I explored what people chose to foreground about dementia when asked a variation of the question, 'what do you associate with dementia?' or, more frequently, 'how would you explain dementia to someone who did not know anything about it?' The latter question was used from Focus Group 3/Interview 3 onwards, as it was determined to be clearer. Despite the shift between an internal ('associate') and external ('explain') focus, the two question variations provided useful insights into the discourses that participants choose to reproduce (or

Table 2.1 Interview and Focus Group Schedule

Stage	Summary	Breakdown of stage and researcher's framing
1	Introductions	Set tone, including organizing food and drink. Introductions for myself and participants (if not already familiar). Explain study's focus and aims. Explain the process of recording and the basic interview structure.
2	Informed consent and demographic information	Give all participants a folder with the following: (1) Full privacy notice (2) Consent form (3) Brief demographic questions Discuss forms and establish whether participants will give informed consent.
3	Turn on the recorder	Agree to turn on the audio recorder and establish that participants can ask to pause or turn it off at any point.
4	Asking about experiences	Initial conversation to gain context about: (1) Participants' engagement with charities and newspapers, including where they get their information about dementia from. (2) What associations participants have for dementia / how participants would explain dementia to others. (3) Participants' experiences of dementia (especially in interviews).
5	Discuss twenty images	Contextualize images as mostly from newspapers and charities, used in relation to dementia. Participants can discuss the images in chronological order or start with the most striking. Overall question: 'What do you think of the images and how do they make you feel?' Four starter questions also written on the front page: (1) What do you think the picture is trying to say? (2) How do you feel about the different photos? (3) What effect do you think these different images have? (4) Do any pictures stand out to you? Why? Also ask participants which image(s) they would/would not use and why.
6	Discuss language	Show participants different phrases, a tagline and two headlines. These are presented in a written form and read aloud. Three starter questions: (1) How do you feel about each word or phrase? (2) Which words would you use and why would you use them? (3) Which words are more familiar/unfamiliar? At the end, ask participants how they would like to see dementia represented.
7	Concluding thoughts	Ask if there is anything else participants would like to add or discuss. Bring the conversation to a close. Stop recording.
8	Finish	Establish future contact preferences and ask for any feedback (verbal or in writing, either during or following the session).

challenge) about dementia. Often, especially in interviews, these questions would be accompanied by questions about participants' experience of dementia. Interviews enabled a more personal (and often more narrative) account than was possible within the time constraints for a focus group, where accounts emerged more spontaneously and were generally more fragmented due to the nature of group conversation.

Next, participants were shown twenty images (Stage 5; see the Appendix for the images). They were encouraged to briefly survey all images to gain an overview and then to either discuss images chronologically or start with a particularly striking personal choice. Images were contextualized as being used in relation to dementia and as being drawn primarily from charities and newspapers, with the overall prompt being 'what do you think of the images and how do they make you feel?' Four written starter questions were also provided (see Table 2.1) from which I drew verbal questions oriented around people's interpretations of what the images depicted and connoted, their feelings about each image (including what stood out), the images' effects on them (and others) and why participants reacted how they did. After a participant in Focus Group 1 asked other group members what images they would use to represent dementia and why, I explicitly incorporated this question into the schedule to further stimulate evaluative discussion.

Linguistic stimuli (Stage 6) were framed similarly to images. Here, I explored participants' responses to initially isolated phrases and then examples of headlines and a tagline (see Figure 2.2 for the linguistic stimuli). Beginning with isolated phrases enabled participants to focus on the words themselves and establish their own context. To help with this, I asked participants how familiar different phrases were, their opinions on each and whether they would use such language. Phrases progressed into three examples of real-world use for some of the terms and broader discourses, which was intended to provide a next step, subject to time, where participants reflected on whole sentences and expanded on their previous discussion accordingly. To conclude, if it had not already been discussed, I planned to ask participants how they would like to see dementia represented, visually, linguistically or otherwise. Finally, participants were invited to share any final thoughts (Stage 7), to facilitate participant-initiated topics and closure.

Sessions ranged from 45 to 105 minutes in length. Individual needs, settings and time constraints necessitated a flexible approach to my interview schedule, in terms of content and questioning, which I adapted to the interests of participants. Although the opening questions and visual stimuli sections were always conducted, linguistic stimuli were not always covered, either partially (e.g. the phrases were discussed but not the sentences, as with Group 3 and Interview 4) or not at all (Groups 6, 7 and 8). This was generally due to a lack of time or participants' energy. Visual stimuli were prioritized over linguistic stimuli because they were deemed more accessible and open to interpretation for participants and responded to a distinct lack of research into people's responses to visual representations of dementia.

Visual and linguistic stimuli

Following an overall discussion of the session structure and framing, I now turn to the stimuli used (see the Appendix and Figure 2.2 for my visual and linguistic stimuli respectively) and the rationale behind these choices. Stimuli were developed in the summer of 2019 and drawn from sources between 2017 and 2019. Both were inspired by existing literature on popular discourses and representations of dementia and were intended to contribute the responses of people affected by dementia to this body of knowledge. Of course, in the years since, this body of work has grown, so the discussion below is reflective of the point of stimuli collection in 2019. Although linguistic stimuli drew greatly on guidance materials for representing dementia, images could not because of a distinct lack of discussion on visual representations in this sphere at the time, besides brief mention of images of hands, people holding their heads and fading faces (Bould, 2018; DEEP, 2014). The sourcing and design of visual stimuli therefore requires greater attention here.

Phrases
  Suffer with dementia / suffer from dementia / dementia sufferer
  Living with dementia
  Living well with dementia
  Dementia patient
  Dementia-friendly
  Fight dementia / beat dementia / defeat dementia
Tagline from a fundraising envelope
  Will you advance research to beat the UK's biggest killer? (Alzheimer's Society, received in the post in 2019)
Newspaper headlines
  Dame Barbara Windsor's heartfelt plea to end Alzheimer's disease agony (*The Express*, 6 August 2019).
  THE LOVE THAT DEFIED DEMENTIA; Most poignant of weddings after sufferer asks wife to marry him … believing she's new love and falling for her all over again (*Scottish Daily Mail*, 22 August 2019).

Figure 2.2 Linguistic stimuli presented to participants.

Visual stimuli were obtained from charity websites (namely, Alzheimer's Society and Alzheimer's Research UK), newspapers/magazines and online 'dementia' image searches, through which stock images were found alongside relevant sources that used them. Importantly, the same image (especially stock images) can be used in a range of contexts, as with Images 10 and 11, which featured in magazines/news media, a leaflet and books. Images were selected and arranged into five pages of four images, with each page engaging with different discourses and types of visual representation, with the aim of sparking discussion and debate. The Appendix provides an overview of the images in the order and layout that they appeared to participants, with descriptions being used for instances where copyright regulations did not allow for the image to be reproduced in this book. It is important to note that stimuli were not selected to represent any kind of ideal; this is reflected in the lack of diversity apparent across the twenty images regarding demographic features such as age, race, ethnicity and sexuality. This lack of inclusivity reflects wider concerns regarding representations of dementia.

Many of the images used as stimuli were stock images, which reflects stock image banks' status as a pervasive, accessible and ever-expanding competitor of traditional photojournalism, with image banks (such as Getty Images) providing a database of millions of images that designers and text producers can search using key words and then purchase for a license fee. Through supplying a range of organizations with images and videos, stock image banks can significantly influence how dementia is visually represented (Harvey and Brookes, 2019). More broadly, their popularity makes image banks a leading force in shifting the world's visual language from one that emphasizes photography as a witness of reality to one that emphasizes photography as a *symbolic system* (Machin and van Leeuwen, 2007: 151). According to Machin and van Leeuwen (2007), stock images are defined by their 'timelessness', genericity and low modality. Rather than capturing 'specific, unrepeatable moments' (152), stock images are more 'timeless', as they denote general concepts, people, places and things through decontextualized backgrounds, props to connote attributes (such as a computer to signify work) and generic models and settings. Stock images tend to have a low modality since, as the heightened colours and coordinated arrangements indicate, they favour abstract, sensory and emotive truths over a naturalistic one. Their genericity means that stock images tend to 'merely reflect or reinforce dominant ideologies' (Bednarek and Caple, 2017: 192). The danger is that such images come to represent 'the whole of a particular time, place and way of life', whereby 'we gradually come to accept them as showing us how the world really is' (Machin and van Leeuwen, 2007: 157). Critically engaging with stock images is key to mitigating the risk of this.

As the Appendix shows, page 1 contrasts two stock images of individuals in a home environment (one with a partner in the background) signalling some kind of a struggle and holding their heads, against two photos of social settings where people are happily engaged in sharing a joke and a group activity. This was intended to juxtapose isolation with social engagement, negative with positive emotions and home with community. It also engages with multiple visual tropes identified for people with dementia at the time of stimuli selection. Firstly, Kessler and Schwender (2012) argue that in their sample of German news magazines between 2000 and 2009, dementia is increasingly visually portrayed as a phenomenon affecting individuals (mostly women) rather than as a medical diagnosis, and that represented participants are more often shown in private individualized contexts (rather than more institutional settings) and with a social partner. Whereas Kessler and Schwender found images to generally depict people with dementia with positive emotions while living autonomous and socially integrated lives, others in the UK have highlighted the trend to show a 'head clutcher image', namely 'stock images of older white women, isolated, holding their head in their hands' (Bould, 2018: 31). Critically analysing this trope, Brookes et al. (2018) deconstruct how such images present people as suffering (illustrated by their pained expressions), passive (they are seated and immobile) and isolated (with downward gazes, they make no social connection with viewers or other participants). This page therefore draws on debates surrounding socially engaged and happy representations (Kessler and Schwender, 2012) versus isolating and suffering oriented ones (Bould, 2018; Brookes et al., 2018). Such broad dichotomies make page 1 a good entry point for discussion.

Page 2 explores who is (usually) represented and how. It juxtaposes two examples of people who tend to be less frequently shown in this context (intending to engage with intersections with race and age) against two hand images. This reflects two trends: first, the overrepresentation of 'older white women' when depicting people with dementia (Bould, 2018: 31; Kessler and Schwender, 2012), and second, the pervasiveness of close-up shots of hands to signify people with dementia (usually older people, perpetuating the conflation of dementia with older age; Ang, Yeo and Koran, 2023; Brookes et al., 2018; Harvey and Brookes, 2019). Regarding the hand trope, Brookes and colleagues observe that the composition of such photos is highly predictable across stock images (and newspapers using such images): the hands are immobile, usually being clasped together or resting, and are shown close up, brightly lit and in sharp focus, foregrounding features such as creases, wrinkles and veins that are culturally associated with fragility, vulnerability and deterioration. Being disembodied, with no chance to see the person's face, these hands therefore 'direct us to see little more than atrophy and depreciation before and instead of the person' (Harvey and Brookes, 2019: 994). More recently, Ang, Yeo and Koran (2023) have noted that alternatively, images of two people's hands interacting can instead signal care and support. Contrasting faces with hands offer the potential to discuss the (de)personalization of people with dementia, while other distinctions provide further nuance, namely regarding whether a close-up of people holding hands is interpreted differently to an individual resting their hands.

Page 3 orients around discourses of decline and loss of personhood, which, as discussed in Chapter 1, dominates much of the literature on dementia. Harvey and Brookes (2019) offer an insightful commentary on how Image 12, showing the woman with a jigsaw piece missing, depicts the represented participant as defective (through the dark cavity in her head/brain) and lifeless (note the dull colour palette and her zombie-like vacantness). Image 10 harks back to the 'head clutcher' image of page 1, but additionally suggests the fragmentation of an individual, again from the area of the head containing the brain. Image 9 continues this disintegration but dehumanizes the process by showing only the main organ featured in loss of self-discourses: the brain. Image 9 was added through an online search to replace an image of a paper head with its brain on fire (analysed in Brookes et al., 2018), which was evaluated as being potentially too alarming or distressing when used in combination with the other three images. Being the only image that is not explicitly from a dementia context (but that incorporates the same metaphorical visualization of disintegration), Image 9 provides an interesting opportunity to explore the role of context in interpretation. Finally, Image 11 illustrates a slower-paced deterioration through the seasonal loss of leaves from the brain area of a head-shaped tree, engaging with the use of plant metaphors to signal brain changes and decline with dementia (Caldwell, Falcus and Sako, 2021; Zimmermann, 2017). As my exchange of the fire image indicates, being the most loss-oriented and therefore potentially difficult, this page required extra consideration. As well as consulting others, such as participants in pilot sessions, I arranged this as the middle page so that participants could become accustomed to the task and contextualize this page within more diverse representations. Specifically, I placed this page next to page 4, which emphasizes a living-well discourse; this counterbalance was intended to mitigate the risk of distress from these loss-oriented images or, conversely, from participants feeling that page 4 was overly sanitizing dementia, which can also be distressing (Bartlett et al., 2017; Fletcher, 2019a).

Returning to the notion of 'giving dementia a face' through portraying individuals with dementia (Kessler and Schwender, 2012), page 4 orients around contrasting photos of ordinary people on the left, and celebrities on the right. As elites, celebrities diagnosed with dementia are especially newsworthy (Bednarek and Caple, 2019) and are key to British newspaper reporting of dementia, with celebrity voices and experiences being showcased by the media more than ordinary people with dementia, who are noticeably absent (Bailey, 2019; O'Malley, Shortt and Carroll, 2022). Image 13 thus depicts an ordinary couple who were in the UK news after they remarried in their garden when the husband, who had dementia, proposed again to his wife, as he did not recall that they were already married. His wife used this media attention as an opportunity to speak out against stigma, and one of the many headlines reporting this event is included within the linguistic stimuli (see below). For Images 15 and 16, British icons Terry Pratchett and Barbara Windsor were chosen because both individuals had dementia and had undertaken significant advocacy roles, with extensive media coverage. Both follow the expected trajectory of celebrities with conditions: after publicly announcing their diagnosis, they share details of their experience and become visible, often optimistic spokespeople (Lerner, 2006). In particular, Terry Pratchett has been associated with the living-well discourse, as indicated in Image 15, and has been presented, more than other celebrities with dementia, as 'an active, successful, articulate member of society' (Bailey, 2019: 187). Celebrities hold great influence and can be a source of inspiration, but can also be dismissed as exceptional and unrepresentative of ordinary people with dementia (Bailey, 2019). If participants are familiar with Pratchett and Windsor, then, discussion could include advocacy and the controversial role of celebrities in representing people with dementia. Otherwise, discussion does not have to incorporate this facet and can, for instance, centre around living (well) with dementia and partners/family.

Finally, page 5 is inspired by the tension between biomedical discourses that emphasize obtaining a cure, and more social discourses that foreground the need to care for people with dementia. Image 17 has been critiqued by Harvey and Brookes (2019: 996) for being inaccessible to non-specialists, but ideologically meaningful nonetheless, including by supporting the status of medical knowledge, reducing people with dementia to their '(seemingly aberrant) neurobiology' and segregating people into an 'us' with a healthy brain (people without dementia) and a 'them' without (people with dementia). Image 18 provides an interesting contrast to this specialist biomedical tool, as it metaphorically displays the brain itself as a jigsaw with a missing piece, and visually foregrounds the medical practitioner/researcher (indicated by the white coat) as the person who can solve the puzzle of dementia (at least according to my interpretation). Together, these images speak to concepts of medical authority and the role of biomedicine in the lives and futures of people with dementia. In contrast, two images of communities and volunteers supporting charities are displayed, to highlight the role of people and charities in supporting individuals affected by dementia. The two images' fundraising connotations also encourage discussions of financial support for cure and/or care-oriented approaches.

Linguistic stimuli (see Figure 2.2) can be divided into three types, the first being common phrases that are either supported ('living (well) with dementia', 'dementia friendly') or discouraged ('dementia sufferer', 'dementia patient') by prominent guidelines on dementia language use (Bould, 2018; DEEP, 2014). Although people with and otherwise affected by dementia are consulted in these guidelines, they are generally presented as one voice, so the aim of including these phrases was to generate discussion to explore the possibility of different usage, views and reasonings. Following the prevalence of battle metaphors in dementia communications and research (Bailey, Dening and Harvey, 2021; George and Whitehouse, 2014; Lane, McLachlan and Philip, 2013), I also included 'fight', 'beat' and 'defeat' dementia for group discussion.

As Figure 2.2 shows, three real-life sentences followed the phrases, the first being from an Alzheimer's Society fundraising envelope that offers an example of a battle metaphor that personifies dementia as 'the UK's biggest killer', which supporters are asked to help 'beat' through (financially) supporting research. The two headlines accompanied the news stories containing Images 13 and 16 and were chosen partly because of this link, which was intended to facilitate engagement, but mainly for their use of language that is advised against by language guidelines for dementia (namely 'Alzheimer's disease agony' and 'sufferer'). The latter use of 'sufferer' is particularly interesting, as it is used in the context of a wedding and love, which would more typically be associated with a living-well discourse. Here, dementia is personified as a powerful force that love manages to defy, creating a headline that is linguistically rich and draws on multiple competing discourses, notably suffering from, fighting ('defied') and living (well) with dementia.

Participants

To participate in this study, an individual needed to have a direct experience of dementia. This could be through having a diagnosed type of dementia, previously/currently supporting or caring for someone with dementia or being a close friend/family member. Participants also needed to be comfortable communicating in English and be able to either travel to or be visited for an in-person session. Of the recruitment channels contacted, the most successful were local support groups, a Memory Café, dementia choir and a patient and public involvement (PPI) group. Dissemination occurred via emails, newsletters, word of mouth and being invited to groups to discuss the study in person. In all contexts, interested individuals could access a promotional poster and an information booklet that summarized the study focus, who could participate, what was involved, ethical practice, anticipated outcomes and how to participate. People were encouraged to digest the information provided before contacting me to arrange participating.

Fifty-one people from the Midlands (in England, UK) participated in sessions between October 2019 and March 2020. As Table 2.2 shows, eight focus groups and seven interviews were conducted. Participants' ages ranged significantly (from twenty-one to eighty-seven, mean age 64.3), and there was a fairly even gender distribution (twenty-two men: twenty-nine women). As far as I am aware, and with one known exception, participants were either in heterosexual relationships or did not currently have a romantic partner. Regarding experience of dementia, seventeen people had a dementia diagnosis and one person had a mild cognitive impairment that she regarded as pre-dementia (in this book, she has the pseudonym PM). Thirty-three participants without dementia identified as carers and/or family/friends, of whom three identified as former carers (a fourth former carer had since developed dementia). Although information about types of dementia and time since diagnosis were not explicitly requested, Alzheimer's disease, vascular dementia and types of young-onset dementia were particularly discussed, while conversations indicated that time since diagnosis ranged from less than a year to over eight years. Twenty-four participants attended sessions alone (five people with dementia, nine carers/previous carers and ten family members/friends), while twenty-seven attended as a pair (with one three) consisting of a person with dementia and carer/supporter(s). Seven participants with a dementia diagnosis were women (and another woman had a mild cognitive impairment), while ten participants with a diagnosis were men. Twelve men

Table 2.2 Summary of Participant Demographics by Group

Group/ interview	Age range	Identified gender		Person with dementia[a]	Carer	Family/friend	Previously a carer	Total number of people
		Male	**Female**					
Group 1	21–83	5	3	3	4		1	8
Group 2	54–61		4			4		4
Group 3	69–80	2	2	2	2			4
Group 4	52–78	2	2	1	3			4
Group 5	26–31	2	1			2	1	3
Group 6	63–87	1	4	2	2	1		5
Group 7	73–87	3	2	3	1	1		5
Group 8	48–64	4	6	4	4	2		10
Interview 1	62		1			1		1
Interview 2	73		1		1			1
Interview 3	84		1	1			1[b]	1
Interview 4	27, 61	2		1		1		2
Interview 5	72		1		1			1
Interview 6	71		1	1				1
Interview 7	69	1					1	1
Total	21–87	22	29	18	18	12	4	51

[a] This includes one participant (PM) in Group 7 with a mild cognitive impairment, which she regarded as pre-dementia.

[b] Following caring for her husband with vascular dementia, this individual now has Alzheimer's disease herself and is therefore included in both categories.

and twenty-one women attended in their capacity as supporters, carers, family members, friends and (previously employed) care workers.

Participants had a range of employment backgrounds, including education (student, teacher, head, learning technologist), healthcare (nurse, speech and language therapist, care worker, GP receptionist, NHS manager), construction (welder, builder, electrician, engineer), industry (coal miner, factory worker, lorry driver, production manager), retail (hairdresser, shop owner), financial sector (tax accountant, clerk, bookkeeper) and civil service (social services, police officer, merchant seaman, civil servant for the Ministry of Defence). Participants were predominately white British (forty-nine of fifty-one participants, with one white Canadian and one participant with a non-specified mixed ethnic background) and were engaged with their local community. These are both typical demographics for individuals who participate in dementia research, especially when using traditional recruitment means, in this case convenience sampling through local networks (Fletcher, 2019b). Recruitment unexpectedly ended in March 2020 with the advent of the first Covid-19 lockdown in the UK.

Due to local recruitment, twenty-five participants already knew me before they agreed to participate, while five of the eight focus groups consisted of people who were already familiar with each other. This reflects that I often organized a focus group before, during or after another group's meeting so that interested individuals could attend at a time and location that was convenient and familiar. This resulted in arranging focus groups around a local Memory Café (twice), a choir (twice), a PPI meeting and a working-age dementia support group, with three interviews also occurring this way. Another group was arranged with PhD students who responded to a call for participants that was made during a presentation, while the final focus group consisted of people who had not met but expressed a preference for a focus group.

Ethical practice

Ethical approval was obtained from my university's Faculty of Arts full-committee review. The participant information sheet was informally reviewed by other academics and members of the community to improve its clarity and accessibility, which resulted in converting a multipage sheet into a more concise booklet. This appeared to be successful, with one interviewee telling me that '[participants] need to know what they're doing that's why I liked, your bit that came out, about the leaflets, they were clear, they were precise' (P33). The consent form and full privacy notice for research participants were deemed the property of the university and, therefore, not altered. As these were quite dense materials, where appropriate I offered these to participants ahead of our session to give people the opportunity to consider them in their own time.

Informed consent requires being able to voluntarily and consciously decide what to do based on sufficient information about the study, including the process, risks and benefits (Pesonen, Remes and Isola, 2011). I recognize consent as an ongoing process rather than a one-off procedure (Dewing, 2008; Samsi and Manthorpe, 2020) and consistently made it clear that participants could withdraw or reschedule at any time. Two focus group participants withdrew beforehand due to an unexpected illness, and one interviewee rescheduled our session upon my arrival due to confusion with the days and not wanting to participate at that time. No one indicated any wish to withdraw during or after the sessions. On the day, the study was discussed before obtaining written formal consent, and I was available to help with any questions or concerns. Participants also collaborated to help each other understand and respond to the forms. The consent process was tailored where possible to suit individual needs, in an attempt to include, rather than exclude, people with dementia with different communicative needs (Fletcher, 2021b). No formal assessments of capacity were carried out, with informal conversation and non-verbal cues being used to determine that participants were happy to take part. Participants with dementia gave written and verbal consent when they clearly had the capacity to do so; otherwise, in the case of the latter, carers were present and could also be consulted.

Capacity according to the Mental Capacity Act requires someone to meet four decision-making criteria: (1) understand the decision and reasons to make it, (2) comprehend likely consequences of not/making the decision, (3) retain and use relevant information and (4) somehow communicate their decision (Department for Constitutional Affairs, 2007). The reality is often slightly uncertain, necessitating subjective researcher evaluations (Fletcher, Lee and Snowden, 2019). My personal stance favours unobtrusive evaluation and inclusion where possible, especially in focus groups where other members are familiar, the atmosphere is collaborative, and exclusion can be detrimental (for more on the exclusionary consequences of current ethical procedures, see Fletcher, 2021b). As the researcher and facilitator/interviewer, I was particularly attentive to any 'possible expressions of verbal, non-verbal and behavioural displeasure, disengagement and discomfort' and tried to respond to participants' needs throughout (Samsi and Manthorpe, 2020: 4).

When running the sessions, I prioritized facilitating a good experience for participants and aimed to establish a simultaneously safe and enjoyable environment (Davies et al., 2022). Following guidance (DEEP, 2013), locations were chosen to suit each participant, which largely entailed running focus groups in familiar community settings used for other groups (such as choirs) that participants belonged to and visiting interviewees at home or in a café of their choice. A small grant provided financial assistance to book rooms and provide refreshments, which ranged from shop-bought squash, cakes and fruit to a professionally catered lunch, or buying participants drinks/lunch at their chosen café. This provided a way of thanking participants, building rapport and establishing a more familiar and friendly environment (McCabe, Robertson and Kelly, 2018). For similar reasons, if visiting someone at home, I would always accept the offer of a cup of tea, since making time for this culturally significant exchange can enhance comfort, trust and mutual respect in a research relationship (Ashworth, 2014).

Ending a research relationship is rarely discussed (Cowdell, 2006), yet it is also important to participants' well-being (and that of the researcher, too). I thus carefully considered this aspect so that participants could leave the sessions feeling valued, with closure and a clear sense of what to expect next. As Table 2.1 shows, after the recorder was turned off, participants had the option to provide me with feedback on the session and any thoughts they had for the study. This could be done in person (verbally or in writing) or via email following the session. All three options were selected by different individuals, reinforcing the need for personalized choice. Feedback was overwhelmingly positive, with participants calling the sessions 'interesting and informative', finding it 'very valuable to me to be able to explore the issues raised during the course of the session', enjoying sharing views with 'likeminded people' and thanking me 'for the opportunity to voice my thoughts and opinions'. One group asserted that it was a good opportunity to discuss a topic that they care about but do not usually want to 'bother anyone' with, finding it 'really really nice to talk about […] it's not often you get to sit down and have that conversation'. Appraising the stimuli, a participant declared, 'Not too much writing, been dropped on our heads [laughs],' while another noted that they were 'interested by the reaction to people and pictures'. One comment evaluated me and the refreshments: 'Emma was extremely pleasant and patient and was interested in our answers. The lunch provided was a bonus.'

I also received constructive feedback, including that 'I probably just needed a little bit more guidance as to what you were asking for when we were looking at the pictures – but maybe that would bias the responses!' After receiving this, I reflected on the scaffolding I provided participants and further emphasized that

I was interested in people's reactions and what they wanted to discuss, to help alleviate concerns. Equally, images were originally not numbered to encourage participants to describe the pictures (and thus draw on particular discourses and foreground certain features), but after participants requested numbering, I amended this and numbered the images in the way shown in the Appendix. Participants were also given the opportunity to provide suggestions for future sessions and my research, and although uptake was low, responses were interesting, particularly that of showing people the stimuli who are not 'primed […] with talking about dementia'. Overall, feedback enabled participants to share their experience and ideas and me to be responsive to participants' needs and suggestions.

Alongside feedback, I asked participants their contact preferences for follow-up questions (if applicable) and for hearing about the study's findings. Participants could opt in or out to either and showed particular excitement about receiving a summary of the study's findings. Finally, to thank everyone again for taking part, I gave participants a thank-you card containing a handwritten note, a small monetary sum for participation and my contact details with an invitation to contact me if participants had any further questions, concerns or ideas. A low reimbursement amount was determined by pragmatic constraints, namely funding and preexisting guidelines on participant payment, and I tried to mitigate some of the exclusionary potential of this through my other actions, such as providing refreshments and prioritizing convenient times and locations. Participants appeared to be pleased by the card and its contents, although I quickly learned to accompany this personal touch with clarifying that the money came from the university, not myself, so that all participants felt comfortable accepting it.

Anonymizing and analysing the data

Following the sessions, any collected data has been kept confidential and securely stored throughout. Participants have been anonymized through pseudonyms, and any other personal information has been screened to avoid making anyone identifiable. Letters are used to refer to participants with a form of dementia (e.g. PA) and numbers to participants without dementia (e.g. P1). With the exception of Sheila (PS), these numbers and letters are chronological according to the order in which I spoke with participants. This system was chosen to enable greater transparency for representing different participants' voices, without intending to unnecessarily label or create in/out groups among my participants.

All sessions were audio-recorded and transcribed verbatim by the researcher, totalling approximately 143,500 words. Sections that were to undergo close analysis and be presented in the book underwent more rigorous transcription, namely through additional screening and timing pauses for greater accuracy. To make for easier reading, where exact timings are not necessary, I have used punctuation to note increasing pauses. The full transcription conventions used throughout this book are outlined in Table 2.3.

Transcription provided the first stage of data familiarization. I listened repeatedly to each recording, then closely read and reread each transcript, making detailed notes regarding how participants represented themselves and other people in relation to dementia. I used NVivo 12 Pro (QSR International, 2018) to help organize quotes from transcripts into categories. These generally matched aspects of the interview schedule (for example, each page of images and linguistic stimuli) to facilitate cross-comparisons across groups and interviewees. As the analysis progressed, more specific folders were added, such as 'change (and flux)' and 'evaluations and recommendations for change'. Simultaneously, I visually mapped the main points for each focus group and interview and identified 'patterns of meaning' among them (Clarke and Braun, 2017: 297). These patterns, after multiple revisions, would develop into my themes and discourses.

This book structures the analysis through broad themes, each of which contains multiple, often competing discourses. Although researchers inevitably approach data with preconceptions, it can be very fruitful to try to ground analysis within actual interactions with participants, especially for traditionally top-down (M)CDA approaches (Breeze, 2011). Here, data analysis incorporates topics and discourses that were planned in advance via the interview schedule (e.g. 'living (well) with' versus 'suffering from' dementia; biomedical versus more social discourses) with themes that emerged from the data, most notably diversity and change, which underlie Chapters 4 and 5 respectively. Structuring analysis around themes and discourses brings the responses of all participants into dialogue together, which both mitigates unnecessarily separating people with and without dementia and enables richer, more nuanced analysis of discursive positionings within each theme. As Chapter 1 explores, people with dementia, carers and loved ones may have different motivations and preferences for representing dementia and people affected. Where relevant, this is recognized in the analysis, and the pseudonym system shown in Table 2.3 enables transparency about whether a participant's contribution is informed by lived experience or otherwise.

Table 2.3 Transcription Conventions

Participants	
Emma	The researcher
P + letter (e.g. PA)	Participant with dementia (or pre-dementia) diagnosis
P + number (e.g. P1)	Participant without dementia
Pauses	
, (comma)	A pause for breath
. (full stop)	A slightly longer pause of <1 second
[2.0]	Any pause of >1 second is timed (this one is 2 seconds)
Other conventions	
[Words]	Inserted by researcher
[…]	Removed by researcher
(xxx)	Unsure of word(s) said
Word- / -word	Interruption
# Words #	Section of simultaneous talk
"Words"	Participant has put on a voice (e.g. to imitate someone else in speech)
<u>Word</u>	Participant has placed emphasis on this word

2.4 Research reflections

The data collected through focus groups and interviews is not the only data that should be analysed. Here, I reflect on my role in the data collection and on the data that I have myself generated through the process of creating connections and telling stories within my analysis (Macgilchrist, 2020: 11). It is to this issue that I now turn.

A key influence on the data generated is that rather than prioritizing separate focus groups according to experience of dementia, groups were instead organized around participants' convenience and thus often (but not always) involved preexisting friendships and couples whereby one partner had dementia and the other partner took on a caring role. Inevitably, this decision will have influenced what participants felt they could discuss, including through considering that people with different perspectives were also present and needing to maintain social relationships beyond the group context. Groups with shared experiences may better encourage peer support and honest discussions, a strength noted in a group of four Memory Café volunteers who had previously cared for family members with dementia: 'I feel like putting on different hats which is why I think that it's good that we got a session separately because I would have felt bit conflicted with our carers' (P8; see Chapter 6). However, mixed and (at least partially) pre-established groups have benefits, too. As well as providing familiarity for participants, groups with a shared history facilitate shared narratives and recall and can consider how individuals interact with people who are part of their life beyond the group (e.g. for an analysis of couples renegotiating their relationships, see Fletcher 2020c).

Dynamics across groups varied significantly. Generally, I found that the smaller the group, the better the balance of voices, although in some groups as small as four, when people with dementia attended with their partners, I observed a tendency for the latter's voices to dominate the conversation, a phenomenon that is certainly not unusual (Davies et al., 2022; Dening, Jones and Sampson, 2013). However, my attempts to bring participants with dementia into the conversation sometimes backfired by putting people on the spot and suggesting lack of a contribution, which can make individuals uncomfortable and reluctant to participate (Sabat, 2018). This is exemplified in Focus Group 3:

Emma Yeah, ok. Thanks. PE PD any thoughts or?
PD Not really
P12 No
PE No not really.
P13 Can't remember what he did yesterday can you love
PE (Yeah) [laughter]

Subsequently, I changed my approach to non-verbally invite people to speak through my gesture and gaze. Of course, it is worth noting that this issue is not representative of everyone. Some people with dementia were confident contributors and occasionally the dominant voices, while other mixed groups actively prioritized the voices of people with dementia, either through consulting such individuals or immediately passing them the conversational floor if they initiated a point. Equally, some people without dementia were also quieter in group discussions, reflecting that individuals have different conversational inclinations, which cautions against misattributing this to dynamics between people with and without dementia.

As an interviewer and facilitator, I tried to 'take a back seat' and refrain from asking too many questions or commenting unless the conversation required it (Barbour, 2007: 106). I also ensured that I gave participants, especially those with dementia, sufficient time to pause 'to retrieve the thread of conversation' without distraction from me, even when this moved beyond the usual limits for conversation (Sabat, 2018: 64). This appeared to be appreciated, with one interviewee with dementia (PH) humorously telling me at the end that 'you've listened, and, and, been encouraging, as well, you know, so it's not been a "oh God not her again" [laughter]'. Of course, this approach meant that sometimes the conversation went off-track, as it can be difficult to distinguish between someone developing a point that will become relevant and going off on a tangent (Barbour, 2007). Indeed, a particularly tangential and self-reflective focus group (Group 7) raised this as we reflected on the session. Collaboratively, we navigated the conversation from a worry that participants '[took] too much of the focus off' (PK) to celebrating that tangents could be useful for coming up with 'ideas and questions […] and answers to questions that Emma [the researcher] would never have thought of' (P25). We thus recognized the importance of flexibility to the research process to avoid pushing participants into a conversational 'cul-de-sac' (P24) and enable new questions and ideas to emerge, which expands the research scope by not limiting it to the researcher's preconceptions.

Frequently, emphasis is on the role that participants want to play in the interview or focus group, how they want to be seen and how their story can serve this purpose (Steeman et al., 2007: 125). However, the researcher similarly wants to present themselves (and participants) in a certain way, which manifests in how they ask about and tell the stories of participants within their research. Research is thus jointly produced by the participants, the researcher and their relationships (Finlay, 2002: 531). Moreover, as Macgilchrist (2020: 13) highlights, our communicative accounts (here, mine and participants') are entwined with ours and others' 'socio-material-economic-ecological-affective spaces' and with popular discourses which serve as 'the dominant plot lines in society' (Murray, 2000). I therefore must attend more closely to my own position as the researcher, since my own 'socio-material-economic-ecological-affective' stance underlies the entire project, from study inception to data collection to the presentation of this book.

Notably, at the time of conducting this research, I was a person in their mid- to late twenties, without dementia, who was both a PhD student and a volunteer in the local community (for the Alzheimer's Society's side-by-side scheme, a local Memory Café and a local carer support group). This influences not only my own standpoint but also my interactions with participants, who were in all but one instance older than me and generally had more direct experience of dementia, whether lived or otherwise. I found that my volunteering and family history of dementia were most often the credentials that participants I had not previously met sought, and that already knowing I had some experience made me more acceptable as a respondent by providing some 'in-group' status (e.g. 'I mean you must have noticed Emma, when you go to the Memory Café': P13).

Although my role as the researcher inevitably gave me power in our interactions since I determined much of the focus (Brinkmann and Kvale, 2018), in many contexts this oft-reported power imbalance was at least partly offset by my youth, student status and limited experience. Multiple participants took on more of a mentor role than would perhaps occur with other researchers, explaining aspects that they assumed I would be unfamiliar with (e.g. 'You won't know this, erm Emma because you've grown up in a different world […] but the Health Service came in the year after I was born': P26), joking about my youth ('the youngsters like Emma': PM) and helping to guide the conversation if they evaluated the group as having gone off-topic (e.g. 'I think though, folks, we're digressing in that we're meant to be talking about pictures' and 'is there any other questions you want answered Emma?': P5, PM). Of course, it is worth noting that group members often help to regulate the group, so the latter is not unusual (Barbour, 2007).

Yet, taking a more introspective turn, I inevitably bring to this project my own predispositions and agendas, which are important to outline. I regard dementia as a complex bio-psycho-social condition (Sabat, 2014) that will be experienced differently according to a person's environment, identity and support needs. Dementia is conceived of as a disability in which a range of relational, social, political and economic variables can (dis)empower people who have dementia (Shakespeare, Zeilig and Mittler, 2019). I do not believe that cognitive abilities underlie personhood or selfhood, nor that this can be something that anyone loses through having dementia. From both the wider literature and conversations with participants, I have come to increasingly advocate for nuance and multiplicity regarding representations. In other words, I seek to diversify our discursive repertoire instead of simply replacing what are currently problematic dominant discourses, such as biomedicine and loss of self, with different but still flawed alternatives like 'living well with dementia' (Bartlett et al., 2017). Therefore, although this book advocates for incorporating less mainstream discourses, it aims to critically engage with the implications of *all* discourses, as it does not wish to reproduce the existing binary choice between tragedy or living-well discourses (McParland, Kelly and Innes, 2017).

As has been discussed, my background in (multimodal) critical discourse studies is likewise influential. Not only does it determine my terminology (most notably discourses) but also my assumption that the data generated is socially constructed. As such, the responses analysed here do not reflect participants' 'true' experiences or opinions but rather how individuals choose to represent their experiences, themselves and dementia, in the specific social context of our interviews and focus groups. My theoretical background also drives some of my aims – notably, to contribute new insights into how individuals affected by dementia interpret and position themselves in relation to different visual and linguistic representations – as this remains considerably understudied both in the (M)CDA and dementia literature. Moreover, I seek to foreground and prioritize participants' discourses and concerns wherever possible while equally recognizing the need to balance this with my own voice as the analyst. As the overarching narrator, I can draw upon the whole dataset, as well as other research and theories, to organize and respond to participants' points throughout the analysis.

Finally, throughout this book, I recognize the role of language (and images) in both reflecting and reproducing ideologies, inequalities and power. I therefore attempt to use more accessible and less passivizing or technical prose (elsewhere called 'pointless' 'fancy jargon': P33) in my writing to try to avoid reproducing the very issues that I and other (M)CDA analysts seek to expose (Billig, 2008). Unfortunately, this is not always possible. For instance, despite attending to the 'us' versus 'them' dichotomy that participants produce in their accounts, in order to evade undue noun repetition, I cannot avoid using third-person pronouns to refer to social groups in my writing. As such, I attempt to share the distribution of 'they' relative to 'us' so that I do not consistently 'other' any particular social groups. Throughout, I seek to prioritize the voices and priorities of participants while being cognisant of the role that I as the researcher play in generating, selecting and presenting the quotes, discourses and overall themes that will be explored in the succeeding chapters.

Part of this curation is, of course, the illustrations that begin each chapter. These are each inspired by quotes from participants and were selected and commissioned by me from the artist Josh Mallalieu. These illustrations were initially intended as a visual response to what people had said to enliven a shortened and more accessible research summary for participants, and, as the project continued, they became integral to how I presented this research project to all audiences. The style of the illustrations is unique to Josh, but I find it comparable to that of Quentin Blake or Tony Husband, two artists that I also admire, with the latter artist having produced many illustrations for UK dementia advocacy groups such as DEEP. The visual style is one that I find to be humanizing, imaginative and engaging, but I recognize that it is one of many visual possibilities for this book, and that the choices made for the illustrations are inherently personal to me. I hope that this choice is taken as it is intended, as an exploration of alternative means of expression from a researcher interested in the multimodality of our communication with one another and as a way of being involved in not only critiquing but also creating images. Indeed, I attempt to combine these two directions in the opening of Chapter 7 through critically reflecting on one of the illustrations, which forms part of a wider reflection on the potential implications and applications of this book's analyses moving forward.

Many of the illustrations imagine scenarios related to participants' accounts or exchanges, and the next illustration, which marks the transition from this chapter to the next, orients around the notion of being able to 'talk the language' of dementia. The scene itself is inspired by my fond memories of interviewing one of my participants, here given the pseudonym Sheila, in her house. The interview was conducted over a nice cup of tea and in the company of many beautiful plants, a sign of Sheila's great love of (and talent with) gardening. For me, Sheila exemplifies the kindness and thoughtfulness that I experienced on so many occasions from my participants, and the succeeding illustration is intended as my tribute to the many conversations that I was able to have with people who each had their own personal experiences and perspectives to communicate.

Unless you’ve had it, you can’t talk the language. It’s like any disease, experience. gives you an insight.

—Sheila (Participant S)

Figure 3.1 ‘Talk the language’ illustration (Josh Mallalieu, artist).

3

Subjective dementia discourses

Sheila and Nancy

3.1 Introduction

This chapter is dedicated to just two participants, here given the pseudonyms Sheila and Nancy but elsewhere referred to as PS and PN, respectively. Both women have dementia and offer noticeably different stances on the subject which, due to both participating in one-to-one interviews, can be explored in greater detail compared to their counterparts in focus groups. Sheila draws on her experiences as a nurse and carer for her husband when he had dementia, as well as her current experience as someone with mild Alzheimer's disease, thus presenting a particularly multifaceted account that can draw on the perspectives of both a carer and a person with dementia. In particular, Sheila focuses on the individual with dementia and their interactions with others and institutions, emphasizing the role of love, family and other sources of support, alongside drawing on discourses of loss and suffering to reflect on her past experiences and future fears. In contrast, as an active advocate for people with dementia who volunteers in the local community and participates in multiple groups, Nancy focuses on the need for structural and social changes, including using the media to raise awareness and decrease stigma.

As such, this chapter first explores the two individuals' distinct self-presentations of experiencing dementia in the UK, drawing on a range of discourses in doing so. It then compares how these two individuals respond to the same three images of people with dementia to consider how different life experiences and discursive preferences can manifest in how individuals interpret and position semiotic resources. Central to this chapter, then, is the subjectivity inherent to both experiencing dementia and representing/interpreting the syndrome.

3.2 Cyclical caring and future fears: Sheila's story

While sitting with a cup of recently brewed tea, Sheila commented on the first of the twenty images that I had brought (Figure 3.2), which shows a couple distanced from each other, each with their head in their hands. Positioning the man in the blurred background as a supporter, she told me that 'he can't understand because unless you've had it, you can't talk the language. It's like any disease, experience. gives you an insight'. I begin with this moment because, to extend the language analogy, Sheila is bilingual in dementia. She was a carer for her husband, here named Stephen, when he had vascular dementia and Parkinson's and, at the time of our interview, had herself also been diagnosed with mild Alzheimer's disease for approximately eight years. She therefore has a remarkable ability to draw on both her perspective as a carer and as someone with dementia.

A carer's account

Sheila has a long-standing history of caring for others. She worked as a nurse and midwife, shared caring responsibilities with her husband for their parents and then cared for her husband, Stephen, when he had vascular dementia and

Figure 3.2 A couple with their head in their hands (Image 1) (iStock.com/Katarzyna Bialasiewicz).

Parkinson's. When I met her, her older cousin had recently died, and until then Sheila had been actively involved in her care. She was currently helping another disabled woman once a week. Meanwhile, Sheila's daughter and family supported her, as will be discussed further in the subsequent section. That Sheila continues to care for others alongside drawing on support herself is an important challenge to broader associations of dementia with dependency. Instead, Sheila highlights the *interdependency* within people's lives and that individuals can have the dual social personae of caregiver and receiver (Boyle, 2017; Sabat, 2018). Notably, there is a gendered dimension to this, as it is typically women with dementia who maintain their caring roles, both practically and emotionally (e.g., Boyle, 2017).

In response to me asking Sheila to describe her experience of dementia, she begins with her experience as a carer, starting her narrative at the point of Stephen's diagnosis and the shock that they felt (see Table 2.3 for transcription conventions):

Sheila Well, initially, um, being told Stephen had dementia was a great shock.

Emma Mm.

Sheila And er, it made my daughter and I sort of go into to each other's arms and cry [laughs].

Emma Yeah.

Sheila So that was hard to take [clears throat] because he'd had a very, high-powered job and. You don't expect it to happen

Emma No

Sheila In any job or any status in life, you don't expect it to happen. But it did.

This account reflects the distress that many report upon diagnosis, although it is notable that rather than providing her own diagnosis story, Sheila narrates her response to her husband's. Stephen's reaction is not mentioned, with Sheila focusing on the grief that she and her daughter share. While Sheila presents dementia as being able to affect anyone, she grapples with the shock of someone with a 'high powered job' developing dementia, citing this as the reason for the difficulty of the diagnosis. Indeed, some research indicates that having a higher social status is associated with more negatively perceiving developing dementia (Hulko, 2009), a point that I will return to in Chapter 4.

Much of Sheila's account of her experience of Stephen having dementia focuses on pragmatic details to explain how she coped with his physical and behavioural changes with dementia:

Sheila And, because I've been a nurse, I was able to cope, with his. Changes. Er. I'd done a bit of mental nursing and. I knew how to go along with it, so I was able to keep him at home.

Emma Mm.

Sheila Er. So when he was, I got the signs of him being violent. He would get hold of my hand and, squeeze it and squeeze it as hard as he could and I'd say, er "Let it go, you're hurting me" and then I learnt not to say that. I'd say, "oh keep squeezing me, keep on Stephen" and he'd let it go then, he did #the opposite.#

Emma #Aahh, ok.#

Sheila So, so sort of that was interesting. Um [clears throat]. He never hit me, he never became violent to that degree, if he was agitated. I would er, get him in the car, day or night, take him out for a ride.

Emma Mm yeah

Sheila Come back, and he'd be settled, he'd think he'd been on an outing it would, soothe him.

Emma Yeah, wow.

Sheila So that was how I used to cope when he was agitated. Er. I took him with me, wherever I went. We went out walked every day, because he had developed a stoop. [… due to Parkinson's] But, we coped, in our own way [laughs], and er, we were quite happy in that, coping with it.

The concept of coping runs throughout this account; indeed, Sheila repeats the word four times in the above exchange. She attributes her ability to cope with Stephen's 'changes' and care for him at home to her nursing background. Sheila certainly presents herself as more confident and pragmatic in this caring role than many partners and family members without this professional background (O'Shaughnessy, Lee and Lintern, 2010; Rayment, Swainston and Wilson, 2019). Her above account is reflective, not emotionally but pragmatically, as Sheila foregrounds several learning points from her experience, such as using reverse psychology and using car journeys to 'soothe' her husband. This pragmatic reflective tone is exemplified by her comment that the success of reverse psychology 'was interesting', which backgrounds any emotional impact of Stephen's changed behaviours, here of him hurting her hand by squeezing it too hard. Although 'coping' is a common feature of carer accounts, often this is more nihilistic and individualistic, presenting coping as the carer's only option (Fletcher, 2020c). Here, Sheila extends her individual coping to include Stephen in a couple identity ('we coped, in our own way'), taking a notably more optimistic and inclusive tone than many other carers by emphasizing their happiness as a couple ('we were quite happy in that, coping with it') and their 'shared togetherness' (Manthorpe et al., 2011: 78).

After establishing that they could 'cope', Sheila shifts her focus from pragmatic to emotional when she considers what she positions as the 'hardest part' of caring for her husband: the change in their relationship.

Sheila The hardest part, is, I changed from being his wife, to being his, mother,

Emma Yeah

Sheila and carer. And [4.2] he needed me, as his focus all the time.

Emma Mm

Sheila But, he forgot to say things like he loved me or, he forgot to say my name. But, he obviously knew me right up to the end, so [2.0].

Renegotiating roles and behaviours within such a long-standing relationship is difficult for carers and people with dementia alike (Fletcher, 2020c). Many spousal carers, such as Sheila, must balance supporting their life partner with overcoming their own distress at no longer receiving the same level of support themselves (Manthorpe et al., 2011). Sheila's metaphor of becoming Stephen's mother reflects their relationship changing from one of equal partners to increasing dependency (O'Shaughnessy, Lee and Lintern, 2010). Sheila struggles with Stephen no longer saying her name or that he loves her, mirroring broader challenges of limited communication and interaction skills impacting the social relationships of people with dementia (Górska, Forsyth and Maciver, 2018). This issue is repeatedly ascribed to Stephen forgetting to say such things, with Sheila securely expressing her certainty through the modal adverb 'obviously' that despite this he continued to know her.

Sheila later explicitly discusses her security in the love they felt for one another in response to looking at images of couples (page 4 of the Appendix). Here, she discusses their own paralinguistic expressions of love:

Sheila And we've talked about that, how love [1.5] helps you through.

Emma Mm

Sheila [2.0] Because that's still [1.8] A recognizable bond between you.

Emma Yeah

Sheila I don’t think, no matter how far it goes or it’s, you see I’m talking of the experience with Stephen and I. Although he didn’t, at the end tell me he loved me. he would still look at me as if he loved me and he would still hold my hand and when we went to bed he would still snuggle me.
Emma Mm
Sheila Erm. So it was still there.
Emma Yeah
Sheila Still there, the physical contact in that way and, just the knowledge [1.9] I never doubted
Emma Yeah
Sheila that he’d. lost the love of me.

It is made clear here that love remained ‘a recognizable bond’ between Sheila and Stephen, and that as Stephen’s dementia progressed, embodied shows of love such as hand-holding, facial expressions and cuddling became increasingly important. This emphasis on the body as a site for communicating and sustaining their identity as a couple speaks to the discourse of embodied selfhood, which challenges equating the self with memory and cognition by highlighting the importance of the body in our identity, interactions with the world and relationships with others (Kontos, 2004). Here, Stephen’s ‘physical contact’ communicated affection to Sheila, reinforcing her ‘knowledge’ that she was loved. Sheila’s interpretation of Stephen’s actions also demonstrates the role of others in our social identity (Hughes, 2014; Sabat, 2018), here for validating Stephen as a loving partner. This account supports the value of a more holistic, embodied approach to selfhood, as Sheila can appreciate the many ways that Stephen can and does express intimacy, rather than focusing on a narrower cognitive approach to recognition and relationships.

Supplementing the above more positive account of continued love and selfhood, Sheila elsewhere reflects on the despair that can be felt by both the person with dementia and their carer in response to change with dementia, discussing ‘the despair, both of when Stephen had it, times, when he was failing and he was changing, from one man to another. I would see him holding his head, and, I know I held my head in despair’. This reflection responds to two images of people with their head in their hands (Image 1 [Figure 3.2] and Image 2 in the Appendix) and uses the metaphor of an (undesired) transformation into a different person to highlight the extent of Stephen’s change and the threat of such changes to his identity (Castaño, 2020). Sheila explains that she was ‘blessed with […] a good six years’ of the eight that her husband had dementia, telling me that 'it was only [for] two years that it became noticeable to everybody else, outside, and that er, that I needed a break'. Through acknowledging her increasing need for support, Sheila reiterates the emphasis of many people affected by dementia of the necessity of 'outside' support, including through aids, respite and support, here for Sheila as the caregiver (Bangerter et al., 2021; Rayment, Swainston and Wilson, 2019).

Sheila's engagement with external support exemplifies the importance of the environment in disabling or enabling people affected by dementia. First, Sheila discusses how technology improved her home life with Stephen:

> They gave me [clears throat], a gadget, which, if you went through the door, it alarmed me, it told me he'd opened the door and gone out. And the other thing was that I had one, under my pillow. And that rumbled if he got out of bed. So, I had help, you know, these things were very helpful, or made it easier, to cope with it.

These subtle surveillance tools help her to cope by becoming a communicative partner ('it alarmed me, it told me', 'I had help') in keeping Stephen safe while at home, reinforcing the importance of aids for carers (Rayment, Swainston and Wilson, 2019). As well as adapting the environment through technology, the couple utilize social support systems, including through a volunteer who took Stephen out for an afternoon a week and a local hospice. Sheila reports that Stephen 'was, incredibly happy there [at the hospice]. So that was, a joy to me and a relief'. What Sheila terms 'joy' and 'relief' reflects a commonly noted improvement in carer well-being when day services provide support and respite (Bangerter et al., 2021).

Sheila recounts that Stephen would always take his briefcase with him to the hospice and would often return home with spare slices of cake, and that 'some days, he would go and get his briefcase because, he liked going'. Revisiting the role of the body and other people in selfhood, here an object (Stephen's briefcase) plays an important role in conveying his identity (since Stephen always takes it) and in communicating his memory of attending the hospice and desire to return (Hughes, 2014). This implicitly recognizes that such social supports can facilitate not only well-being but also selfhood, exemplified here by Stephen's embodied self-expression (his briefcase). Even if Stephen's use of the briefcase is not interpreted as helping to communicate a professional identity (indeed, a work identity is important for many men with dementia especially; Boyle, 2017), Stephen's briefcase helps to communicate what Bryden (2020) refers to as an embodied, relational and narrative self (here narrative is defined as finding meaning and narrative identity in the *present* moment), as the briefcase enables Stephen to communicate his current desire to go to the hospice and see the people there.

As well as supporting Stephen, Sheila foregrounds the importance of health and social care support services for her, especially during a period of depression while she was a carer:

> And so I could have which I wanted, and then for therapy, because you could have six. And then the other Monday afternoons, I went and I talked to a counsellor [2.6] But, I painted. We didn't just er, talk face to face I was painting because I like painting. Er. And. And she would talk and sometimes I might have a little weep and sometimes we'd have a laugh and [5.0] I think it perhaps shows in the painting. And then. there was a point. Maybe, I'll say maybe, six years into Stephen's, when I got depressed, and I couldn't understand it. I'd been, a ward sister, a district nurse, worked in hospitals. been night sister over a hospital you know, how could that happen to me? [Laughs]. But it did. And then I found that, I did take some medication, my doctor was excellent and said it was just, first aid. And erm, in that time. I started painting myself, erm, like a collage. And, as I was getting, started at one end when I was feeling really down, and as I was feeling better it got brighter and brighter and then when I was well, the end of it, it's, got butterflies and flowers and things [laughs] […] And that was very therapeutic.

That the service provision is finite is quickly established by Sheila, who remembers the exact number of therapy sessions people were entitled to ('six'). Most of the focus of her narrative is on her experience of art therapy and the sharing of laughter and tears as they talked while she painted. The stigma of having depression is implicit in Sheila's listing of all the responsible nursing roles she had held, climaxing with her rhetorical question 'how could that happen to me?' Her surprise at having depression is comparable to a dementia diagnosis, and indeed, Sheila's succeeding clause 'But it did' exactly parallels her earlier conclusion to the difference between expectations and reality for Stephen's diagnosis. Yet, caring is shown to increase the risk of depression alongside anxiety and stress (Erol, Brooker and Peel, 2016). Although stressors will increase over time for spousal carers, family and community support can facilitate people's resilience (Donnellan, Bennett and Soulsby, 2019). Sheila's narrative echoes this, as with support from the doctor (whose analogy of 'first aid' helps Sheila handle having her depression treated) and art therapy, Sheila recovers, metaphorically representing this visually through 'brighter' colours and springtime symbols (butterflies and flowers), which are popularly associated with hope and optimism. In Sheila's account of her depression, then, we can see one of the many health issues that carers may face. That Sheila here foregrounds her doctor, counsellor and art therapy in her recovery process positions the support she received from health and social services as instrumental in helping her at a particularly low point in her life as a carer.

A person with dementia

Sheila's account of her caring experience often leads onto her experience of having dementia, meaning that she consistently negotiates these two contrasting perspectives throughout the interview. She begins her account as someone with dementia by foregrounding that she can continue her pre-diagnosis roles of caring for and driving herself, emphasizing continuity (indicated by the repetition of 'still') and autonomy:

> So, about myself. [Clears throat]. Well I was diagnosed eight years ago. And, I started on donepezil, one, a day, which I know doesn't cure it, but it, retards it hopefully and I think that has worked, because, I'm having a long open window and I'm still caring for myself, I'm still driving.

Beginning accounts of dementia with an optimistic mood and emphasizing a sense of productivity is common (Buggins, Clarke and Wolverson, 2021), and maintaining continuity, including a sense of agency and independence, reflects a key strategy for protecting selfhood and coping with dementia (Górska, Forsyth and Maciver, 2018). Through this strategy, Sheila presents herself as adhering to dominant hypercognitive standards of a competent and meaningful person by being independent, rational and self-controlled (Post, 2000b). This reflects wider management strategies by people with dementia to address the cultural devaluation of this social group (Steeman et al., 2007). Sheila attributes her abilities to her medication, and, while she mitigates her assurance of its effectiveness ('hopefully', 'think'), she later positions it as 'my lifeline' (this relationship to biomedicine is addressed further in Chapter 6). Notably, Sheila clearly establishes that this state of continuing pre-diagnosis activities is finite and that there will be future change, later demonstrating her critical awareness through her driving, as 'I make sure that my grandsons go out with me periodically, to make sure I'm driving ok, because when you drive alone, perhaps you wouldn't be aware of it'. Sheila explains that with her dementia, 'you do know what's happening. As it's gradual. And you're aware that, certain things you can't cope with'.

Following a trend in personal dementia narratives of transitioning from the ‘high point’ above to reflecting upon current limitations (Buggins, Clarke and Wolverson, 2021), Sheila then details how her dementia (specifically mild Alzheimer’s disease) affects her and her response. She focuses primarily on forgetting short-term memories and the word she wants to find, tending to remember her earlier life in better detail:

Sheila I forget. I would forget, next week. probably our conversation, this week. Sometimes I forget [1.9] yesterday if it wasn’t very important.

Emma Yeah

Sheila Then I have these lasps [lapses] where I can’t find the word I want. And I tend to go back, we used to have horses. So I had stables. So I call my garage the stable

Emma Oh that’s interesting

Sheila very frequently and. And when they ask me where I live, I go back to [name of old home], which is where I lived before for 43 years, so that’s firmer in my mind than [name of current house number and street]. But it doesn’t happen all the time, but it’s these things that I know [1.6] that I’m gradually, very gradually [3.1] inverted commas ‘losing it’ [laughs]. Sadly. [Clears throat] So. Er. But God’s good, he knows, he’s given me this trial. So [2.0] There’ll be, a reason to it, and I just have to trust. And when the time comes my daughter will look after me I know, because she looks after me now, she rings every single day.

Sheila’s discussion reflects that individuals living with dementia are more likely to experience difficulties with word finding, autobiographical facts and their memory for recent events, in contrast to remembering the distant past, engaging in the here-and-now and ‘muscle memory’ (for more on each of these aspects of memory, see Hamilton, 2019). Here, Sheila finds that when asked where she lives (an autobiographical fact), she sometimes recalls a previous long-term home rather than her current one. She also recounts substituting her target word (‘garage’) for a semantically related one (‘stable’) that is associated with her childhood (long-term memory) in response to struggling to recall her target word. Her emphasis that her memory difficulties are not consistent is reflected in the accounts of other participants in this book. Sheila positions these kinds of experiences as how ‘I know. that I’m gradually, very gradually, inverted commas “losing it” [laughs]. Sadly.’ This moment exemplifies the complexities of participants’ engagement with socially dominant discourses. On one level, Sheila draws on language associated with loss (of self) to describe her experience of a progressive decline in abilities, which has elsewhere been observed within the reflections of bloggers with dementia (Castaño, 2020). Yet, the ‘inverted commas’ here mark Sheila’s resistance by indicating that this is not necessarily a perspective that she aligns with, corroborating that people with lived experience can simultaneously incorporate and challenge dominant discourses (Bryden, 2020; Hillman et al., 2018).

In the face of her deteriorating abilities, Sheila turns to her relationships with others, particularly God and her daughter. Sheila positions her faith in God as fundamental to her navigation of having dementia, and that it provides comfort is indicated by her countering the ‘sad[dening]’ prospect of ‘losing it’ through turning to her faith (‘But God’s good’). She regards her dementia as a trial that will enable personal and spiritual growth, and her faith in God’s goodness and omniscience sustains her. Spirituality, whether religious or not, is ‘part and parcel of what it is to be a person’ (Hughes 2011: 205) and can greatly support individuals’ psychological well-being, resilience and meaning-making for dementia (Katsuno, 2003). During this interview, Sheila presents a shift in her health and subsequent social roles (as carer then cared-for). Countering this, her unwavering faith in God, alongside her other relationships, sustains Sheila’s ‘relational self’, which Bryden defines as ‘an aspect of my self that gives me my sense of being an embodied self in relationships with God and with others’ (2020: 79).

Indeed, Sheila is certain that when needed her daughter, who is a palliative care nurse, will look after her, citing her daughter’s current support of her as evidence of this. Here we see Sheila shift from caring for others to being supported herself, something that she explicitly reflects on:

Sheila Wheels go round don’t they.
Emma Yeah
Sheila Stephen and I, we cared for my mother and dad. and we cared for his mother and dad.
Emma Yeah
Sheila And [my daughter] helped me care for Stephen, and, and you know.
Emma Circles, (as you say)
Sheila As the Bible says as you sow so shall you reap.

Contrasting her earlier emphasis on her independence, which takes an individualistic approach to care, here Sheila reproduces an alternative ideology to individualism, that of ‘familism’, which emphasizes family commitment and obligation to care for loved ones (Ward-Griffin, Bol and Oudshoorn, 2006). Sheila’s reference to the Bible’s teaching of cyclical care interweaves Christian morals of care with familism, an account that supports both her relational and narrative self (Bryden, 2020), since she finds meaning and identity in her place within the network of familial care and substantiates this through her knowledge of biblical teachings. Sheila’s account draws on multiple common motivations for caregiving, which include a combination of expectation and obligation alongside love, religion and repaying care received as children (Erol, Brooker and Peel, 2016).

As the interview continues, Sheila’s reflections as a carer stimulate reflections on her fears for her future self and the care she can expect. Following observations that the boundaries that caring dyads initially establish are often later ignored or overcome, for instance, regarding help with toileting (Fletcher, 2020c), Sheila explains that experiences ‘swing’ and you ‘think, you can’t cope and then, you go on’. This account of resilience triggers a concern for what will happen when Sheila’s dementia progresses, particularly how she will change and whether her daughter will be able to ‘cope’:

> Now, I worry about myself, at times, I try to put it in the back of my mind. What is to become of me? What will I be like? [1.8] Would I become violent, and have to be taken away? [2.4] I know what it’s like in those places. [1.8] And I wouldn’t, want to be there. But [1.5] whether my daughter could <u>cope</u> with me. You see I had twenty-four hours with Stephen, I was retired, I’d got the time. but my situation will be different [1.5] So, I don’t know. But I’m not going to worry about it, or try not to worry about it.

Sheila’s question of ‘what will I be like’ is of great concern to many people, especially in the context of dementia, since the progressive condition poses an existential threat for individuals (Caddell and Clare, 2011; Castaño, 2020; Cheston, Christopher and Ismail, 2015). Here, Sheila particularly fears becoming violent, possibly because of the change to her character, and certainly because of the consequences of this behaviour. Returning to the disabling impact of a person’s environment, it is notable that Sheila’s future fear is that her daughter will not be able to cope with her, highlighting the distinct stressors within their mother and working daughter caregiving dynamic (Erol, Brooker and Peel, 2016). Here, not coping would lead to Sheila being ‘taken away’ to an institutional home against her wishes. Predicting her own future dependency and loss of agency, Sheila acknowledges that she may ‘have to’ end up at one of ‘those places’; her euphemistic language associates this kind of social institution with fear and taboo, which is furthered by the deictic demonstrative pronoun ‘those’, since it establishes a firm sense of distance (that she wishes to maintain) between herself and the ‘places’ that they send people to once the familial network that she favours can no longer ‘cope’. Elsewhere, Bryden (2016: 185) shares Sheila’s dread of ‘being put in dementia prison’, critiquing the lack of human dignity or care of such places, which is reinforced by frequent reports of human rights violations that can occur (Cahill, 2018; Steele et al., 2023). Sheila copes by avoiding thinking about future fears, a common coping strategy for dementia (Buggins, Clarke and Wolverson, 2021; Wawrziczny et al., 2017). As her modality amendment in her final sentence indicates, she can only state that she will ‘try not to worry’, leaving a more ambiguous impression regarding distress levels that acknowledges the complexity and emotional toll of living with dementia (Bartlett et al., 2017).

Sheila’s multifaceted account of both the positives and negatives of life as a carer and person with dementia culminates in a reflection on how ‘there is a suffering for both of you’. This is inspired by a discussion of using ‘suffering’ and ‘sufferer’ (see Chapter 5 for a discussion of the distinction between these terms). This is a concept that Sheila has not previously considered, as indicated by her repetition that ‘I’ve never thought about [it] before’ and that ‘it’s giving me more thought’. The frequent lengthy pauses further support the impression that she is processing less familiar, more difficult thoughts and trying to communicate some of these to me:

Sheila [1.8] You do suffer. You suffer the loss of them [2.4] You suffer [2.8] their [1.6] erm. lack of ability [6.0] They suffer. because for a long time, they are probably aware that they’re helpless.
Emma Mm
Sheila They’re dependant on somebody else [2.7] And that it’s [1.9] a grief of mind [1.5] Which is what suffering is isn’t it, grief. […] it’s giving me more thought. And I would have said at the time I didn’t think I was suffering.
Emma Yeah.
Sheila It’s in hindsight, and talking about it now,
Emma Yeah

Sheila that I realize that. there is this process of suffering. because there's the loss.

Emma Mm

Sheila The loss of the person that they were. [6.3] Which made me realize, there'll be a loss, to what I was [2.0] A very competent, efficient, er. in the nursing world, fairly high powered. erm, to [2.7] not being that anymore [2.6] Just er. forgetful and [1.6] effort to function. Don't know how long I can go on driving.

As with care, Sheila's reflections on suffering begin from the perspective of herself as the carer and culminate in herself as someone with dementia. Her stance on suffering is attributed to 'hindsight' and as different to her opinion while caring, indicating the continuous and contextual nature of people's subjective constructions of their experiences, and that interviews can facilitate greater introspection (Bloor et al., 2001). Due to its intensely personal nature, suffering is hard to define (Bartlett et al., 2017). Here, Sheila defines suffering as 'grief', the emotional response to loss, explicitly linking its cause to a loss of abilities, independence and 'the person that they were' as dementia progresses. This reflects the sense of loss that can accompany dementia's challenge to certain proposed psychological needs, such as independence, competence, relatedness and identity (Castaño, 2020; Cheston, Christopher and Ismail, 2015).

Initially, Sheila positions herself as a carer, establishing an out-group ('they' and 'them') of people with dementia. After a longer pause (6.3 seconds), she transitions into the perspective of someone with dementia, indicating that her reflections as a carer have made her 'realize, there'll be a loss, to what I was' as well. Notably, Sheila focuses on the loss of hypercognitive attributes: competence, efficiency and accountability (in the sense of being 'fairly high powered'), which echoes the socially assigned value of these abilities above more emotional, relational, expressive and/or experiential ones (Post, 2000b). By implying that she will lose power, Sheila ties social status and respect to her cognitive competencies, reflecting her 'loss' in value through shifting from the intensifier 'very' for her competencies to the reductive 'just', which lowers her status once she identifies as forgetful and requiring more 'effort to function'. Through positioning this within the 'loss, to what I was', Sheila individualizes this process, backgrounding the role of social relationships and broader structural inequalities in this shift (Bartlett and O'Connor, 2010; Sabat, 2018). Sheila's reflections here are a stark reminder that when value is overly tied to hypercognitive attributes and people are treated as such, people only stand to lose (abilities, identities, freedoms, etc.) with dementia.

Our conversation was interrupted by my recorder beeping to signal a low battery, but Sheila returned to the questions around suffering when I asked her how she found the session. Since the recorder was turned off, the following response is taken from my detailed written notes, which are as close as possible to being verbatim:

> I was apprehensive at first as I didn't know how to help but I enjoyed it. It was good for reminiscing. I was interested by the reaction to people and pictures, it made me think about suffering which at the time I didn't realize we were suffering but because I now can talk the language of Alzheimer's I can push to be helpful for carers, but I don't know anyone at the moment.

Sheila foregrounds her retrospective reflection on the suffering that she and Stephen experienced with dementia here, the concept that appears to resonate most from this interview. Ending this interview where we began, Sheila continues the language analogy by positioning herself as someone who 'can now talk the language of Alzheimer's'. The metaphor of having learnt a new language can be read as positioning Sheila as now being enlightened through lived experience (since Sheila is the partner with Alzheimer's disease), and thus able to act as a 'helpful' bridge for carers of people with Alzheimer's disease, reinforcing the wider recognition of people with dementia as experts through experience (Bryden, 2016, 2019). Alternatively, if this reflects the popular use of 'Alzheimer's' as a synonym for its superordinate 'dementia', then Sheila's *combined* experience as a carer and person with dementia may provide this understanding. Either way, this analogy reinforces the necessity of direct experience to being able to communicate about Alzheimer's disease and/or dementia, explored further in relation to peer support in Chapter 6. It also continues Sheila's caring identity and agency as someone who can 'push' to help in the care of others and emphasizes interdependency between carers and people with dementia.

3.3 Society's sidelines: Nancy and dementia advocacy

In contrast to Sheila, Nancy approaches dementia primarily through a rights-based, structuralist lens, since she is consistently concerned with how sociopolitical structures affect citizens' experiences of dementia. Indeed, in many ways, Nancy is the quintessence of what Bartlett and O'Connor (2010) describe when they state the rights of people with dementia to be free from discrimination, to seek personal growth and to have recognized social positions, meaningful purpose, participation and solidarity with others to create sociopolitical change. Nancy is greatly involved in her community and activist groups, from which she forms networks and critically engages with broader social issues. I first met Nancy through a patient and public involvement group at university, and beyond this, Nancy mentions being a member of DEEP (the UK network of dementia voices) and a dementia choir, as well as volunteering for Alzheimer's Society, participating in research, doing radio interviews, being in pamphlets and on advisory boards. Our interview has a particularly outward-looking focus, with Nancy consistently positioning her experience of having dementia within wider representations and social structures and offering her views on the role that media and society as a whole have to play within the context of dementia.

Dementia in society

In response to being asked about her experience of dementia, Nancy initially focuses on her diagnosis process and interaction with different service providers. She begins by describing seeking a diagnosis because she 'knew there was something [1.1] going on', since 'my daughter said I was double booking myself which meant I was having problems organizing myself […] And that, that to me is, is very important'. This account demonstrates that individuals and/or their family often notice symptoms first (Pratt and Wilkinson, 2001) and reinforces the important role that loved ones can play for recognizing and validating changes (Brossard, 2017). Asides this nod to her daughter, Nancy instead foregrounds her interactions with a range of medical professionals and organizations, initially the GP practice and memory clinic. She tells me that she was informed of her diagnosis through a 'letter from the consultant', which she was then told in person at the memory clinic. Here, 'they give you the pills and then they check that the pills are [1.2] are comfortable with you […] And then, that's it'. Expanding on this pharmacologically oriented intervention that swiftly ends, Nancy states:

Nancy You are dropped back to the, GPs
Emma Yeah
Nancy Who don't know what to do with you because they haven't got the experience.
Emma Mm
Nancy And, and the time,
Emma Yeah

Nancy And, it's only when you get somebody that's really interested in dementia that you get to know a lot more.

The choice of 'dropped back' here is striking, since it provides a sense of Nancy's disempowerment through the sudden withdrawal of specialized support. This utilizes the common orientational up-down metaphor, whereby 'GOOD [and power, control] IS UP; BAD IS DOWN' (Lakoff and Johnson, 1980: 16) to present Nancy as involuntarily moving down the hierarchy, here back to non-experts. Critiquing the GPs' lack of experience and time, Nancy argues that learning more about dementia happens by chance, according to whether the person you see is 'really interested in dementia'. Through shifting from the first person (used to outline Nancy's initiation of the diagnostic process) to the second person when discussing the subsequent processes, Nancy situates her experience as commonplace. Indeed, inconsistent and insufficient support and professional understanding is critiqued by multiple participants (see Chapter 6) and other people affected by dementia, demonstrating a wider dissatisfaction with support for many individuals following diagnosis (Pratt and Wilkinson, 2001; Prorok, Horgan and Seitz, 2013). Against this, Nancy presents herself as actively seeking information from the community about 'what was available' and 'what I could do', evaluating her local council and Alzheimer's Society as the 'most helpful', as opposed to her GPs and the more general charity Age UK. That Nancy approached Age UK 'first […] because of my age' but did not find it as helpful reinforces the diversity of the population that is consistently discursively and structurally homogenized as being 'over sixty-five' (Perel-Levin, 2019).

Although, as will become increasingly apparent, Nancy frequently aligns with other people with dementia to establish a collective group identity, she also emphasizes the heterogeneity within this typically homogenized social group. In response to seeing Image 6 showing a person with young-onset dementia (see the Appendix), Nancy tells me that 'it's nice to see that age' because she knows someone (Bill) through her choir, who has Alzheimer's disease and is aged thirty-two:

Nancy And Bill came and you could see that he was, fu-, progressing fur- quicker. Because they say that the working - it gives such as me a better understanding of the different types of dementia, because you're only talked about your, your diagnosis.

Emma Yeah

Nancy They don't tell you about. erm, the ones that are going to lose their voice, you know the speech, part of the brain, or that, and,

> so sometimes when you are in the Memory Café you don't know how to, deal with those people and you have to go through the carer first sometimes and that's wrong. You shouldn't have to you should be able to approach the person, but without the understanding of what, how the disease is taking it, away from them, it's very difficult, to start a conversation sometimes.

Here, Nancy reflects on the barriers that are created through ignorance, including between people with different dementias to your own. This is reflected linguistically in her choice of 'those people' that 'you don't know how to deal with' and therefore 'need to go through the carer first' for. Through the distancing demonstrative pronoun 'those', Nancy situates herself as apart from individuals with dementia that she doesn't understand how to communicate with, with the carer subsequently becoming the bridge between them. Nancy firmly evaluates this as 'wrong', emphasizing that 'you should be able to approach the person'. However, she emphasizes that 'without the understanding', it becomes 'very difficult'. Specifically, Nancy mentions understanding 'what, how the disease is taking it, away from them'. Dementia is simultaneously presented in biomedical terms as a 'disease' and personified as a thief. Although the ambiguity of 'it' as a referent raises questions about what exactly dementia takes, if Nancy's earlier discussions in this account of different symptoms (such as losing speech) are assumed to be the antecedents, then she would appear to be describing the loss of abilities rather than, as in much mainstream discourse, of selfhood (van Gorp and Vercruysse, 2012). These other people with dementia, then, are not separated due to a loss of self or status but rather an ignorance of how to communicate with them, since people are insufficiently educated on the diverse conditions within the 'umbrella term' dementia that means that 'everything's different' across individuals.

Relatedly, Nancy attends to broader attitudinal barriers, namely the double stigmatization of being old and having dementia (Evans, 2018). Responding to two images of people socializing in groups (Images 3 and 4 in the Appendix), Nancy tells me of the need for marginalized people to connect and be listened to. She begins by stating the value of 'sitting two people together and letting them talk'. In the context of the stigmatization and silencing of older adults, the permissive connotations of 'let' imply the need to enable, rather than obstruct, such adults to speak for themselves. Indeed, although Nancy acknowledges that sometimes conversations do need 'directing', she quickly counters this with:

> But very often. people who have been. are, older in age. have got a lot to talk about, a lot of memories, a lot of expertise that, that, gets lost because we've become [2.4] not part of society so easily, it's, that we're sort of side-lined [. . .] It's more for families and that sort of thing and, young, professionals.

Here, through shifting to the plural personal pronoun 'we', Nancy positions herself as a spokesperson for older people, critiquing the marginalization of older citizens, whereby 'a lot of memories' and 'expertise [. . .] gets lost' because people's voices are no longer heard in a society where older adults are 'largely invisible' and systemically discriminated against (Perel-Levin, 2019: 90). Many people with dementia share Nancy's frustration at their extensive life skills, work skills and experience being 'written off', being instead 'defined by dementia' and treated as lesser (Davies et al., 2022: 17). In such a hostile environment, Nancy emphasizes how 'important' it is to 'get people together, like-minded people together', a position on peer support that is shared among many participants (see Chapter 6). However, contextualizing this within an unstable funding environment (another signal of older citizens being devalued), Nancy indicates that such groups rely on voluntary support or unpredictable council funding, meaning that it 'just gets started and then (is) stopped abruptly'. She focuses on how this impacts the individuals involved: 'It's awful for the people that have. built up relationships, and, you don't know where to go from there, do you?' A sense of powerlessness and abandonment is presented in the abruptness of the end of such support, as reflected in the more concrete, 'built' relationships giving way to uncertainty. Structural issues, namely the unreliable council funding, are given a human face by Nancy focusing on the people affected by structural shifts and explicitly drawing me into the experience of not knowing what to do through her tag question 'do you?'

Throughout, Nancy foregrounds how the environment can enable or disable people with dementia. Above, she discusses attitudinal barriers (lack of understanding and stigma), but she also attends to social inequalities and structural issues within the social environment. This includes accessing more holistic support, whereby 'this social prescribing is taking so slow to get mo- [coughs] to move, that er, people are being left behind'. Social prescription is an increasingly influential aspect of healthcare that refers people to non-clinical activities to improve their well-being, usually delivered by community services and voluntary groups (Baker and Irving, 2016). Recognizing the influence of social, physical and economic factors on health, schemes range from advice services (e.g. regarding benefits) to activities grounded in the arts or nature

(Hamilton-West, Milne and Hotham, 2020). Social prescribing is increasingly popular, but researchers warn that these heterogeneous provisions require appropriate coordination and support, and that they are not a 'silver bullet' for austerity measures, with other services such as public transport and libraries remaining important for well-being (Hamilton-West, Milne and Hotham, 2020). Reflecting this broader discussion, Nancy highlights that she enjoys the independence of travel, which is facilitated by her bus pass:

> I seem to travel because I enjoy the independence and my bus pass. and that's one of the things I've been looking at in the erm political pamphlets. to see who's going to offer me, my bus pass because each time we have a general election that's one of my worries […] Because it's not only for me is it, it's for all people, senior citizens.

Here, Nancy's continual concern about bus passes remaining a right for older citizens is conveyed through the simple present tense when discussing elections, which suggests a continuation between Nancy's past, present and future concern about this issue due to the precarity of many social services. Through this, Nancy constructs a persevering identity that is related to her habitual activity (bus travel), the object that enables this (her bus pass) and her social persona as a politically engaged citizen concerned with the treatment of 'senior citizens' more broadly. This reiterates the interconnectedness of identity with our relations with people and artefacts within the social world (Hughes, 2014; Sabat, 2018). Nancy self-reflects on her positioning relative to other citizens, telling me that 'I'm lucky, I get two private pensions, erm. a, a state pension and an attendance allowance so [2.2] I'm comfortable. I can do what I what I want to do […] And that's, that's important'. Situating her financial situation as one that enables rather than disables her, Nancy positions herself as 'lucky', implicitly acknowledging the limitations that other people face. This mirrors her concern that 'people are being left behind' by services and her further discussion that without 'a good doctor or a good welfare support worker', people 'on their own […] can miss out on a whole range of support'. Through her attention to structural and financial inequalities, Nancy emphasizes that not everyone has equal access to support for dementia, focusing particularly on people 'on their own' who have less of a support network. Indeed, people with dementia who live in deprived areas and do not have a carer are at particular risk of having unmet needs and lower well-being (Wu et al., 2018).

Throughout her interview, Nancy presents a personalized account of dementia that actively engages with the wider sociopolitical climate. She foregrounds the role of the environment in (dis)abling people with dementia, including through social attitudes, financial (in)stability and structural support, or lack thereof. This section has focused primarily on healthcare provision, broader non-profit community support, structural support (bus pass), the homogenization of people with dementia due to insufficient understanding and the marginalization of older people, including those with dementia. As part of her engagement with society's role in experiencing dementia, Nancy also foregrounds the role and potential of the media, considering current tropes in relation to lived experience. It is to this issue that I now turn.

Media and lived experience

Reflecting on the role of the media and consumers, Nancy positions the media as an important source for disseminating information and influencing its consumers' worldviews: 'The media is handy because it helps you to form. Not decisions, but opinions […] And it keeps your mind awake […] the media is good because it's thought-provoking, sometimes it's, problem-solving.' Here, Nancy establishes consumers, herself included, as actively constructing meaning when engaging with media, since consumers are attributed the agency to deliberate and form opinions, while media content 'helps' by informing these. Beyond influencing people's 'opinions' by being 'thought-provoking', Nancy positions the media as 'problem-solving', and thus as influencing real-world actions and social change. Expanding on this, Nancy establishes a problem–solution structure, whereby carers face insufficient structural support, for which the awareness that media can provide is instrumental to creating change:

Nancy carers can get so worn down by, erm their er usage of being used by the person and, the care system, not helping them enough,
Emma Yeah,
Nancy So, the media needs to get to the care system too, and start waking their ideas up by pointing the finger and saying excuse me, are you? Because that's what the media is part of isn't it is
Emma Definitely
Nancy Questioning and, developing services and all sorts of things

Again, Nancy utilizes an awakening metaphor ('waking' ideas up) that positions the media as an illuminating institution; here, rather than keeping 'your mind awake', the media must expose the issues in the care system and push stakeholders to face them. Through 'questioning' social issues and 'developing' responses, Nancy positions the media as an advocate for the public (here, carers), since media organizations are attributed greater agency than individuals to achieve change through critical coverage. This explicitly calls upon the media's broader sociopolitical power in its ability to frame public priorities, through which it can influence the political agenda and, therefore, push for change (Bednarek and Caple, 2019; Walsh-Childers, 2017).

Recognizing the importance of the media, Nancy critiques current representations of people living with (and otherwise affected by) dementia and suggests improvements so that media representations can better reflect lived reality to improve the lives of people affected by dementia. Aligning with many other participants, Nancy critiques the lack of diversity in media representations, including for dementia as a syndrome, which needs to be recognized as an 'umbrella term' with 'different forms of disease', meaning that 'everything's different'. She also criticizes the negativity and narrow focus of representations (explored further in Chapters 4–6), telling me that 'a lot of it is, headline grabbing erm. Always the negative side, erm, usually it's just one-sided in that it's just dealing with the dementia'. Focusing on newspapers here, Nancy touches on the purpose of the news media to garner readership (through 'headline grabbing'), critiquing their 'one-sided' rather than more holistic depiction and overall 'negative' focus. This recognizes that news stories tend to favour negative aspects when reporting on dementia, reflecting (and reinforcing) the broader news value whereby negativity makes an event more newsworthy (Bednarek and Caple, 2019). She supports her argument with a 'Dementia Friends talk' she attended, where they 'got loads of headlines, but it all seemed very negative. Er. They don't show a lot of the positives of dementia'. This positions Alzheimer's Society, who run these sessions, as a trusted information source, something that Nancy questions for newspapers, suggesting that 'it's probably with somebody who doesn't know what they're talking about'. Indeed, most journalists will not be knowledgeable about dementia or recommended terminology, reflecting (and reiterating) a broader lack of understanding among the public (Kelly, 2019).

In response, Nancy promotes amplifying the voices of people affected by dementia in the media, arguing that this can provide expertise, nuance, diversity and a 'human side' to dementia. Nancy emphasizes the value of people with dementia working with the media to improve awareness of the condition, telling me that

> the media are important in doing that, to say there is life after the diagnosis. And that needs to be pointed out every time, […] I love, in [image] 15 where the guy

> is actually using the media. Because I think the more we can use the media, the more people realize that we, we are ok and and that we aren't to be feared […] that's where the media is there, isn't it? It's, to lose that fear, to make people more aware of the pros and the cons of dementia,

Throughout the interview, Nancy aligns with the living-well discourse's message that 'there is life after the diagnosis', elsewhere presenting the phrase 'living well' as a necessary counterweight to the negativity surrounding dementia by 'inspiring' people and reflecting that you can be 'enjoying life' while living with dementia (see Chapter 5 for more on 'living well'). Image 15 depicts the renowned British author Terry Pratchett holding up a sign saying, 'It's possible to live well with dementia and write bestsellers "like wot I do"' (Figure 5.2). Nancy praises this advocacy and calls for more examples like this, arguing that greater visibility of people with dementia can reduce the fear and stigma surrounding those with the condition, as individuals with dementia will become less 'side-lined' (to use Nancy's previous criticism) and can improve awareness by addressing both the positive and negative aspects of dementia. Indeed, since fear, silence, misconceptions and stigma are all interrelated, improving communication via the media is instrumental to improving people's perceptions and thus experiences of dementia (Kelly, 2019). Here, Nancy establishes a collective group identity for herself and other people with dementia through the plural first-person pronoun 'we'. This 'we' is contrasted against the generic, more distanced 'people' who need to become 'more aware' about dementia by learning from people with lived experience. This situates people with dementia as experts through experience, furthered elsewhere by Nancy's foregrounding of national advocates living with dementia, such as Agnes Houston and Wendy Mitchell who are 'doing, lots of sterling work'.

Thus, Nancy promotes showcasing the 'human side' of having dementia through working with individuals with first-hand experience and showing what they and their lives are like. Reflecting on her own experiences with television crews covering activities such as conferences, swimming and groups that she is involved in, she tells me that 'It's just such a good insight into how we are actually working, and reacting and talking […] Why isn't it done more?' This distinguishes between how people with dementia are 'actually' acting in real life versus how they are represented, indicating the need for this better 'insight' into reality. Notably, Nancy appears to focus here on responsivity ('reacting'), 'working' (note that this may be interpreted in relation to referring to "how we are actually [operating]" or about doing socially productive work) and verbal communication ('talking'). These activities construct an image of the engaged, active citizen with dementia as found in the structural, rights-based discourse (Bartlett and O'Connor, 2010). Missing from Nancy's and other accounts that focus on active citizenship and 'living well' are people living with the most challenging aspects of this syndrome, who cannot participate in this cognitively oriented way (McParland, Kelly and Innes, 2017).

Expanding on her experience with television shows reporting on aspects of life with dementia, Nancy situates people living with dementia within television programmes about disabilities and illnesses more broadly. She calls for greater coverage of what it is like to live with a diagnosis and some of the ways that your environment can (dis)empower you:

Emma So, just to see if I've got the right erm, understanding, are you saying that it would be beneficial to kind of just show more ordinary life?

Nancy Yes, you don't see that, there isn't erm, a consistent programme each week. of, the hidden demen- of the hidden diagnosees or, the other side of living with a diagnosis and it's not just. it could be cancer, it could be a physical disability, it could be anything but, this Brexit's just taken over.

[…]

Emma Yeah, that's true. So when you say the other side, which sides do you think there are?

Nancy There's a human side because erm, there's a lot of people, getting through diversity with erm horrendous problems and, and solving those problems. There are television programmes that are highlighting those programs like the Nick Knowles program, where they go and sort out homes and that. Because, physically, there aren't enough, erm, the constraints of their home means that they can't have a proper life because they're forever, struggling, with their home life and until you've got your home life sorted you can't afford to get out and do other things can you?

This focus appears to be on normalizing life with diagnoses by following the lives of individuals, all of which would help to show what Nancy describes as the 'human side' of dementia. It is here that Nancy explicitly raises 'highlighting' 'diversity' and some of the 'horrendous problems' that people face. She refers to a popular British show (named *DIY SOS*) hosted by Nick Knowles, which improves the lives of ordinary people facing hardships through transforming their home, to exemplify that the media can contribute to improving people's lives through adapting their physical environments to enable rather than disable them. Alongside foregrounding individual and environmental barriers, this can model ways of addressing environmental obstacles (for example, by changing the architecture and introducing aids) while simultaneously conveying 'various stigma-busting messages' when exploring the people's lives, which contributes to breaking down attitudinal barriers for people affected by dementia (Kelly, 2019: 96). Here, dementia is very much situated within the larger context of disability activism and the need to improve structural support for people with disabilities, in part through collaborating to provide newsworthy human-interest stories that bring in revenue for media organizations while simultaneously benefiting the individuals and community featured (here through home improvements) and overall, giving a relatable human face to dementia (Bednarek and Caple, 2019; Kelly, 2019). To facilitate such a relationship, Nancy insists that media representatives must 'be a lot more thoughtful in how you approach your subject', 'let[] people talk' and use more accessible 'language that the person would probably understand more', including by avoiding acronyms where possible. This again takes a rights-based approach that focuses on reducing power inequalities that are inherent in interactions between institutions, such as the media, and disenfranchised citizens, such as people living with dementia.

Nancy also calls for greater visibility of carers, arguing that it is 'so important, for, you know, a lot of carers to be recognized and to know that they have a voice. Um. A lot of people with dementia have a voice and can't use it, and the, the carers use that voice but they then they have their own voice and their own thoughts'. This emphasis on carers' voices may be seen by some to challenge the shift towards recognizing the voices of people with dementia after decades of privileging carers and health professionals while silencing and discrediting people with dementia (Bailey, 2019; Clarke, 2006; Villar, Serrat and Bravo-Segal, 2019). Yet, it also recognizes the historic ignoring and undervaluing of carers, associated with a lack of support and the negative social, physical, psychological and economic effects of caring (Fletcher, 2020a). Nancy's contribution acknowledges the complexity of the dynamics between caregivers and people with dementia, with carers sometimes needing to advocate on behalf of the person they support while simultaneously having their 'own voice' and 'thoughts' that must, too, be recognized.

In her concern for heterogeneity and more accurately representing people affected by dementia, Nancy also highlights the need for visual representations to be more diverse. Nancy establishes images as 'more important than the text' for many people, with images first drawing the eye, contextualizing the piece and telling 'the story'. She references the popular saying 'a picture can say a thousand words' to describe the amount of information that images convey and positions images and articles as 'the starter of a conversation', again situating the media as a means of stimulating social change. She explicitly critiques the collection of twenty images shown in the session, telling me that 'I think it's an interesting collection of pictures. I think you could have, more could be developed but, I think, that's the deficit of the, media, there's a lot of things written, but their illustrations, aren't always in line with the, the text'. In saying this, Nancy arguably aligns herself with her DEEP network's criticism that 'sometimes the images selected to illustrate articles can serve to undermine the actual story' (DEEP, 2014: 4). It is within this ideological context that Nancy considers who is included in visual representations of dementia.

Telling me about her feedback for a local art gallery, Nancy recalls that the people they featured 'were all white' and 'all elderly or young children'. Here, in line with communication guidelines (Alzheimer Europe, 2022; Bould, 2018; KYN et al., 2023), Nancy clearly establishes different ages, racial identities and ethnicities as important features of visual representations that need diversification. In the context of evaluating the twenty images I provided for participants, Nancy similarly notes that 'on the whole I think it's a good cross section of people, mainly white people. A couple of. I love the hands, I think that is so age related'. In an overwhelmingly white British majority group of participants, Nancy was the only participant to identify the overrepresentation of white people in the images, reflecting the normalization of disparities in representations across popular culture and research (Bould, 2018; Hulko, 2009), which itself is indicative of broader structural inequalities (Culley, 2006). Evidently, people and experiences with dementia beyond that of a white British perspective need foregrounding. Of course, individual identities are significantly more multifarious than using distinct, fixed racial and ethnic group categories allow, whether for minority or mainstream groups (Culley, 2006; Khan, 2015; Mullay et al., 2018). Nancy touches upon this when discussing the intersection of 'age, gender', race and ethnicity for how people experience dementia, concluding that 'it's all related as to how you cope with it. How your family copes with it […] And how you see it'. Throughout, whether for social demographics, types of dementia, positive and negative experiences or for people affected, Nancy situates diverse representations as fundamental to the role of media and as a means of improving the experiences of people with dementia and their loved ones.

Equally, Nancy acknowledges that in the context of such diversity, interpreting good practice in the media is subjective and depends on a person's 'upbringing […] life experiences […] family situations, and when you roll that into one, they're all different for everybody, you can't say that one, one thing suits everybody, and so it's very difficult when you write articles, to please everybody'. What she touches upon here is that not only does the media influence consumers' worldviews, but an individual's 'life experiences' (social, cultural, economic, historical, physical and psychological, etc.) affect how different consumers interpret media representations (Gamson and Modigliani, 1989). It is therefore vital to situate responses to media portrayals and discourses within individual contexts. Subsequently, this chapter concludes with an exploration of how some of Nancy and Sheila's personal 'life experiences' interact with their responses to particular representations.

3.4 Is a picture worth a thousand words? Interpreting the same images

Building on the above analysis of Sheila and Nancy's personal accounts, here the focus shifts to foreground some of the ways in which they each respond to visual depictions of people with dementia. Specifically, this section compares how Sheila and Nancy respond to three images, one literal and two metaphorical, which are used to represent people with dementia in charity and newspaper contexts. I consider how the two women's personal experiences and discursive preferences inform their responses, asking: what do they each choose to foreground when interpreting the same images?

Images 5, 10 and 12 (Figures 3.3–3.5, respectively) are selected for analysis here for multiple reasons. Firstly, they are each used to represent someone with dementia, with Image 5 depicting a man smiling in his garden (aligning more with a living-well discourse), while Images 10 and 12 show a fragmenting or fragmented individual, either through a disintegrating head or missing jigsaw piece, which arguably reflects a loss-oriented 'tragedy' discourse. Whereas Image 5 was drawn from an Alzheimer's Society's webpage, Images 10 and 12 are stock images that feature in newspaper articles. Intriguingly, researcher-led analysis often differs from the points raised by these interviewees, with Image 12 providing a particularly useful contrast, as it has previously been subjected to multimodal critical discourse analysis (Harvey and Brookes, 2019). A more pragmatic reason for selecting these three images is that both Nancy and Sheila comment on them in detail, enabling a more substantial comparison between the two women.

For context, it must be noted that the images that appear to resonate the most with Sheila depict the couples, hands and the women holding their head in their hands (Images 1, 2, 7, 8, 13, 14 and 16 in the Appendix). While the 'head holding' images are interpreted in relation to the despair that she and Stephen both felt from the challenges of dementia, the other images are associated with love and embodied forms of expression:

> Those, I thought, holding hands [7][8] went with these [13][14][16] which is, love. That, holding hands, often conveys a lot more than words, particularly if they're not fully understanding. Erm. To hold hands is a great thing, and um, probably. your love for each other gets you through some of the difficult times.

As such, the images Sheila foregrounds clearly reflect her experiences as a carer for her husband, both regarding their strong couple identity and embodied communication of love and suffering. Her responses to these images, however, are used in the previous section to help illuminate her reflections on caring for Stephen, while Nancy's responses are either also interwoven into her above points or are insufficiently detailed to feature. For example, Nancy's response to the images of couples is to emphasize that 'there is life after the diagnosis' and discuss the role of the media in supporting this message, a point that is more relevant to the above exploration of her discursive positioning. Nancy praises many images, including the hands images (Images 7, 8) and tree image (Image 11), but she declares that two of the images examined here 'represent dementia for me so much' (Images 10 and 12). Although the images align more with Nancy's preferences, then, they have been selected for the interpretations and associations that both women respond with, which are distinct from the quotes discussed in the above sections and can provide useful insights into the subjectivity of interpretation.

Beginning with an example of a literal image, which denotes a man smiling in a garden and resting on his broom (Figure 3.3), it becomes clear that the two women draw different connotations that relate to their own experiences. As befits her earlier discussions, Sheila foregrounds the concept of 'coping' with dementia:

Sheila Erm. That just conveyed to me. that the man was coping?
Emma Mm.

Figure 3.3 An artist's impression of a man in his garden (Image 5) (by Chris Chikodzore-Paterson, with permission from Alzheimer's Society).

Sheila Was making the best of things. Er. Perhaps you see a bit of anxiety, about his eyes. But. On the whole it's a cheerful, cheerful er face. And erm [2.9] the fact that it's in his garden, and that he's, still sweeping up [laughs]

Emma [Laughs] yeah

Sheila Just making the best of it.

Underlying Sheila's admiration that the man is 'still sweeping up' is an implicit assumption of deteriorating abilities, which indicates that she interprets him as having dementia. She analyses his 'face' as 'cheerful' overall and repeats that he's 'making the best of things', admiring that he's being active in his garden (Sheila is herself a keen gardener), which presents a fairly optimistic account of 'coping'. Yet, interestingly, Sheila also suggests 'a bit of anxiety' that shows 'around his eyes'. The eyes are widely associated with revealing someone's emotional state, including potentially signalling anxiety through a lack of eye contact (Waxer, 1997), which may here be indicated by the off-camera gaze of the represented participant. The suggestion that the man's anxious emotional state contradicts his external display of cheeriness assigns a complex emotional identity to the figure. This reflects the external positivity that both people with dementia and carers can emanate, masking their actual (often less optimistic) emotional states out of concern for others' well-being, a desire to present a positive self-image and/

or the pressure to adhere to expectations of a person ‘living well’ with dementia (Bartlett, 2014; Birt et al., 2020; Manthorpe et al., 2011). When contextualized in relation to her other responses, Sheila’s interpretation of the man in Image 5 may reflect a tension that she too feels between presenting an optimistic front as someone who can ‘cope’ and her internal suffering and anxieties, including fears about her future with dementia.

While Sheila focuses on what she sees in the photo and in relating this to anxiety and coping with dementia, Nancy’s response to the image reinforces her structural, rights-based focus. Namely, she highlights her personal growth through becoming friends with someone from the Caribbean (Vera) and considers some of the additional structural barriers that immigrants face in the UK. This is initiated through foregrounding the man’s status as an ‘ethnic minority’:

Nancy Number 5 for the gentleman who’s erm, of an ethnic minority […] I’ve already discussed because I love, I have a friend called [Vera] who lives in the [Willows], and she’s woken me up to the differences. She talks about her childhood, she talks about her food, and, we’ve become quite close that way in that it shows me the differences. The way I think of white and, normal food and she thinks of Caribbean food as normal. We see a lot of differences but we see a lot of similarities.

Emma Yeah

Nancy Because she didn’t come over in the Windrush she came over just after.

Emma Ok.

Nancy But she’s still had problems with passports and, family, problems trying to get, nationality sorted out. Because it’s, encompassing, as soon as the media starts on one thing. it makes you think of other things and and.

Again, through her friend having ‘woken me up to the differences’, Nancy uses an awakening metaphor for the greater awareness of the diversity of life experiences that she as a white British citizen gains from exploring Vera’s citizen perspective. This account is among Nancy’s most self-reflective and foregrounds her personal growth, which is a fundamental right proposed for citizens with dementia (Bartlett and O’Connor, 2010). Her individual growth supplements the broader social awakening she previously suggested the media can achieve through foregrounding issues and diverse perspectives. That Nancy focuses on 'differences' in experiences and structural concerns (here, issues with nationality) reiterates her above emphasis on recognizing the diversity of people affected by dementia and on situating people's experiences within the broader structural barriers that individuals can face. Notably, Nancy spends very little time on the image itself here, and indeed she acknowledges her associative thought process with: 'As soon as the media starts on one thing. it makes you think of other things.' This example serves as a useful reminder to analysts that it is impossible to predict the many connections that individuals will make when presented with representations of a particular topic, here dementia, due to the countless intersections with a person's experiences and beliefs.

Whereas Image 5 is a naturalistic photograph, Images 10 and 12 (Figures 3.4 and 3.5 respectively) are examples of what Forceville (2008: 465) terms a hybrid metaphor, in that at least 'two phenomena are visually represented as occupying the same space in a manner that is physically impossible', consequently creating a new meaning that is more than the entities individually. Here, people are merged with the process of disintegration and an incomplete jigsaw, both of which are clearly impossible in the literal sense. This literal impossibility consequently encourages metaphorical interpretations, such as the brain being a disintegrating object or a puzzle. While this section focuses on Nancy and Sheila's responses to Images 10 and 12, Chapter 5 examines how all participants respond to the full page of decline-oriented visual metaphors. Being monomodal visual metaphors without any explanatory text, there are ambiguities regarding what these two images mean. This is furthered by their non-specific, blank backgrounds that remove the depicted participants from real-life scenarios, a characteristic that reflects their origin as generic stock images (Machin and van Leeuwen, 2007). Much is left, therefore, to the subjective interpretations of viewers.

As Figure 3.6 shows, Sheila and Nancy both identify the direction of movement of the fragments in Image 10 as going 'away' from the man. They also both map their own experiences onto the image, reinforcing the ability of metaphors to resonate with and help communicate personal and intangible psychological, physical and emotional experiences (Castaño, 2020; Semino, 2008). For Sheila, this image initially resonates not with her Alzheimer's disease but with her spinal problem, specifically the movement of 'pain' through her body: 'up' her spine to her head where it 'goes out, there, and then it comes up again'. This cyclical flowing of pain has a clear locus (her lower spine) and direction ('up' and 'out'), which situates the head fragments as Sheila's spine-related pain and as nothing to do with her thoughts, intellect and memories, which are more

Figure 3.4 A man with a fragmenting head (Image 10) (iStock.com/Siphotography).

Figure 3.5 A woman with a missing jigsaw piece (Image 12) (Andrew Bret Wallis/The Image Bank via Getty Images).

Sheila	I equated with that [10], funnily enough, not out of dementia, or Alzheimer's, but I have a spinal problem that causes me a lot of pain and it goes up my spine, and it comes out of my head and it goes out, there,
Emma	Oh wow
Sheila	And then it comes up again, and goes out, and [laughs] that made me think of that. […] Erm. [6.3] Because I put that to pain-related, erm, I suppose it's really saying, the man's got his hands on his forehead and, wishing it all away [laughs].
Emma	Mm.
Sheila	[3.5] (Or) saying "I can't bear it anymore", or "I know what's happening go away." Because, you do know what's happening.
Emma	Yeah
Sheila	As it's gradual. And er, you're aware that, certain things you can't cope with.
Nancy	This, number 10 is so, erm. It's like an advert, for dementia, where. the guy's looking a bit perplexed, and everything's just flying away from him. and, I think, that happens to me quite often. It happened to me on a street corner erm, last year. And I do remember it, in that, erm, I stood on the street corner and I didn't know which way to go. And it was only about fifteen twenty yards away from my home. But I couldn't, organize my thoughts enough, and there was nobody around to say "are you alright?" [1.5]
Emma	What happened?
Nancy	I just stood still. And then I looked round and then I spotted somewhere that I recognized.
Emma	That's good
Nancy	I took a [breathes in] big deep breath [laughs]. And 12 is so amazing I'd say those two represent dementia for me so much.

Figure 3.6 Sheila and Nancy's responses to Image 10.

usually associated with the head (Harvey and Brookes, 2019). The difficulty of expressing pain is widely documented, due to its intensely personal, intangible and contextual nature and a widespread inability to find the right words (Biro, 2010). As such, visual metaphors are a powerful resource for helping to visualize the invisible experience of pain (Padfield et al., 2018).

Sheila revises her initial pain-oriented response to match the session's dementia context, suggesting that what 'it's really saying' is that the man is cognisant of 'what's happening', for which she hypothesizes three reactions: that he 'can't bear it anymore', is 'wishing it all away' or is saying 'go away'. Although Sheila distinguishes this from being 'pain-related', it could be argued that here she shifts from physical symptoms of pain for the spinal problem to psychological ones for dementia, such as despair and anger (Biro, 2010: 12). Indeed, noting the man's hand on his forehead, Sheila foregrounds the emotional experience that accompanies being 'aware' that you are changing when you have 'gradual' dementia. The fragments become, as with Sheila's pain, an aspect of yourself that you wish to lose; for instance, with knowledge comes despair and the wish for the unwelcome dementia to leave the body and 'go away'. Although implicit, assuming that the dementia is the intended recipient, Sheila's directive to 'go away' personifies the condition as an unwelcome, animate entity, therefore connecting this visual metaphor to the desire to remove an unwelcome intruder, itself a common metaphor used to describe dementia (Castaño, 2020; van Gorp and Vercruysse, 2012). Her emphasis on suffering with dementia, including due to an awareness that you cannot 'cope' with certain things and are gradually changing, notably mirrors her earlier discussion of suffering and her future fears for herself.

In contrast, Nancy positions Image 10 as a visual metaphor for a different intangible experience, namely being unable to organize your thoughts, which Nancy experiences 'quite often'. Indeed, she utilizes her own metaphor, that 'everything's just flying away from him' to express this common cognitive change with dementia (Górska, Forsyth and Maciver, 2018). Again, Nancy maps her personal experience onto the image, exemplifying this by telling me of a moment last year when, alone and nearby her home, she did not 'know which way to go'. This is presented as a short-term obstacle for Nancy, since after staying 'still' and looking around, she 'spotted somewhere that I recognized', took a 'big deep breath' and continued on. As such, the fragments 'flying away' in Image 10 are not positioned as a permanent loss but as a temporary cognitive experience associated with her dementia.

It is interesting that while both interviewees relate their own experiences to the man in Image 10 and therefore, to an extent, identify with the represented participant, they both approach the woman in Image 12 as observers viewing someone else with dementia (see Figure 3.7). Sheila focuses on 'physical signs' that 'you can see' (namely becoming 'more vacant'), which positions her as an external onlooker rather than the person experiencing dementia. This socially distances Sheila from the represented woman, which notably contrasts her consideration of internal emotional experiences for the men in Images 5 and 10. Similar to Image 5, Sheila uses the woman's eyes to point to the external 'physical signs' of internal processes (here brain 'tangles' getting worse and the person becoming 'more vacant'). Likewise, Nancy explicitly relates the woman to other people with dementia and positions herself as an observer ('you see so many people with that'), interpreting the woman as looking 'lost', with 'the piece of the puzzle […] missing'.

Sheila	The lady with the piece of jigsaw [12] is, you can see, this look that, as you're getting worse, comes over your eyes and things you can become more vacant. And so the er. as the pieces of the tangles get, get worse, it, you get physical signs. At first nobody knows, and then it becomes obvious, gradually.
Nancy	[…] 12 is so amazing I'd say those two represent dementia for me so much.
Emma	Ok, 10 and 12
Nancy	In that, you know that the piece of the puzzle is missing [1.9] and wow, yes and she looks, sort of lost, and that's, you see so many people with that.
Emma	Yeah
Nancy	And when you go, I went to sing with a choir in the care home [1.8] and there was one lady that looked like that, and as soon as we started singing, her face lit up, and she started singing with us
Emma	Mmm, okay
Nancy	But until then she was in the care home sat in an armchair and it was the typical picture of a care home resident.
Emma	Mm. Yeah
Nancy	Just, sat there. no stimulation and I think stimulation is so, important in those care homes.
Emma	Definitely
Nancy	And it's taking a long time for the activities people to realize, or management, for people to realize.

Figure 3.7 Sheila and Nancy's responses to Image 12.

A closer analysis of the two images may help to explain why both women align themselves with one metaphorical representation and not the other. Regarding Image 12, multimodal critical discourse analysts Harvey and Brookes (2019) argue that this visual metaphor positions the woman as having been eroded (i.e. note the gaping hole in her head) and even as zombie-like through her vacant expression and the muted colour palette. They warn that although evocative, such a depiction potentially encourages fear and revulsion in viewers rather than empathy and compassion. Neither person in these images makes eye contact with viewers, which arguably situates them as "offer" images of what dementia could look like, rather than demanding any social engagement with viewers through eye contact (Kress and van Leeuwen, 2021). However, with his finger pointing to his head, the man looks busy in thought (or at least in trying to gather his thoughts); while sitting still and staring off-camera, the woman looks, as Sheila and the researchers (Harvey and Brookes 2019) note, 'vacant'. Perhaps these differences explain why Nancy and Sheila identify with the more active participant and distance themselves from the woman; despite Nancy evaluating Image 12 as an 'amazing' representation of dementia, the representation is for other people with dementia, not her.

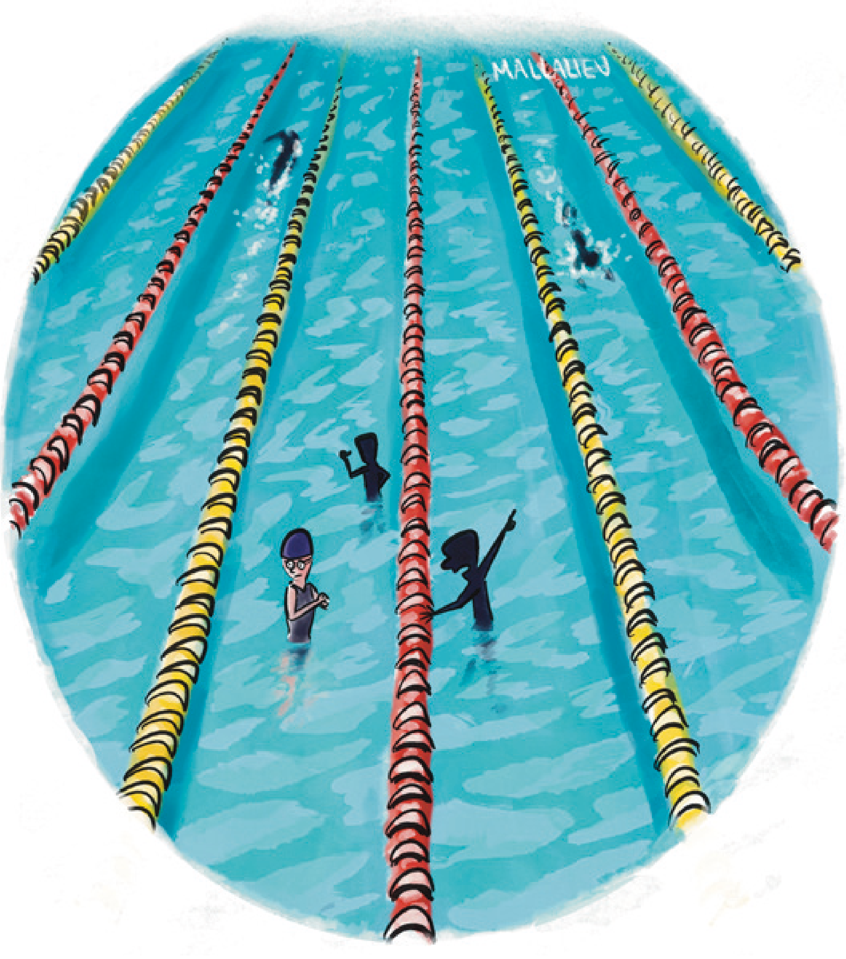
Again, Nancy associates a personal story with the image, recalling a specific person she met as looking like the lady in Image 12. Notably, this is not someone close but simply 'one lady' that she sees when going with her choir to sing in a care home. Unnamed and unknown on a personal level to Nancy, she is situated as 'the typical picture of a care home resident', sitting 'in an armchair' with 'no stimulation'. Yet, Nancy states that 'as soon as we started singing, her face lit up, and she started singing with us'. Two aspects of Nancy's account are key here. The first is that the lady's state is not depicted as permanent, since upon the choir singing, her face lights up (with the brightening metaphor connoting increasing happiness and engagement), and the lady herself bridges the initial separation by joining Nancy's 'us' group through singing with them. Secondly, rather than attributing the lady's initial disengaged state to her dementia, Nancy foregrounds the role of the external environment, claiming that people such as the lady need 'stimulation' and that the 'management' need to realize this. For Nancy, the woman that she associates with Image 12 is not herself a zombie – instead, her treatment and social positioning situate her as such (Latimer, 2018). Nancy concludes her narrative by advocating for broader social change in 'those care homes', again aligning with her overall structural, rights-based discourse by targeting environmental barriers to meaningful connections and well-being.

The above examples are powerful illustrations of the subjectivity of our interpretations. Of course, these responses occurred in a specific environment, and if presented with accompanying text or a different arrangement of images, Sheila and Nancy may have responded very differently. Here, despite interpreting the same three images representing people with dementia, Sheila tends to foreground emotional and physical aspects of dementia, particularly attending to the concept of suffering and coping alongside how individuals change with dementia. In contrast, although Nancy's recounting of her confusing episode provides a more personal insight into her own experience of living with dementia, she continues her structural rights-based discourse overall. This includes emphasizing her personal growth through increasing awareness of diverse life experiences and promoting the right of people with dementia to an empowering rather than disabling (here, unstimulating) environment. Sheila and Nancy's examples reiterate that responses to images are personal; we may agree on what the image literally shows (for example, the fragments moving away from the man in Image 10), but the connotations that we draw are heavily influenced by our subjective experiences and discourses (Barthes, 1977).

3.5 Summary

This chapter provides an in-depth consideration of how two interviewees represent their distinct experiences and stances towards dementia. Close analysis demonstrates the complexity of representations, with both women engaging with and sometimes resisting a range of discourses. Nonetheless, each participant clearly has their own signature stances, with Sheila drawing on 'familism', embodiment and Christian principles, prioritizing her relationships with close others and God to present a self-identity grounded in relationships and caring for others. Throughout the interview, Sheila discusses 'coping', yet a discourse of suffering also seems to particularly resonate with her, and Sheila positions it as a useful means of communicating her experience of the loss that dementia entails, both as a carer and a person with dementia. In contrast, Nancy presents herself as an active citizen, advocating for the rights of people with dementia, which includes recognizing the diverse range of people affected, addressing a range of attitudinal, structural and financial barriers and working with the media to achieve this on a mass scale.

Comparing how the two women interpret and position themselves in relation to three different visual representations of people with dementia further corroborates the influence of viewers' personal preconceptions and history on interpretations (e.g. Breeze, 2011; Gamson and Modigliani, 1989; Kitzinger, 1993). The rich complexity of the responses provided here showcases the potential of complementing existing academic-led analysis with the perspectives of non-academics with different expertise (here, lived experience) to provide a more comprehensive picture of how people differently engage with representations. Expanding this focus, the succeeding analysis chapters consider the contributions of all participants, comparing how different individuals and groups reproduce, resist and revise dementia discourses, both in general conversation and when responding to visual and linguistic stimuli. This begins by considering in greater detail what Nancy highlights in this chapter: the often-unrecognized diversity that the terms 'people with dementia' and 'dementia' entail.



There was I in the lane that was specially for the Alzheimer's and […] she said erm, "well, I'm sorry, but you can't go there. That's for the dementia group". And I said, "how do you tell?"

—Participant H

Figure 4.1 'The dementia group' illustration (Josh Mallalieu, artist).

4

The 'diverse face of dementia'

4.1 Introduction

> *I think, that if someone was to ask me, can you explain it? No I can't. And I don't think there's anybody else on the planet that can at the moment […] But if you get different pers- […] read someone else's perception, of what it means to them, and then the next person, and then the next person. And you will then get a, a knowledge, of, what it's like to have dementia, and you're getting it from, all sorts of, things. (Participant K)*

The above declaration was made by a gentleman with Alzheimer's disease, hereafter referred to as PK, while I and five others sat around a table in a quiet university room, snacking on flapjacks and discussing exactly how you might try to explain dementia to someone who did not know what it was. It followed two other participants arguing over whether forgetfulness was entirely in the domain of dementia when even 'the youngsters like Emma [the researcher]' could forget things (PM), alongside PK's playful future book promotion, for which he promised I could find the answers to my questions in the book he was currently writing about his experiences.

I begin with this moment because it speaks so well to this book's aim to expand 'knowledge' of dementia through bringing together multiple voices to debate current representations in relation to people's different experiences and 'perception[s]'. Complementing the close focus of Chapter 3 on how two participants' personal life histories and discourses interacted with their responses to media representations, in this and succeeding analysis chapters, all participants' contributions are brought into dialogue with one another. Here, I examine how participants differently explain dementia and explore the diversity that the umbrella term incorporates. This diversity is set against participants' accounts of more homogenizing popular portrayals that perpetuate misunderstandings of dementia.

4.2 What can dementia mean?

Considering the number of books, articles and other sources of information that open by defining dementia, it seems fitting to begin this analysis chapter with my participants' explanations of and associations with dementia. In other words, I explore what people who have experience of dementia select to say when asked variations of these two questions: What do you associate with dementia, and how would you explain it to others? Upon asking care workers a similar question, Heap and Wolverson (2020: 2025) found that dementia was explained as an 'illness', 'awful' and like seeing a person 'disappear', with care workers generally reproducing medical discourses of loss, non-communication and lack of personhood (which largely reflect the 'tragedy' discourse discussed in Chapter 1). Although participants affected by dementia in this study do draw on these discourses, the accounts they provide are notably more varied, and both reproduce and counter dominant discourses.

In line with other studies, many participants initially focus on changes with dementia and frame these as losses (Beard, 2016). Memory, specifically a 'bad memory' (PJ) since it 'isn't functioning as it used to' (P12), emerges as a key feature of dementia across interviewees, reflecting the broader emphasis upon memory loss as characterizing dementia. Participants emphasize experiencing 'short-term memory problems' (P6), whereby people remember 'things from way past' (P13) but are 'forgetting what you've just been told, forgetting where you put your coat forgetting. where the bathroom is' (P14). Dementia may also affect language use, with some people returning to using their first language(s) rather than more recently learned ones, which is positioned as particularly affecting immigrants in the UK who learnt English in later life (P25, PK). Short-term memory problems are clearly situated in people's everyday experiences, something that P33, who cared for his wife when she had young-onset dementia, expands on: 'Memory is not, as somebody quoted to me "he keeps forgetting my address", it's not that. It's how to live your life. And I had to learn all that.' Here, P33 critiques the popular oversimplification of memory as factual recall (Basting, 2009), positioning dementia-related memory problems as a way of learning about memory's more expansive nature.

Relatedly, the working-age dementia support group offer an expansive list of changes with dementia experienced within everyday life:

PQ Yeah it affects everything, it affects the memory, it affects-
P30 -it's knowing how to eat, how to hold their knife and fork they lose that, the toilet, it's just everything it's not just memory, #you know#
P28 #Temperament#
P30 Yeah
P28 Walking
P30 Yeah, walking.
P28 Even finding a chair to sit in yeah
P30 Getting in and out of car yeah

Dementia is thus presented through its behavioural manifestations within daily activities, to show that it can affect 'everything'. Echoing the critiques of scholars (Lock, 2013; Whitehouse and George, 2008), numerous participants explicitly challenge the conflation of dementia with memory. Notably, P12, whose husband, PD, had been more recently diagnosed with dementia, explicitly revises her initial phrasing to shift the emphasis from changes to 'memory' to the 'brain' more broadly:

P12 I think when I said that your memory isn't working, as well as it used to do I think I should change that to you know your brain isn't working, #as well as it used to be?#
P13 #That's it, yeah#
PE #Mm mm#
P12 Because it's not just memory. It's everything. I think, you know, and everyone's different, every time

Accordingly, P12 replaces her reproduction of the 'crude formula' that 'dementia = memory loss' (Brookes, Putland and Harvey, 2021: 254), with a more holistic approach ('It's everything') and a focus on different experiences according to the individual ('everyone's different, every time'). This expansion reflects the iterative nature of expressing what dementia means and indicates that people 'learn' about its impacts through experience (P33).

For many people, discussions move to not only behavioural but also personality changes. One couple suggest:

P14 it's not just that [forgetting] it's been a huge change I've found in PG's personality he's become withdrawn. He wasn't like that at all. He was very outgoing. He was a sergeant major in the army very,

very outgoing, yeah. Now he's. Totally different. It's like living with a different person.
[…]
PG No I. Er. What my wife says is, real. (Damn.) See my ay I've gone again now.

An alternative to the loss of self-discourse is a transformation of self, whereby individuals feel as if they have become an entirely different person with dementia (or at least a fundamentally different version of themselves; Castaño, 2020, 2023). Here, PG reinforces his wife's description of him as 'a different person', comparing himself as he is now to his previous, more 'outgoing' personality, which is exemplified by his role as a sergeant major. The discussion of PG's changed personality and social persona aligns with Sabat's (2002, 2018) theorized second and third selves. Since these selves pertain to attributes and attitudes towards these (e.g. being outgoing versus withdrawn) and to social personae that need the cooperation of others to continue (e.g. as a sergeant major), both aspects of self are particularly vulnerable to change with dementia (see Chapter 1). The couple's interaction reflects that impression management is often shared between couples, with carers notably becoming more influential in their public-facing representations of their partner as dementia progresses (Fletcher, 2020a). Here, PG struggles to, as other people note, 'communicate' 'the right words' (PL, PK). He reacts with 'I've gone again now'. Although a common phrase, PG's exclamation reflects the cultural privileging of linguistic communication as a means of self-expression, since it suggests that PG can indeed 'go' anywhere when he loses his words but is still physically present and engaging with us in the room. As explored in this chapter (Section 4.4) and Chapter 3, embodied forms of expression become increasingly important when living with a condition that makes verbal communication more difficult, and recognizing this can help to challenge the conflation of self-expression with verbosity.

The overall narrative of loss and negative changes is resisted by some participants. Demonstrating the value of humour as a tool of resistance (Beard, 2016), one couple uses humour within a Memory Café group to challenge the assumption that dementia entails only negative behaviour and personality changes:

PC I've cheered up [laughing] since having the dementia [laughs]
Emma [laughing] you've cheered up you said?
P5 Mm. Yeah you used to be a miserable old. curmudgeon [PC laughs] he's quite, he's quite chirpy now
[group laughter]

Much of the humour here appears to come from challenging the assumption that dementia necessarily entails a degradation in behaviour and overall happiness. The couple explicitly situate themselves as a contrast to this, which encourages group laughter (as well as the idea that PC used to be anything other than the good-humoured wit he is known as). Elsewhere, when explaining dementia, P18 highlights that his grandmother 'had pretty severe dementia by the end, but then like she's always cracking jokes. She's happy […] in some instances, you do get the, the sort of joyful bliss, even though they don't remember things'. Returning to the above accounts of memory, here, not remembering can be accompanied by 'bliss' rather than suffering. Alongside emphasizing that his grandmother's humour continues as her dementia progresses, P18 argues that in his experience, dementia is 'gradual', so you can 'forget it's happening'. This highlights that your lives do not always revolve around dementia when you or a loved one develop it, challenging the trend to regard dementia 'as if diagnosis is akin to falling off a cliff' by acknowledging that you can have symptom-free seconds, minutes, hours or days (Basting, 2009: 156). P18's use of 'forget' in a more general sense also serves as a reminder that, as numerous participants explicitly touch upon, forgetfulness is certainly not constrained to people living with dementia.

Moving beyond externally obvious changes, some individuals highlight that 'it's hard to describe what it's like', especially to those without experience of dementia (P28). When unable to fully express a personal, complex and intangible condition, many people turn to metaphorical language to express dementia (Biro, 2010). PH, a retired teacher with young-onset dementia, offers an insight into some of the ways that dementia is 'a right bugger' for him personally: 'Well, it's er, stops me doing a lot of things. That I would like to do. Erm. so, simple things like can't drive now […] I can't do DIY, in the way that I, used to, a lot […] Mr Alzheimer's have got a, a lot to answer for.' By personifying his dementia as 'Mr Alzheimer's', PH positions the condition as an agentive individual with the power to stop him from undertaking everyday tasks that he considers 'simple', such as driving. Mr Alzheimer's is depicted as an antagonist here, reflecting the 'unwanted companion' metaphorical trope used by other people with dementia, including Kate Swaffer (2016), who gives 'Mr Dementia' the name 'Larry'. Elsewhere, 'Mr Dementia' is shortened to 'Mr D' (Castaño, 2023: 113). Through PH's pronoun use ('it' versus 'I') and his metaphorical positioning of dementia as another person ('Mr Alzheimer's'), dementia is separated from PH and his body in a way that contrasts many of the other participants' grounding of dementia *in* their minds and bodies. Notably, PS summarizes the experience as 'a gradual confusion of your mind', while PN envisions her dementia as situated firmly within her brain cells (‘the clogging up of the neurones er the, you know the cells that, that is why we, the Alzheimer’s, disease develops’). Here, the concept of ‘clogging’ metaphorically presents the body as a machine that can get increasingly impacted by blockages, which arguably simplifies the biochemical processes to more relatable and concrete events for lay audiences (Bailey, 2019). In line with other people with dementia, here, PN adapts a biomedical discourse to suit her personal understanding (Beard, 2016; Fletcher, 2020b). Meanwhile, PH and PS provide alternate representations to a biomedical one, respectively attributing dementia agency as a separate (if interfering) entity and focusing on the *experience* of dementia, namely, increasing confusion (located in the mind).

In another group, P19, who was previously employed as a care worker for a range of people with dementia, both in the community and care homes, foregrounds the need for a pluralistic depiction that balances positives and negatives. This aligns with the recent turn in scholarship and provides a more holistic counterpoint to the loss-oriented responses of care workers found elsewhere (Heap and Wolverson, 2020). P19 tells me:

> I would want to put across the idea of, sort of a pluralism, like, there are <u>dementias</u>, and probably, sort of think different instances, so rather than going “dementia is this”, not only are there different types of dementia but within that, you know it’s a constant sort of like a tree. You know, it’s going it keeps splitting off and splitting off into something else so within the different types of dementia there are different instances of how it, manifests, itself and er, that sort of thing. And also, there’s obviously, the sad side to it, and at the same time, you know, there can be moments of, great humour, […] I think to try and, allow it to be, erm, sort of this multi-headed thing

Here, P19 advocates for using the plural term ‘dementias’ to acknowledge the ‘pluralism’ of dementia(s), both regarding types and individuals’ experiences, including ‘sad’ moments and times of ‘great humour’. Dementia’s complexity and conceptual slipperiness (Zeilig, 2014a) is reflected in P19’s harnessing of multiple metaphors; dementia is envisaged as ‘this multi-headed thing’ that ‘manifests itself’ differently, being ‘like a tree’ in that it keeps branching off into an increasingly complex and diverse entity as opposed to being just ‘one thing’. While positioning dementia as a ‘multi-headed thing’ could potentially have monstrous connotations, it does not seem to be the case here; indeed, P19’s dominant metaphor is that of a tree branching off, which instead situates dementia within a symbol of life and growth. This appears to be a more idiosyncratic use of the tree metaphor to conceptualize dementia itself as a diverse range of conditions. More often, when trees are metaphorically used, it is to communicate the progression of dementia, notably through the seasonal loss of leaves (Zimmermann, 2017, explored further in Chapter 5). In P19's context, it is instead the plurality and multidirectionality within dementia that is expressed through its association with a living entity with multiple branches or heads.

In the PhD student focus group, the members explicitly establish three key focuses when explaining dementia, namely biomedical, positive and negative:

P17 I guess you could go the route of explaining exactly what it, is in general terms, it's you know parts of the brain shutting down and things like that and so people? [Sighs] It's hard because like you say like it's so different for different people as to what happens. Erm.

P18 And I guess like it's, when you explain it do you put a positive spin on it, do you put a negative spin on it or do you just do this sort of #scientific objective answer?#

P17 #Yeah. Just like this is what it is.#

P18 Honestly, you could probably give all three. Here's what, here's what science says. Here's the, you know, worst case scenarios that I've experienced and here's, the best case scenarios I've experienced kind of thing and then, you give them a sort of broad idea of what it entails

Here, a scientific explanation is presented as 'objective' and 'general', since it provides a neurobiological account of dementia (although note again the body as a machine metaphor in '<u>parts</u> of the brain <u>shutting</u> down', which exemplifies how understandings of scientific concepts are influenced by social discourses). This impersonal biomedical 'route of explaining' comes first to the participants, before they expand to consider using their worst and best scenarios from their own experience to help give a 'broad idea of what it entails' on a day-to-day basis, introducing another type of expert voice, this time, experience-led (see Chapter 6). These accounts are associated with 'spin', acknowledging the tendency for any discourse to 'spin' dementia a particular way through the details that are picked out, here dichotomized as 'positive' and 'negative', which is comparable to the 'tragedy' and 'living well' dichotomy critiqued by McParland and colleagues (2017).

Already apparent, then, is that despite some patterns of agreement, there are a multitude of ways to represent dementia, even among a comparatively small group of people. Diversity is a prominent theme across participants; as PC later declares, when portraying dementia, ‘it’s got to be a personal thing, everybody’s dementia’s different like everybody’s fingerprint is different’. This contradicts the widespread homogenization of people with dementia, who are too often ‘all put in the same bag, as if we were all the same’ (Perel-Levin, 2019: 90). The issue of diversity thus warrants greater consideration.

4.3 The diversity of people with dementia

Arguably the most unanimous discourse to materialize across the focus groups and interviews is the individual variance within the label ‘dementia’ – what P17 refers to as ‘the diverse face of dementia’. As PH reflects, ‘there’s lots of difference, we come in all different shapes, sizes and, and all that. And, so. people are going to be different. There’s going to be a lot – there’s not, necessarily, a one track, for something like this’. Consistently, participants raise that despite stereotypes there is no typical person with dementia. Instead, ‘it’s a lottery’ (PH) and ‘it happens to everybody’ (P6), irrespective of status, age and other personal features.

Having said this, as Sheila indicates in Chapter 3 when discussing their shock at her husband’s diagnosis, a person’s social location can greatly impact the reception of a dementia diagnosis. P6, who previously worked as a paid carer, explores this most explicitly when she reflects on the association between influence, attributed intelligence and dementia, stating that ‘it seems somehow more shocking’ that her ‘locally respected’ headteacher, previously so influential, is now ‘unable to do anything for himself’. P6 compares this headteacher to a woman that she used to work with when she was a care worker, who could not read and write:

> She used to say “well I’ve never been very bright anyway!” [laughs] […] I actually think, I think she had dyslexia I think that’s what it was because I mean she was very good at playing cards and I think that, you know, she always thought of herself as not being very bright because she couldn’t read and write you see […] and so when she got dementia she was just like “ah well, more of the same” [laughs].

Two things are particularly striking here. First is the link that the woman in P6’s narrative makes between her low literacy levels and her intelligence, despite P6 noting other forms of intelligence (namely, her card-playing skills). This likely reflects the lower status afforded to illiterate individuals in a hypercognitive society that overly values certain forms of intelligence above others (Post, 2000a), which leads to the second point of interest, that the idea of not being 'very bright' is used to joke that having dementia therefore won't make much difference to her. Here, then, it would seem that a hierarchy is created in which dementia affects people more if they have greater pride in their cognitive abilities and written communication, and it is suggested that for someone accustomed to living life without such abilities being perceived as central to her identity, having dementia brings less of a change. Underlying these accounts is the discourse that people with dementia are socially inferior, including in intelligence and social standing, and that dementia is primarily a matter of intellectual decline rather than the behavioural and emotional changes noted by other participants above. Combined, these accounts align with Hulko's (2009) observation that more socially privileged individuals appear to encounter greater 'shock' upon being given the stigmatized label of dementia than people who are already more marginalized – for instance by class, ethnicity and gender.

Two more frequently discussed points of contrast between participants' experiences and public perceptions of dementia are being younger and/or having a type of dementia other than Alzheimer's. Since 'dementia doesn't always show' (PC; see Chapter 6 for more), numerous participants depict their experience of existing outside of the cultural stereotype of someone with dementia as a point of tension between their 'reality' and the social 'preconception' of what dementia means (P20). Oftentimes, participants' own place of understanding is positioned as being due to their personal experience, which has enabled them to move beyond the popular social narratives that generally conflate dementia with Alzheimer's disease and older age (Low and Purwaningrum, 2020). Such discourses are embedded in British social structures, including in national organizations such as Alzheimer's Society, which positions itself as the UK's leading dementia charity while being named after only the most common type, and in commissioned reports, including one on the cost of dementia care that only incorporates people with dementia aged sixty-five and over in its figures (Wittenberg et al., 2019).

Participants consistently emphasize the need to stress the range of conditions within the term 'dementia', lamenting that 'people just don't understand all the different types' and that too often the many types of dementia are simply 'put under an Alzheimer's umbrella' (P30). The personal impact of using dementia synonymously with Alzheimer's disease is elaborated on by P6, whose mother had vascular dementia:

> A lot of people […] have got something different so as soon as you say she's got dementia or he's got dementia and then it's like they automatically think

> they've got Alzheimer's and actually, they're wrong and they're thinking it's going to follow the progress of Alzheimer's and of course with my mum it was like steps, because it was only when she had a stroke and then she'd go down, you know. And I didn't know that and I was her daughter […] I think there's misunderstandings, at the moment.

Here, P6 shifts between the present state of unknowing for others ('they're wrong', 'there's misunderstandings') and her own progression, where she moves from also not knowing about alternative types of dementia, including her mother's ('I didn't know that and I was her daughter'), to her current more enlightened position reached through experience. Notably, she compares her mother's progression to 'steps' that she descends following a stroke. This provides an alternative, more fragmented representation of progression to the linear decline often associated with Alzheimer's (Wilkosz et al., 2010), opening up other ways of visualizing dementia pathways (here, stairways).

Participants with experience of young-onset dementia similarly present a process of realization that dementia is not constrained to older members of society. P28 reports that 'we were doing the same I guess before we got, involved in it. If you were watching the news and that you just assume that dementia's an old person's […] it's only when you get involved in it that you realize that [laughs] it's not'. Here, P28 attributes her realization to personal experience interacting with younger people with dementia. It is 'being involved' in this aspect that allows her to see the nuance within dementia that is often missing in popular social narratives that conflate dementia with older age. Similarly, P19, who was employed as a care worker for a sixty-two-year-old man with dementia, considers the implications of such a realization: 'We associate it with being elderly. So then you take that away suddenly, what does dementia actually look like? And that sort of took some getting used to.' Here, P19 interrogates his previously held assumptions of who a person with dementia is (in this case, 'elderly') when life experiences challenge this social stereotypes. Without such stereotypes, the question of what dementia looks like becomes much more complex and, as P19 suggests, can be difficult to adjust to.

A story by sixty-one-year-old PH exemplifies both the personal impact of preconceptions for what a person with dementia looks like and the educational role that many people with experience subsequently take on in social scenarios where their presence challenges associations of dementia with older age. PH recalls:

> **PH** I go to [a local area] on a, on, once a week, and er, there's a swimming pool, to go swimming. And it's actually there's a, lane,

set out for us. So that's for the dementia group, coz we did go there and we sort of have a, coffee and biscuits and all the other stuff you know. Erm. And, erm ah I'm losing the plot

P20 Someone told you to get out didn't they

PH Sorry?

P20 Someone told you that you're in the wrong place.

PH Oh yeah that was it. Erm. Yes, er, there was I in the lane that was specially for the Alzheimer's and they said erm, "I'm sorry", one of these you know little,

P20 Enough about that!

PH [Laughs] she'd not been there for long, but she said erm, "well, I'm sorry, but you can't go there. That's for the dementia group". And I said, "how do you tell?" coz she said you know you need to go to the other side and I said "how do you tell?" [Laughs]

[…]

P20 But it shows doesn't it-

PH -You can't tell-

P20 -that people have the preconception

PH Yeah

P20 And you understand that the preconception is not reality.

PH Yeah. Course I do [2.9] Yeah, so, that's a good way of putting it.

In a collaborative account with his son, PH positions himself as a challenge to preconceptions, asking the staff member who assumes he does not have dementia, 'how can you tell?' Yet, upon being diagnosed, PH remembers thinking 'I shouldn't have that, it's sort of for er, my Dad, instead', reproducing the widespread assumption that dementia is for older generations. Consistently, participants' place of knowledge regarding the diversity of people with dementia is attributed, whether explicitly or implicitly, to their less conventional personal experience of dementia. PH extends his argument that 'you can't tell' to his judgements of other people too, since when discussing the images I show him, he emphasizes that all of the individuals depicted are 'just normal people' and asks – concerned that I am asking him to evaluate whether they have dementia – 'how do I know?'

Throughout, the participants highlight the need to acknowledge the heterogeneity of people with dementia, consistently drawing on personal experience to do so. It is notable that here participants foreground age, types of dementia and education/social status in their depictions of diversity, implicitly backgrounding other important aspects of a person's experience, including gender, sexuality, race and ethnicity (Hulko, 2009). Continuing the discussion surrounding age, I now turn to two images that became particularly pertinent to the discourses explored in this section, that of individuals' hands.

4.4 Visual case study: Hands and dementia

A discussion of age in relation to dementia quickly materializes across groups in response to the two stock images of hands reproduced in Figures 4.2 and 4.3. Participants consistently critique the link between older age and dementia, but beyond this, interpretations diverge much more broadly, both between images and participants, exemplifying how image-specific semiotic resources (such as proximity, angle and colour) can intersect with viewers' personal experiences and worldviews. Indeed, in a dementia context, close-up images of hands have been both critiqued by researchers for being reductive and dehumanizing (Brookes et al., 2018; Harvey and Brookes, 2019) and praised by charity representatives for signalling comfort and support (Ang, Yeo and Koran, 2023). Overall, the images in Figures 4.2 and 4.3 raise more questions than they answer. Who do the hands belong to? What are they doing? What is the emotional tone of each picture? The responses throughout this section demonstrate that for these two photos there are many potential answers.

Figure 4.2 Holding hands (Image 7) (Sebastien Bozon/AFP via Getty Images).

Figure 4.3 Clasped hands (Image 8) (iStock.com/Handsome Bob).

Participants with and without experience of young-onset dementia alike critique the conflation of dementia with older age that is established through these stock images of older people's hands in the context of dementia. While acknowledging that the 'statistics are that people with dementia are more elderly', participants argue that by 'enforcing' that dementia is confined to 'the elderly', such images misrepresent what is actually a more complex and 'mixed pattern' of people with dementia (P8). The process of interpreting such age-related images is presented in greater detail in the following focus group:

PK I looked at those, and my first impression would be, if I'd not, thingymabobs. Dementia, is, age related. It isn't. You look at the hands and say well, you know when you get to the stage where your hands are like that you're probably in your eighties, you're likely to have dementia. But you could be in your forties

PL #Mmm#

PM #Mmm#

PK #So, this is where your study what you're doing# with the media,

PM #because that's it yeah, this is just saying it's for elderly, very elderly#

PK they are, although they might be working or moving in the right direction, they ain't moving fast enough, and they are, still,

> projecting to the public with pictures like these, which are open to too much misinterpretation.

Here, the hands are identified as the signifiers of the 'very elderly'. In both images, the actors' hands are the salient visual component and display the wrinkles, creases and prominent bones associated with ageing. This is noted as even more extreme for Image 8: 'These look really old to me don't they, like ancient, I've never seen anyone with hands quite like that' (P6, speaker's emphasis). Consistently, participants use intensifiers to mark these hands as 'very' or 'really' old, situating them beyond the benchmark of 'old', which is perhaps best demonstrated through P6's use of 'ancient'. What PK highlights in the above extract is that, when these images that denote the physical signs of ageing are situated in the context of dementia, they give the false 'impression' that dementia is 'age-related' and are subsequently 'open to too much misinterpretation'. The concern, then, is with the connotations or 'meaning potential' of the aged hands in a dementia context (Machin and Mayr, 2023).

Beyond the consistent age link, participants demonstrate a range of interpretative and emotional responses to the two images. Such variety is likely in part due to the decontextualized nature of these stock images, which feature anonymous individuals without stories, voices or indeed faces, which are the body part traditionally privileged as the conveyor of character and psychological insight (Archer et al., 1983; Harvey and Brookes, 2019). Participants position the hands as some of the most ambiguous of the twenty images shown ('I'm not sure what the hands, are saying really': P7; 'I don't know what to say about the hands': P14). Of the two, Image 8 is met with the most confusion ('Not quite sure what it's saying': P10). Without the more obvious cues that could be provided through showing whole bodies, the same pair of hands evokes conflicting readings of Image 8's emotional tone, ranging from 'harsh' (P6) and 'very sad' to looking 'peaceful' (P10) and showing 'contentment' (P2).

Still, overall differences in participants' interpretations of each image emerge, demonstrating how different semiotic choices in positioning, lighting and represented participants (namely showing one person versus two people interacting) can encourage divergent readings of what are fundamentally similar images of 'disembodied hands' (Brookes et al., 2018: 384). Most notably, participants show an overall preference and alignment with Image 7 (Figure 4.2) over Image 8 (Figure 4.3). P6 explains that although both images are 'harsh', Image 8 especially is 'not a nice picture' because 'it looks like the hands of someone who is er, ill, in some way' and is 'not relaxed'. Another group describes Image 8 as 'victim-y?' (P19) and 'very sad' (P18). P6 picks out the role of the camera angle in achieving this sad, victim-like reading: 'I think partly it's just the angle it's taken at [laughs]'. As Figure 4.2 shows, Image 7 is shot from a slightly lower, close and front-facing camera angle in a way that viewers could almost reach out to touch the hands of the people; it is likely this close proximity combined with the moment of physical connection that makes Image 7 'an intimate picture' for P10. In contrast, in Image 8, a higher and slightly side-on camera angle, combined with a more distanced shot, places viewers in a position of relative social distance and superiority through looking down and across at an individual's hands; thus, instead of interacting, we are invited to observe the woman featured as a 'victim' of dementia (Ledin and Machin, 2018a). Arguably, the 'subject' and 'object' distinction that is usually identified through the presence or absence of front-facing eye contact with represented participants is here partly achieved through the positioning of their hands; viewers are encouraged to see the people in Image 7 as subjects who could be interacted with as social equals, and the woman in Image 8 as an 'object' to observe and pity (Kress and van Leeuwen, 2021).

Moving beyond pitying the represented individual, three participants situate the hands in Image 8 as 'frightening' (PJ) and 'scary' for being 'the, sign of things to come' (P22). Upon closer inspection, it appears to be the focus on physical markers of age – the 'crinkly', 'thin' skin and prominent 'veins' (P23) – that evoke such fear. P22 relates the reaction to Image 8 to her own feelings towards similar age-related features on her hands, telling us that 'mine are like that […] I hide mine sometimes when they (xxx) the veins just come up'. Her revulsion towards physical signifiers of ageing, as indicated by her desire to 'hide' her 'bodily betrayals' (Featherstone and Wernick, 1995: 7) and her fear of 'things to come', signals the damaging effects of internalizing demeaning cultural discourses surrounding ageing. Popular discourses either associate ageing with irreversible mental/physical deterioration (and an associated declining social status) or promote defying ageing altogether (Laceulle and Baars, 2014), rather than respecting ageing as 'a process of learning to live a finite life' (Baars, 2017: 285). P22 is far from alone in her repulsion towards her own and others' ageing; for instance, van Wijngaarden et al. (2019) note the prevalence of profoundly negative discourses of old age (including metaphors of struggle, victimhood, breakdown and being subhuman) among a group of socially disengaged and fearful Dutch older people who wish to die rather than continue ageing.

The bright, high-contrast lighting of Image 8 relative to Image 7 contradicts the above desire to defy or 'hide' ageing, potentially helping to explain the reaction of disgust and fear in PJ, P22 and P23. The camera angles interact with the images' lighting: partly due to the softer lighting and partly the lower angle, shadows are more prominent in Image 7, obscuring much of the bottom right-hand side so that 'you can see one hand, but you can't really see the other one' (P7). In contrast, the brighter lighting of Image 8 foregrounds the physical markers of age, since every vein, joint and skin crease is clearly defined, especially for the top hand, while the higher camera angle reduces the softening impact of shadows. Such a 'harsh' focus on displaying the physical frailties of an older person's body in Image 8 over Image 7 likely encourages P6's association with being 'ill' and the fear that PJ, P22 and P23 report feeling towards it.

Consider, for a moment, what is missing from these two images due to the close-up shot of the participants' hands. No visual information is provided about the person themselves, something that P7 reflects on: 'Just seeing the hands and so close up, in a way it kind of separates it from the whole person for me actually'. Harvey and Brookes (2019) raise the same criticism of a similar hands image in the context of dementia, arguing that disembodied images diminish the 'whole person', both literally, as viewers are presented with a fragment of an individual (here their hands), and figuratively, since this fragment can be construed as the symbolic substitution for the incomplete individual. They propose that 'these participants are transformed and dehumanised to the point where, acutely excised from the frame as they are, it is impossible to personally or meaningfully relate to them' (994). The disgust and fear mentioned previously towards the represented participant in Image 8 would certainly support the figure's treatment as being more symbolic of broader issues than of a person's experience. This is also suggested by P11's reading of Image 8: 'Where there's just two hands sitting there, that just says, it kind of says old age and loneliness'. By only discussing the 'two hands' (which are ascribed the ability to be 'sitting there'), P8 removes any reference to the person that the hands belong to. Moreover, she generalizes the experience she associates with the hands to 'old age and loneliness' which, while potentially being interpreted in an individual sense, when combined with the lack of any such reference can more likely be interpreted as being positioned as a society-wide issue. Notably, not all participants adhere to this depersonalizing trend; PI and P22 instead position the figure as a relatable individual when they imagine that the woman in Image 8 is doing something that 'we all do' (P22) – namely falling asleep: 'I bet you somebody's sitting there dropping off [laughter]' (PI).

Nonetheless, that participants generally appear to identify more with Image 7 over Image 8 indicates that other features determine whether or not disembodied hands can be meaningfully related to on a personal level. The most important element in this context appears to be the social interaction indexed by two people's joined hands, which suggests greater action and agency than the inactivity of the hands passively resting in the woman's lap in Image 8. Directly countering the fragmentation and dehumanization noted by P7 and Harvey and Brookes (2019), P19 praises Image 7 for its 'very human' representation of 'hand holding'. He tells me, 'I like that. It seems. It's not too sentimental, it's quite accurate, and I think it leaves enough open to interpretation […] There's something very human about it, just sort of, fact. That's what happens.' Whereas PK previously criticized the images as too 'open' to 'misinterpretation', P19 commends the lack of context that enables individual interpretations of Image 7 (at least in these sessions, where the image is not contextualized by any accompanying text). Often, participants' interpretations and/or associations are grounded in personal experiences, suggesting an ability to meaningfully project their own lives and emotions onto these disembodied figures in Image 7. Due to the study context of representations of dementia, it is regularly assumed that one of the participants in Image 7 has dementia, and that the other is a family member or supporter/carer. However, as P10 states, 'it could be either' of the participants who have dementia. The lack of specificity enables a range of imagined identities for the participants, as exemplified by the following interaction among the working-age dementia focus group:

P28 -it could be a husband and wife, husband and wife holding hands-
P30 -or could be daughter-
P28 -growing old together, it's nice-
P32 -It's old isn't it together-
P30 -but that looks like a young hand so could be daughter and mother couldn't it really, do you think?
[…]
P30 And in actual fact you've got parents, supporting their own children with dementia.

Here, the participants are always imagined as having a close familial relationship, primarily as spouses, or parents and children. As spouses, the idea of 'growing old together' is positioned as 'nice' rather than fear-inducing, but due to a lack of wrinkles, the other hand is interpreted as 'young', and as such, P30 advocates for his parent–child relationship reading. By claiming that either the parent or child could be the person with dementia, P30 presents an interpretation of Image 7 that can challenge as well as enforce the conflation of dementia with older age.

Broadly, the interaction of the hands is interpreted as being one of ‘support’ (P8), ‘nurturing’ (P7), ‘reassuring’ (P16) and ‘comfort/comforting’ (P5, P22, P23). Such interpretations align with those of the four charity representatives that Ang and colleagues (2023: 637) consult, who regard holding/touching hands as ‘comforting and reassuring, signifying the presence of support’. For P22, while the hands in Image 8 are ‘scary’, the ones in Image 7 are ‘comfy and friendly’. An overall sense of supportive interactions is thus established, and many participants relate the hands’ actions to their own relationships. For PI, this image encourages a reflection on her own relationship with her daughter-in-law, P21:

PI I often get that don’t I [laughs]
P21 [laughter] You do
PI She’s my carer [laughs] aren’t you P21 [laughs]
PJ Nice to-
PI -oh we have fun though don’t we P21.

Here, PI brings her sense of ‘fun’ and laughter with her carer to the interaction, offering a valuable reminder that the moment of ‘hand holding’ may be a regular, cheerful reminder of love and sharing of joy as much as it could be an attempt to soothe.

Touch is frequently foregrounded by participants as ‘a way of making that kind of contact’ and ‘communication’ with people with dementia (P10). Similar to Sheila’s emphasis in Chapter 3 on embodied ways of being with each other and in the world, P11 feels that ‘the tactile aspect is important’, while P33 emphasizes that interactions are grounded not in words but in a shared space and mutual engagement:

> Communication, communication. You don’t, need, to talk, to person with dementia. Hold their hand. Talk to them, face to face. Gobbledegook. I speak gobbledegook. If that person is talking “blergh blergh blergh is erm in” I’ll repeat it back to them because they know what it means. I don’t, but they- they’re, they’re face to face, they’re having a conversation, that’s communication. Holding hands, talking to people.

Communication is envisaged in its broader sense as being far more than the words spoken. As such, conversation does not need to be semantically comprehensible since it is the ‘exchange itself’ and ‘way of being together’ that is the point (Taylor, 2008: 327). As Kontos (2006: 207) explains, the body has an ‘inherent ability to apprehend and convey meaning’, including through pitch, facial expressions, gesture and turn-taking. A particular moment stands out for me here in relation to the inherent conveyance and interpretation of meaning through the body. During my focus group with people with working-age dementia, PP happily sings a string of vocalizations. While her husband P28 addresses us, she pauses to kiss her husband on the cheek, making him laugh as he thanks her, which he achieves as much with his gestures and smiling intonation as with his verbal response 'oh thank you oh that's nice'. Love is communicated through the culturally significant act of a kiss, and both individuals give and receive in this interaction, expressing their enjoyment through their tones and posture. Clearly, there is far more to a meaningful interaction than linguistic communication.

However, the holding of hands is not always seen to be an 'expression' of anything on the part of someone with dementia. For P1, who used to care for his wife when she had Alzheimer's, 'it can be an instinctive reaction for someone with Alzheimer's to grip and grip so hard that in reality it's not an expression it's an instinctive clutch and painful and there is no feeling with it in terms of the mind it's a physical reaction'. This raises an interesting point of tension regarding intentionality in non-verbal communication. P1's contrasting response to the hands is demonstrated in his semantically and phonetically harsher language; it is not 'hand holding' but 'an instinctive clutch' and 'hard' 'grip' by the person with dementia that can bring the recipient pain rather than comfort. P1 presents such a 'grip' as a purely 'physical reaction' without conscious emotionality or intent. Part of what P1 seems to be drawing on here is the intent of the *body*, which does not need to align with conscious thought. Indeed, citing more positive moments, Kontos (2003: 166) explores how aspects of a person, such as their creativity, can actually be 'held in [the] hand'. This is exemplified by the ability of Willem de Kooning to paint during Alzheimer's disease (Kontos, 2003) and the observation that, despite being convinced she has forgotten, as soon as 'Ethel' holds a needle and thread, she can confidently and swiftly stitch (Kontos, 2006). Whether it sparks joy or pain in the recipient, our bodies can express and engage with others and the world in ways that go far deeper than the surface level of conscious cognition – this is true for people with and without dementia.

In the context of embodied forms of self, then, the hands take on new prominence; hands can express feelings through gesture, connect with others via physical touch and even create, all without needing conscious planning (Kontos, 2006). From this 'broader understanding of what it is to be a person' (Hughes, 2014: 19), these images of hands have the potential to become a more apt metonym for people, both with and without dementia, than representations of brains/heads (see Chapter 6). After all, hands' abilities extend beyond cognitive impairment and help to hold and express a richer, more fundamental self and engagement with the world than the traditional Western intellectual model that privileges the mind as the source of personhood (Hughes, 2014; Kontos, 2006). Although Images 7 and 8 can certainly be seen to engage with damaging and dehumanizing discourses regarding people with dementia (Brookes et al., 2018; Harvey and Brookes, 2019), discussions with a range of people with experience of dementia highlight that, when decontextualized from accompanying text, these images hold the potential for multiple readings, which range from 'harsh' and impersonal representations to depicting 'very human' moments and embodied ways of being in the world.

4.5 Summary

This chapter demonstrates the importance of acknowledging the diversity of people with dementia and of dementia as a syndrome. The participants explain dementia in a range of ways, including by focusing on external manifestations of cognitive changes but also resisting loss-oriented discourses through humour and presenting a multifaceted depiction that incorporates both sad and fun moments and situates dementia as an aspect of life that is not always at the forefront. Metaphorical expressions offer a useful resource for expressing a condition that cannot be fully communicated through language. Dementia is presented as intersecting with other factors, including (il)literacy and age. Participants whose experiences defy stereotypes of people with dementia explore the impact of living outside these stereotypes, particularly attending to people experiencing young-onset dementia and subtypes besides Alzheimer's disease. Debates surrounding ageing and diversity materialize in participants' responses to two images depicting the hands of older people, with the similarities and differences across participants exemplifying how image-specific semiotic resources intersect with viewers' personal experiences and worldviews to establish varying interpretations in relation to dementia.

> *Like a tree […] it keeps splitting off and splitting off into something else […] there's obviously, the sad side to it, and at the same time, you know, there can be moments of, great humour.*
>
> —Participant 19

Figure 5.1 'Like a tree' illustration (Josh Mallalieu, artist).

5

Representing life with dementia

5.1 Introduction

This chapter begins with an illustration of a tree (Figure 5.1) that is drawn from a quote introduced in Chapter 4, which metaphorically visualizes the multiple and often diverging branches of experiences and emotions that can accompany life with dementia. I begin with this illustration because its emphasis on multiplicity encapsulates much of this chapter's discussion regarding navigating and representing life with dementia. Negotiating change emerges as integral to life with dementia (Górska, Forsyth and Maciver, 2018; Read, Toye and Wynaden, 2017). There are, of course, behavioural, cognitive and lifestyle changes that accompany having dementia, ranging from everyday fluxes to long-term changes that accompany the progression of the condition. Simultaneously, people face shifting social roles, relationships and identities (Sabat, 2018). As Sheila demonstrates in Chapter 3, people navigate previous, current and future change. Recognizing that 'these processes of transformation and change typically take place in collaboration with other persons' (Hydén, Lindemann and Brockmeier, 2014: 1), this chapter considers throughout how participants situate themselves and others in relation to transformation and change.

As such, this chapter begins with a discussion oriented around participants' accounts of past, present and future experiences and people's often collaborative impression management in the face of change (Fletcher, 2020a). From here, the focus turns to debating particular linguistic and visual choices that can be made when representing life with dementia, attending to the diverse perspectives among even this relatively small group of participants to consider the implications of communicative choices. In particular, this chapter focuses on metaphors, which are important tools when communicating about a complex and subjective syndrome such as dementia.

5.2 Navigating change with dementia

As Chapter 4 demonstrates, participants often cite changes in cognitive abilities, behaviour and everyday life when exploring what dementia means for them. This section examines the concept of change in more depth, beginning with how participants navigate their past, present and future relationships, identities and lives. While acknowledging that all 'people do change' (P33), many participants affected by dementia position the condition as initiating 'a total life change' (P28 and P30). Indeed, existing research highlights the substantial shifts in self-identity, relationships and abilities that experiencing dementia can generate for individuals, couples and loved ones (Boyle, 2017; Enright et al., 2020; Holdsworth and McCabe, 2018; Spreadbury and Kipps, 2019). As a currently incurable condition that progresses over time, dementia poses an 'existential threat' and is a significant stimulus for ongoing transformation (Cheston, Christopher and Ismail, 2015).

Change is identified at multiple levels. In stating to his wife that 'I know I vary day to day quite considerably don't I', PC situates himself as fluctuating in his behaviours and capabilities, emphasizing the everyday changes that people must navigate. P6 positions changing together over the course of dementia as necessary to navigating life with the syndrome: 'People say "oh she's not my mother anymore, she's not the person she was", no they're [laughs] they're going to be different in many ways. But that doesn't – you've got to change, with them.' Larger, life-changing transformations materialize at varying rates; notably, P30 tells us that her husband has 'changed dramatically, in six months, he went from, me being able to live, at home with him, to having to go into care, and not through my choice'. Experiencing these changes can be deeply traumatic, as P30 shows when she discusses the consequences of now being unable to share decision-making with her husband:

> When you've got to make decisions for somebody you've loved, and you don't know whether they're right or not, it's awful. Sorry [P29 comforts P30 as she cries]. I can't talk without crying but, you have to make the decisions for them, and hope you make the right decisions, more or less.

Clearly, this is a deeply felt issue for P30, whose husband, at the time of the interview, is living in one of the only care homes that would accept him with young-onset dementia and 'challenging behaviour' (P30). The increased distance P30 feels from her husband in his current state is suggested by the past participle, 'loved', which foregrounds her past love for her husband while still tying it to the present moment. Her account signals their transformed relationship dynamics, here, due to the imbalance in decision-making and communication difficulties. P30 is certainly not alone here; spouses of people with young onset dementia frequently report a decline in the quality of their relationship and struggle with significant shifts in their roles and responsibilities (Holdsworth and McCabe, 2018). This is not always the case; when reflecting on the impact of his wife's young onset dementia, P33 declares that 'I got, as I say I probably got closer to [my wife] we was not had the perfect marriage. There was no serious problems it was just plodding along. And because I had to care for her and I had to do everything and whatever that was it'. Combined, these accounts indicate that changing roles and responsibilities may push people apart or bring them closer together, with existing research reinforcing that this sense of connectedness and separateness can oscillate over time (O'Shaughnessy, Lee and Lintern, 2010).

Many participants note the challenges that changes in communicative abilities pose, and the collaborative nature of subsequent transformations in social interactions and relationships (Hydén, Lindemann and Brockmeier, 2014). These may be facilitative or disempowering, with PK and PL arguing that carers may not recognize that people with dementia understand something, due to communicative barriers:

> **PK** When people. To some degree I suppose, detach themselves from the person they're caring for because they think or perceive that "they don't understand what I'm saying anyway". But they probably do. It's just that they're not able to project (it)
>
> **PL** Communicate mm

This exchange highlights the subjectivity of assessing another's understanding, especially without explicit verbal feedback, reminding people without dementia to avoid conflating (verbal) communication with comprehension. Building on the distinction between communication and comprehension, P28 emphasizes the communicative change in his partner, PP, by comparing her previous social roles, when she 'was a fantastic nurse' and 'fantastic manager', to her present communicative state: 'Now, no she can't even write her name, give her a pen she don't know what a pen is.' P28 reflects on the communicative barriers that they currently work with:

> […] not being able to tell you what they want, as well. So, toilet needs I have to guess, so every two or three hours, we go, just in case. Food times, she don't tell me she wants food but I think, it's time we're going to eat. She wants a drink, she can

> tell me sometimes she wants a drink, which is really nice, I know she's not going to be dehydrated then. But other things, she can't say "oh I want to go out and do this, can we go to the shops then we go to the park". None of that. None of that comes out. And, so you have to be their mind, as well [...] And hope, that you're doing the right thing. It's impossible to know if you are. I suppose, if she didn't want to do something, then she'd probably tell me, in one way, or another so, I guess we've done the right thing, but we're not perfect, so sometimes, I do make a mistake

P28 clearly establishes that his partner, PP, generally cannot now 'tell' him what she wants. Therefore, being unable to ascertain her needs, he must 'guess' and, in doing so, take on the responsibility for expressing what is in her 'mind'. PP is subsequently positioned as obviously having wants and needs and opinions, which can occasionally be expressed, while P28 situates himself as striving to hold for her the aspects of her 'mind' that she cannot communicate to him (Hughes, 2014). P28's combination of the second-person inclusive 'we' with the clearly distinct person markers of 'I' and 'she' linguistically indicates this collaborative partnership, while his admission of occasional mistakes establishes that, regardless of this transformation, PP and P28 remain unique individuals as he cannot always guess what is in PP's mind. Underlying both accounts, then, is the acknowledgement that people with dementia who cannot currently communicate their intentions are social beings who require the attentiveness of those around them to support aspects of their 'mind' that newfound communicative barriers may otherwise prevent them from fulfilling in the moment. This aligns in many ways with the psychosocial discourse's emphasis on valuing each other and supporting one another's personhood, or selfhood, through our interactions (Hughes, 2014).

As P28 demonstrates above, participants frequently situate themselves in relation to their past identities and lives. For PI, this manifests through sharing stories of her family and friends in response to conversational topics, especially of her 'mam', who 'taught us a lot' and would take her children 'to another world' with her songs on a Sunday afternoon, and PI's 'lovely lad' of a late husband who, despite being as 'quiet' as she was 'noisy', seemed to love PI as much as she does him: 'I was potty over him I loved him to bits!' However, not all recollections are fond ones. Some participants, especially in my first focus group, contextualize their present state in relation to previously difficult times, in this case when they were first coming to terms with dementia. P4 tells us of the change in PB's attitude towards forgetting:

> **P4** she accepts and laughs about it whereas at one time it was really, she would wake up, I wish I were dead, I'm useless, I can't, I don't know

anything I know what's happening and she realized, very, in a brutal way what could happen or whatever. Don't help because we go to care homes and see family people and we see people go downhill very quick, […] it's scary and it upsets me but

PB Yeah. It upsets me as well

For PB and P4, watching the people they know 'go downhill very quick' (a metaphorical expression of decline; see Section 5.4 for more on this) is scary and upsetting. Initially, P4 positions PB as reacting to her current and anticipated future self with dementia by feeling 'useless' and wishing she 'were dead' rather than have to experience 'what could happen'. Elsewhere, this is referred to as 'anticipatory helplessness', whereby people are paralysed by fears of the future, driven by the stereotype of the end stage of dementia rather than considering all that may lie in between (Bryden, 2016: 272). Similar outcomes have been observed in relation to ageing, with van Wijngaarden et al. (2019) finding that older adults with a death wish often spoke of feeling socially redundant and feared future decline. P4 suggests that, over time, PB has come to accept and laugh about her dementia, showcasing two common coping strategies in the face of great change (Górska, Forsyth and Maciver, 2018; Wawrziczny et al., 2017). Notably, though, PB's own retelling is largely missing from this account.

Similarly, P2 describes a time when her husband PA 'was really bad' but 'knew what was happening to him', reporting that he told her that 'I've had enough I want to kill myself'. PA adds that 'I'd got doctors and other people coming specially to see and none of them were talking the same'. PA's addition presents support from medical professionals as inconsistent (see Chapter 6 for more on this topic), and foregrounds his confusion and disorientation at this time, something that, as well as loss and grief, commonly accompanies a dementia diagnosis (Derksen et al., 2006). The inclusion of the wish of two participants with dementia to die rather than experience the progression of their condition reinforces research that notes an increased risk of suicide for older adults with dementia (Serafini et al., 2016). It is a sobering reminder of the importance of investigating the impact and (in)accuracies of discourses surrounding dementia, since these form an influential frame of reference for what life with dementia means (Bryden, 2016; Mitchell, 2018; van Gorp and Vercruysse, 2012). As is explored throughout this book, communicative choices and attitudes regularly shift together. Notably, Castaño (2020) observes a similar transition in the blogs of people with early-onset dementia, which drift away from their initial conceptualization of a dementia diagnosis as a 'death sentence' (a culturally pervasive metaphor that equates dementia with death) once bloggers adjust to life with dementia and determine that the threat is less imminent than first imagined. This communicative transition mirrors the shift from thoughts of death to an acceptance of life with dementia that the participants portray here.

Building on the above exploration of PA and PB's 'low' (P2) points with dementia, P2 provides her own perspective regarding navigating her and PA's past, present and future experiences of life with dementia. She recalls a 'hard' time during which PA's initial medication made him feel 'really bad':

> I used to work as a carer with dementia but when he was really really bad I couldn't cope with PA and yet I'd worked with it […] So it made it really hard for me because I kept used to think I was useless "why can't you cope with it" do you know what I mean because you've been trained how to look after people and yet you can't cope with it. So at the time I was in despair especially when he was waking me up at night and getting dressed and getting undressed and getting dressed and he wouldn't listen to that it wasn't time to get up so I was losing my sleep there plus I'm disabled as well so it makes it harder to do anything when he decided to run away that's when I thought how am I going to get him back?

P2's 'despair' emerges in the increasing speed with which she delivers the story that climaxes with PA running away (here, this is indicated by the increasing lack of pauses). She highlights the pressure of social roles and expectations in telling how she, as a 'trained' carer, 'can't cope' with her husband's dementia, causing her, like PB, to feel 'useless'. This exemplifies how a carer's sense of self can also change when trying to support a loved one with dementia (Rayment, Swainston and Wilson, 2019). P2's additional difficulties from being disabled highlight the importance of recognizing how coexisting health conditions and being disabled can impact on people's experience of (informal) caring, an issue that remains under-examined even in intersectional research (Hengelaar et al., 2023).

Now, after changing PA's medication, P2 proudly positions PA as practically 'back to normal' and 'making cups of tea again aren't you whereas he couldn't do that he couldn't do anything'. Although PA's present state challenges the discourse of a linear decline, P2 does not communicate a happy ending. Instead, she uses her retelling of the past to exemplify her fears for their future: 'I'm just waiting waiting for it to change. At the moment it's marvellous he can do everything but I'm just waiting for that one day where he's going to get up, and he's going to go back to where he was before.' Through her repetition of 'waiting', P2 emphasizes her anxious anticipation of this change, and indeed, her consistently high epistemic modality indexes her certainty that 'he's going to go back to where he was before', positioning a return to PA's past abilities and mood as inevitable rather than a future possibility. Many carers report similar resignation, behind which Wawrziczny et al. (2017) identify great sadness, a sense of fatalism and powerlessness.

Future fears materialize time and again, both across this study (see above and Chapter 3) and in the field at large (Chappell et al., 2015; Clare and Shakespeare, 2004). Accordingly, multiple discursive strategies for coping with change accompany participants' narratives. For instance, P5, who beyond this focus group leads a carer support group, evaluates P2's approach as 'negative'. Instead, P5 advises P2 to enact 'Mindfulness. Enjoy today. Don't worry about what tomorrow's going to bring whatever it brings you'll deal with it.' This combines a common avoidance strategy, of deferring the future in favour of living in the moment, with one of acceptance, namely displaying self-confidence and trusting your abilities (Wawrziczny et al., 2017).

Throughout focus groups and interviews, many participants display or reference humour as an important coping mechanism, reinforcing the wider literature (Beard, 2016; Birt et al., 2020; Hickman, Clarke and Wolverson, 2020; Wawrziczny et al., 2017). However, as P4 raises, humour is 'not always that easy', hence 'you have to keep the humour if you can' (P5). In these sessions, the function of humorous exchanges ranges from entertaining others and strengthening social bonds to making a point or mitigating the face-threatening potential of a disclosure (Norrick and Chiaro, 2009). In an interactive move that covers many of the above functions, PD uses humour to diffuse his wife's account about the 'difficult subject' of him having to stop driving due to dementia:

P12 it was becoming dangerous, but PD didn't understand why so it was quite a, a #difficult subject#
PD #It was something# to do with running over those railway lines [laughter]
P12 No [laughs]! You're joke- you've still got a sense of humour
P13 Yeah, [laughs] PE has
PE #[Laughing] we're together we are me and you are#

PD's joke may be read as a way of resisting his wife's face-threatening, problem-oriented account of his deteriorating driving and lack of understanding. The clash between P12 and PD's approaches to impression management here reflects a central issue, both to this book and interactions more broadly: often, carers and people with dementia have different motivations and approaches to how they represent dementia. People with the condition often prefer invisibility or managed visibility that leaves a positive impression, while carers may seek greater visibility of dementia's challenges, in part since this reinforces their own carer identity (Fletcher, 2020a). In many instances, as above with P28, P4 and P2, carers provide extensive representations of their partners' changes and challenges, which is oftentimes either supported or unopposed by their partner with dementia, reflecting a broader imbalance in the voices representing dementia (Bailey, 2019; Davies et al., 2022; Dening, Jones and Sampson, 2013). Yet, PD's resistance reinforces that people with dementia can and do reject their partner's positioning of them (Clare and Shakespeare, 2004). PD's joke appears to be effective, since P12 responds by observing a positive attribute of PD, notably his humour. That both wives appreciate that their husbands 'still' have 'a sense of humour' reflects the importance that sharing humour can hold for couples experiencing dementia (Hickman, Clarke and Wolverson, 2020). It also demonstrates that people's accounts can foreground continuity (here of humour) as well as change in the context of life-altering conditions (Whiffin et al., 2019).

PE's response to the above conversation raises another notable means of coping with change with dementia, that of valuing togetherness. This is reflected in PE's combination of pronouns that situate his collective 'we' as 'me and you' (his wife, P13) 'together'. Their strong couple 'us identity' (Davies, 2011) materializes in their subsequent collaborative narrative of PE's changed relationship with driving:

P13 That was his life
PE Yeah that was my life
P13 Teaching
PE Yeah I started teaching, people, to drive a car properly [laughs]
P13 Well not people. Policemen
PE No well, #not people but er drivers yeah#
[…]
P13 Now, who drives you now?
PE You [laughter]
P12 Who drives you #crazy in the house# [laughs]
PE #She's a good driver.# She's a very good driver.
P13 [1.6] Yeah
PE Yeah, so I. I showed her a lot
P13 Yeah.

Their joint telling of PE's 'life' as a driving instructor for police officers is demonstrated through mirroring the other's words and expanding on their partner's previous turn. P13 then shifts their focus from the past to 'now', where she drives PE. Ignoring another participant's prompt to discuss relationship conflict ('who drives you crazy in the house'), PE compliments his partner's skill ('she's a very good driver') and relates this to his role in her success ('I showed her a lot'), which maintains his teaching identity and attributes important roles to them both within their relationship. His pride in his partner's skill and their couple identity ('we're together we are') challenges the cultural privileging of individuality and independent action above *inter*dependence, an imbalance that Boyle (2017: 1791) suggests contributes to the lack of agency commonly ascribed to people with dementia. Offering a carer's perspective, P33 similarly reports that as well as feeling 'closer' to his wife through caring for her, 'I've gained more. In myself. Through helping, through doing.' By presenting 'helping' as a means of personal growth, P33 ties interdependence with action ('doing') and development. Evidently, the transformative experience of dementia can be presented as a source of (inter)personal growth for everyone involved, as well as of pain and struggle.

Of course, participants' accounts of change, identity and experiences with dementia are inherently subjective, something that is reflected on by P19, who was previously employed as a care worker, and P18, whose grandparent moved into a care home. P19 highlights that 'background knowledge' impacts perceptions of the same individual with dementia to the point that it is 'almost like a different person that you're seeing'. To him and the other care workers at the care home, an individual 'was just who they were when they came through the door', and someone that you would gradually discover more about through 'lucid moments' and 'relatives visiting'. In contrast, P18 positions relatives as 'there to kind of interact with who that person, like was as well, in the past'. Notably, P18 argues that familiarity affects perceptions of change, suggesting that upon their loved one moving into care, families must adapt from a place of 'constant contact' to 'now' just getting 'snippets', where 'each snippet is they're changing and the family has to get used to this new baseline for this person, which is also changing constantly', whereas the care worker is 'now constant contact. Erm, you know seeing this person getting to know them and everything as, as they are'. Just as time is relative, so is change. Length and frequency of time spent, relative to your familiarity in the past, is presented as inevitably colouring subsequent interactions and interpretations of the same individual with dementia and the concept of change.

5.3 Dementia metaphors: Living, suffering, battling or journeying?

How would you describe your life? This question lies at the heart of the next section, so I begin by asking you to consider your answer. Is your life a journey, and if so, what does this mean to you? Would you consider yourself to battle your obstacles, whatever or whomever they may be? What role has suffering played in your life and identity? Finally, what does it mean to live life 'well', and is it useful or detrimental to measure life in such a way?

As the previous chapters and the above discussion about navigating change with dementia have touched upon, metaphors are a key tool when communicating about a complex and subjective condition such as dementia. For the remainder of this chapter, I therefore consider metaphors in greater detail, informed by the cognitive and discourse approaches outlined in Chapter 2. In particular, I examine how participants differently respond to examples of linguistic and visual metaphor use in a dementia context and how participants themselves use metaphor to represent life with dementia. Combined, these sections reflect on how the same metaphors might be differently interpreted and further support that a diverse collection of metaphors is needed to account for people's different experiences, emotions and evaluations.

Living and suffering with dementia

As Figure 5.2 demonstrates, discussing life with dementia equally entails discussing the person living it. There are multiple guidelines in place to advise on appropriate language use for dementia-related topics that are made by or with people affected by dementia (Alzheimer Europe, 2013, 2022; Alzheimer's Society, 2018; Bould, 2018; DEEP, 2014; KYN et al., 2023). Chapter 1 outlines how these guidelines prioritize 'accurate, balanced and respectful' word and image choices that emphasize the person, such as people/person 'with dementia', 'living with dementia' and/or 'living well with dementia' rather than 'curl up and die' words such as 'dementia sufferer', 'victim', 'senile', 'living death' and 'burden' (DEEP, 2014: 1–2). PN (Nancy), herself a DEEP member, situates herself within this linguistic change: 'We had a long time er, talking to people, because they were saying that we suffered from dementia, whereas we try to say that we lived with, we live with dementia.' Her movement from past to present tense reflects the linguistic shift from 'suffering' to 'living' that has occurred in recent decades, as well as the greater prominence of the voices and desires of people with dementia,

Phrases:

Suffer with dementia / suffer from dementia / dementia sufferer
Living with dementia
Living well with dementia

Headlines:

Dame Barbara Windsor's heartfelt plea to end Alzheimer's disease agony (*The Express*, 6 August 2019).

THE LOVE THAT DEFIED DEMENTIA; Most poignant of weddings after sufferer asks wife to marry him … believing she's new love and falling for her all over again (*Scottish Daily Mail*, 22 August 2019).

Image:

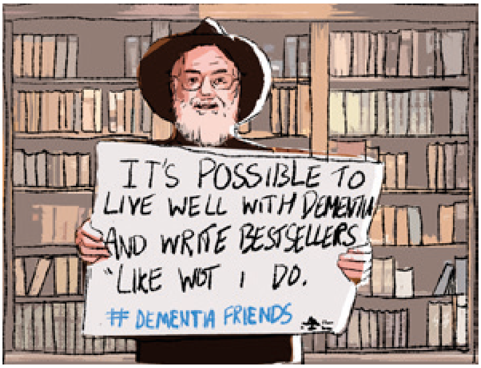


Image 15 shows the author Terry Pratchett holding up a sign saying 'It's possible to live well with dementia and write bestsellers "like wot I do" #dementiafriends' (Artist's impression by Chris Chikodzore-Paterson, with permission from Alzheimer's Society).

Figure 5.2 Stimuli that explicitly relate to the 'living well'/'suffering' debate.

who have increasingly challenged externally attributed labels (Beard, Knauss and Moyer, 2009b; Bryden, 2016; Mason et al., 2024; Swaffer, 2014). Overall, participants display similar linguistic preferences to those of advocates and the aforementioned guidelines. Nonetheless, there are many variations regarding the implications of 'suffering'/'sufferer', 'living with' and 'living well', which will be outlined below.

Participants take different stances towards suffering-related language. Some individuals intimate that the words used do not matter (PH), with PC quoting a famous saying drawn from William Shakespeare's play *Romeo and Juliet*: 'A rose by any other name would smell as sweet.' Meanwhile, others oppose these labels ('I don't like suffer': P7), often for being too 'negative' (PN, P11, P14). People generally distinguish between the experience of 'suffering' and the identity of being a 'sufferer'. As such, PS positions herself as willing to say that 'I suffer from dementia' to close friends, but resists being called a 'dementia sufferer', since 'it demeans me'. Indeed, very few participants use the term 'sufferer' themselves to refer to people with dementia. Two carers use 'sufferer' once outside of deliberating the word (P15, P16), and one when discussing the headline in Figure 5.2 that uses 'sufferer' (P26), whereas eight participants use variants of 'suffering with/from' dementia (PC, PS, P5, P6, P11, P23, P25, P26). Some of the tensions between suffering as an identity versus an experience are exemplified below, when a participant stops herself from saying 'sufferer', but then attempts to justify this censored word:

P5 Although actually they look like suff- people with dementia, nearly said the s-word then
Emma What do you think of the s-word out of interest? Sufferers?
P5 I don't see it's as bad it's like you suffer from headaches, suffer from indigestion, why shouldn't you suffer from dementia?

There is clearly a tension here between 'sufferers' and the more socially acceptable replacement phrase, 'people with dementia', likely in part due to the focus group's social context being that of a Memory Café, which is an environment that (at the time of data collection) officially upholds a living-well discourse and Alzheimer's Society's language guidelines. P5's self-censorship is expressed through her joke, 'nearly said the s-word then', which situates 'sufferer' as a taboo word. Yet, potentially in an attempt to save face, P5 then justifies the label, all while never explicitly referring to people as 'sufferers' and rationalizing the term wholly in terms of the *experience* of suffering, since she changes the noun 'sufferer' to its verb 'suffer', thus shifting the focus from people themselves to the act of suffering. Through presenting alternative, non-stigmatizing uses of 'suffer from' (such as headaches), P5 constructs an argument for also suffering from dementia by normalizing it within more commonplace (and generally temporary) conditions, effectively recontextualizing the initial identity-oriented debate within an experiential one. By using 'suffer' while avoiding 'sufferer', P5 implicitly distinguishes between these two terms.

However, in other sessions, these distinctions become more explicit. In particular, 'sufferer' is often rejected for being 'horrible' (P10) as it undermines personhood: 'People with dementia are not sufferers, they have dementia, they are a person, and that is very important, a person with dementia […] It's politeness, it's, dignity […] Treat the person as a person' (P33). The emphasis within P33's account is strikingly similar to Kitwood's (1997: 7) oft-quoted call to recognize people with dementia 'in their full humanity' and shift the frame of reference from ‘person-with-DEMENTIA’ (as signalled by ‘dementia sufferers’) to ‘PERSON-with-dementia’ (original emphasis). Reflecting on his experience as a care worker, P19 upholds this professional shift to person-centred language: ‘I mean usually you’d call them by their name, er, you know, shock! [Laughter] But er, when you couldn’t do that, you were working with people with dementia […] never dementia, sufferers, ever.’ In contrast, participants more frequently accept and use the verb ‘suffer’; for example, PC is reminded of ‘my mother and grandmother who suffered from it’. As justification, people point to the suffering that people with dementia and carers experience: ‘Obviously it is a negative term but I mean, it’s [laughs] not a nice thing to have’ (P6; see Chapter 3 for further discussion of suffering). This reflects a wider move in the literature to acknowledge that dementia can be a ‘site of distress, disgust and despair’ (Gilleard, 2018: 29), with Keith Oliver making explicit what remains an implicit distinction among my participants: ‘I don’t see myself as a sufferer but I do suffer from dementia. I find dementia extremely challenging and frustrating but I am not a sufferer because if I become a sufferer that’s how I’m defined and that’s how I’m treated’ (Bartlett et al., 2017: 177).

Against this, some participants, notably P19, caution against the blanket use of suffering to describe having dementia (‘you have to be pretty sure […] that suffer is the word’), suggesting that ‘suffer’ is too ‘black or white you’re either suffering [or] you’re not suffering’, when the reality of life with dementia is ‘a grey area’. For many people, shifting the focus to *life* with dementia is more helpful (‘the living with dementia is much better isn’t it’: P13). As P7 points out, ‘you are still living with it, you know, […] it’s not killing you straight away or whatever’. Within this discussion of life with dementia, there are many distinct stances regarding what it means to live, or live well, with dementia.

For many people with dementia in particular, the concept of ‘living well’ is something they strongly identify with (‘living well with the dementia yeah I am’: PE) and aspire to, as it provides something ‘to aim for’ (PH) and ‘look forward to‘ (PD), as ‘we all need that pressure […] That incentive, to live well’ (PN). The discourse can give ‘help, and hope’, since it ‘conveys to you, you can do something, you can eat healthily, you can go out, you can walk. You can still do things, you can keep your life going’ (PS; see also Mason et al., 2024). PN argues that this discourse is an ‘inspiring’ counter to ‘the way people often talk to you and professionals, talk to you’ about dementia from the moment of diagnosis, as if ‘it's time to get ready to die. It's time to start planning long term care and that sort of thing and you think well excuse me, I feel healthy, I'm enjoying life’.

In this context, the image of Terry Pratchett (Image 15, Figure 5.2) is praised for its depiction of a living-well narrative ('I love number 15 where he's actually said it's possible to live well with dementia': PN). For PS, the image shows that 'You can be happy and you can do things. This man's still writing, he's written a bestseller! I keep thinking I want to try and write a, a little story.' PS makes a particularly personal connection with this image, identifying her own goal as, like the author shown, she too would like to write a story that could feature in a 'lovely magazine' she reads with 'nice […] wholesome stories'. These responses indicate that the more positive outlook of the living-well discourse can be empowering (indeed, note PS's repetition of the modal verb 'can', to signal all that you are able to do) by promoting that 'life does not stop' (Morgan, 2018: 306), and that 'it is possible to continue to live and grow and to appreciate life' after a dementia diagnosis (Sabat, 2018: 136).

Notably, these participant responses, particularly PS's discussion of actions that 'you can do' as an individual, such as go for a walk and eat healthily, tend to take an individualistic approach to 'living well' (Peel, 2014), rather than necessarily considering wider society's responsibility to provide an enabling (and not disabling) environment. In this context, the individualized living-well focus is positioned as empowering, since participants can evaluate their lives positively and express agency in how they choose to 'live well' with dementia.

However, the living-well discourse is also critiqued by participants (predominately those without dementia) for being inaccurate compared to the 'brutal' 'reality' of life with dementia (P8, P10). It is seen to carry an 'implication that like if you're not living well, you're not doing it properly' (P17) and are 'failing' if you are 'at screaming point' (P6). Declaring that 'I don't like Terry Pratchett's "live well"', P1 suggests a less pressurizing alternative: 'Live as well as you possibly can!', which is enthusiastically received by many of the other focus group members. The term itself, 'live well' is positioned as being vague and subjective, with P28 asking, 'how do you live well?' and other participants foregrounding how different abilities makes comparing people detrimental. Notably, Terry Pratchett is distanced from other people with dementia as being an 'unusual guy' with an 'unusual form of [dementia]' (P7), with three carers contrasting his bestseller to the inability of their loved one with dementia to now write (e.g. 'PO can't even write his name': P27). PH also notes in relation to the image of Terry Pratchett that, 'you can still do things, some things, but, there are things that are, erm, much more difficult for me to do, now'. For some people, the addition of the evaluative 'well' to 'living with' is 'unnecessary', as it fails to acknowledge the nuance of daily life (P19). For P30, the term is 'one of my bugbears', as 'I know lots of people [affected by dementia] but I don't know anybody that's living well with it'. At its worst, 'living well' is evaluated by P28 as 'an evil way of putting it' because 'you can't live well with it', as 'it affects everyone's life […] dramatically'. P28 initiates a collaborative compilation of alternative emotions experienced that challenge the living-well narrative:

P28 it's, frustration, it's annoying, upsetting, depressing, anything else?
P31 Anger.
P28 Anger, good game good game carry on yeah [laughter]
P30 Isolating?
P28 Yeah yeah, isolating, you are isolated.
P29 You are you are

Such a response reinforces arguments that by overly pushing the living-well discourse, we 'risk sanitising negative experiences' of dementia that equally need to be acknowledged (Fletcher, 2019a: 2).

P28's discussion of how everyone's life is 'dramatically' affected touches on an unanticipated trend in distinguishing 'living with' from 'living well with'. A few carers argue that carers are 'the person living with dementia' because 'they have to adapt to that person's life' (P33). Indeed, Dementia UK's recent 'We live with dementia campaign' posits that 'If you love someone living with dementia, you're living with it too' (Dementia UK, 2024a). Distinguishing between living with/well, P14 tells us that 'I'm living with dementia but want my mum to live well with dementia', thus positioning carers as providing the support needed for people with dementia to 'live well'. This noticeably diverges from language guidelines which, following the preferences of their interviewees with dementia, suggest that it 'is usually not useful' to say that people without the condition are living with it, instead encouraging the term 'affected by dementia' to refer to both people with dementia and anyone close or who offers support, such as carers (Alzheimer's Society, 2018: 15). Regardless of the linguistic choice, a key point that emerges in carers' discussions here is the importance of others in supporting, rather than impeding, someone's ability to 'live well' with dementia (Bartlett et al., 2017; Sabat, 2018). Notably, P13 suggests that 'living with dementia to me is, not being stimulated' while 'living well is', explicitly tying the ability to live well to a facilitative social environment. This supporter perspective presents a more interdependent, environment-oriented approach compared to the more individualistic envisioning of 'living well' by participants diagnosed with dementia, a distinction that has also been observed regarding priorities for empowerment more broadly (van Corven et al., 2021). Of course, this is not always the case, as Nancy's (PN) emphasis on structural and interpersonal factors in Chapter 3 exemplifies.

Clearly, there are many competing interpretations of what life with dementia means, and some participants, such as P6, suggest that 'you would need both' 'living with' and 'living well with dementia', as they are each appropriate in 'certain contexts'. Other participants would argue the need for 'suffering' to also be included in the language used to discuss dementia. Throughout, participants' responses clearly support the need for a nuanced representation of dementia, 'rather than understanding it as a dichotomised experience of tragedy or living well' (McParland, Kelly and Innes, 2017: 83). Returning to the focus on the person within these discussions of life and suffering with dementia, P17 highlights another type of nuance that is rarely discussed, memorably distinguishing between being a person who *has/had* dementia versus a person (living/suffering) *with* dementia:

> I would say my Granddad has, slash had, dementia. I'm not sure about 'with', because. That implies to me that they've got like a little gremlin on their shoulder? And it's something they have to cope with? I don't know. Maybe, maybe some people are comfortable with that but. Suffer with or from, living with. It's like a, a burden, it's like a thing you have to have when actually. It's just you. You have it, you are, you know [...] it's just like, I'm living with this thing and it's, separate to me, I don't know that's kind of what that implies to me anyway. And it's not because it's your brain, and it's you and. You're just changing.

P17 challenges the preposition 'with' in suffering/living (well) with dementia discourses. She draws on metaphors of dementia as a travelling companion (here, a gremlin that sits on your shoulder) and a 'burden' (van Gorp and Vercruysse, 2012) to argue that for her, 'with' envisions dementia as an additional 'separate' entity whose weight people must bear. P17 argues that this does not reflect that 'actually. It's just you', explicitly situating dementia within the person and their body ('it's your brain, and it's you'). Subsequently, P17 promotes that dementia is something that you 'have', advocating for a metaphorical conceptualization of dementia as something you possess rather than as an accompanying entity that a person must bear for life. In this sense, the importance of dementia is reduced from the prominent description of what/who you spend your life 'with' ('It's almost like it makes you part of a couple or something it's like, "oh here comes Bridget and her dementia"': P19) to one of many conditions and attributes that you 'have' (thus conceptualizing dementia as a possession, as 'everyone has something don't, they': P17). Although this stance only occurred in this particular focus group, it is reflective of a broader trend of people opting to say that they 'have dementia' (Bailey, 2020) or, as P33 recalls someone writing in a letter addressed to their dementia: '"I've got you, but you haven't got me"' (this fighting stance is explored further below). Other participants share P17's emphasis that dementia is one of many problems, albeit through different language choices. Notably, PN advocates for greater coverage of 'Life. as a person living with a problem', using 'living with' interchangeably with the possessive 'have' to make a similar point that 'most people have more than one problem'.

Life as a fight against dementia

It is worth attending to P17's choice of 'a little gremlin on their shoulder' more closely. A gremlin is widely associated with being an antagonistic character that causes problems for others, and elsewhere P17 again personifies dementia, this time as comparable to an abductor/thief: 'It kind of takes people away.' P17 is not alone in drawing on the metaphorical envisioning of dementia as a harm-causing adversary. Elsewhere, P28 positions dementia as a malevolent, imprisoning force: 'There's another person in there, that's fighting, frustrated, trying to get out, but can't get out. And it's not her fault, it's not, it's not. You don't ask for it, you wouldn't wish it on anyone. It's evil, it is, it's evil.' Invasion metaphors that position dementia as a combative 'evil' enemy force, alien invader or predatory thief are widespread socially (Brookes, 2023; George and Whitehouse, 2014; Johnstone, 2013; van Gorp and Vercruysse, 2012) and, as with P28's description, are often fatalistic and nihilistic, with no way out for people with dementia.

Although here P28 uses the metaphor to alleviate blame from his partner with dementia who cannot escape the imprisonment of dementia despite her 'fighting', elsewhere, the expectation for people to fight and 'stave […] off' dementia (P11) can stigmatize alternative ways of coping. This is exemplified by P14's comment, 'are you going to give into this thing and be a dementia sufferer or, you know, live with it', whereby the only acceptable route is for people to resist, which is not always attainable, especially for people with coexisting health conditions (Lane, McLachlan and Philip, 2013). More specifically, P26 suggests that 'you can fight dementia' through 'food' and 'your attitude', reproducing discourses of self-responsibility for preventative/mitigative responses to dementia in order to attribute agency to the individual to 'fight', which simultaneously conveys 'a moral identity' for how individuals *should* behave (Lawless, Augoustinos and LeCouteur, 2018: 1547). Resisting this discourse, P6 describes this fight as unrealistic as 'you're not going to beat the dementia itself of course'. Notably, P33 distinguishes between the notions of ‘fighting’ and ‘beating’, arguing that ‘you’re not gonna beat it but yeah you can fight it’. It is therefore the day-to-day battles and small successes that matter here, not the overall victory, mirroring Castaño’s (2020, 2023) findings for bloggers with early-onset dementia, who draw agency from a ‘fighter’ identity, despite simultaneously acknowledging that, ultimately, theirs is an unwinnable battle.

Considering the social prevalence of combative metaphors, it is striking that in this research project, relatively few participants explicitly discuss dementia through these metaphors or even use them at all other than in response to my stimuli. Notably, PK presents an unconventional use of the alien invader metaphor, which supports a humorous shared understanding of the experience of dementia with his vicar. Elsewhere, a *Star Trek* alien’s invasion of a character’s body has been used to position having dementia as meaning that ‘my body will have been taken over by another being with a disturbing but illusory resemblance to my former self’ (Davis 2007: 61). This utilizes the invasion metaphor to reinforce loss of self, which is clearly attributed to mental capacities since the body remains. For PK, the same metaphor, also initiated by his vicar watching an alien invader *Star Trek* episode, is instead used to facilitate a representation of dementia that is grounded in the actual lived experience of the person with dementia, as, like the person taken over by the alien, ‘you know things, you want to do something. You know things coming on, er go going on, but you can’t do anything about it, and that is, can be what it’s really like’. When the vicar asks PK ‘how’s the alien?’ it makes him ‘smile’ and ‘takes all the tension out of (what) might have been [in] your mind because of? The Alzheimer’s’. Rather than being helpless against the invader, which is a frequent consequence of military metaphors (Lane, McLachlan and Philip, 2013), PK presents his Alzheimer’s as a separate but accompanying entity that he has a two-way relationship with, as ‘you’ve got to work with it’. He positions figures in his life, here the vicar, as allies who have the ability to alleviate ‘all the tension’ triggered by socially interacting with Alzheimer’s disease, again highlighting the reactions of others as integral to a person’s experience with dementia.

Similarly, while the media have been shown to establish dementia as ‘our biggest killer’ in response to changing regulations surrounding death certificates (Brookes et al., 2018; Putland and Brookes, in press), participants challenge this sensationalist representation of dementia. Participants consistently position it as ‘misleading’ and ‘negative’ (PN), likening it to a ‘horror story’ rather than being ‘factual’ as dementia ‘doesn’t actually kill you’ (P11). P19 emphasizes its distance from everyday reality, telling us that ‘I don’t think carers go in, in the morning and think like "oh here we go, dealing with the nation's biggest killer" [laughter]'. Even the biggest advocate of the term, P33, says that 'it is a killer but it just brings death, sooner', acknowledging the role of 'underlying illnesses' in dying with dementia. Multiple participants link the term's use on the charity fundraising envelope ('Will you advance research to beat the UK's biggest killer?'; Figure 2.2) to a financial motive ('it's obviously meaning, come on [rubs fingers together] we want we want your money': P11), with PN highlighting the consequences of this language for 'mental health', since seeing something like this could make someone feel 'awful about themselves'. As Peel (2014) found when comparing carer and media discourse, people affected by dementia here do not tend to reproduce hyperbolic media metaphors such as 'biggest killer', although it is evident above and below that combative metaphors more broadly are used.

Moving beyond hyperbolic metaphors, it is worth further considering how participants use and extend combative metaphors in their representations of life with dementia. Numerous participants express a sense of and a need to fight, but the conditions and motivations of these fights vary. Taken together, these provide a more nuanced insight into the multiplicity of battle metaphors in relation to dementia. Firstly, some participants take a macro approach to fighting dementia as a society, for the benefit of others rather than themselves:

P16 I don't know whether it [a treatment/cure] will come or well it certainly won't come to help, my wife, and such like
P14 Or my husband
P16 But, we've got to keep fighting for it
PG Yeah

This group explores the need to 'keep fighting' for a cause that is bigger than them, touching on the imperative to maintain faith in, and support for, future success, here in relation to a cure or treatment (see Chapter 6 for further discussion of seeking a cure). P33 extends the usual emphasis on a cure to include good care within the fight metaphor: 'It carries on when I've gone, the fight must carry on. You know. But it's not just the fight for the cure it's the fight, to help, the people 'til they get the cure.' Yet participants also articulate this fight in terms of individual battles, either against dementia, stereotypes or social structures. P33 reconceptualizes the meaning of success when battling dementia, arguing that 'It's a battle. Some you win, some you don't […] [My wife] didn't win. I didn't win in that respect but, I've gained more. In myself.' That personal growth becomes a 'win' from experiencing dementia reflects that 'in some cases, our greatest leaps in personal growth occur when we are confronted with challenges of great magnitude' (Sabat, 2018: 134), which presents an alternative form of winning to the more familiar (but less attainable goal) of treating or curing dementia (Kenigsberg et al., 2016).

Offering an alternative to fighting dementia altogether, some participants instead foreground their fight against a system and society that does not understand or provide what people affected by dementia need. P29, P26 and P11 talk about the 'fight' for benefits and support for people with dementia and their families, indicating a struggle for sufficient financial, medical and social care, while P29 further discusses battling against the preconception that dementia is 'about the old people', telling us that 'I go to meetings at work and I'm constantly fighting, against it, and it's like, it's like deaf ears'. Here, the perpetual battle is against misunderstandings, not dementia, demonstrating the variety of uses of combative metaphors in a dementia context beyond the primarily disease-oriented ones perpetuated by the media (Bailey, Dening and Harvey, 2021; Brookes, 2023; Lane, McLachlan and Philip, 2013). Reinforcing previous findings of both individual and collective fighter identities (Castaño, 2020, 2023), here, battles can occur at both levels, and adversaries include not only dementia but wider society and social structures in need of change.

Having said this, fighting is not a useful metaphor for everyone. P6 dismisses it as 'army sort of language', also suggesting that 'it's not defeating the dementia is it it's more defeating the erm, say the stigma, or the implications, erm overcome would be better wouldn't it, overcome'. Similarly to above, P6 presents the social treatment of dementia as needing to be fought, but goes a step further than changing the enemy (here to 'stigma') by also exchanging the metaphor 'fight' for the less combative 'overcome'. Other participants also suggest 'better' alternatives to the combative metaphor. PN tells me that fighting dementia is

> not part of the general public's life is it? It's part of the scientists' life, it's part of research life, it's part of medical life. but does it touch the general public? No, they want to live with it, don't they? They want to, learn how to survive with it. I think survive with dementia might be better.

Here, a sense of separation from researchers and medical staff (which is explored further in Chapter 6) is conveyed by metaphorically establishing spatial distance between these groups and the general public, since the researchers and medical practitioners' fight does not 'touch' the public's experience of dementia. Subsequently, PN emphasizes that it is learning survival skills for life with dementia that becomes important, as people cannot fight off dementia, but can 'learn' to adapt to a life that includes it. Personal development through learning, with the aim of enduring a progressive long-term condition, becomes the more meaningful goal for the individual than a collective 'fight' against a condition that is 'with' them for the rest of their life. Likewise, P13 tells us that 'You can't really can you, fight, fighting dementia is, doing the best you can. Er. While you can […] You #cope with it.'

Coping, overcoming and surviving are striking alternatives to combative metaphors. The verbs are united by the act of prevailing in the face of adversity, thus providing agency and hope for individuals much like combative metaphors, but without the emphasis on violence and adversaries. Dementia is positioned here as a source of adversity and challenge but is not personified as an animate enemy. The focus therefore remains on the *people* experiencing dementia, providing greater space for promoting change and adaptation as people assimilate the impact of dementia into their lives. This contrasts the loss that combative metaphors implicitly foreground through their winning/losing dichotomy for something that individuals cannot beat (Lane, McLachlan and Philip, 2013). Presenting these alternatives to people affected by dementia in future research would provide valuable insight into the potential of such linguistic choices beyond these individuals since, as is established throughout this book, responses to the same word or metaphor are deeply personal.

Life as a journey with dementia

Another metaphor that emerges from participants' responses is that life, here with dementia, is a journey. Existing research indicates that this metaphor is a popular means of envisioning dementia in the written works of people with dementia (Castaño, 2020, 2023; Zimmermann, 2017) as well as for life and illness more broadly (Lakoff and Johnson, 1980; Semino et al., 2017; Sontag, 1979). Much like the combative metaphors, it is not useful for everybody (Gerritsen, Oyebode and Gove, 2018). Since this metaphor was not a stimulus, it is worth noting that only people who reproduce the metaphor can be discussed here, necessarily excluding those who do not align with it.

About a tenth of participants explicitly situate life with dementia as a journey. As your dementia progresses, you are seen as moving 'further along' and 'deeper into the journey' (P7, PN). These do not have to be solitary travels; PS tells me that 'you're taking this journey together', and P26 similarly reflects on 'the friends you've made along the journey', indicating a sense of community and togetherness within their dementia journeys that is elsewhere expressed by talking of other people affected by dementia as 'fellow travellers' (Castaño, 2020: 125). When asked why she uses the journey metaphor, PN explains that 'the course of the disease is a bit boring and a bit sort of err, negative [. . .] Whereas a journey means it can be, good or bad can't it and it explains my journey, it explains how I'm dealing with the disease'. Here, the journey metaphor is presented as more interesting and less imbued with 'negative' associations of decline than the medical equivalent PN provides ('course of the disease'). It is worth noting that 'course' itself has metaphorical roots in the journey metaphor, which exemplifies how metaphors can become normalized within speech (Lakoff and Johnson, 1980). PN notes the flexibility of the journey source domain, as a journey can be good or bad, and is uniquely personal to the individual. Indeed, 'my journey' will be different to yours, in a way that a fight may not, since fights include expected tactics and behaviours, and require an adversary (Lane, McLachlan and Philip, 2013). In contrast, there are many ways to 'deal' with dementia on your 'journey', which has many routes, contrasting the more limited win, lose or draw outcomes of a fight.

Inevitable, though, is the potentially disturbing fact that a person with dementia cannot return to a life without dementia, making this a 'one-way' 'journey of no return' (Castaño, 2020; Zimmermann, 2017). This is acknowledged in one focus group, who discuss that:

PK But also there's, there's, the concept from the media I think is, or the thing that it points you in. there's only one direction. #And to some extent# that's true.

Emma #What's the direction?#

PK It's a terminal disease. You're only going to go in one way. But you're not going to go in one way, in a straight line.

P25 Yeah but we're all going in that same direction generally

PK Yeah

PM Yeah, even if you're well [laughs]

What sets this discussion apart is the alignment of the unidirectionality of the dementia journey with the life journey in general, as indeed, we all share the same destination of death, irrespective of the conditions we experience beforehand. The tension between being powerless to stop dementia's progression while having agency over your experience is evident in PK's later comment that 'It is what it is, you know, you can't alter it. Or you can. But you can't change the direction you're going in so you've gotta live with it.' Here, building on PK's earlier envisioning of the dementia journey as going ultimately in 'one direction' but not 'in a straight line', PK indicates that you can 'alter' your path even as you move in the same overall direction.

5.4 How useful are visual metaphors for decline?

Complementing earlier discussions of navigating change (and continuity) alongside linguistic metaphors for dementia, this section orients around participants' responses to four images (Images 9–12, page 3 of the Appendix), which each act as visual metaphors of change, notably of loss and deterioration when used in a dementia context. Building on Chapter 3's examination of how Nancy and Sheila respond to Images 10 and 12 (Figures 3.4 and 3.5 respectively), the present section considers participants' overall responses to this page before focusing on Image 11 (Figure 5.3), as the most discussed and debated image of the group (see also Putland, 2022).

The four images on page 3 of the Appendix are 'hybrid metaphors', since multiple phenomena are visually represented as interacting in the same space

Figure 5.3 Seasonal tree heads (Image 11) (iStock.com/wildpixel).

in a way that would be impossible physically – a brain blurs and disintegrates into pixels; a man's head turns to fragments; three head-shaped trees in different seasons stand in a row; and a woman loses a jigsaw piece from her head, leaving a dark void where it should be – combinations that subsequently establish new meanings beyond each individual component (Forceville, 2008: 465). The process of a hybrid metaphor is reflected in a focus group's discussion about the realism of the brain in Image 9:

> **P7** I mean that's quite a realistic looking one actually
> **P10** I suppose it is yes
> **P7** But yes
> **P10** But maybe because it's disappearing it's less
> **P7** It's not a realistic thing is it.

Here, combining different phenomena, namely the brain and the process of disintegrating, makes what is otherwise 'quite a realistic' brain unrealistic. Instead, the brain takes on metaphorical meaning, where, in a particular scenario of the broader conceptual domain whereby the body is a machine, the brain with dementia can be interpreted as a data processor that is losing data, and therefore breaking down in pixels. Bailey (2019) observes the prominence of the machine metaphor within newspapers' discussions of dementia and highlights the dangers of subsequently representing people with dementia as broken. It is generally immediately clear to participants that these are metaphorical images. As soon as P33 turns the page, he notes the symbolic quality of these combinations of phenomena, exclaiming that 'now we're going onto symbols, symbols yes'. Through this label, P33 separates these images from the more literal photographs that make up much of the visual stimuli shown to participants (see the Appendix).

Cognitive Metaphor Theory (see Chapter 2) helps explain the prominence of metaphor in the images used here to depict the target domains of progression, loss and/or change. These target domains are 'relatively abstract, complex, unfamiliar, subjective or poorly delineated' experiences, meaning that mapping these onto more concrete and familiar source domains, such as a jigsaw or seasonal changes, provides a more tangible, experience-based explanation for these otherwise abstract phenomena (Semino, 2008: 6–7). Participants frequently remark on the source domain first, before elaborating to explore the metaphorical meaning by relating the source to the dementia-related target domain. When justifying why she likes Image 12, P21 draws on the cultural familiarity of the source domain: 'Everyone knows a jigsaw don't you, and understands it, even children probably you know, understand that.' However, the mapping of the source to the target domain is not always clear for Image 12:

PI And the piece missing out that one I wonder what that one's for. Why would that piece be missing like that.
P21 It's like, it's #portraying what dementia# so it's something about the brain isn't it
PI #this is the brain# Mmm
Emma What do you think about it? [4.9]
P21 Do you understand that what it's telling you about how to explain what dementia is? #Do you understand #
PI #Mmmm#
P21 what it is?
PI Ay?
P21 Do you understand what that's saying
PI [sighs] No.

This exchange highlights that regardless of the familiarity of a jigsaw and missing piece, the metaphorical meaning is not always clear for individuals. It may also not be desirable; PH resists identifying a target domain for Image 11, stating that 'being a physicist, it's a bloody tree'. Meanwhile, in response to being asked what he thinks of the four images on page 3, PA situates them as 'just a pretty picture, and if you don't know what it's about, and you can't read it, in the field or whatever, you just drive past'. Such responses caution against assuming that everyone engages at the connotative level for metaphorical images.

Of the four images, Image 9 appears particularly confusing and is the least positively received. While also signalling disintegration, the relative unfamiliarity of the source domain for dementia may contribute to such confusion and disregard; indeed, elsewhere Getty Images (2019) situates it not in the realm of dementia but of digital data processing: 'human brain dissolving into squares representing data'. Few participants refer to it as showing 'your, brain dissolving' (P16) or 'disintegrating' (P17). The most evident issue appears to be the ambiguity of what is shown. My first interviewee, P6, exclaims that 'Ooh my goodness me [laugh] I don't know what that's supposed to be and I wouldn't like to speculate,' later adding that 'it looks like a clump of clay I mean that one doesn't mean anything to me'. PS tells me that 'I don't understand this that, I'm not sure if it's a snail or something going down into water?' Here, then, we see a breakdown between intended meaning and interpreted meaninglessness, as participants cannot clearly identify the components depicted in the image, let alone the wider discourses it engages with.

Often, the more concrete aspects of the target domain, such as a brain or face, are noted by participants first since they are clearly shown alongside the source domain in the image. PI exemplifies this when she exclaims upon seeing the page: 'They're faces they are! That's the brain. They're faces they are. She looks how I feel.' PI identifies three aspects of the target domains that are literally shown in the images, that of the brain, faces and the woman's expression. In contrast to Sheila and Nancy in Chapter 3, who create a sense of distance between themselves and the lady depicted in Image 12, PI explicitly aligns herself as feeling how the woman looks. This reiterates the subjectivity involved in relating to represented participants in images, regardless of the piece's composition. PI is not alone in initially foregrounding the woman's expression in Image 12; PD tells me that 'she looks a bit sad there' while P26 also suggests that she has 'sad eyes' and 'looks, lost'.

Equally, many participants discuss metaphorical connotations, going beyond what is literally depicted by each image. Remaining with Image 12, participants consistently pick out the concept of the 'puzzle piece missing' (P17), often identifying a loss of brain function as the metaphor's target domain: 'Obviously the mentality is that people are (losing) losing functions of the brain' (P8). For P6, it is this discourse that makes Image 12 'possibly. better?' than the other three images, 'because it's like a piece, of your brain, that's gone, you know. I wouldn't have such a big piece [laughs]'. The location of the missing piece from the woman's head encourages participants' consistent associations with the brain, the organ situated there. Object size also matters: P6 does not resist the metaphor that you lose pieces of your brain with dementia – she instead resists the *amount* of loss that is signalled through the puzzle piece's size (it is approximately one-ninth of the area showing the woman's head). Sometimes the missing piece is interpreted in relation to the whole person, as with P33 who positions Image 12 as 'the real one there that, says, you know, part of me is missing. And a carer would say that about mum, part of her is missing'. Although it may be a literal reading of the fact that the woman is missing a piece in the picture, that it is not specified to be the person's brain but their *whole* being that is incomplete can be seen to reproduce the popular discourse that dementia involves a loss of self, which is itself entangled with the prioritization of the brain as the source of human identity.

Although some people, such as P6 and P33, align themselves with the representation in Image 12, a notable number of participants resist the discourses that this image engages with. P8 criticizes it as 'stark', while PJ tells me that 'I'm a bit dubious of this one' and that 'it affects me'. Within his explanation of its effect, PJ identifies the woman's 'blank' expression and situates it as a frightening part of life. The focus group of PhD students also explore the implications of the woman's expression and missing puzzle piece for them:

> **P19** It's also it kind of implies that. I'm not saying she is, but I think it implies that she's stupid
> […]
> You don't suddenly become, gormless or you know, and I think that's slightly implied, probably not intentionally I don't imagine it would be intentional. But it is sort of, she looks like she's not quite sure?
>
> **P18** Or like losing your mind in terms of like you go kind of, not crazy but you know what I mean, like erm
>
> **P17** Lose your marbles that's what we're getting from that
>
> **P18** Yeah, like that's sort of what it's, like, just because you, forget something doesn't mean you're an idiot and it doesn't mean you're insane. It's just you forget things.

This conversation is remarkably similar to Harvey and Brookes's (2019) criticism of the same image. What P19 identifies as a 'gormless' expression is linked by Harvey and Brookes to the 'living dead' metaphor, in which the woman is positioned as a zombie, a 'non-person' through her vacancy (997). The PhD students instead link this image to denigration through low intelligence and insanity, factors that also accord people 'less-than-full membership' in society, partly due to a perceived lower conversational competence (Clare and Shakespeare, 2004: 213). The students utilize common metaphorical phrases associated with the discourse of loss and madness ('losing your mind', 'lose your marbles') to explain their associations of insanity and stupidity from the image's missing piece and the woman's 'gormless' expression. Here we see a return to the stigmatizing association of dementia with low intelligence (see Chapter 4) and insanity, and the students' clear rejection of such discourses as separate from dementia. P28 takes a similar stance, arguing that 'someone could look at that and think, they're loopy, because, a piece missing, this person's a, a lunatic, you know, or something else. You couldn't think "might have dementia" from that, you'd just think "oh, something's missing from her"'. In this account, P28 makes the link between the missing piece and being 'loopy' explicit through the causality of 'because', just as he firmly separates having dementia from having something missing. This leads P28 to declare that the woman in Image 12 is ‘being misrepresented in society’, definitively rejecting this particular loss-oriented representation in the context of having dementia.

Visual case study: Seasonal trees and dementia

Overall, Image 11 (Figure 5.3) emerges as the clear favourite among participants. The responses included here range from Image 11 being grouped with Images 10 or 12 as the more favourable pair, being positioned as ‘better’ than the other three on the same page (P16), to being favoured above all other images shown, with P28 even asking to photograph Image 11 to show people beyond the group. In part, the preference for Image 11 can be linked to the use of more varied and saturated (brighter) colours, which are widely associated with a greater exuberance (Ledin and Machin, 2018b). Image 11’s colours are positioned as ‘nice’, being evaluated as ‘happier’ and ‘more gentle’ than ‘the dim, ones’ (P22), which are critiqued for their ‘quite cold […] stark background’ (P19). However, much of the focus in evaluating the image revolves around the visual metaphor itself, and its perceived accuracy and clarity for representing change with dementia. Image 11 is positioned as ‘meaningful’ (P11, P28) and lauded as ‘clever’ (P11, P22) yet ‘done simply’ (P23). For PG, ‘you can see what’s happening’ with dementia in this image, and for P22, it ‘explains more to me than anything else in the book’. PJ makes explicit the underlying connection with processes in the brain when he declares that ‘I’m going through it myself and. Every time you- looking at this, it explains what happens to your brain’. What is it about this visual metaphor that makes it such a widely accepted, even celebrated, analogy for dementia?

The tree, a ‘symbol of life and image of seasonal change’, is popularly associated with the brain (Zimmermann, 2017: 80). As Zeilig (2014a: 259) explains, the metaphorical connection is so strong that trees influence not only how the brain is discussed but how it is labelled, for instance, neuron ‘dendrites’ mean ‘tree like’ in Greek and are often referred to as ‘branch-like structures’ (National Institute on Aging, 2024). References to a ‘brain forest’ or ‘neuron forest’ can be easily identified in scientific papers and public-facing explanations of the brain alike, ‘because a neuron is more or less similar to a tree’ (Akram et al., 2018; Prasantha, 2019: para.1). Tree metaphors are also an important feature of people’s accounts of dementia (both fiction and non-fiction: Zeilig, 2014a, 2014b; Zimmermann, 2017), to the point that Christine Thelker’s (2018) blog for Dementia Alliance International is titled ‘Walking through the Neuron

Forest … called Dementia'. In an analysis of picture books, Caldwell, Falcus and Sako (2021: 124–5) highlight the use of weeds growing in a garden to represent dementia as tangles in the brain, with the plant metaphor enabling a biomedical explanation of dementia that is grounded in the ordinary realities of a garden for children. For audiences of any age, then, linking trees with dementia can facilitate a biomedically oriented depiction of complex changes in the brain during dementia.

Image 11 explains changes to the brain with dementia through the seasonal decay of deciduous trees' leaves in autumn. This is achieved through the three 'different colours of the season' (P22) corresponding to the increasing loss of leaves located only in the tree heads' side profile where the brain would be. Moving from left to right, the first green tree is full of leaves, the middle yellow tree has begun to lose leaves and by last red tree, the area that would be the brain has very few leaves remaining. Although not mentioned by participants, elsewhere, these three tree head colours have been linked to traffic lights, whereby 'green denotes traffic or life going on without hindrances, yellow is a warning for one to be careful as life is coming to a stop, and red suggests a stop or halt in one's brain activity' (Ang, Yeo and Koran, 2023: 635). The trees' facial resemblance is so strong that some participants refer to them as 'faces' (PI, P20, P22), or 'heads' (PS) rather than trees, while occasionally, the two domains are conflated: 'The leaves are dropping off from the brain' (P26). Many individuals emphasize loss when explaining brain changes through the trees' seasonal cycle. For instance, PM likens a tree losing an increasing number of leaves in autumn/winter to a brain losing cells during dementia:

> That's why these pictures are good because you're suddenly normal, and then you start, to lose more, like a tree, when it's, it's losing its leaves in the winter time […] and then you lose some, like in the winter time your tree will lose some leaves, and then it will lose more, and then it will lose more, and that's just like your brain. It loses more, and more, brain cells.

That PM repeats 'lose/losing' seven times reflects the extent to which loss is foregrounded. The concept of loss is referred to throughout participants' accounts, both directly (P22, P23), and via a range of partially synonymous terms, including 'it's deteriorating' (P22), 'everything's fading away, slowing down, degrading' (P28), 'it's […] dying off' (P28, P30) and 'the brain disappears' (P2). The terms 'fading away', 'dying off' and 'disappears' are particularly reminiscent of other metaphors that more explicitly associate cognitive losses during dementia with a loss of self, particularly dementia being a living death, through which people are positioned as fading/faded and lesser (Aquilina and Hughes, 2006; Behuniak, 2011).

The visualization of internal biological processes is evident even when the image is discussed solely in terms of this metaphor's target domain (the head/brain) without mentioning the source (the autumnal tree). PS tells me:

> The one with three heads, um, I take it or I feel, that that's [the green head], very imperceptibly starting, and then the goldie one is, the tangles are getting worse and the nerve endings are not going through and giving you the right coordination, and then the red one is when it's got destroyed a lot, the latter stages.

Here, PS consistently links increasing internal changes to their external manifestation. Initially, changes are imperceptible: the person is not showing signs of the subtle changes occurring, just as the tree's full, green foliage hides the biochemical processes occurring when, as sunlight reduces, leaves stop making food and the green-coloured chlorophyll molecule begins to be broken down (which will reveal yellow pigments as this process increases). As the 'tangles' get 'worse' and 'nerve endings are not going through' for the 'goldie'/yellow head, PS presents your 'coordination' as affected, an obvious external manifestation that notably contrasts the usual focus on changes to memory. The red head, with its near empty branches, is positioned as when the brain has 'got destroyed a lot' and is firmly situated in 'the latter stages' of dementia.

As PS's discussion of destruction of the brain indicates, this image can evoke quite violent and disturbing descriptions of dementia, to the point that 'at the end your brain's gone' (P2). However, the metaphor is seen by some to soften the underlying discourse of loss and degeneration, as it is 'showing you without the kind of human expression' present in the others (P17). For P10, that 'it's not an actual human face' helps avoid the implication of a 'person's humanity [...] disappearing'. Such responses would seem to suggest that, reflecting the broader literature that ties the tree metaphor to the brain, participants' responses emphasize biological changes and the manifestations of these, as opposed to the emotional, personal aspects of dementia. This is evident in the many evaluations of what the metaphor is useful for, with people such as P2 declaring it is 'ideal for saying what a brain does what's happening when you've got dementia'.

Weaving throughout the above responses to this visual metaphor is the concept of time, an inherent factor in trees' seasonal changes. Indeed, P22 explicitly highlights that 'it looks like it's deteriorated over time'. Participants consistently emphasize the slowness of the progression (often referring to 'gradual/gradually': PN, P2, P7; and 'slowly': PI, P28), while P14 interprets it as meaning a 'steady decline [...] Because Alzheimer's is a steady decline'. This sense of time is achieved through placing three different stages alongside each other, since, as opposed to the one moment in time captured by the other images, here, moving from left to right, 'you can see how it's going along' (P21). As such, P28 declares that 'You trace it from the beginning, everything's fading away, slowing down, degrading [...] it's just slowly dying off, so that is one way, of portraying it.' To this P30 adds that 'in some it's quickly dying off, like in [my husband]'. Clearly, P28 and P30 agree on the underlying discourse of 'dying off' over time, as it is the speed with which this process can occur that is debated, based on P30's experience of her husband's quick progression, until they concur that 'you can't put a time limit' on this (P28). Notably, the movement from left to right reflects the reading process in Western cultures across the page, and the associated trend noted by Kress and van Leeuwen (2021), whereby information on the left is deemed already familiar, or 'given', and information towards the right-hand side is less familiar, or 'new' (180). According to such a theory, the green head on the left is positioned as the 'normal' person (PM, PN) and moving right reflects not only time passing but a shift away from the familiar to the unfamiliar, abnormal state of increasingly progressive dementia.

The seasons metaphor is sometimes used to situate dementia within the overall life course, whereby the metaphor that a lifetime is a year generally positions springtime as youth, summer as adult maturity, autumn as older age and winter as the end of life (Lakoff and Turner, 2009: 18). Elsewhere, individuals normalize their dementia within the life course using this metaphor: 'Like leaves fall to the ground from a tree, old people lose their memories' (Langdon, Eagle and Warner, 2007). Here, though, when P11 interprets Image 11 as situating dementia as a natural stage of reaching 'winter', she resists this by arguing that 'not everybody who gets to the fall of their lives is going to [get dementia], but of course, a large proportion are'. Taking a broader perspective of health, P33 quickly identifies 'summer, autumn, winter', and positions winter as the last stage of life, explaining that 'unfortunately winter is when things don't start working right [laughs] in people's body'. Meanwhile, P2, whose partner with dementia is aged seventy-three, explicitly locates dementia as the endpoint of older age: 'As the brain disappears that's when you're younger when you're all bright and (xxx) and as you get older your brain starts to go and as you get Alzheimer's or dementia your brain goes away.' She later adds that 'you start off young and vibrant and then gradually your brain starts to go and then at the end your brain's gone'. Mirroring the metaphor of decaying leaves and drawing on the discourse that dementia is a natural aspect of ageing, P2 establishes three stages: (1) green: being 'young' (which is marked by being 'bright' and 'vibrant'), (2) yellow: getting older, whereby 'your brain starts to go', and (3) red: where with dementia 'your brain goes away' until it is 'gone'. This speaks to a core aspect of the seasons metaphor when it ends with winter: there is no spring, no renewal. Instead, abilities, brains and/or lives, according to what is being discussed, degrade until, in time, they disappear.

The change portrayed in Image 11 is not constrained to a dementia context. P33 jokes that it could be about hair loss, while PN initially declares that 'it's how. most. people get eroded I mean, it could be a child couldn't it. if the child is starved of imagination and. love and care.' Despite situating the image in non-dementia contexts, both accounts clearly engage with the image as a means of metaphorically conveying loss, with P33 positioning it as external (loss of hair) and PN as internal (a wearing down of a person through their environment). PN's interpretation is particularly striking, as she draws on another source domain, erosion, to position people of all ages as vulnerable to the effects of their surroundings, in which adverse exposure (here to a lack of care, love and imagination) can gradually wear away at individuals. It is notable that when in a dementia context, the eroding force is attributed to internal changes from the condition, both in these interviews and in published written works (see Zimmermann, 2017: 80). By considering the image in a broader life setting, PN foregrounds another essential factor in people 'degrading' or becoming 'eroded' (P28): that of a person's social environment. This integral social factor seems to be missing when this image is applied to dementia, whereupon it becomes a biomedically oriented metaphor for degeneration.

As well as accepting, praising and reproducing many of the metaphors communicated by Image 11, participants show multiple moments of resistance, both to Image 11 and its counterparts on page 3 of the Appendix. For instance, P5 dismisses the four images as 'too stark' and reductive, emphasizing that 'there's a lot more to dementia than they are portraying' (P5). The contention surrounding Image 11 is epitomized by the following exchange between two members of another focus group:

PK Dementia doesn't quite work like that does it, it's not a straight line […]

PM -That's why these pictures are good because you're suddenly normal, and then you start, to lose more, like a tree, when it's, it's losing its leaves in the winter time

PK But they point, as three stages
PM Yeah but it is #stages#
PK #You# could have a forest, of those trees-

Having examined PM's contribution earlier, the focus here is on PK's two main criticisms of the image's underlying discourses. First, recognizing the linearity of the direction of time (left to right) in the image, PK emphasizes that dementia is *not* a linear decline, as evident in his metaphorical conceptualization that 'it's not a straight line'. Second, he resists the 'three stages' as an oversimplification of the reality of dementia, suggesting instead that a 'forest' of trees would better represent its diversity. Intriguingly, PK's arguments are remarkably similar to those of the other dissenters across the groups. Throughout, people present the multiplicity, individuality and changeability of dementia as their key counter-discourse.

Participants consistently critique the linearity and finality of the images' depiction of progression with dementia. P1, whose wife used to have dementia, argues that Image 11 'apparently shows a constant deterioration whereas if you've been with someone who has dementia you know that that's not the case', as there are 'moments of lucidity and those moments it's as if everything is restored, even the memory, and you can't cope because within a second it's […] gone'. Rather than a forest, he suggests altering the image to show 'leaves floating around because it can always come back'. The group supports this as a more accurate portrayal and later P3 returns to P1's idea of incorporating changeability, adapting the tree metaphor accordingly:

> You know, it feels like ah I've got dementia I look at this – everything in my head is just going to dissipate you know but from my experience that's not true, and it's just like what P1 said about how the leaves, they do gravitate around the tree and sometimes they come back, you know and I think that's very true and I think these images kind of take away from that silver lining, you could say, that people with dementia. I think it's a very good point about the trees- the leaves do stay around the trees you know sometimes they settle back down, sometimes they blow away.

P3 touches on a flaw in the autumn to winter metaphor for trees here, that leaves, once fallen, cannot reattach. To get around this, he extends the conceptualization of what it means to be lost, highlighting that leaves 'do gravitate around the tree' and can 'come back' in the wind or 'settle back down', still with their tree, separating this from the permanent loss of 'blow[ing] away'. This possibility of things to return is the 'silver lining' that he suggests Image 11's linear degeneration is currently missing. Focusing instead on the metaphor's emphasis on decay, a couple from the same group, PC and P5, argue that 'your brain's not decaying, it's just not working properly. in different areas' (P5). Subsequently, PC tells us how 'I can talk about all sorts of things, if you ask me about something I did yesterday I can't remember […] But er, I've done quite a lot of fairly interesting things in my lifetime and er (I remember all them)'. Rather than the finality of the degeneration implied by decaying autumn leaves, this group advocate for a focus on partiality and flux, as you certainly do not lose everything with dementia and losses are not necessarily permanent.

In another focus group, P18, whose grandmother had dementia, recommends varying the areas experiencing leaf-loss to demonstrate that the effects of dementia for people can be unpredictable, changing on a day-to-day basis:

> I think like with the tree one, if they had it and, it's like, yes, things are missing, but like like different, like if the head sort of like if there was one and then part of it was missing and the other one was like that, another part, but not the same part was, missing you know what I mean, because we're saying like things do come back once in a while so it's like. You never know what you're going to get. Like when I go visit my grandma's like I'm either going to get the grandmother, I grew up with, I'm going to get the grandmother, my mother grew up with so it's like. But that's still them. You just get a different part of them when you visit.

Extending the changeability of life with dementia, where a 'missing' 'part' can return to people, P18's account positions the person as a constant ('that's still them'), and just as presenting 'a different part of them' depending on the day. This reflects the fluidity and relational nature of self (Sabat, 2018), something that P3 also recognizes: 'The person that we all know or whatever isn't leaving, they're not disappearing as the pictures kind of portray in a very this is what's going to happen. It's not as simple as that, it's very hit and miss, come and go, very personal, very built within that relationship or that person not just that it's gone.' Here, P3 foregrounds the personal, embodied and relational aspects of identity, emphasizing that identities are 'built within' our relationships and beings, and therefore cannot disappear. Both P3 and P18 strongly resist the images' underlying discourse of loss of self, instead presenting a more nuanced alternative conceptualization whereby people have plural and fluctuating identities that are in part held by their relationships with the people around them (Hughes, 2014).

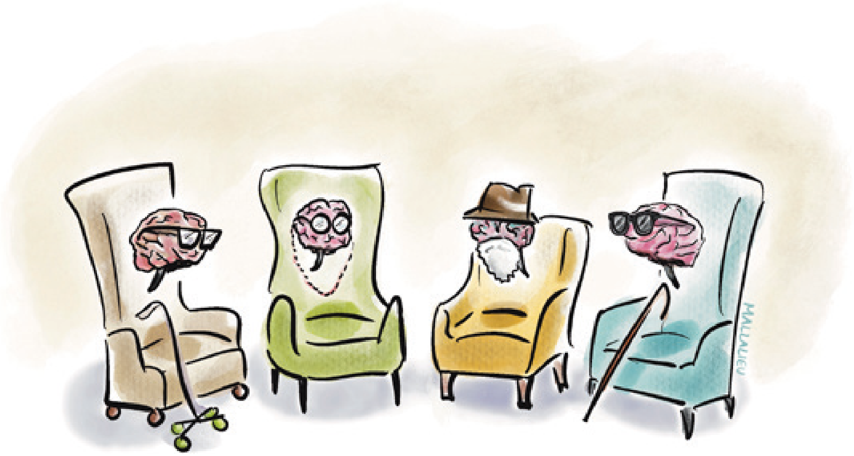
It is with these counter-discourses that participants highlight that people with dementia are far more than their progressive biomedical condition (Bryden,

2020) and offer creative solutions to better match the visual metaphor to their experiences of dementia and identity. What becomes increasingly evident through the debates in this and other sections is the subjectivity of truth – it is through this phenomenon that for the very same image of the trees, PM asserts that 'they [are] true', while PK equally confidently responds to her that 'no it's not true'. In another group, P5 offers us an insight into her personal perspective and her subsequent emotional response to the pictures: 'They're kind of hopeless pictures to me and dementia in my case, I can only speak personally, it's not hopeless to me. It's difficult sometimes, it's funny sometimes and that's just portraying the brain decaying.'

5.5 Summary

Accounts of experiencing life with dementia in this chapter foreground both change and continuity, and both losses and gains. The range of perspectives on life with dementia are showcased by people's different interpretations and responses to the metaphors examined throughout this chapter. When discussing visual metaphors, for instance, while many participants commend the simplified biomedical explanations of brain changes, particularly for Image 11, other participants resist the underlying emphasis on loss and degeneration in the biomedical discourse. Such individuals counter this with representations that instead emphasize the multiplicity, individuality and changeability of dementia, alongside a more holistic approach to selfhood that incorporates relational, embodied and contextual aspects.

When reflecting on language use, overall, participants indicate a need to acknowledge that experiencing dementia can involve suffering without reducing people with dementia to sufferers. Whereas participants with dementia more often identify with and are inspired by an individual approach to 'living well' as an empowering concept, carers might focus more on relational and environmental factors in supporting people with dementia to live well. Multiple participants position 'living well' as unrealistic, and thus as contributing potentially harmful expectations, which reiterates existing criticisms of the discourse (Beard, Knauss and Moyer, 2009b; Hillman et al., 2018; McParland, Kelly and Innes, 2017). Both popular and more idiosyncratic metaphors are examined as a means of expressing complex and intangible experiences with dementia. Here, fighting metaphors incorporate personal growth and more socially oriented battles, expanding the existing focus on primarily biomedical applications of this metaphor (see also Castaño, 2020, 2023). Throughout, participants' engagements with both linguistic and visual metaphors showcase the personal and creative nature of representations, demonstrating that the discourses of people affected by dementia are a rich source of alternatives to, and adaptations of, dominant discourses.



You don't go into a care home and just see brains, sort of, floating there [laughter]. You see people.

—Participant 19

Figure 6.1 'Brains [...] floating' illustration (Josh Mallalieu, artist).

6

Medicine, media and experience-led expertise

6.1 Introduction

This final analysis chapter ties together much of the preceding discussion by exploring the interrelationships between medical, media and personal spheres when it comes to life with dementia and advocating for better support for people affected moving forward. The present chapter begins by examining how participants situate themselves in relation to biomedical discourses, technologies, figures and practices. As Figure 6.1 indicates, this includes a discussion of the brain in relation to dementia and how individuals are positioned in relation to their brains. While some participants are staunch advocates of biomedicine, others question its practices and expert status, particularly regarding the decontextualized knowledge on which clinicians' expertise is founded. This tension is exemplified by a debate regarding prioritizing finding a cure versus better supporting people affected by dementia. This leads on to examining how people experience dementia as a social being rather than a patient (Sabat, 2018), particularly attending to how participants construct relationships with other people affected by dementia through peer support. After establishing that people affected by dementia gain a type of expertise through experience that can complement medical expertise, the chapter concludes by exploring how participants draw on their personal experiences of dementia to critique media representations and recommend ways to improve such representations moving forward.

6.2 The brain and dementia

When discussing words that he dislikes, PC argues that 'you don't get any sort of sympathy for dementia. If you've broke, if you've got say half your leg missing everybody's jumping up and all that but dementia doesn't always show'. PC is not alone in contrasting dementia with the obviousness of missing or broken limbs; in another group, P13 declares that 'a lot of people with dementia don't look ill do they they're not ill it's not like having a broken arm'. It becomes clear that 'it's very difficult when people look alright' (P4), as understandings of health and sickness are often tied to external manifestations of (ill)health, motivating people to seek ways of visualizing internal conditions (Cohn, 2010).

While the above participants compare dementia to a broken limb, many others look to medical images, such as brain scans (which in a dementia context include but are not limited to CT, MRI, fMRI, EEG, PET and SPECT scans; see Taylor, 2022) to make these internal biological processes in the brain visible. This visualization can thus validate people's experiences by 'mak[ing] the illness external' (Cohn, 2010: 74). Brain scans compress a complex reality into a clear, aesthetically pleasing visual resource that is often positioned as objectively making visible, in a hyper-realistic way, what human eyes cannot see without technology: the brain and its processes (Beaulieu, 2002; Dumit, 2004; Harvey and Brookes, 2019). However, it is important to recognize that brain images are not objective but 'stylized representations' (for example, they might exaggerate small statistical differences for viewers through stark colour contrasts; Dumit, 1999: 174).

Overall, participant narratives support the explanatory power of brain scans in a diagnostic context, with P2 positioning them as able to 'tell you whether the brain's been damaged', irrespective of external signs, as 'we didn't know PA had had two strokes but his brain scan showed us that he'd had two strokes so that's how his dementia started'. Elsewhere, P6 promotes the importance of being able to tangibly 'see' brain damage on a scan. She recalls that when her mother had 'a TIA [a transient ischaemic attack, also known as a mini stroke] she would often get, nasty, very nasty and say nasty things and, scratch and all this sort of thing', even though 'she was the sweetest person actually'. P6 therefore emphasizes that 'it's important, that people understand, that's because her brain has been, damaged' rather than being angry with her for her behaviour during these times. According to P6, the insight that brain scans give can help promote greater tolerance and improve the treatment of people with (here, vascular) dementia by shifting the responsibility for behaviour from the person to their biological 'changes'. This indicates that defining dementia as a medical condition can lessen blame felt by the individual or their family by foregrounding decontextualized biological causes, such as 'a "mistake" of nature', pathogens, life cycle transitions and/or ageing, rather than the person themselves (Lock, 2013: 14).

As P6 and scholar Joseph Dumit (1999, 2003, 2004) highlight, brain scans have wide-ranging implications for interpreting both health conditions and individuals' identities beyond the diagnostic context. Brain scans are highly technical and persuasive; they are what Dumit (1999: 173) terms 'expert images', since they are imbued with scientific authority and are difficult for non-experts to interpret and understand without appropriate context. This inaccessibility is exemplified by participants' responses to Image 17 (Figure 6.2), with P12 declaring that 'I don't think anybody without medical training would be able to tell what [the scans] portrayed'. Numerous participants show difficulty initially identifying the brain scans:

P23 I don't [laughs] I don't understand it I'm sorry [laughs]

Emma No no a lot of people don't so this is one of the points is, do people know what this is about because I agree that it's a bit ambiguous

PI I don't know what this is

P23 I suppose you'd have to sit and study it and then you would understand it a bit more but immediately you don't

Figure 6.2 Brain scan (Image 17) (Andrew Brookes/Connect Images via Getty Images).

P22 What's it supposed to say?
PJ That's the brain that is. That's the brain
P22 Well I would say it's all to do with the brain
P23 Charts of-
PI -That's the brain isn't it there
P22 X-rays of a brain?

Admittedly, the stylized effect of the photo (see the prominence of the different coloured lens flare, in primarily pink and blue) provides what Harvey and Brookes (2019: 996) suggest is an 'ethereal quality' that is at odds with the scan's hyperreality; were we to look at the brain scans featured here in real life, they would not be bordered by the abstract shapes of the lens flare. This stylized presentation likely contributes to some participants' difficulty in interpreting the image ('I hadn't got a clue what it was to be honest, it looked like a disco': P6). In our interview, PS's description of the image foregrounds these stylistic features and format: 'Signposts, but, you see, clearly here and then it's fading. You can't read it there. And then, it seems to be oblivion there. Erm. These could be the cells, indicating the cells that. I don't know, you tell me what it's about.' Despite her difficulty in ascertaining what the image shows, PS still clearly relates the image to a biomedical context, substituting the brain for the micro level of the 'cell'. Even when participants are confident that the image shows brain scans, they suggest that 'the everyday general public' would not know what the scans actually show 'unless you're into technology and things' (P22). Indeed, one focus group humorously relate the image to a 'murder documentary' (P18) or science fiction films ('like a nineties Independence Day or Godzilla. It's like the battle plan': P19; 'They're using one hundred percent of their brains, what shall we do?': P18).

Such responses reinforce that without the appropriate knowledge, these scans become meaningless as diagnostic tools, making it important to consider wider discourses that tend to be drawn upon, including that of the brain's relation to personal identity (Dumit, 2003, 2004). At best, participants identify that the image is 'obviously a scan' (P12) and that 'in this context, it could be, the the type of, a type of, dementia' (PH). In another focus group, P28 points out that the scans, despite being used here to represent dementia, could, for all they know, be portraying 'anything' related to the brain:

P28 Number 17 just looks like, they're doing scans for a tumour
Emma Yes
PQ Yeah

P28 that does, or it could be anything couldn't it that could be cancer of the brain, anything, that's not portraying dementia that's portraying everything-

P32 Unless you know what a scan of a good brain looks #like# you won't know

Instead of representing specific processes and changes in the brain, a different, more general meaning emerges. This is exemplified by P32's contribution, which indicates the existence of a 'good' – and implicitly a 'bad' – type of brain. This is a key criticism of brain imaging techniques, as they consistently mark human differences, 'dividing us and measuring our deviation from "normal" ' in a way that reinforces an 'us' versus 'them' discourse of people who are 'normal' (with a 'good' brain) versus those who are 'abnormal' (Dumit, 2003: 36). These distinctions oversimplify reality; for instance, the density of amyloid plaques and neurofibrillary tangles in someone's brain does not clearly correlate with normal or abnormal cognitive function, despite being considered a hallmark of Alzheimer's disease (Lock, 2013; Whitehouse and George, 2008).

That brain images can greatly impact lay understandings is indicated by a group member's subsequent response to Image 18 (Figure 6.3), which visually realizes a biomedical discourse through icons of medicine such as the white lab coat, a surgical instrument and the isolation of bodily organs (here a 'fleshy' (P10) brain). Building on Chapter 5, Image 18 is clearly metaphorical, since the brain is patterned as a jigsaw, and one of its puzzle pieces is held by a hand in a white coat using a surgical instrument. Echoing the brain shrinkage (cerebral atrophy) that brain scans often visualize (Taylor, 2022), P29 challenges the brain's fleshiness and apparent health, arguing that 'to portray dementia you won't have much of a brain there', since 'the brain is shrinking, from the core'.

In our hypercognitive society (Post, 2000a), conceptualizing people with dementia as having a degrading, abnormal brain has significant ramifications for identity, since the two are so entwined. This reflects a phenomenon that Vidal (2009: 6) terms 'brainhood': 'the property or quality of *being*, rather than simply *having*, a brain'. In such a cultural context, images of the brain can be regarded as showing 'a disembodied self' that offers viewers a narrow way to make sense of themselves, their thoughts and behaviours (Cohn, 2004: 71). Indeed, whether participants reproduce or challenge the incomplete jigsaw metaphor in response to Image 18, there appears to be a conflation between a person's brain and their overall being. Reflecting on her husband with young-onset dementia, who at the time of our focus group had had to move into a care home, P30 states, 'But I mean

Figure 6.3 Brain jigsaw (Image 18) (John M Lund Photography Inc/DigitalVision via Getty Images).

number 18 has got one, one piece of the jigsaw missing. My husband's probably got three quarters of the jigsaw missing.' A sense of extreme loss is achieved through P30's inference that rather than missing one piece, her husband only retains a quarter of his personal jigsaw. Since only her husband is offered as a subject here, whether P30 is implicitly referring to his brain (likely due to the comparison to the brain in Image 18), or whether she is referring to her husband in his entirety is ambiguous. Either way, that there is not a clear distinction between her husband and his brain is telling. There is a similar ambiguity regarding the location of the missing piece(s) when participants from the Memory Café challenge the underlying metaphor of being incomplete:

P5 People used to say that years ago ooh there's a bit missing it's derogatory
P1 And, it's not true
P5 No
PC Of course not. I hope not! [laughs]

PC's response 'I hope not!' is a timely reminder that it is unlikely that anyone wishes to be seen as being less than a whole or "normal" person, here, through being compared to an incomplete puzzle. Perhaps the clearest instance of the conflation between the brain and personhood is in P28's critique that Image 18 is 'making it look like other people are taking pieces out of there and not, not the brain itself', preferring Image 11 (which shows three head-shaped trees with increasingly bare branches where the brain is, analysed in Chapter 5) since 'you're being degraded, on something like that, so, it's quite an effective picture there'. Here it is you, the person, who is being 'degraded', as opposed to the brain. This is another instance of the manifestation of hypercognitive values (Post, 2000a), in which 'the-mind-in-the-brain' (Beaulieu, 2000) is the locus of personhood, making your brain indistinguishable from your identity and status as a person.

The counter-discourse that people are certainly not reducible to their brains is humorously explored in response to Image 18 through the PhD student focus group, who expand on what they evaluate as a 'creepy' (P17) image by imagining P19, who was previously employed as a care worker, working in a care home filled with floating brains:

P19 -also let's be honest, brains are not the most attractive thing in the world [group agreement] and if you put, a face, to it, it's suddenly going to be a little. Like you don't go into a care home and just see brains, sort of, floating there [laughter]. You see people. I guess so, well.
P18 Yeah. Well, I gu- depends where you are I guess,
P19 Maybe in a weirdly themed care home
P17 This doesn't really happen then? [Laughs]
P19 No. we're constantly just like hoovering bits up off the floor [laughter] "Clive!" You know
P17 "Oh Clive"
P18 Just like taking some super glue and like carefully replacing little bits, yeah
P19 Like ceramic
P17 This is not, a representation of your job then, trying to fit, fit-
P19 -It's not. That's all we did. I didn't get a lab coat either.

Through creating a ridiculous imaginary scenario, in which the carers must constantly hoover up, or try to reattach, 'little bits' that a floating brain named Clive continually sheds, the students challenge the discourse that 'we are our brains' (Gillies, 2009: 74 in Zimmermann, 2017: 87), and by extension, that brain atrophy equals degradation of a person. Here, the brain damage associated with people with dementia is made literal, with the suggestion that, like with ceramic, carers could attempt to reattach these lost ‘little bits’ if people really were losing pieces of themselves. Through this scenario, the students reinforce the fact that, in reality, you do not ‘just see brains […] You see people’. Their emphasis on personhood over people’s biology reflects a wider movement to see beyond damaged brains and value the person above their dementia, which is widespread in accounts of people with dementia and their supporters (Bryden, 2016; Hillman et al., 2018; Talbot et al., 2020).

When P19 jokes above that ‘I didn’t get a lab coat’ (an iconic symbol of hospitals and laboratories), he separates his professional caring role from the clinical realm. This brings us to the other notable component of Image 18: the hand of someone in a white coat, which, using a surgical instrument, holds the missing puzzle piece. Who does the hand belong to and what are they doing with the piece of the brain? This image is widely agreed to be ‘ambiguous’ (P7, P8) and something that participants are ‘not sure about’ (P22). From the ‘white slither’, P8 ponders: ‘So is that a clinician, is it a research person is it a clinician?’ The figure’s action appears no less controversial, with people wondering if the person is ‘removing’ the piece (P7) or ‘putting it in or?’ (P9). PI raises that it might be both when she declares, ‘Took a piece out hadn’t they. Putting it back in again.’ Some participants suggest that it might be a ‘surgical intervention’ (P11), remarking that ‘you can’t put a piece of your brain back in so, it’s silly’ (P6). Meanwhile, others read the action metaphorically, aligning it with ‘research into dementia and trying to get that final jigsaw, piece of the jigsaw put back in again’ (P16). Participants indicate that this missing piece metaphor for research is an oversimplification of a very complex reality, wishing ‘if it was only so easy’ (PH) as ‘it’s not a matter of putting the missing jigsaw bit back in is it? It’s more complex than that’ (P12). Following his research interpretation, P16 acknowledges the uncertainty within his interpretive process, stating that ‘well it could be picking it out but, suspect it’s trying to fit it back in [PG laughs]’. Context is likely playing a key role here, something that another group confirm explicitly:

P9 I thought if it was fundraising [group agreement], this side, it was about finding a cure or putting #(the missing piece back in)#

P7 But, yes but I would have only have thought that because of the #other ones#

P9 #Because you’d seen it# with the fundraising

P7 Yeah

Emma If you don't look at the other ones, what would you think of this bottom left [18]?
P8 What, on its own?
Emma Yeah
P7 I think it is very ambiguous [group agreement].

This is a very clear illustration of the influence of my framing as a researcher on participants' contributions. Here, the selection and layout of the four images (see page 5 in the Appendix) is positioned as encouraging people to link Image 18 with 'finding a cure' and putting 'the missing piece back in' because of interpreting the accompanying charity images as 'fundraising' (P9) and seeking a connection between these and Images 17 and 18. Putting the contextual influence aside, what is already emerging is the mixed reaction to the role and helpfulness of the figure in Image 18. More broadly, beyond responding to these images, participants position biomedicine and medical practitioners differently; a trust in scientists/clinicians to offer the solution to dementia is contradicted by others' wariness of these experts and in the ability of medicine to help. It is to this issue that I shall now turn.

6.3 Representing the role of medicine

Participants present various stances on the medical sphere and the extent to which dementia is and should be medicalized. While some participants indicate a desire to 'move away from the clinical, medical, stuff' (P19) and prefer non medicalized contexts (P6), in the working-age dementia group, the carers express frustration that dementia is not medicalized enough, directly linking biomedical explanations of dementia with more resources and support than they currently receive. P30 passionately declares:

> Dementia is a disease, it's the same as heart disease. If your heart is, if your heart muscle dies, you will die. Dementia is the brain dying. So, what, what's the difference between your heart muscle dying and your brain dying because one's portrayed as medical, and one's portrayed as social [...] it's a brain disease.

In contrast to the earlier participants' comparison of dementia to an externally obvious broken leg, here P30 positions dementia as the 'same as heart disease', a better understood and treatable, but nonetheless internal, condition. Here, both are positioned as diseases caused by organs 'dying' and are used to argue that dementia 'should be the responsibility of the NHS and not the local authorities', with the latter being depicted as having 'no money' (P32), 'not [being] educated in' dementia (P30) and as reluctant to 'fund anything' (P28). Returning to the issue of social stigma, P28 recalls that she and her husband 'went to the doctors and were told it were social they don't medicate', feeling amalgamated with 'alcoholics, drug abusers, because that's a social disease. My husband's never drunk in his life let alone took drugs'. Here P28 separates her husband from people exhibiting socially undesirable traits to resist his placement in the same group by healthcare services, through the categorization in this context of dementia as 'a social disease'. P28's account returns to the earlier point that medicalizing dementia can help reduce social stigma by foregrounding a biological explanation (such as 'your brain dying') over individual responsibility (although, of course, the two can also be combined in a potentially stigmatizing way through an individualistic focus on the self-management of risk; Putland and Brookes, 2024a). This particular group of participants, then, position the medicalization of dementia as a means of reducing stigma and achieving better financial and interpersonal support. Yet, as will be explored further in the next section, the same members also distrust the expertise of many healthcare professionals and the efficacy of drugs, presenting a complex, tense and contradictory relationship with medicine.

For some participants, medical research, treatments and working towards a cure offer hope, especially for people with a dementia diagnosis. Reflecting upon his experience of biomedicine, PJ foregrounds the importance of learning and researching for saving lives, including his own:

PJ I think it's a good idea. People will get into this seriousness of looking into people's brains, inside their skulls […] you've got to learn, and look into these things. Because if we hadn't got these (xxx) people I don't think I'd be, here at the moment, with the trouble I had. You know, a lot of people keep going in and (xxx) nurses, and students, looking into-

P23 -to, the research-

PJ -researching things. I think it's a good idea. Brilliant. Yeah.

Explicitly picking out 'nurses, and students', PJ presents himself as indebted to the people involved in research and medical care, as he would not 'be here' without them. Similarly, PS foregrounds the importance of medical treatments when she discusses her reliance on her medication (donepezil) for managing her Alzheimer's, which she positions as 'my lifeline'. Looking to the future, PS references the success of medication in her life to support a case for potential advances, hoping that one day society will 'find something that will say, there is a cure for it. Because donepezil had to be found'.

Building on Chapter 5's exploration of a fighting metaphor, multiple participants position biomedical research as offering them hope through the promise of a future cure that can ultimately defeat dementia. In our interview, PH, a sixty-one-year-old retired headteacher and self-identified physicist, argues that a hope for defeating dementia entails trusting 'very clever' biomedical experts to achieve this: 'I hope, that that is the case. And I hope that somebody who is very clever, will sort it out.' In the meantime, PH has signed up to local university research because 'You know, never know I might get a trial drug [laughs].' He situates the 'actual chances' as 'minimal, probably almost lottery like [laughs]. But erm, I just think it's a good idea to. think about it and, do it, you know, so I signed up'. PH's account presents the very action of him thinking about and being involved in clinical research for an effective drug as 'good' for him, indicating the hope that he, as a person with young-onset dementia, takes from even 'minimal' chances of treatment that will improve his experience. PH draws on 'how much medical science has advanced, in the last, ten years' to argue that even if not in time for him, 'I'm sure it'll happen. By the time you're [referring to me as a researcher in her twenties] my age you'll be er, you'll be able to ignore it.' This contribution reflects a broader commitment of people with dementia to participate in research in the hope of benefitting science, future generations and their own lives (Beard, 2016). Throughout our interview, PH consistently emphasizes that 'without [a cure], you can't go anywhere', positioning biomedical advances as the counter to his 'degradation' and 'gradually slipping back'.

While biomedicine is positioned by the above individuals as both life enhancing and lifesaving, other participants complicate the picture. This is exemplified by portrayals of drugs, since, contrasting PS's 'lifeline' medication, some participants highlight bad side effects, difficult transitions between drugs and their uncertainty about the effectiveness of certain treatments. Sometimes no medication is presented as better than dealing with the side effects, as for P7's father, 'I think my dad tried a couple of types of medication which had bad side effects so it really wasn't worth him pursuing it.' Reflecting on going through 'three different drugs' with his wife, P1 foregrounds the notion that not only can the medication 'cause more problems' than the dementia, but that when 'the side effects become so great that they decide to change […] you've got a very difficult period of weaning one off and bringing the other one in'. Such is the impact on the person taking the medication that P1 likens the point at which 'it can settle after that period' to being 'in a different world altogether'. Alternatively, P14 expresses the difficulty of telling, on an individual level, whether medication has been helpful, since 'it's six years now and we don't know what [PG] would be like if he hadn't had them'. If you cannot see a change or compare what you would be like without medication, you can only trust that the medication is doing what it is 'supposed to', which for P14 is 'to slow down the memory loss'.

Medical versus lived expertise

Trust and the related issue of social power emerge as a consistent thread among participants' discussions of medical professionals and biomedicine at large. PM explicitly raises this when she discusses her diagnosis: 'I've got dementia, I've got impairment, prescribed, by a consultant, and you have to take his word for it, don't you.' Through her declarative clauses (i.e. statements), PM presents the consultant's diagnosis that she has 'got' dementia and 'impairment' as her present reality. PM's subsequent clause, that 'you *have* to take *his word* for it' (my emphasis), foregrounds that the consultant is the person who has proclaimed this state of the world, whereby PM has dementia/impairment. Here, patients must trust and accept the consultant's perception of the world, reproducing the traditionally unequal relationship between a medical professional as the voice of 'biomedical expertise' and their patient (Gwyn, 2002: 64).

Although many people accept this practitioner–patient dynamic and place their faith in the expertise of medical professionals, in the working-age dementia group especially, a dissatisfaction with and distrust of the voices of medicine emerges. This distrust is exemplified by the following conversation that contrasts the medical experts' claimed efficacy of drugs against the carers' experiences and opinions:

P28 They say the drugs, slow it down, but I feel,
P30 I don't think they do
[…]
P27 #and I think it only slows it# down then for so long anyway don't it, they say the first eighteen months like I read about that donepezil
P28 So, these drugs they're giving out, I'm not sure, one hundred percent what's in them but I don't think it's doing what they say, it's doing #because I've looked at other people#
P30 #they're not sure themselves#

The carers in this group consistently establish two opposing voices in this exchange, the unspecified medical professionals ('they say' is repeated three times), versus the focus group participants. Almost every conversational turn disputes a claim from the medical professionals, who are distanced as a collective 'other' from the group of participants through the constant use of 'they'. This delegitimization culminates in P30's statement that 'they're not sure themselves', directly challenging the expertise of the experts through anecdotal observations in a way that is atypical of many but not all participants. For instance, in another focus group PK provides a similar challenge, that 'the professionals sometimes are not very professional'. He evidences his claim by telling us of an 'experience' last September when 'my GP packed me straight off to a stroke clinic' for an MRI (magnetic resonance imaging) scan but the consultant neurologist told PK that '"there is no evidence of a bleed, therefore you have not had a stroke"'. PK's issue here appears to be with the neurologist's certainty that a stroke has not occurred, implicitly questioning the ability of technology and consultants to always provide a definitively correct answer. The tension between being both beholden to medical professionals, and dubious of them, is most extreme for P26, who identifies as a 'free thinker' and tells me in our interview, 'You'll always get people that live on the doctor's words. I never have […] I've been quite disappointed in the past.' Yet, despite consistently questioning individual practitioners and medicine as an institution throughout our interview (for instance with 'Doctors don't know'), P26 nonetheless relies on doctors to help her mother when she is unwell, pressing doctors to visit her mother and provide second opinions when she is 'poorly'.

By comparison, an individual such as PN, who supports biomedical research to the extent that she participates in studies, may also establish an 'us' versus 'them' narrative to indicate a dissatisfaction with current practice, here the distance between her and biomedical professionals' understandings. Responding to Image 17 of the brain scans (Figure 6.2), PN argues that as a research participant 'you only see your side of it. You don't see, medical side, they don't say come and have a look, in the office' at the 'MRI scan'. These two sides (the person's and the 'medical side') are linguistically achieved through the separation of 'you' (here, a research participant) from the 'they' of medical professionals. The 'office' that 'you' cannot enter spatially establishes a hierarchy that privileges researchers and makes certain medical knowledge, here PN's brain scans, off-limits to her. She would like to see her brain scan, as 'I've had three now and yet I feel that. I'm being used as a guinea pig […] Not as a participant'. Instead PN wants 'for them to tell me what I should understand and wha-, and why. And why […] I think that would be interesting'. Returning to the status of brain scans as 'expert images' (Dumit, 1999), PN reinforces the reliance of the lay public on medical experts to explain the meaning and implications of these scans. PN positions herself here as wanting to be an active, engaged 'participant' with a desire to learn new things, but as being disempowered through the normalized practices (as this occurs 'three' times) of medical research, in which she is a passive recipient of researchers' actions and is consistently excluded from the conversations that would help her to understand the 'why'.

Presenting distinct areas of expertise, numerous participants articulate a need to bridge the divide between professionals and people affected by dementia by collaborating and sharing their different forms of knowledge. In our interview, P33 emphasizes the need to 'hear other people's opinions' because 'the doctors, the specialists, for a long time were blinkered. They, had, the, idea, of, what, to, do. And not listen to the carers'. Here, P33 resists the traditional unidirectional dynamic of a doctor–patient relationship, emphasizing the need for reciprocity, notably through listening to carers. Reflecting on hospitals more broadly after her recent hip surgery, PN highlights the lack of understanding that many medical professionals have: 'The. staff and administrative staff at the hospital, didn't know enough about dementia, and all they had was the experience of one patient that they had recently and, and I fear that, it wasn't [2.8] it wasn't a good representative of people living with dementia.' While PN challenges the homogenization of people with dementia that stems from inexperience, P28 also critiques certain specialists' knowledge of dementia as inadequate, despite providing guidance to people affected:

> But, half of these specialists, haven't lived with the dementia. So they don't really, understand it. It's easier for them to say "look this is what can be done here's a piece of paper follow this". It's rubbish there is no kind of guideline on a piece of paper that you can actually follow. So, they ought to, live with someone with dementia for a week, […] Two weeks, to get a better understanding of what dementia is all about. Because all they see is someone sat there, not responding to the questions but there's other things that you can do to help someone through that, times of grief and everything, 'tis awkward, but they don't understand it. Some of the specialists you look at them and you think, "nah. Waste of time".

The 'piece of paper' repeatedly referred to in this account arguably acts like a metonym, standing in for the specialists' (lack of) expertise. By recommending the paper guidelines that P28 evaluates as 'rubbish' and inapplicable to actual life beyond the institution, these specialists' advice is disregarded as thin, irrelevant and something to be ignored and thrown away. Medical knowledge is not the form of understanding that P28 is concerned with here; 'understanding' is repeated three times and is twice explicitly linked to understanding through actually *experiencing* living with someone with dementia. P28 is far from the only person to foreground experience as the means of gaining a true understanding of dementia; when discussing organizations being accredited as dementia friendly, P14 asks, 'do they actually understand though? I don't think. Until you actually live with it I don't think you ever do', while PK similarly highlights to his group that as people with dementia 'we understand, what it's like to have dementia', whereas others do not. Throughout P28's above account, he positions himself and other carers as 'experts by experience' (Parveen et al., 2018) who can see more than the specialists, since 'all they see is someone sat there, not responding to the questions' (P28; for a critique of inappropriate questioning methods in clinical assessments see Sabat, 2018). Twice, then, these specialists are metaphorically depicted as having narrow vision ('all they see' is one aspect: P28; they are 'blinkered': P33), and therefore being unable to understand other sides of having dementia without collaborating with carers and people with dementia, who are the experts through experience. Although P28 continues the 'us' versus 'them' narrative here, he directs his critique at only 'half'/'some' of 'the specialists', therefore acknowledging that specialists are a diverse collective rather than one homogenous 'they' group; some but not all specialists are a 'waste of time' and need to better understand dementia.

Often, participants present their experiences with medical professionals and their support as inconsistent, frequently depending on the doctor that you see or the area you live in ('what I found, is that every district as far as a healthcare in [this county] is totally different, and they have their own organization and funding […] So you'd get a different response': P12). When comparing contradictory stories about vascular dementia (that people do or do not have scans and medication), P12 summarizes this confusion thus: 'Again. Different story again.' Participants tell many stories of their encounters with biomedicine. At the extreme, medical professionals are cast in these accounts as 'very clever' (PH) heroes, who save lives, and at other times as a 'waste of time' (P28). Medicine can be positioned as a 'lifeline' (PS), or as causing more problems than the condition itself (P1). Clearly, participants' stances on the role of biomedicine are conflicting and often contradictory. P26 emphasizes that 'I don't think it's always the medical route […] Because they don't know about so many things', foregrounding the impact of 'all the toxins out that are there, all the plastic, all the, all the medication drugs that people are on and, they have an adverse effect', asking 'what are we doing to our bodies?' Similar critiques are shared by some members of the medical profession, who raise the uncertainties inherent within current medical knowledge, including for neurological assessments and treatments for dementia, and the need to look outwards, to other influences on health (George and Whitehouse, 2021; Whitehouse and George, 2008). What is the role of biomedicine when discussing dementia? How far should biomedical discourses extend and are we, as Whitehouse and George (2008: 14) suggest, currently 'wast[ing] massive resources in quests for magic bullets to "fix" brain ageing – putting cure before care and prevention, and trying to achieve dominance over a domain that will continue to resist our control'? The section below considers the cure versus care debate by examining how different participants position a biomedically oriented prioritization of finding a cure, contrasted against a more social/structural emphasis on how society supports people affected by dementia.

'Cure' versus 'care'

In some groups, I asked people directly what their thoughts were on the debate surrounding cure versus care. At other times, the issue emerged spontaneously or was implicitly touched upon during discussions, as with P33, who raises his desire for 'an even playing field' compared to the funding of other conditions such as cancer, declaring that dementia 'need[s] a lot more research money, but it's not just only research there is Admiral Nurses […] hoping to increase'. Overall, whether implicitly or explicitly, participant accounts support achieving some sort of balance between an emphasis on cure versus care. This is exemplified by P16, a carer who set up his local Memory Café, when he tells us:

> I know there's this conflict, isn't there, that's going off. About whether the money should be going into support or whether it should be going into, research […] I mean it's got to be a bit of both really, hasn't it. erm. It's just where, where do you put the balancing line on it all.

Drawing on the well-established metaphor of a debate being a 'conflict', P16 presents the obvious and necessary solution as being 'a bit of both'. P16 then raises that *how* exactly support and research should be balanced is the primary, and much more nuanced concern. Elsewhere, P11 raises the need for flexible and multiple different approaches to supporting people affected by dementia, 'because there is no single answer'.

Of course, individuals exhibit different priorities. In my interview with PH and his son, P20, the subjective positionings and self-interests of participants are highlighted as an important influence on how individuals allocate attention to cure versus care:

Emma Erm, if you were in charge of the government you know funding pot for dementia [PH laughs], how would you divide it up between cure and then support for people who have dementia?

PH [3.9] I think, well the main bit is to get a cure. Would be (to get a cure) because, without that, you can't go anywhere.

P20 But you have to declare an interest don't you

PH But. Yeah but

P20 Because you're not, I mean, you're not very wealthy, but you're not poor either, and we can, get you on the bus for instance. You've got money to get the bus, or, you've got your bus pass now but you see what I mean.

Here, P20 foregrounds what has long been noted in research: people choose discourses that best reflect their interests (Kress and van Leeuwen, 2001). Considering that PH constructs an identity that is aligned with science ('being a physicist') and consistently presents finding a cure for dementia as his hope for living with the condition, his advocacy of finding a cure as the main way of creating meaningful change ('without that, you can't go anywhere') is logical. His son shifts the focus from PH's argument to his social position, attributing PH's prioritization of a cure to his financial security, which means that he could continue a similar lifestyle without the support structures currently in place, reducing their importance for PH.

Elsewhere, the financial implications of accessing support are instead foregrounded, particularly by partners, with P28 explaining that it is so expensive to get support from care workers that if he wanted to go out for the day, 'that's not a break, that's a worry, because I've got to break into the piggy bank when I get back, and then when I'm out I'm thinking "well I can't afford to do this thing because it's costing me so much"'. Likewise, P33 emphasizes the impact of a person's socioeconomic status on access to support when he criticizes an article written about a woman who looked at twenty-four care homes for her husband and couldn't 'find the right one'. To this, P33 retorts that 'I'm on income support, I have no choice where my wife goes, so don't complain about you've got twenty-four to pick from'. Participants discuss having to 'rely on family and friends' (P11) which, for people with younger-onset dementia, can be multigenerational, including both parents (although notably only mothers are mentioned) and children (P27, P29, P32). Family networks are not always successful at offering support, as P33 exemplifies when he talks of his mother's failed attempt to 'dominate' his wife when the two spent a few hours together. Many participants are grateful for the day centres and other (sometimes free) support that they can access, as Sheila discussed in relation to her husband in Chapter 3, but there is an overall sense that 'if they say there's care out there, it's not evenly spread' (P28) as 'some people have got none, some people have got all this, some people don't want it' (P4) and 'some have to pay, some don't have to pay' (P28). This uneven allocation of support is discussed by participants both in relation to familial/friend/community networks and to formalized care. Support also fluctuates according to the time of day, with a lack of out-of-hours help also emerging as an issue, with P30 recalling 'desperately need[ing] somebody to come out to you and it's gone past five o'clock and they say to you, if you feel threatened by your husband call the police […] so they can lock him up in a cell?'

Reflecting the increasingly exploitative practices of the UK's largely privatized care sector (Blakeley and Quilter-Pinner, 2019; Dowling, 2021), while some participants express outrage at high care costs (e.g. 'it doesn't cost £850 a week to care for somebody. It's just ridiculous': P26), it is also acknowledged that the employees providing direct care are often 'paid peanuts' (P11). P26 summarizes her experience thus: 'The girls are paid minimum wage and worked to death, it's all wrong.' There is a tension, even in the same interview, between forming close personal relationships with care workers ('they've [daily care workers] become part of my life of course. I mean, there's going to come a point when I'm not going to just lose my mum I'm going to lose a lot of friends') and struggling with the care sector more broadly ('it's pot luck who turns up and whether they know what you like and what you don't like and if it's a care home, who knows what sort of treatment they get': P11). It is also worth noting the gendered aspect to both professional and informal caring here, as it is 'mothers' and 'girls' who are explicitly mentioned in the above quotes about paid and unpaid care, reflecting the broader gender imbalance in caring. In the UK, approximately two-thirds of unpaid carers are women, who on average spend more hours in their caring role than men (Alzheimer's Research UK, 2022), while approximately 81 per cent of employees in the UK's adult social care sector are women, and 18 per cent men (Skills for Care, 2023). Indeed, the statistic for unpaid care is roughly reflected in the number of supporters participating in this study: twelve supporters identify as men, and twenty-one as women (which rises to twenty-two with Sheila included as a former carer).

Overall, for many participants, the cost, quality and overall access to different forms of care (such as care homes, visiting care workers, support groups, etc.) are key concerns. Issues are largely with inequalities and inconsistencies across the care sector, with a recognition that the current systems can exploit both people affected by dementia and care workers. Supporters and people diagnosed with dementia alike critique the lack of support that carers receive, and foreground that carers are 'human too' (P5) and need more recognition across society of 'the problems that the carers have got. Which gets worse and worse and worse for them' (PK). Returning to a more individual perspective, P5 responds to me asking what people think 'about the whole cure versus care thing that's going on' by positioning the concept of a cure as being far removed from her everyday experiences and concerns:

P5 Well there's not really any comparison is there between cure and care they're two different things aren't they. You know, I don't think any of us sit and worry, or hope, or care about a cure appearing we just cope everyday with what we're faced with so, you know, the research bit doesn't really – I mean I'll support it, financially, when appropriate, but it's not something I feel I want to dive into or find out about because I haven't got the brain power left after [laughter and group agreement]
PC I've (xxx) this one up
P5 And what bit of brain power I do have left I want to use doing something I enjoy

Here P5 establishes a clear role for herself in relation to research seeking a cure: she will financially 'support it' in 'appropriate' situations but does not want to waste her 'brain power' on understanding what is happening in that particular biomedical sphere. That the hypothetical cure is presented as 'appearing' reinforces P5's presentation of research as abstract and unknown, since the cure appears much like an object does in a magic trick, where the behind-the-scenes workings are kept secret, and the public simply admire the result. Through the collective pronoun 'us', P5 speaks on behalf of herself and other people affected by dementia as not worrying, hoping or indeed caring 'about a cure appearing' because 'we just cope everyday with what we're faced with' and direct remaining energies towards enjoyable activities in life, a key component of well-being (Rayment, Swainston and Wilson, 2019). Research into a cure is thus presented as a peripheral concern that P5 wishes to remain distanced from to best preserve her limited supply of energy, since caring for each other in the face of the challenges that dementia presents is the necessary day-to-day focus for people affected. The subsequent section explores this more everyday lens further, particularly regarding how participants engage with social support and care for people affected by dementia. This complements Chapter 3's in-depth discussion of the role of care in a couple's life and the implications of structural inequalities and changes for individuals accessing support services.

6.4 Humans as social beings: Understanding through experience

Throughout these chapters, participants frequently indicate the need to acknowledge that humans are social beings and that we experience life with dementia accordingly. As such, agency is to a great extent relational – people can be empowered or disempowered by their environment, physically through interactions, as well as through internalizing particular attitudes such as ageism (Pritchard-Jones, 2017). Within their social environment, participants consistently position peer interactions and support groups as important sources of help, social connection and growth, reinforcing findings of the importance of peer support and friendships in existing work with people affected by dementia (Clare, Rowlands and Quin, 2008; Harris, 2013; Keyes et al., 2016; Ward et al., 2012). It is worth noting that due to the nature of my recruitment, whereby information of my study was disseminated by local support groups, the majority of participants had regularly attended at least one of the following local sources of support: (1) a carer-run group for any carers and the people that they support, (2) Memory Cafés, some of which included carer peer support groups, (3) a care group that provided, among other things, carer groups, training and supported day care with a range of activities, and (4) singing groups for people affected by dementia, with coffee and a chat afterwards. The participants represented here are thus especially engaged with and invested in social groups as part of their lives with dementia.

Several discussions around peer support are sparked by the first page of images shown to participants (see the Appendix). As will be explored further below, people overwhelmingly position the left-hand side, showing individuals or couples at home, as more 'isolated', and the right-hand side, showing groups in communal settings, as 'very social' (PN). Alongside this social focus, numerous people question who (if anyone) depicted has dementia and highlight that the images themselves are not directly related to dementia. For example, P13 immediately responds: 'I don't think that defines dementia at all to me that's just elderly people,' while PH declares that 'they're normal people'. P33 argues that 'it's got to be in context' to give viewers 'clarity', suggesting accompanying Image 2 (Figure 6.4) with text, such as 'how does wife deal with dementia, it's stressful and whatever' so that it clearly 'shows' something to do with dementia. Discussing the generic nature of the images (especially Images 1 and 2), participants argue that 'you could interpret those in quite a few ways' (P9), since they 'could be anything' (PM, P12).

Images 1 and 2 (Figures 3.2 and 6.4 respectively) reproduce the 'head clutcher' trope, namely 'generic stock images of older white women, isolated, holding their head in their hands' (Bould, 2018: 31). Reflecting associations between the head and cognition, multiple participants provide cognitive oriented readings of these 'head clutcher' images, including that the women are 'studying […] something and wondering what it is' (PI), 'trying to remember things' (PJ) or are 'confused' (P4). Four people suggest that the women have headaches, or a migraine (P9, P12, PI, P24), while someone else suggests it 'just looks like she's, trying to do the crossword' (P32). However, more often participants highlight the emotional rather than cognitive aspects of these images. Readings can be broadly grouped into three types of emotions: frustration, unhappiness/despair and loneliness, although of course, there are overlaps between these. Readings of frustration range from being 'grouchy' because 'you've had a bad night the night before' (PH) to being 'frustrated' by 'struggling' with something (P13, P16), and being 'under stress' (P33). Other people read the women as being 'sad' (P14), 'distressed' (P6), 'obviously unhappy' (P11), showing 'despair' (PS) or as 'depressed or, tired' (P28). Meanwhile, for some, the pictures 'could be more for, loneliness. Depression' than dementia (PM). The experience of loneliness appears to especially resonate with a quieter participant, PL, who lives alone and tells us that 'I was crying out for someone to visit me, the other day, because I was lonely […] on my own', reinforcing the impact of loneliness and isolation for people affected by dementia (e.g. Clare, Rowlands and Quin, 2008; Holdsworth and McCabe, 2018). Throughout, then, emotional experiences tend to especially resonate with participants, who frequently position these individuals as struggling in some way and needing support.

Against this, participants consistently highlight social engagement and happiness in response to Images 3 and 4 of people in social settings with peers (see the Appendix). The individuals are said to 'look happier' (P21, P23), even 'healthier' (P21), as they are 'making friends' (PI), whether it is the laughing couple in Image 3 'sharing […] joy' (P21) and 'a little laugh' together (P23), or the group 'having a game of cards' in Image 4 (PI). Participants report a difference in their own emotional response; the left-hand side images are evaluated as

Figure 6.4 Woman touching her head (Image 2) (iStock.com/dragana991).

'hard-hitting' and 'distressing' by P11, while P6 reports that 'because these people are engaging that makes me, very happy, looking at that'. This is not always the case; P32 criticizes the figures as 'too happy smiley' to be representative. A current Memory Café volunteer whose father had dementia, P7, suggests that the 'contrast' across the images could reflect the tension that she and other volunteers highlight between the 'good, and positive', 'living well in the moment […] philosophy' that groups such as the Memory Café promote and that Images 3 and 4 'illustrate', against the 'reality' beyond this group setting, here that 'it can also be isolating' (Images 1 and 2). Distinguishing between the 'philosophy' promoted by official sources of support, here the Memory Café, and the 'reality' of people's lives beyond this group, P7 indicates that both spheres of experience may coexist in people's lives, and that the 'living well […] philosophy' is not always representative or attainable, echoing existing criticisms of the living-well discourse as unrealistic (McParland, Kelly and Innes, 2017). Depending on their own experiences of peer support/interaction, participants interpret the images as showing 'dementia groups' (P33) or as 'quite an accurate representation […] Of that sort of hubbub that you can get in the communal room of a care home' during cake (P19) or a 'planned activity' (P18). Whether attributed to groups in the community or care homes, it is in response to these two community-oriented images that many discussions of the value, and potential limitations, of peer interaction and support emerge.

Across accounts, peer groups and support networks emerge as a vital source of knowledge exchange and learning. People provide many sources when asked at the beginning of sessions where they get their information from, including sometimes healthcare services (such as GPs), the media and local councils. However, charities (especially Alzheimer's Society) and peer support networks are more frequently discussed and positioned as useful. Sometimes, the need for peer groups is due to a perceived lack of information, and at other times to being 'bombarded with information', but the commonality is that such groups 'actually come along and explain, the things you need' (P16). For some participants, although charities and other organizations offer useful information through sources such as websites and booklets, other people are their most important source of knowledge about local services and support. P22 declares that 'it's word of mouth isn't it, all the time […] It's all coming from people', to which P23 jokingly responds: 'So you've got to join one to get your information from somebody else [laughter].' In another group, P13 tells us that 'we started going [to the Memory Café] a year ago and I've learned everything from them'.

Peer groups are presented as being about more than simply sharing resources, however; they are about collaborative, shared learning and community (Keyes et al., 2016). This is something that PI raises when, discussing the choir, she says, 'You learn each other if you know what I mean you pick something up from each other.' She continues to reflect on the enjoyment she gains from singing in the choir: 'You can't sing you soon learn don't you […] I love to join in with the singing it's lovely isn't it if you all sing together.' Here, PI foregrounds the potential for learning and growth through engaging in this communal activity, an aspect of personal development that is too often denied to people with dementia (Bartlett and O'Connor, 2010; Sabat, 2018). Music brings back fond memories of PI's 'mam', as 'I loved it when she sang to us it were lovely'. The value of creating an environment that enables people with dementia to be themselves and enjoy what they can do, rather than lament what they cannot, is then discussed by the same focus group, with P21 reminding us that 'the Memory Café is a lot about reminiscing because they talk about what happened, years ago, and erm it just makes everybody feel brighter about what they're remembering, not what they've forgotten'. P21's metaphor of becoming brighter reinforces the value of an empowering social environment in which the impact of dementia does not matter (Ovenden, Dening and Beer, 2019), therefore allowing everyone to take 'a bit of time out of the dementia' (P10). In P21's example, this involves enjoying sharing recollections, and as PJ reminds us just before P21 speaks, that's 'What life's all about isn't it […] Different stories. And people build on the stories that they're from, especially the older generation of what they went through, to the present day.' From the perspective of a volunteer at a local Memory Café, P6 raises the importance of being 'careful' to facilitate this environment by avoiding actions that put people 'on the spot' and could make 'people aware, that they have lost their memory', situating this as an environment that needs to be properly cultivated, with great care. Meanwhile, in another focus group, P13 emphasizes that these groups and activities are equally important to her as a partner: 'I get as much out of going to the Memory Café and all these other things as [PE] does. I mean, it's it's an outlet is to talk to other people […] We've got to be stimulated as well as you know.' Supporters, as much as people with dementia, need spaces that can provide a release, stimulation, participation and the potential for growth (Górska, Forsyth and Maciver, 2018; Rayment, Swainston and Wilson, 2019).

To be with other people experiencing dementia is regularly positioned as not only an opportunity to have 'a good social' (P21) with 'a nice lot' of people who 'all join in' (PI), but as being integral to the well-being of people with dementia and carers alike. P14 tells us:

> You go to a group, especially like the Memory Cafés and things like that where people understand, erm and. They seem to come alive, you know, because they're with other people and. I think it's just human beings we like to be together […] We are a, pack. animal [laughs].

Reinforcing the widespread acknowledgement of the importance of supportive and understanding relationships for an enabling environment, P14 explicitly links being with others in this environment as the impetus for people with dementia (and supporters) to metaphorically 'come alive'. This language is noticeably similar to P21's above observation of people feeling 'brighter', P13's of being 'stimulated' and to the 'spark' that carers observe in people with dementia who are usually apathetic when they find a passion (Chang et al., 2021). P14 sets this within a broader narrative of humans as a 'pack. animal', whereby positive relationships, including friendships, whether facilitated by a practitioner or spontaneous, are essential for maximizing our quality of life (Ward et al., 2012). In particular, P33 reflects on the increase in the depth of his friendships through gaining this support network, as 'since [my wife] got dementia and I became her carer, I have more friends, and proper friends real friends coz friends disappear, families disappear'. Friendships gained through 'dementia groups' and 'carers groups' replace the relationships that 'disappear' following a dementia diagnosis, and P33 situates these as more authentic ('proper' and 'real') than those that disappeared when his wife had dementia.

Consistently, participants foreground the importance of being in 'non-judgemental' (P9) and 'accepting' (P8) settings 'where people understand' (P14) 'what that daily grind is' (P9). Indeed, seven participants explicitly use the word 'understand' to discuss the shared understanding that comes from mutual experience of dementia (PS, PK, P9, P12, P14, P28, P33). This notably contrasts the lack of understanding attributed to people without such experience, particularly other friends and family, members of the public and health professionals. P33 explicitly distinguishes the understanding of peers from specialists, telling me that 'I'm a great believer' in peer groups, as 'these people, you can talk to, they'll, they know within five minutes that you know, how they feel, and they know how you feel. Because you're talking on the same wavelength. You don't "oh I understand" that's professional talk, right, no you don't'. Here, peers share an unspoken understanding and emotional connection through their comparable experiences. While peer understanding is unspoken and felt, 'professional talk' is instead characterized by P33 as inauthentic, by professing to understand when 'no you don't'. Another carer, P28, also explicitly distinguishes the support of peers from specialists: 'When we've got a group […] I think that's a help, [group agreement] because everyone understands […] we understand each other which, most of the time is a bigger help than the specialists.' Both accounts create an in-group of peers who understand, and an out-group of professionals, who do not. This builds on the same two carers' critiques of the lack of shared understanding between people affected by dementia and specialists (see Section 6.3) and reflects that peer support involves different relationships, experiences and outcomes compared to interactions with health professionals (Hillman et al., 2018; Keyes et al., 2016).

However, a tension materializes between a sense of a collective group identity and acknowledging individual differences, especially when talking to people affected by young-onset dementia. A limitation of groups is that they can be exclusionary (Beard, 2016) at both a structural and an individual level. When reflecting on her grandfather's care home, P17 recalls, 'there was a room that was decked out like the kind of forties fifties and they'd have events in there and obviously they're trying to kind of put the sort of majority demographic at ease in an environment that they're used to'. The working-age dementia group provides insights into the difficulties of being the minority age demographic, with carers raising that any reminiscence-based activities and 'wartime songs' are 'good for older people' but not for their younger partners, who like 'a bit of heavy metal' (P30) and are 'a rocker' (P32). This is part of a larger conflation, as discussed in Chapter 4, of dementia with older age, which perpetuates the failure to accommodate the true diversity of age groups who experience dementia (and, equally, the diversity of older people who will also have different music tastes; see Hamilton and Hamaguchi, 2015). Beyond this, P29, whose husband has dementia with Lewy bodies and Parkinson's disease, indicates that even for a group of similar individuals such as the working-age dementia group, there is a tension between togetherness and individuality. In her capacity as a working-age dementia peer support lead, P29 advocates for the need for resources that enable both a 'support network like these' and being able to be 'independent at home', indicating that 'it's about supporting you guys [...] together, but also sort of separate?' Summarizing the totality of the participants views set out across this chapter, P29 presents people with dementia and their carers as simultaneously a collective group and as separate individuals, with their own unique experiences and needs.

6.5 Audiences, the media and recommending change

Throughout this book, I have explored how participants differently reproduce, resist and revise existing dementia discourses and associated visual and linguistic representations. Building on the above discussion of gaining expertise through experience and of gaps in knowledge between people who do and do not have personal experience, this final analytical section gives space to some key reflections and suggestions made by participants regarding dementia representations. The section begins by considering participants' evaluations of the importance of the audience and of the media's role in communicating about dementia. This leads onto three key recommendations for how to represent dementia in a way that better aligns with the perspectives and experiences of people affected, which while often aimed at the media can equally be applied beyond this sphere of public life. The recommendations have been compiled from participants' contributions throughout this and preceding chapters, particularly their critiques and suggestions for change. This section includes further examples of how participants have altered existing stimuli and suggested alternative portrayals, which demonstrate the creative potential of working with people affected by dementia. Since these contributions generally emerged spontaneously through conversation, the voices of certain participants, particularly people without dementia, are overrepresented in this section, as the input of people who did not explicitly discuss these topics is unknown. Readers are also directed to Nancy's discussion of the media in Chapter 3, which is highly pertinent to the issues discussed here.

Within participants' contributions is a tension between what can be broadly referred to as 'living well' and 'tragedy' discourses (see Chapter 1). Many participants stress the importance of considering the intended audience for representations, as 'it depends who it's aimed at' (P9). Thus, the daughter of someone recently diagnosed critiques the decline and loss-oriented images (page 3 of the Appendix), arguing that her mother would not like photographs that suggest 'she'd have bits of her brain missing' as 'it's not a positive message to a person with dementia. still at the early stages', since it can lead them to think 'is that what's going to happen to me' (P15). This echoes the fears and despair discussed in Chapter 5, reinforcing that tragedy-oriented discourses can exacerbate fear and insecurity about a person's future with dementia (Bryden, 2016; Górska, Forsyth and Maciver, 2018; Zeilig, 2014a). In contrast, some Memory Café volunteers discuss their internal conflict from feeling that the living-well discourse they publicly uphold does not reflect lived reality:

P8 Mm. It's a very hard one because I'm like having like P7 had a parent and experienced dementia from that angle. But also be concerned to promote the Dementia Friends message and our philosophy for the Memory Café that is a bit of a push pull kind of thing [group agreement], you know, because it is really important that we're positive and there's a lovely environment, and supportive, but, you know, I mean, we know it's brutal and, and that's, you know, the reality, so I'm kind of, conflicted at times [group agreement]

P7 Me too, me too

P8 I feel like putting on different hats […] You know, because we're giving a different face to them.

P10 Yeah, I completely agree. Because you know the push is very much about living well with dementia isn't it [group agreement] and that's great. But the reality is so [laughs] very different [group agreement]. And the gritty day to day stuff that carers go through is a nightmare for most people.

Here, the living-well discourse is consistently positioned as ideological (as a 'message' and 'philosophy'), and as something that, in their role as representatives, they should 'promote'. Meanwhile, the 'brutal' side of living with dementia is portrayed as 'the reality' that 'we know' through personal experience with loved ones with dementia. Their identities as volunteers that represent the Memory Café and 'promote the Dementia Friends message' are thus positioned as at odds with their personal ideas regarding dementia's ‘reality’, necessitating the repression of the latter through wearing ‘different hats’ and showing group attendees ‘a different face’. The reference to changing guises is indicative of their sense of deception, where they purposefully change their portrayal, much like an actor, in order to adapt their ‘message’ to the situation and audience. Underlying this exchange appears to be a desire to be able to acknowledge both the ‘positive’ and ‘brutal’ facets of dementia, reinforcing previous discussions of balancing positive and negative aspects. A similar tension materializes in a conversation with P33, who recounts that a dementia magazine published the celebration of their wedding anniversary but not how his wife would ‘hit me around the head. And walk away or I’d walk away. Two or three minutes later she’s forgotten she’s done it walks in “oh I do love you” ’. From this experience, P33 concludes that representations must ‘be balanced’ rather than overly ‘goody goody’ as ‘I don’t want, the nasty stuff, I just want, reality stuff, you know, it’s not all the pretty pretty living with dementia it’s not. [Laughs] it’s far from it’. Combined, these accounts indicate the tension between providing support and hope without overly regulating and repressing the more ‘brutal’ realities that many people affected by dementia face.

Although it is acknowledged that consumers do hold some responsibility to ‘challenge’ and ‘find out a bit more’ by reading multiple sources (PK), participants overwhelmingly recognize the media as a powerful influence on social understandings and attitudes towards dementia (also see Chapter 3 for Nancy’s discussion of the media’s role and Chapter 4 for more on how stereotypes impact participants). P16’s stance, that ‘it’s the way it’s portrayed obviously. But you do need to keep it in the news’, appears to be widely supported, with people acknowledging the importance of media coverage but wanting to alter how dementia is portrayed, due to what they currently evaluate as the ‘wrong publicity’ (P22). Criticisms of current social representations include that the media ‘sensationalize’ (P7, P25) and ‘generalize’ (PK). This contributes to a ‘general, erm, perception […] that everybody’s the same’ (PK), whether regarding age (‘watching the news and that you just assume that dementia’s an old person’s [disease]’: P28), tone (‘when the media look at it it’s all quite very like low and, solemn, you know’: P21), or dementia symptoms (PK suggests that charities and the media often ‘push people’ towards a certain set of ‘symptoms’ for dementia, citing a popular Alzheimer’s Society booklet that foregrounds just ‘five, symptoms of dementia’).

Occasionally, the media are praised for an increasing level of nuance. PM advocates that ‘papers do, are trying their best, to highlight dementia, and the difference between dementia and Alzheimer's', subsequently initiating an exchange about social progress:

PM when I was growing up, […] they didn't seem to know much about it, about what, the differences were, you were just put in a box and that were it #you know#

PK #You're still# put in a box #as well#

PL #You were# labelled in other words

PK Yes

PM I don't think you are as much – I think people are more aware now

PL Yes

PM Of the different types of dementia, and the fact that you don't wake up one morning and you've got dementia. It comes and-

PK -it's going in the right direction yeah

PL It is

Returning to the journey metaphor discussed in Chapter 5, social understandings are presented here as moving 'in the right direction' towards greater awareness and less labelling, although PK counters this with the point that people with dementia remain a homogenized social group with restrictive associations (i.e. they are 'put in a box') in the public imagination. Elsewhere, participants reflect on how perpetuating a 'victim mentality' through the media 'means that people are scared to get diagnosed' due to 'stigma' (P8), as dementia is seen as 'dirty' (P10), which reiterates the global concern with dementia stigma (Alzheimer's Disease International, 2024). Overall, despite recognizing improvements in social representations and understandings, and acknowledging that the media are ultimately 'trying to sell' a product, so 'you can't blame them for that that's their business isn't it' (P6), participants firmly express a need for media portrayals to develop further. Their suggestions can be divided into three key areas: (1) normalize dementia; (2) provide more nuanced representations; and (3) expand the attribution of value and notions of personhood to better support advocacy for people with dementia.

Normalize dementia

Firstly, participants emphasize that dementia needs to be normalized and familiarized for the public, to help people to connect with the issue and better integrate life with dementia into wider society. P16 highlights that people invest time, energy and money into 'causes that they think [are] going to affect them', acknowledging that the same applies to us all, since although people affected by dementia are very familiar with the syndrome (or with subtypes), ‘we might know nothing about something else, another disease or whatever’. He thus advocates ‘getting the message across, that it will affect you in your lifetime or one of the members of your family or someone and er. Let’s try and do something about it, while we can’. P16’s attempt to expand the group of people invested in dementia is reflected in his pronoun shift from the generic second person ‘you’, which is more individualistic, to a collective ‘we’, by directly relating dementia to people’s lives. Similarly, P8 shares that ‘everybody is going to be affected by dementia in some way, they’ll know somebody […] So it’s kind of normalizing it in a way that’s, you know, the press should play a powerful role in that’. Indeed, UK-based estimates suggest that during our lifetime, one in two of us will be diagnosed with dementia and/or support someone who has (Besley et al., 2023). Considering that proximity to the audience is a key aspect of newsworthiness (Bednarek and Caple, 2014, 2019; see Chapter 1), emphasizing dementia’s prevalence becomes a means of reaching more people who may not otherwise engage with the topic. The press is positioned as an institution that can and indeed ‘should’ play a ‘powerful role’ in normalizing dementia in this way (P8).

To normalize, rather than ‘sensationalize’ dementia (P7), participants also call to ground dementia representations within personal experiences of daily life and broader support structures, aligning with the personalization news value of emphasizing the ‘“human” face’ of a story (Bednarek and Caple, 2017: 61). In P28’s words: ‘They’ve just got to put a truer story out there, that reflects what’s happening, on the day to day challenges, of the carer, and, the person that’s affected with the dementia,’ so that ‘people would understand it a little bit more, and they may be more, sympathetic, when they see you’. Attending to ‘how, visually, dementia is presented’, P19 ‘would really like to see a move away from the clinical, medical, stuff’, suggesting that ‘it needs to be warmer, […] more familiar and […] more of a, a story, more personal more approachable and. within that, then also be truthful so there are those positives and negatives […] Something that’s a little more. familiar I think, would be good’. Combined, P28 and P19’s accounts position foregrounding personal experiences as more accurate (e.g. ‘truer’), as a means of connecting with audiences through being ‘more familiar’ and ‘approachable’, and as potentially addressing stigma through improving understanding and compassion (i.e. being more ‘sympathetic’). In Chapter 3, Nancy also advocates for foregrounding individuals’ experiences with dementia, alongside exploring how to enable rather than disable individuals through their environment. Within this, the media can also provide tangible help for people affected by dementia through 'telling people, carers. What's available' in terms of support and activities (P13). In sum, participants' first recommendation is that dementia needs to be made more familiar and relatable for people, which can be achieved through emphasizing dementia's relevance to audiences and providing more normalizing and person-oriented accounts of life with the condition.

Greater nuance

Secondly, building on the discussions in Chapters 3 to 5 and above, participants advocate for greater nuance when representing dementia, to reflect that a diverse array of people can have a range of types and experiences of dementia. Included within calls for nuance is 'toning things down' in terms of 'telling the story a bit more objectively' (P7), with 'more facts' (P15) and through achieving 'a balance of' positive and negative experiences and emotions when representing different facets of life with dementia (P19). There should be space to explore both 'the happy side' and 'when things are bad, when things are tough' with dementia (P3), although participants acknowledge that it 'is hard to get a balance' of the two (P10). Returning to Chapter 5's discussion of language use, P9 suggests 'keeping it just the living with dementia', thus favouring the midpoint between 'living well' and 'suffering' discourses for media representations rather than either extreme. Alongside a need for emotional nuance, framing life with dementia should also engage with a range of factors, including social structures. For instance, reflecting on media representations, P21 suggests that 'I don't think it highlights, the fun that people can have with – not because of their dementia but what is available to them'. Promoting a consideration of what life with dementia means beyond the condition itself, P21's account situates people's experience of life with dementia within their opportunities and engagement with wider society, acknowledging the importance of social structures to people's experiences. Such a point engages, albeit implicitly, with calls to consider the rights and social well-being of people with dementia (Bartlett and O'Connor, 2010; Cahill, 2018; Sabat, 2018), moving beyond the typical biomedical focus attributed to the media (Bailey, Dening and Harvey, 2021; Putland and Brookes, 2024a).

Many participants also promote providing a more nuanced account of who can have dementia rather than conflating a person with dementia with older age and particular stages and types. Some older people with earlier stages of dementia suggest that 'the media, have concentrated too far up the line' on 'the later stages of dementia', which can exacerbate 'ignorance', whereby people 'say well you seem to be doing ok, when you're not' (PK). In contrast, carers of people with advanced young-onset dementia argue that when people with dementia feature on media, it's people with 'the earlier stage and it's only just been diagnosed', leading people to think 'that's what dementia is', when the reality is far more diverse. It is important to represent every stage of dementia rather than concentrating on extremes (McParland, Kelly and Innes, 2017). Similarly, P6 raises the issue that many people have Alzheimer's 'stuck in their head' when they think of dementia, and that different types of dementia are conflated, creating 'false beliefs' such as there being drugs available, when this is not the case for all dementia types. She therefore upholds that 'we just need to be a bit sort of broader I think in understanding the different types'.

Extending the common metaphor of dementia being an umbrella term for a range of different conditions, P29 asserts that 'in the media […] they need to look at it as an umbrella of people who, unfortunately have this disease dementia […] instead of portraying it as an older person's disease'. Here, diverse individuals are incorporated within the dementia umbrella, as well as types. P29 hopes that then people will realize that 'actually there's no age attached to anything, and then we can start tackling and dividing resources, as individuals'. Again, the participants associate improved understandings of who can have dementia and what life with dementia involves with improved outcomes for people affected. Here, it is that resources can be allocated on a more individual basis rather than concentrating on older people with dementia, as the working-age dementia group consistently demonstrate how this often results in their exclusion from care and support because of their younger age. The group subsequently adapt the images of the man with a fragmenting head (Image 10; Figure 3.4) and the three seasonal tree heads (Image 11; Figure 5.3) as examples of how to achieve better awareness. Specifically, they change Image 10 to show 'one young and one old' person, and propose linguistically foregrounding that 'there's no age' for the tree heads through adding 'wording' such as 'Dementia can affect any age' (P28, P30).

Throughout, participants promote the need to expand what it means to have dementia. This includes challenging the focus on declining memory, with P30 declaring, 'media wise don't portray everything as being memory because it's not memory'. Simultaneously, participants provide a more nuanced account of memory than is popularly represented. In two different groups, the analogy of bookshelves is linked to an account of changes to memory with dementia. In one group, a carer recollects how Alzheimer's Society explained dementia on a course, summarizing it thus: 'It's like a bookshelf and you've got books falling off the shelves you might get one or two just leaning a bit and as it, progresses, the books start tumbling off and end up with an almost empty bookshelf' (P21).

Metaphorically representing memory and knowledge through books, here, P21 presents a fairly typical, linear account of progressive memory loss, with a steadily increasing loss of books until the brain's bookshelf is 'almost empty'. It appears that P21 is referring to the bookcase that Alzheimer's Society (2017) associate with factual and biographical recall (in the hippocampus), whereby more recent information/memories are represented by books at the top of the bookcase and are thus more likely to fall off when it is shaken than those on lower shelves from previous decades, ending with the most stable shelf, childhood, at the bottom. Notably though, Alzheimer's Society (2017) also represent another bookcase that represents the part of the brain (the amygdala) that manages emotions, which is far more resistant to dementia. Thus, although someone with dementia may forget that they had an argument with a relative, they will likely still feel sadness, anger and frustration even if they have no event to relate it to, or equally, following a nice day out with a loved one, someone might forget what happened but continue to feel happy and loved following their time together.

In the other group, the bookshelf analogy instead foregrounds a state of flux, as in Chapter 5, when participants challenge the representation of dementia as a linear progression:

P17 sometimes it's not there, sometimes it is there and I'm sure that there are, some parts that aren't but like different kind of ways to get to those memories can help as well so?
P19 It's more like bookshelves, or something [group agreement]. You know, sort of sometimes, it's on the shelf, other times it's, it's out.
P17 Yeah exactly
P18 Or they've misplaced it and put on another bookshelf.
P17 Yeah, it's been miscatalogued [laughs].

Situating books as being sometimes 'on the shelf' and sometimes 'out' or 'miscatalogued' adapts P21's linear account of books falling off to allow for more transient changes. Rather than emphasizing what is lost, this foregrounds how changes to the organizing system can create unpredictable shifts in what memories a person can access at a particular time. Viewing memories as inaccessible rather than necessarily gone facilitates focusing on various 'ways to get to those memories' that can help recall. This broadens the discussion surrounding dementia from a linear loss to flux, whereby the latter both provides more nuance and enables strategies to help cope with the challenges of changes to memory. For instance, PK talks of leaving a crossword that he cannot complete, as 'you get up the following morning, you pick up the crossword and finish it', concluding that 'your brain, can carry on doing the crossword'. Reflecting a widespread association between music and memory (Rahman, 2015), P26 reinforces the latter model of memory in her anecdote that when a researcher interviewing her mother about her wedding day played her meaningful songs, 'the response was amazing. She could remember so much more about her wedding day'. Much as dementia affects more than memory, changes to memory are more than a linear loss. Dementia representations therefore need to better highlight the diversity within dementia as an umbrella term, regarding not only types but also people and their experiences.

Social value and advocacy

Building on a more nuanced notion of dementia and memory, the third suggestion is to expand understandings of personhood and social value to better support advocacy for people with dementia. When discussing media portrayals, multiple participants emphasize the need to acknowledge that someone with dementia is 'still the same person' (P23), even if 'certain traits that happen aren't there' (P21). While not necessarily unanimous, there are several examples throughout this book of participants problematizing the conflation of cognitive abilities with an individual's personhood, which then assumes a loss of self and social value with dementia (Post, 2000a; van Gorp and Vercruysse, 2012). Rather than images that perpetuate a discourse of a loss of self, one group proposes the following:

P19 it could be a quite an evocative picture. To have almost like a family photo, just sort of going with the typical sort of having an older woman for instance, then a thirty-year-old woman and a little girl and the implication being that, […] that's all going on in there because actually you. You see all those different layers er, sort of. Er. And there's no order to it, it sort of it flits between, each one [… to] Promote the sort of idea of the […] layered individual
[…]

P18 And I guess before this sort of like, as individuals we are the make-up of whatever experiences. We've #had. But we don't.#

P17 #We are the sum of our experiences#

P18 But we don't separate them out

P17 Yeah

P18 But for them. It's like they're the sum of their experiences. But they like, but those experiences have now like sort of detached from one another.

This image of the same person at multiple points of their life promotes the concept of a 'layered individual', which becomes more fragmented and fluid with dementia. Such an image recognizes that people with dementia can 'flit' between present and past selves, positioning the self as a temporal culmination of a person's life that can vary from one moment to the next. This has parallels with Sabat's (2002, 2018) theory of selfhood whereby a person's 'I/my' expression (self 1) remains constant while their attributes and social personae can shift (selves 2 and 3). Since memories of experiences can be held in the mind or the body (Kontos, 2003), such a representation has the potential to recognize a more holistic version of personhood than the hypercognitive model (Post, 2000a). Building on Chapter 5, this image exemplifies how, through being led by people affected by dementia, metaphorical visual portrayals could be expanded beyond loss-oriented ones to better value and support the personhood and identities of people with dementia.

Relatedly, participants raise the issue of expertise and voice within media representations. People highlight the responsibility of the media 'to question themselves' and their notions of expertise, which tends to 'come from a specialist', so that they become 'less tunnel visioned' (PK). This aligns with the recognition earlier in this chapter that medical specialists are not the only experts, and that people with dementia (and carers) must also be valued as experts by experience (Parveen et al., 2018). This recognition needs to occur in not only research and medical spheres but also in the media, where the voices of people with dementia are still lacking (Putland and Brookes, 2024a). As Nancy emphasizes in Chapter 3, through utilizing the media, people with dementia can show the public that 'we aren't to be feared'. Thus, foregrounding the voices and perspectives of people with direct personal experience can help to better advocate for people diagnosed with and otherwise affected by dementia. Simultaneously, sharing more personal accounts and concerns can help to normalize dementia and provide more nuanced representations.

Evidently, there is a collective will among participants to reappropriate what it means to live with dementia and advocate for people affected through altering media portrayals (see also Hillman et al., 2018). Within this, it is important to acknowledge what semiotic modes (e.g. language, image, audio, gesture) are used to represent dementia to achieve the above suggestions. Each semiotic mode contains its own available semiotic resources to communicate meaning; for instance, an image includes the resources of colour, focus and the spatial organization of elements, each of which communicates meaning in a way that language does not. Notably, some participants critique the ability of images and written text to represent dementia, advocating for something more dynamic as a means of promoting a more multifaceted, nuanced understanding. While other focus groups praise the ability of video to provide a less ‘startling’ account of progressive dementia compared to the images of decline examined in Chapter 5 (P7), the following discussion offers the most explicit discussion of semiotic modes:

> **P12** I think it’s got to be. Some sort of interaction with a person with dementia or a film or a programme involving someone with dementia. Because then I think it comes over, erm, the variety of it all, and the effect on the people. I don’t think anything like this [gestures to pictures] can ever. Convey what actually happens you know and the effect on that person
>
> **P13** No. Got to be more physical hasn’t it.
>
> **P12** Yeah

Ultimately, a static picture cannot ‘convey’ dementia. Nor can a newspaper article or charity blog post. It is an extended ‘interaction’, whether in real life or (partially) captured in a film/programme, that is necessary to communicate ‘the variety of it all, and the effect’ of dementia on people, as well as the fact that dementia is ‘a process’ (P12, P13). While images and language present important insights and have the potential to greatly influence perceptions, what P12 and P13 highlight is the need to carefully select an appropriate means through which to communicate the ideas expressed here. On a small scale, the nuance and diversity that participants recommend is indeed better suited to a more expansive multimodal medium, such as film or personal interaction. Ultimately, though, all relevant avenues for communication ought to be considered, since it is the overall discourses that they collectively reproduce, reinforce or challenge that shape our understandings of dementia.

6.6 Summary

This chapter examines the tensions and interrelationships between medical, personal and media spheres, all of which are integral to life with dementia. The participants’ discussions suggest that a biomedical explanation of dementia emphasizing brain changes can help validate people’s behaviours and experiences, but visualizing people with dementia as abnormal brains can reproduce harmful hypercognitive discourses that marginalize people with dementia. Similarly, while some medical professionals and outcomes, such as medication, are situated as integral to certain participants' hope for the future, other participants dismiss or resist hopes of a cure and critique problematic practices within medical institutions. Against this, participants praise the activities and shared understanding found in groups with peers, and many position people affected by dementia as the 'experts by experience' (Parveen et al., 2018), indicating that both medical experts and non-experts could benefit from listening to people with direct personal experience of dementia to better understand what dementia means.

Finally, bringing together key threads throughout Chapters 3 to 6, this chapter explores how participants evaluate popular discourses and ways of representing dementia. Within this, three key interrelated recommendations are established. First, to make dementia more familiar and relatable for people through person-oriented accounts of life with the condition that promote understanding and compassion. Second, to provide more nuanced representations that acknowledge the diversity of subtypes, people and experiences in relation to dementia. Third, to better value people with dementia, who need to be recognized not only as fellow persons but as experts through their experiences with dementia, and to be provided with appropriate avenues (and resources) to promote change. These recommendations build upon the overarching concerns with diversity, multiplicity and better supporting people affected by dementia that have been expressed throughout the analysis. The application of these recommendations will be considered further in Chapter 7 in relation to news values, within a broader discussion of the implications of this study's findings and avenues for future research.

> *I think the more we can use the media, the more people realize that we, we are ok and and that we aren't to be feared […] that's where the media is there, isn't it? It's, to lose that fear, to make people more aware of the pros and the cons of dementia.*
>
> —Nancy (Participant N)

Figure 7.1 'We aren't to be feared' illustration (Josh Mallalieu, artist).

7

What now? Reflections and next steps

7.1 Introduction

The illustration that begins this chapter is inspired by Nancy's words in Chapter 3 about the potential for people living with (and otherwise affected by) dementia to encourage, through a greater media presence, more nuanced understandings of dementia. Reflecting her discussion of the awareness-raising and agenda-setting capabilities of the media, her aim here appears to be to use this greater media presence to address the fear that currently surrounds not only the condition but also people affected. Placards are used in the above illustration as a homage to Terry Pratchett's placard in Image 15 (Figure 5.2), since this image inspires Nancy's point, as she appreciates that Pratchett 'is actually using the media'. Relating to this advocacy aim, the above illustration is intended to be interpreted as one that is personizing and that enables, rather than disables, people living with dementia (Ang, Yeo and Koran, 2023). To achieve this, various choices have been made in the creation of this illustration, some through conversation between myself and the illustrator Josh Mallalieu, and others as artistic choices that I left entirely to Josh to avoid overly controlling the process. Before I go into further detail below about these choices from my perspective as the analyst and commissioner of the image, I invite you as the reader to interpret this illustration yourself and to consider what the implications are for you of the choices that were made.

From my perspective, it is important that everyone shown in the illustration directs their gaze at the viewer, making this what Kress and van Leeuwen (2021) would term a 'demand' image, since their eye contact both directly addresses the viewer (as a visual form of 'you') and 'demands' a social interaction and thus a social relationship, even if on an imaginary level. Attending to other visual choices provides further detail on what exactly this relationship is intended to be.

In terms of framing, it is worth mentioning that the five individuals are presented at the kind of distance typically associated with strangers in the public sphere (since you can see multiple people in full, which necessitates a certain physical distance, rather than being physically close the way you would be with more intimate acquaintances; Kress and van Leeuwen, 2021: 124). Arguably, this artistic choice reflects how protesters would be seen by onlookers in a real-life public space. Through other visual choices, viewers are encouraged to relate to these five illustrated individuals. Notably, the figures are positioned as at eye level with viewers, conveying equality, rather than the power imbalance indicated by being above or below viewers. They are also at a frontal angle (i.e. directly facing and thus involving viewers). These choices help to establish that even if not socially close to the viewer, the five figures are 'part of our world' (Kress and van Leeuwen, 2021: 136). Through the action of holding placards, the represented individuals request that viewers listen to their message that 'we aren't to be feared', while everyone's smiles encourage viewers to feel social affinity by evoking a sense of friendliness. When the group's smiles are combined with the use of varied and often bright colours, the positive affect that is established (see Ang, Yeo and Koran, 2023) offers a direct challenge to the fear-inducing reputation that the group rejects.

By each holding a placard with a word on to form their message, the individuals visually and linguistically form a collective 'we' (which, indeed, is the first word of the placards), here as a group of five people living with dementia who are not to be feared, with the implication being that neither are people with dementia more broadly. Rather than being homogenized, the five people in the illustration are differentiated through a range of characteristics, which is intended to individualize the five people shown and better reflect the heterogeneity of people living with dementia that Nancy and other participants highlight throughout this book. Responding to the multiple calls of participants to challenge the stereotypical association of dementia with older age, many of these individuals clearly have young-onset dementia.

Of course, alone, this illustration cannot accurately reflect the diversity of people diagnosed with dementia, and it is instead intended to be just one example among many. For instance, in other images, it would be important to consider the experiences of people in different racial and ethnic groups and with other coexisting health conditions alongside dementia. Likewise, a range of emotions and experiences with dementia would need to be explored to provide a more comprehensive portrayal. Represented individuals can also be framed in different ways, including as socially close to viewers through close-up shots that mimic the more intimate personal distance of people familiar with one another (Kress and van Leeuwen, 2021: 124). When used alongside other visual choices, such as direct gaze (i.e. making eye contact), the intimacy facilitated by close-up shots would be an important inclusion to support participants' calls for dementia to be normalized and made more familiar for audiences (see Chapter 6). Equally important is the process of image creation; although this and the other illustrations respond to quotes from participants, such participants are noticeably absent in both the design and interpretation of these images. This for me is a very clear next step in answer to the question that underpins this chapter: what now?

This concluding chapter asks: how might the findings and questions raised throughout this book inform potential routes for change? In a nutshell: what now? The chapter begins by drawing together and summarizing some of the book's main conclusions and contributions, situating these in relation to existing literature. From there, the focus shifts to this book's recommendations and potential routes for change, paying particular attention to how news values (introduced in Chapter 1) might be reimagined and repurposed with the aim of promoting more nuanced and supportive media representations. The chapter then concludes by reflecting upon some of this book's key limitations and proposing avenues for future research.

7.2 Reinforcing, resisting and reshaping discourses

Conversations are an important avenue for reinforcing, resisting and reshaping discourses which, whether realized through language, visual choices or otherwise, hold immense power in upholding or challenging existing power structures and inequalities, including the stigmatization of dementia (Putland and Brookes, 2024a, 2024b). Overall, participants' accounts corroborate the nuance and multiplicity of people's dementia experiences and often challenge the reductive and stigmatizing assumptions encountered in their daily lives (see also Mason et al., 2024). Especially considering participants' recommendations to encourage more experience-led representations of dementia that can provide greater nuance and normalization (see Chapter 6), it is important to bring together participants' contributions from Chapters 3 to 6 here and to reflect upon how these relate to (and may help reform) wider portrayals. This discussion is organized around some central themes that have emerged from the previous chapters, namely, the diversity of dementia and associated discourses, navigating identity and transformation with dementia and the (re) shaping potential of semiotic resources. While organizing these within separate subsections is intended to structure the reading experience, in reality, there are many overlaps between themes.

Dementia, diversity and discourses

Throughout, participants' accounts challenge reductive dementia tropes, such as the conflation of dementia with older age, with memory loss (specifically, recall), with tragedy and with its most common subtype, Alzheimer's disease. Instead, participants emphasize the syndrome's *diversity*, particularly regarding types, symptoms, experiences and people diagnosed. Within this, participants draw on a range of discourses and consistently call for a better balance of both positive and negative aspects of experiencing life with dementia, to enable greater nuance and representativeness.

Reflecting the dominance of memory loss as the most cited symptom of dementia, when participants are asked to explain dementia (see Chapter 4), changes to memory emerge as key. A more multifaceted account of changes to memory arises from participants' accounts than from other sources, such as the news and public health campaigns, which tend to conflate dementia with progressive memory loss and memory with recall (Bailey, 2019; Brookes, Putland and Harvey, 2021). Of course, participants do discuss memory in terms of recall, for instance by acknowledging that someone can experience short-term memory loss (for example, forgetting where the bathroom is), while long-term memory often remains. Although some participants indicate a linear and lasting memory loss, others highlight that changes to memory are fluid. This tension materializes in two groups' different uses of a bookcase metaphor in Chapter 6; one presents an increasing loss of books from the shelves over time, while the other presents the books as moving on and off the shelves and occasionally being miscatalogued, to provide a more fluid account of memory that allows for changes to and strategies to reach memories. The latter use of the metaphor reinforces what Basting (2009: 15) states, that memory is more complex than is often represented and can be thought of in terms of:

1. short-term (including working memory) and long-term memory;
2. procedural (how we do things), episodic (specific people, events and information) and semantic memory (general knowledge);
3. implicit (subconscious) and explicit (conscious) memory.

A person with dementia might therefore be unable to recall an argument but still feel hurt through implicit memory, or be unable to dress themselves, yet happily reflect on what dementia means to them and how they are (or are not) coping with its effects (Sabat, 2018). Overall, participants reinforce this more nuanced view of memory rather than conflating particular types of memory loss with a complete loss of memory. This shift is significant as it encourages people to develop strategies to work with memory changes as much as is possible (such as using music to aid recall) to better support people to live with dementia (Sabat, 2018).

Moving beyond the 'crude formula' apparent across much of popular culture that 'dementia = memory loss' (Brookes, Putland and Harvey, 2021: 254), participants simultaneously foreground other signs of dementia, including personality and behaviour changes (which, as one couple humorously remind us in Chapter 4, are not automatically bad), alongside a range of abilities that can be impacted, from walking to doing DIY. This corroborates that dementia is experienced as not only altered memory but also changes to other cognitive functions, such as thinking, judgement, orientation, calculation, motor control and language, as well as emotional control, motivation and social behaviour (World Health Organization, 2023).

Importantly, although rare when asked to explain dementia, elsewhere across their accounts, participants accompany the above discussions of loss in relation to abilities with those of regained, maintained or adapted abilities, such as making tea, an individual's sense of humour or nonverbally expressing love despite no longer saying it aloud. Furthermore, many people indicate gaining new abilities and/or experiences, including taking up new activities and joining new groups since having dementia, such as advocacy work, research participation and peer groups (e.g. choirs, swimming groups and Memory Cafés). This reinforces what Sabat (2018: 37) highlights: that if, for instance, you struggle with conscious recall or recognition (explicit memory), you can still learn new information, retain this for long periods of time and act on the basis of that new information or new experience – in other words, learn and grow as a person. As Bartlett and O'Connor (2010) argue, growth is a fundamental right that must be respected for everyone. Many people with dementia highlight activity and growth within their lives, which can offer a means of resisting being devalued by others (Buggins, Clarke and Wolverson, 2021; Talbot et al., 2020). Despite some examples (see Low and Purwaningrum, 2020), learning and growth are worryingly absent in popular and clinical representations of dementia, which tend to overwhelmingly orient around the loss of memory and other abilities (Beard, 2016; Brookes, Putland and Harvey, 2021; Putland and Brookes, 2024a).

Overall, participants' representations of dementia attend to both losses and gains, change and continuity, and suffering and enjoyment. This is in stark contrast to discursive trends observed in the public sphere, which traditionally foreground a 'tragedy' discourse (see Chapter 1). Participants' foregrounding of nuance is also evident in their use of and responses to the arguably most prominent counter-discourse to the dominant 'tragedy' discourse, which is referred to throughout this book as the living-well discourse. While this counter-discourse is positioned by multiple participants as a valuable source of hope and empowerment, other participants critique it for failing to recognize the difficulties and suffering associated with people's dementia experiences. For instance, the Memory Café volunteers reflect on their internal conflict from feeling that the living-well discourse that they publicly uphold does not reflect the 'brutal' reality of dementia (P8). Overall, participants' discussions indicate that discourses which overly foreground either 'tragedy' or 'living well' can be harmful. Such discourses thus require careful balancing to avoid being constraining, with more nuanced explorations of life with dementia being needed that recognize that it is a 'grey area' (P19).

Throughout, participants also indicate a complex relationship with the biomedical discourse and its implications for life with dementia. While participants frequently draw upon biomedical understandings of dementia and positively position technologies (such as brain scans), treatments and hopes of a future cure, simultaneously, a tension often emerges between the 'voice of medicine' (encapsulated by a biomedical discourse) and 'the voice of the lifeworld' (i.e. participants' subjective realities of life with dementia; Mishler, 1984). Participants often present a disconnect between biomedicine and their own subjective positions, whether presenting medical research as irrelevant to (or failing to understand) the day-to-day realities of dementia or feeling excluded as a research participant within medical settings.

Reflecting the overuse of a biomedical discourse in society more broadly and the depersonalization associated with it, whereby 'the person disappears behind the diagnosis' (van Gorp and Vercruysse, 2012: 1276), multiple participants explicitly push to 'move away from the clinical, medical, stuff' when representing dementia, towards more 'personal' and 'familiar' depictions (P19) that give 'a good insight into how we are actually working, and reacting and talking' (Nancy/PN). Instead, participants consistently emphasize the *person* with dementia and their subjective experience; this aligns more with a psychosocial approach's emphasis on the person and resists the disease-oriented focus of biomedicine (Kitwood, 1997). The notable exception to this is that despite criticizing biomedicine, some carers in the working age dementia group also call to *further* medicalize dementia, rationalizing this by associating medicalization with increasing resources and support relative to their current experience of what they term a 'social' model (P30). Their concern with resource allocation reflects wider systemic issues with dementia care (Peel and Harding, 2014) and the decades-long use of a biomedical discourse to justify funding and medical intervention, boosting the resources available (but largely for medical research; Fletcher, 2024; Fox, 1989). Here, then, the participants signal an acute awareness of the material impacts (here, resource allocation) of how dementia is discursively constructed.

Another motivating factor for calling to further medicalize dementia appears to be the carers' assumption that positioning dementia as a 'brain disease' (rather than a 'social disease', such as alcoholism: P28) bestows a certain level of 'respectability' that shifts any blame from the person's behaviours to their biology (Gerritsen, Oyebode and Gove, 2018: 598). Other participants also present dementia as an unpredictable event that is beyond individual control, including through a 'lottery' metaphor (PH). This arguably contrasts an increasing focus in medicine on modifiable risk factors (both structural and individual; Livingston et al., 2024) and a neoliberal discursive trend, particularly in the media, of attributing responsibility to individuals to reduce their risk of getting dementia (or manage their symptoms; Lawless, Augoustinos and LeCouteur, 2018; Peel, 2014; Peterson and Schicktanz, 2021). Focusing on management strategies, participants sometimes associate individual healthy behaviours, such as going for a walk and eating well, with 'living well' with dementia. Contrasting this individualistic focus, others take a more structural approach to managing health by discussing factors such as access to support and meaningful activities. Exemplifying the fluidity of discourses, here 'living well' may be combined with a more neoliberal discourse to encourage individual management of health, or with a more structural/rights-based discourse to instead foreground the role of the state and/or society in providing a facilitative environment for citizens to live well. While not an explicit focus here, how discourses regarding state and individual responsibilities might be navigated is a key point of interest moving forward (for some discussion of this in relation to dementia risk, see Slocombe, 2024).

Throughout, participants resist the homogenization of people with dementia across the media, medicine and in daily life, which, as Bailey (2019: 186) observes for the news media, assembles people into an undifferentiated, anonymous mass, obscuring any sense of individuality or selfhood. Instead, participants emphasize that stereotypes of older age and a conflation of dementia with its most common type, Alzheimer's disease, constrain the image of who a person with dementia can be, contributing to misunderstandings (as with P6's mother's vascular dementia) and exclusion (e.g. in care homes and music/activity choices) for people who do not fit either or both of these stereotypes. In Chapter 6, PN/Nancy critiques the homogenization of people with dementia by medical staff due to insufficient understanding, and in Chapter 3, she discusses how she sometimes struggles to engage with other people with dementia as she is not knowledgeable about how different types affect individuals. That this lack of understanding extends to people with different types of dementia highlights the diversity of individuals who are so commonly homogenized as a collective. Homogenization is further resisted through participants' acknowledgement (drawing on a structural discourse) that the experience of having dementia intersects with other facets of a person's social location, here with a particular focus on age and socioeconomic status (Hengelaar et al., 2023; Hulko, 2009).

Age is particularly foregrounded as an important factor in a person's experience of dementia within an ageist society. Firstly, there is the 'double stigma' experienced by people who are older in age and have dementia (Evans, 2018: 272), with Nancy claiming that older people are commonly 'side-lined' in Chapter 3 and advocating challenging these ageist practices by recognizing the 'expertise' of older people (with dementia). Whereas Nancy resists ageist ideologies, some participants demonstrate internalized negative views of ageing, particularly in Chapter 4, with individuals expressing fear and repulsion at signs of older age when examining the hands images. As Latimer (2018) explores, dementia can be seen to embody some of the worst fears of growing old, which orient around the hollowing out of personhood and an existence as a disintegrating body that is the subject of widespread revulsion. Such discourses can cause great harm to older people and/or people with dementia (van Wijngaarden et al., 2019), which is demonstrated in the extreme by P4's reporting of PB's wish that she 'were dead' because 'I'm useless'. Conversely, people with young-onset dementia emphasize that the 'ageing–dementia relation' (Latimer, 2018) is such that if people do not fit into the social category of an older person, they face a unique set of challenges when trying to navigate the world as someone with dementia, since existing support structures and understandings of dementia overwhelmingly exclude them. This may result in difficulty finding a place in institutional care or with a person's identity as someone with dementia being challenged, as PH reports when swimming. Although the prevalence of dementia undeniably increases with age, participants' accounts highlight the need to consider the perspectives of people with dementia of *all* ages to make the dementia–ageing relation less harmful moving forward.

As well as age, socioeconomic status (or class) is also highlighted by participants as intersecting with experiences of dementia. Alongside influencing the support that someone can access in society (e.g. 'I'm on income support, I have no choice where my wife goes, so don't complain about you've got 24 [care homes] to pick from': P33), socioeconomic status is positioned as also potentially impacting upon how a diagnosis is received. Diagnoses are positioned as more shocking for people with a high-powered job or high social status (namely a headteacher and Sheila's husband), while P6 recalls someone with low literacy dismissing dementia as just being 'more of the same' as 'I've never been very bright anyway!' This contrast appears to support Hulko's (2009: 141) theorization that the more marginalized someone is in society (here through their socioeconomic status but elsewhere through gender, race, ethnicity, etc.), the more likely it is that dementia simply 'becomes one more hurdle to overcome or just another thing to be getting on with in life', with individuals being able to draw upon the resilience acquired through having already experienced some form(s) of disadvantage and/or discrimination. Further research into the impact of socioeconomic status is needed to explore this further, alongside a consideration of the complex interrelationships between other factors such as gender, race, ethnicity and (dis)ability, which tended not to feature among this study's discussions, likely reflecting both the research focus and the participant demographics. Also important to explore further is how the experience of supporting someone with dementia is impacted by someone's social location, with examples of caring for someone while being disabled (P2) or having a dementia diagnosis (Sheila) highlighting the need for intersectional models to attend to (dis)ability for supporters/carers too, which is a focus currently lacking in research (Hengelaar et al., 2023).

Navigating identity and transformation with dementia

Following previous research on identity work by people who have dementia, participants with dementia both acknowledge dementia as part of their identity and resist being defined by it (Bailey, 2020; Beard, 2016). In Bryden's (2019: xii) words, 'we are people who happen to live with dementia'. This is evident throughout; participants diagnosed with dementia will discuss their experiences of dementia and explore it as part of their identity while equally emphasizing *other* aspects of their identity, whether this is as a physicist (PH), activist (Nancy/PN) or author (PK). While certainly not the only strategy used, humour emerges as an important means of coping with dementia and the stressors (such as identity threats) that it entails (Hickman, Clarke and Wolverson, 2020). As well as enabling social bonding, humour can diffuse tension in a social interaction and mitigate the face-threatening potential of a disclosure (Birt et al., 2020; Norrick and Chiaro, 2009), as when PD diffuses his wife's narrative about the 'difficult subject' of him having to stop driving due to his dementia. This exchange results in the group appreciating the sense of humour that the two husbands with dementia have, showcasing that people's accounts can foreground continuity for a person (here, their humour) as well as change in the context of life-altering conditions (Whiffin et al., 2019). In line with existing research, then, participants with dementia highlight their identity *beyond* dementia and may challenge perceived threats to their identity through humour, which can be an important resource for social connection and identity work.

Navigating changes to both people's life and identity is a central aspect of participants' representations of what it means to experience dementia, whether this is through having a diagnosis or supporting someone diagnosed. Adding to existing findings on change (Buggins, Clarke and Wolverson, 2021; Holdsworth and McCabe, 2018; Spreadbury and Kipps, 2019), here, change can manifest through changing abilities or personality traits with dementia, as well as changed attitudes and social positioning within the world, including experiencing stigma, relationship changes, new opportunities and the loss of old ones, such as driving. Whereas PC talks of cheering up, in the same focus group, two other couples discuss an initial wish to die upon being diagnosed with dementia, due to feeling useless, overwhelmed and fearful of the future. Beyond this study, being diagnosed with dementia is consistently shown to be traumatic, often unnecessarily so, with fear-inducing cultural conceptions and specialists failing to offer sufficient hope or clarity (Beard, 2016; Sabat, 2018). Combined with the challenges of current and future changes, and the stigma associated with the condition, unfortunately, my participants' accounts reflect an increased risk of suicide for older adults with dementia more broadly (Serafini et al., 2016).

In this study, both participants who expressed a wish to die are represented by their partners as moving towards acceptance of the condition. Against these carer accounts, Sheila's interview in Chapter 3 offers a useful first-hand insight into some of the complexities of navigating your status as someone with dementia, here a diagnosis of mild Alzheimer's disease. Throughout much of the interview, Sheila positions herself as a carer and as someone who is currently coping well with her mild Alzheimer's disease. However, later in the interview, Sheila draws on her account of her husband's changes and increasing dependency when he had vascular dementia and Parkinson's to also predict that 'there'll be, a loss, to what I was [2.0] A very competent, efficient, er. in the nursing world, fairly high powered. erm, to [2.7] not being that anymore'. This loss-oriented list diverges from her previous discussions of her abilities and activities, such as driving and caring for others, which are each associated with independence and responsibility. Here, Sheila reveals an initially concealed vulnerable and fearful side, highlighting the existential threat that dementia poses to individuals' lives and sense of identity (Cheston, Christopher and Ismail, 2015). While this is frequently expressed by other people with dementia (Castaño, 2020), it can also be masked beneath overly positive self-representations (Talbot et al., 2020), likely in resistance to cultural devaluation (Steeman et al., 2007).

Notably, Sheila's foregrounded (lost) abilities reproduce the valuing of hypercognitive abilities such as efficiency above more emotional, relational, expressive and/or experiential ones in (Western) culture (Post, 2000b). Her distress reiterates first-hand the damage of exclusionary hypercognitive values, which further amplify the identity threat that dementia poses. Moreover, that Sheila particularly fears being 'taken away' to an institution, despite not wanting to be there, indicates that many fears of loss and future treatment as a person with dementia are *socially situated*. These fears are notably worsened by structural inequalities and the normalization of human rights violations for people with dementia, upheld by discourses that position people living with dementia as somehow being lesser humans and as lacking in personhood (at the extreme, being the 'living dead'), due to the cognitive difficulties that they experience (Cahill, 2018; Heap and Wolverson, 2020; Steele et al., 2023). Indeed, Behuniak (2010: 231) argues that the loss of self (or personhood) discourse 'precedes other [legal] losses such as the right to personal autonomy and claims to privacy, liberty, and due process'.

Throughout, participants' (self-)presentations of people with dementia may reinforce but also more often resist and replace hypercognitive and 'loss of self' discourses. Notably, while some participants in Chapter 6 appear to conflate the brain with the person, others explicitly reject this discourse by emphasizing that people are *not* reducible to their brains (P19). In the same chapter, while some carers for people with more advanced dementia suggest that there are pieces of their loved one missing (note that nowhere does anyone suggest that their loved one is *not* a person), other participants (both with and without dementia) reject this discourse, including by positioning the phrase 'a piece missing' as false.

Accompanying these moments of resistance are multiple counter-discourses that align with more embodied, relational and inclusive conceptualizations of personhood. Notably, Bryden (2020) convincingly argues that people with dementia continue to have a sense of themselves as an embodied, relational self, with a narrative of meaning that is grounded in the present moment rather than past events. Similarly, participants frequently discuss *changes* to a person (rather than loss of self) and consistently indicate the importance of narrative, relational and embodied aspects of the self. Accounts such as PE and P13's prioritization of their couple identity value *inter*dependence and ways of supporting the agency and identities of people with dementia through relationships with others. This is important since, despite being central to human relationships across the lifecycle, interdependency remains devalued in a society dominated by an 'individualistic and "strongly purposive"' conceptualization of agency, an imbalance that has been linked to the lack of agency ascribed to people with dementia (Boyle, 2017: 1792). Relatedly, multiple participants discuss the need to stimulate both people with and without dementia and to support individuals to engage with others. Within such relations, meaningful interactions are shown to include more than linguistic communication, particularly in Chapters 3 and 4, with the body being recognized as an important site of intent and engagement (Kontos, 2004, 2006).

Participants' counter-discourses parallel the disability movement more broadly, where disabled people and their allies are challenging society to rethink what it means to be human and to find 'more human and humane possibilities' for how we treat one another (Goodley, 2020: 13). As Behuniak (2011: 88) argues, a powerful alternative to socially othering discourses is emphasising that 'it is connectedness and mutual interdependence that makes us human' to encourage greater respect and compassion towards all members of humanity. At a time when society is grappling with reduced community support and when individual-oriented technology (such as robotic pets for companionship) is being suggested as a solution for dementia care, it is vital to recognize the importance of our interrelationships and interdependencies, both with other humans and with other living organisms (Jenkins et al., 2021). Given appropriate conditions and sufficient resources, by valuing and strengthening such interrelationships, we can collectively thrive as the social and embodied beings that we are.

It is important to contextualize the above discussions by recognizing that dementia can be regarded as what Paul (2014) terms a *transformative experience*, in that experiencing the syndrome (both first-hand through a diagnosis and second-hand as a supporter) can fundamentally change a person's knowledge, identity, experience of the world and/or outlook in ways that were hitherto unforeseeable (Carel, Kidd and Pettigrew, 2016). For instance, Chapter 4 explores how participants' initial understandings and (mis)perceptions of dementia evolved in response to their direct experiences. Subsequently, while participants emphasize the individuality of people affected by dementia, simultaneously, a sense of a shared understanding is constructed that unites people with direct personal experience of the syndrome (e.g. 'we understand, what it's like to have dementia': PK). That seven participants explicitly use the word 'understand' to discuss the shared knowledge that comes from mutually experiencing dementia highlights the importance of this concept. Thus, peer support is regularly praised as a source of collaborative, shared learning that boosts the sense of connection and well-being of people affected by dementia, and that involves alternative (and often better) relationships, experiences and outcomes to interactions with health professionals (Hillman et al., 2018; Keyes et al., 2016).

Throughout this book, then, participants broadly establish two groups: an 'in group' of people directly affected by dementia, and an 'out group' of everyone who has not (yet) had this experience and thus does not 'understand'. To bridge this 'understanding' gap, participants advocate for better communication between their community and those without experience of dementia, including organizations (e.g. the media and businesses), medical professionals and members of the public. People with dementia and their supporters are thus positioned as being the 'experts by experience' (Parveen et al., 2018), reflecting a broader social shift towards recognizing the integral role of people with dementia within research and social responses to dementia (Davies et al., 2022; Hillman et al., 2018). While here, such expertise is considered in the context of dementia, elsewhere, it has been argued that people's experiences of and adaptations to the syndrome also present valuable learning points for society more broadly (for a discussion of how adapting to the transformative changes associated with dementia may inform collective approaches to the transformative changes associated with the climate crisis, see McShane, 2018).

A spotlight on semiotic resources

As shown above, participants reinforce, challenge and reshape a range of dementia-related discourses, both in their own accounts and in their responses to different examples of images and language use. This section focuses on that process, namely, how participants variously interpret, use and reshape available semiotic resources and associated discourses. I outline how individuals' interpretations of language and images can be informed by their discursive preferences and interact with different semiotic resources, such as camera angle. I then consider issues of accessibility, accuracy and the ideological consequences of some of the images used to represent dementia, before attending to participants' often novel and creative uses of metaphors to resist existing portrayals and/or express dementia.

Across chapters, participants' various interpretations of the same words and images reinforces the subjectivity of people's responses to social texts (Breeze, 2011; Kitzinger, 1993). Chapter 3 provides a focused exploration of how two interviewees living with dementia, Sheila and Nancy, differently represent their experiences of dementia and how their personal experiences and discursive positionings materialize in their unique responses to the same three images. Overall, Sheila draws on more psychosocial discourses, being concerned with relationships and her subjective experience, while Nancy takes a more structural, rights-based approach to dementia in her focus on inequalities and advocating for people with dementia through the media. Although the women similarly recognize what an image depicts – for instance, the movement of fragments away from the man represented in Image 10 (Figure 3.4) – both draw on different personal experiences to contextualize their individual interpretations of what that may mean, here, in relation to back pain versus disorientating moments. In general, Sheila is more likely to emphasize emotions, change and identity when interpreting the images, and Nancy to link her interpretations to structural points, such as the need to improve care homes. Evidently, people may similarly interpret what the image literally denotes, but the connotations drawn are heavily influenced by our subjective experiences and discourses (Barthes, 1977).

Throughout the analysis chapters, participants' interpretations are compared where possible to those of advocates and academics to explore the issue of subjectivity further. Image 12 (Figure 3.5, showing the woman with the missing jigsaw piece) is a good case study for this, since Chapter 3 examines Sheila and Nancy's responses and compares these to the analysis of the same image by MCDA analysts, Harvey and Brookes (2019). Chapter 5 then returns to consider Image 12 in relation to all participants and in the context of the other three images that it was presented alongside (page 3 of the Appendix). What emerges from this exploration is a diverse array of interpretations, which variously reinforce and contradict one another, highlighting the 'plurality of possible interpretations' to the same social text, here an image (Widdowson, 1998: 150). Through incorporating different voices in response to the same image, this book aims to model one way of eliciting greater dialogue between people with differing perspectives and experiences to provide a more comprehensive picture of engagement with discourses than is usually provided in author-oriented (multimodal) critical discourse analyses (Breeze, 2011).

The choice of semiotic resources also informs participants' interpretations, which Chapter 4 exemplifies with the two photographs of hands (Figures 4.2 and 4.3). In these close-up shots, signs of ageing, such as wrinkles, are foregrounded; subsequently, many participants comment on the hands as signifying older age. Beyond this, the ambiguity of a decontextualized close-up of only hands evokes uncertainty, with many contradictory interpretations. In general, though, while some individuals consider semiotic choices such as the angle and differences in lighting, many participants distinguish between the two photos of hands through the represented participants (Kress and van Leeuwen, 2021). Notably, participants are more likely to relate to the image of two people holding hands than of one individual's clasped hands. The two hands tend to be associated with supportive relationships and non-verbal communication, alluding to the embodied nature of the self (Kontos, 2006) and mirroring Ang, Yeo and Koran's (2023) findings that four charity representatives associated similar images of hands in a dementia context with care, support and assurance. Conversely, without anything to engage with, the solitary hands more frequently evoke interpretations of victimhood, depersonalization and sadness, in line with existing analyses of solitary hands, which are a common visual trope (Brookes et al., 2018; Harvey and Brookes, 2019). This contrast between the photos of one and two pairs of hands demonstrates the importance of attending to specific choices made within the same broader trope, here of close-up, decontextualized hands.

Furthermore, as participants' responses to the brain scan (Image 17; Figure 6.2) and visual tree metaphor (Image 11; Figure 5.3) exemplify, it is also worth attending to issues of accessibility, perceived accuracy and the ideological implications of images that are popularly used to illustrate or explain dementia. Conversations with participants about Image 17 in Chapter 6 reinforce existing criticisms of brain imaging, as although participants position brain scans as a means of showing internal brain changes, without being specialists, no one can confidently read what the scans show (Cohn, 2010; Dumit, 2004). Despite the obscure and inaccessible nature of the scans, participants appear to overwhelmingly trust their accuracy. Indeed, the only criticism of brain scans is implicit, when PK challenges a medical professional's diagnosis based on not seeing a bleed, thus implying that scans cannot show everything. Instead, participants draw generalized conclusions, such as the scans in Image 17 showing 'a type of, dementia' (PH). Being imbued with social as well as scientific meaning, the brain scan exemplifies how visual choices have ideological implications that can extend far beyond the image's original context. Notably, the inference of the existence of a 'good' (P32) and bad/ill type of brain reinforces Cohn's (2004: 69) assertion that 'visual styles and conventions can serve as non-linguistic constructions that can contain and shape discursive elements without ever having to refer to them explicitly'. Here, through being used to diagnose conditions, brain scans can indirectly convey a dichotomy between 'healthy' and 'unhealthy' individuals, which risks becoming inherently divisionary and stigmatizing when combined with the widespread conflation of people with their brains (Harvey and Brookes, 2019; Vidal, 2009).

The tree metaphor image in Chapter 5 offers an alternative visualization of dementia through drawing on a more tangible source domain (deciduous trees) to metaphorically depict people with dementia losing brain cells the way trees lose their leaves in autumn. This biomedical reading is the primary, but not only, interpretation here. Although not everyone reads the image metaphorically, most do, and many participants praise the metaphor for its ability to meaningfully show and explain what is happening in the brain with dementia. This exemplifies the ability of metaphors to resonate with people's psychological, physical and emotional experiences, offering a valuable means of self-expression and understanding (Castaño, 2020, 2023; Padfield et al., 2018). Interestingly, the visual metaphor is more likely to be criticized than the brain scan, perhaps in part as it is more accessible and not imbued with any 'expert' status or scientific authority (Cohn, 2004; Dumit, 2004), and in part as it extends the (un)healthy brain connotation further.

Notably, multiple participants resist the tree metaphor's implications of a linear loss and the conflation of a deteriorating brain with a loss of self. Participants instead suggest alternative visual choices, namely (1) showing a forest to present the multiplicity of dementia rather than reducing it to three stages, and (2) including floating leaves or varying the areas experiencing leaf-loss to acknowledge changeability and flux in both abilities and identity with dementia. That participants employ metaphor to visually illustrate their counter-discourses demonstrates its importance as a semiotic resource for expressing intangible and complex phenomena. In Chapter 6, participants additionally propose using language to foreground that the non-specified ages of the tree heads supports that 'Dementia can affect any age' (P30), signalling an awareness of the interrelationship between linguistic and visual forms in guiding interpretations (Forceville, 1996). Overall, the debates surrounding the ideological implications of the tree metaphor in this study reinforce the subjectivity and plurality of individuals' responses to manifestations of discourse(s), with people here differently accepting, rejecting or reframing the same visual metaphor (Breeze, 2011; Kitzinger, 1993).

There are multiple instances throughout this book of participants metaphorically countering dominant dementia discourses, including suggesting visualising a 'layered individual' at multiple ages to reflect a fluidity rather than loss of self for people with dementia (Chapter 6). To explore participants' use of metaphor further, it is useful to draw upon van Gorp and Vercruysse's (2012) classifications of dominant dementia frames and their counter-frames, which are comparable to discourses and counter-discourses in this book. Turning to some of the metaphors used in Chapter 4, it is notable that PH's 'Mr Alzheimer's' figure aligns with the 'strange travelling companion' counter-frame, which provides a less catastrophic and potentially more empowering alternative to the more popular 'invader' frame whereby dementia possesses people and destroys their lives. Moreover, PK's use of the 'alien' metaphor demonstrates that participants may reshape dominant frames *into* counter-frames, as the typically monstrous alien invader is humorously converted into a companion that PK works with, to the point that his vicar asks 'how's the alien?' much as one would ask after a family member or pet. This example corroborates that the connotations of metaphors are not fixed and can vary according to contextual factors like attitude (Castaño, 2020; Semino et al., 2018).

Other participants also demonstrate novel applications of popular source domains, such as a tree, with P19 comparing dementia to a 'tree' that keeps branching off into different types and experiences to emphasize 'pluralism' with dementia. This use contrasts the typical deficit-oriented plant metaphors of weeds growing in the mind or trees losing their leaves (Ang, Yeo and Koran, 2023; Caldwell, Falcus and Sako, 2021; Zimmermann, 2017). Evidently, simply dismissing alien metaphors as damaging or tree metaphors as loss oriented ignores people's creative self-expression and the potential to reinterpret and reshape semiotic resources associated with a dominant discourse to present alternatives.

7.3 Recommending routes for change

Both the dementia literature and participants' responses indicate that how we as a society communicate about dementia needs to change. In Chapter 6, I summarized participants' critiques and suggestions regarding popular representations into three recommendations:

1. *Normalization:* Make dementia more familiar and relatable for people through person-oriented accounts of life with the condition that promote understanding and compassion.
2. *Nuance:* Provide more multifaceted representations that acknowledge the diversity of subtypes, people and experiences in relation to dementia.
3. *Advocacy:* Better value people living with (and otherwise affected by) dementia, who need to be respected as experts through their experiences with dementia and provided appropriate resources to promote change.

These recommendations echo calls across research and dementia advocates for more holistic and empowering representations (e.g. Bailey, 2019; Bryden, 2016; Mason et al., 2024; Talbot et al., 2020). To strive for meaningful social change, however, it is important to consider these recommendations within the broader (media) context. Here, I focus particularly on the concept of news values in relation to journalism (Bednarek and Caple, 2012, 2017; Caple and Bednarek, 2016). As Chapter 1 details, many of the same values, such as negativity, are evident across a range of communicative contexts, including not only news media but also charity campaigns, speeches and films (Brookes, Putland and Harvey, 2021; Low and Purwaningrum, 2020; Zeilig, 2014a). Relatedly, media, non-profit and other organizations face comparable structural, social and economic factors, which impact upon the discourses they align with (Fox, 1989; Lock, 2013; Macgilchrist, 2007). Such parallels ensure that the below discussion is relevant beyond news media.

Firstly, when considering routes for change, it is worth noting the potential of constructive journalism, which is 'a type of reporting that seeks to balance the overemphasis on problems and negativity in mainstream news with a focus on how social problems can be responded to' (Atanasova, 2022: 388). Such journalism has been tied to positive psychology through its emphasis on hope and supporting both individual and community well-being, and it is in turn associated with a more holistic representation of the world than one that only focuses on negativity (McIntyre and Gyldensted, 2018). As such, the principles of constructive journalism align well with a person-first reporting of dementia that promotes nuance and encourages social change, as well as with providing a platform for experience-led expertise and advocacy. Indeed, one of the questions that constructive journalists are encouraged to consider when writing a piece is: 'Does the story draw on sources that have ground-level expertise, not just a 30,000-foot understanding?' (Curry and Hammonds, 2014: 6).

Moreover, imaginative reframings of what *may* be possible for life with dementia can be disseminated using constructive journalism to better support people living with and otherwise affected by dementia to thrive as much as is possible. For instance, the #SocialCareFuture movement presents imaginative solutions to social care provision in the UK, a key concern for many participants in this study. #SocialCareFuture (2024: n.p.) states that to encourage action it is important 'to balance an account of what's wrong, with what it will look like when we get it right, why people have reason to value that and a believable plan for getting there'. Evidence does suggest that constructive news can yield positive results, such as increasing knowledge and engagement with a topic, alongside improving readers' sense of agency (Curry and Hammonds, 2014). However, while constructive journalism is especially suited to promoting social change, it is still itself a counter movement to the current news landscape, which presents multiple obstacles to the implementation of the above recommendations. The remainder of this section is dedicated to considering some of these obstacles through the lens of news values and postulating potential avenues for circumnavigating these.

The first recommendation, to normalize dementia, responds to participants' criticisms of the media for sensationalizing dementia. In other words, normalizing dementia contradicts multiple news values that inform media content, inevitably restricting the uptake of this recommendation. These values are primarily superlativeness (i.e. high intensity or large scope = more newsworthy), impact (serious consequences = more newsworthy), negativity (negative framings = newsworthy) and eliteness (higher status = more newsworthy; Bednarek and Caple, 2017). Indeed, following an analysis of news representations of dementia, Bailey (2019: 193) concludes that 'if the news media depicted dementia as a commonplace, unexceptional change in daily life and showed people with dementia continuing to work and contribute to society […] the topic would become inherently less newsworthy'. The same standard applies to non-profit communications, which often rely on emphasizing the impact, negativity and intensity of dementia to garner financial support (Fox, 1989; Lock, 2013).

Visual trends also offer barriers to the uptake of ordinary, everyday visual representations. Despite recommendations to show images of ordinary people (KYN et al., 2023), stock images increasingly dominate publications and are largely defined through their genericity, timelessness and low modality, favouring actors in non-specific settings who can be used to represent a range of concepts (Machin and van Leeuwen, 2007). To show normal people in an everyday, specific setting contradicts this trend of visually representing dementia in more abstract, non-specific terms using premade stock images (Brookes et al., 2018; Harvey and Brookes, 2019). There are practical and ethical constraints too; interviews with non-profit representatives indicate that although it would be ideal to use images of real-life people with dementia and their carers in a personal way, this must be balanced with respecting people's confidentiality and privacy (Ang, Yeo and Koran, 2023). Having said this, there are possible alternatives, including people affected by dementia being involved in image production not necessarily as the represented subjects but as the creators, which is a point that I return to at the end of this chapter.

Providing more nuance in representations is problematized by text producers often having limited space to convey their messages, which can lead to cutting anything that undermines or confuses the central argument(s) (Macgilchrist, 2007). Here, successfully rendering the issue more complex arguably requires balancing the news value of consonance, which entails connecting to pre-existing understandings and stereotypes about the topic and people involved, with that of unexpectedness, which refers to the 'out of the ordinary' aspects of an issue (Bednarek and Caple, 2017: 66). Macgilchrist (2007: 88) envisions this through the 'curiosity gap' model, arguing that 'if the article is too far from the reader's current knowledge of the world, it will be ignored; if the article tells readers what they already know, it will be deemed uninteresting. The key is to meet the readers where they are and add a manageable amount of new information'. In this context, then, complicating an issue by challenging dominant discourses (unexpectedness) requires sufficient alignment with these discourses (consonance) that audiences have enough scaffolding to engage with unfamiliar counter-discourses.

This unexpectedness–consonance balance informs the uptake of all three recommendations. For instance, increasingly nuanced representations of personhood may need to use the currently dominant hypercognitive discourse as a bridge towards normalizing a more holistic alternative, similarly to how researchers have built upon existing personhood work to progress over time. In this way, what are initially counter-discourses, such as Kitwood's (1997) theory of personhood, can become normalized, encouraging new areas of focus and further developments as a result (Brooker and Kitwood, 2019; Katz and Leibing, 2023). The same may be true for the third recommendation: advocacy. It is now more established among academics and advocacy/non-profit groups that listening to the perspectives of people diagnosed with (and otherwise affected by) dementia is 'an obvious and viable way to explore new, alternative representations and eventually draw a richer, more comprehensive and multifaceted picture of living with dementia in the public sphere' (Schweda, 2019: 7). As such, mainstream portrayals, too, have the potential to transition into better respecting this diverse social group as experts through experience. Through recognizing experience-led expertise, people with dementia could join the social groups often valued as 'elite' sources by media, such as researchers, politicians and medical professionals (see Bailey, 2019; Bednarek and Caple, 2017) by being celebrated for providing unparalleled access into what it is like to subjectively experience life with dementia.

One news article from this dataset in particular offers a useful example of how normalization, nuance and advocacy may be incorporated into mainstream portrayals through addressing this unexpectedness–consonance balance, alongside the news value of personalization (the personal or 'human' face that explores how an event/issue impacts real individuals). This is *The Times* article, entitled 'End dementia stigma, says Anne Duncan who "remarried" sufferer' (Horne, 2019). Image 13 is drawn from this article, which depicts an ordinary couple getting (re)married in their garden, clearly photographed by a guest. The photograph showcases another trend observed in news media that provides an alternative to stock images: that of using photos taken by ordinary witnesses of news events (Bednarek and Caple, 2017). The article is one of many that featured this national human-interest story in August 2019; indeed, an alternative headline was used in the linguistic stimuli from the *Scottish Daily Mail* (Figure 2.2). The story orients around the novelty of a married couple holding a wedding-like ceremony following the partner with dementia forgetting their original marriage and proposing again to his wife.

Although *The Times* article arguably aligns with disempowering discourses (e.g. 'his illness robbed him of all memories of their relationship'), it simultaneously complicates these through representing a loving partner with dementia, who clearly has agency, enduring selfhood and meaningful relationships (e.g. 'He's still my Bill'). Its headline captures this tension, reading 'End dementia stigma, says Anne Duncan who "remarried" sufferer'. While 'remarried' indexes unexpectedness in this context, 'sufferers' is a long-held term that despite being discouraged by language guidelines is still popularly used and familiar to readers (consonance; Bailey, 2019). Despite using such terms, this story elevates advocates' voices, who call to 'end dementia stigma' in the headline and, as the article later explores, to increase 'visibility' for people with dementia, to highlight that life with dementia can have 'rubbish' but also 'completely magical' moments and to promote ways of improving the well-being and connection of people with dementia. Such aims are strikingly similar to the recommendations drawn from discussions with participants in this book, too. Conspicuously missing from this article, though, are any voices of people with dementia, with supporters being left to speak on their behalf. This article, then, can be seen as a stepping-stone; while drawing on long-standing linguistic practices associated with disempowerment (such as suffering-oriented, dementia-first language and excluding the voices of people with dementia), it simultaneously builds on these to explore alternative discourses. These alternatives foreground the continuance of self and relationships with dementia, the multiplicity of life with the condition, and aim to improve social responses to better support people with dementia.

The story of the couple who remarried in their garden exemplifies that appealing to personalization offers an important route to making representations more normalized, nuanced and empowering for people with dementia. As journalist Kelly (2019: 95) notes, 'the media and dementia sectors can benefit each other. The media need powerful, newsworthy human-interest stories and it's up to those in the dementia community to understand what these are and provide them, quickly and accurately'. That the above article combined reporting on a couple remarrying with efforts to challenge dementia stigma demonstrates that human-interest stories can explore both individual and broader societal issues. It is important, however, for these human-interest stories about individuals affected by dementia to reflect 'the diverse face of dementia' (P17), including regarding people affected, dementia subtypes and people's overall experiences of both dementia and of life beyond the condition (e.g. other interests and roles). Equally, wherever possible, people with dementia should be acknowledged as the expert voices that they are and cited accordingly, rather than others being consulted on their behalf (Bryden, 2016).

While balancing unexpectedness with consonance offers a path to shift discourses over time, it is also worth considering how news values initially envisioned as obstacles can be repurposed to fit participants' recommendations. Notably, the newsworthiness of negativity could be drawn on to foreground systemic issues such as institutional human rights violations and the intersectionality of discrimination, including ageism, sexism and racism (Boyle, 2017; Evans, 2018; Hulko, 2009). When combined with a rights-based and more inclusive framing, such coverage could help to push forward improvements to the support provided for people with dementia through raising public awareness and shifting understandings, especially if presented alongside viable solutions (as is the case with constructive journalism).

By presenting participants' recommendations alongside current journalistic alternatives (namely, constructive news) and a theoretical exploration of news values, this book aims to demonstrate some of the ways in which it may be possible for text producers to normalize dementia, increase nuance and advocate for people with dementia without detracting from the 'newsworthiness' of their message (Bednarek and Caple, 2017). Considering that this book's focus is not on text production, the above discussion would benefit from further refinement in collaboration with a range of stakeholders, including text producers such as journalists and non-profit communication teams. In the meantime, the intention here is to spark discussion and reflection about how alternative practices might be achieved. I return to this issue at the end of this chapter when I reflect on the possibilities associated with collaboratively creating alternative portrayals of dementia.

7.4 Contributions, limitations and looking to the future

This book's central contribution is its exploration of how people affected by dementia navigate a range of dementia discourses, including how individuals respond to a selection of images and language choices. This adds to an increasing recognition of the integral role that people with dementia, as well as their supporters, need to play in improving understandings and the social treatment of dementia. With researchers such as Carmody, Traynor and Marchetti (2015) having called for more qualitative research to address the experiences of people with dementia and carers, this book is part of a shift in academia towards redressing the historic exclusion of the voices of people with dementia and acknowledging this social group as experts through experience (Davies et al., 2022). Including explicit discussions about dementia representations adds another perspective that supplements the rich wealth of research into how people affected by dementia use language in other contexts, such as books, online forums, blogs and interviews oriented around other topics (e.g. Bailey, 2020; Bös and Schneider, 2022; Castaño, 2020; Hamilton, 2019; Peel and Harding, 2014; Zeilig, 2014b; Zimmermann, 2017). Since this research project began in 2018, it has been encouraging to both witness and be part of an increasing emphasis on how people living with dementia and/or supporting people diagnosed respond to social texts, including images, language, headlines and video adverts (see Ang, Yeo and Koran, 2023; Mason et al., 2024; Putland, 2022; Slocombe, 2024; Vermeer, Higgs and Charlesworth, 2022). Considering the complexity of this issue, and the diversity of people affected by dementia, I am excited to see this area advance and branch off to explore different communicative contexts, cultures and communities moving forward.

This book's multimodal focus adds to a small but growing body of literature that attends to both linguistic and visual representations of dementia (Brookes, Putland and Harvey, 2021; Brookes et al., 2018; Caldwell, Falcus and Sako, 2021). Multimodal analysis recognizes that in a society increasingly saturated by, and literate in, visual communication, it is important to interrogate both verbal and non-verbal manifestations of discourses, since both greatly influence our engagement with the world (Ledin and Machin, 2018a, 2018b). By consulting people affected by dementia, this book diverges from existing multimodal work and addresses some key limitations of (multimodal) critical discourse analysis ([M]CDA), in the hopes of modelling a more grassroots-led application of this approach. Breaking with the traditional (M)CDA focus on the researcher's reaction to a text facilitates an empirically grounded examination of the range of interpretations and responses to discourses that individuals may give, including accepting and reiterating, challenging and rejecting, or adapting and reshaping dementia discourses (Breeze, 2011).

Participants' responses to the degenerative images in Chapter 5 demonstrate how people without an MCDA background can not only deconstruct ideologies connoted by semiotic resources but also suggest changes so that these resources (particularly for the tree visual metaphor) can better align with their own experiences and discursive positionings (e.g. by showing the leaves floating around the tree). By including stimuli that are identical or similar to those analysed by other MCDA researchers (notably, Brookes et al., 2018; Harvey and Brookes, 2019), this book has compared the responses of academics specializing in semiotics and participants with experience-led expertise in dementia. Working with people affected by dementia, then, enables greater exploration of how individuals from a traditionally disenfranchised social group, with extensive experience themselves of dementia, (re)interpret and resist mainstream discourses and generate counter-discourses (Breeze, 2011; Luke, 2002). Attending to not only problematic but also potentially more empowering practices holds great potential for positive social change by aiming to construct, as well as deconstruct, instances of discourse (Bartlett, 2018). Considering the need for more scholarship that aligns with this more constructive emphasis in (M)CDA, I hope that this book can be a useful example for other researchers interested in this area.

Beyond academia, this book aims to be a useful resource for promoting nuance when representing dementia. This work is intended to complement the communication guidelines that many non-profit organizations have created or co-produced with people affected by dementia (see Alzheimer Europe, 2022; Alzheimer's Society, 2018; Bould, 2018; DEEP, 2014; KYN et al., 2023). Whereas guidelines must concisely amalgamate participants' voices to produce clear directives regarding communicative choices, this book has the space to explore, in depth, a variety of individual accounts, interpretations and expressions. It therefore hopes to form a useful resource that guidelines can signpost readers to for a more in-depth and nuanced exploration of how individuals affected by dementia might respond to semiotic resources and their associated dementia discourses.

Likewise, while useful, guidelines have until recently prioritized language (for a more sustained discussion of images, see KYN et al., 2023), and so this book's detailed examination of visual representations can contribute further information on this topic. As the tree visual metaphor (Image 11) demonstrates, even images that are not as obviously stigmatizing may reinforce loss-oriented, disempowering discourses. Combined with findings that a public health campaign by Alzheimer's Society and NHS visually infringed many of the person-centred recommendations found in the charity's own language-based guidelines (Brookes, Putland and Harvey, 2021: 262), it is apparent that there is an acute need for in-depth explorations of the implications of not only different linguistic but also *visual* choices.

As discussed in the previous section, I also consider alternative practices that either align with constructive journalism or draw on dominant news values (such as negativity) to bridge from existing norms towards discourses that are more aligned with dementia advocacy efforts, such as addressing structural inequalities. Since news values are not restricted to the world of journalism but can also affect other spheres, notably non-profit communications, these recommendations have the potential for wider application, and how to refine and support this is one of this book's 'what now?' questions.

The above contributions must be contextualized in relation to this book's limitations, particularly regarding the study's design, conduct and analysis. Underlying all of these is the issue of voice. In a review of studies that engage people with dementia in research, Cowdell (2006: 91) asks: 'Has the voice of the participants been heard?' To this, I further question *whose* voices are heard, and how I as the researcher affect what is said and heard, both in the sessions and the subsequent writeup. Multiple factors shape whose voices are heard in this study. As discussed in Chapter 2, my recruitment strategies resulted in a group of predominately white British participants in heterosexual relationships (as far as I am aware), who lived in and around Nottinghamshire and were engaged with their local community. Unfortunately, the national Covid-19 lockdown in March 2020 permanently halted recruitment at a point where I was exploring reaching out to different networks and individuals to try to consider more diverse perspectives, and this also means that the discussions are grounded in a pre-pandemic context. This is a key limitation of my study, and with my participants' demographics (e.g. white British, heterosexual) being overrepresented in dementia imagery (Bould, 2018; Tilsed, 2019), it is crucial to explore the perspectives of people who are regularly excluded from representations, as well as from research. That mine is the typical participant sample for research projects reflects broader structural inequalities within academia and society (Fletcher, 2019b; Innes, 2009). Often, members of society such as the LGBTQ+ community, neurodivergent individuals, people from minority ethnic groups and those in rural locations, low socioeconomic situations or without a support network are categorized as 'hard to reach', when the reality is that such individuals are 'easy to ignore' and thus 'seldom heard' (Tilsed, 2019). As Fletcher (2019b) points out, however, the fluidity, approachability and adaptability that is necessary for researchers to improve their reach is often undermined by the procedures that govern projects, making this an ethical and practical priority for academia moving forward.

Another central limitation is that once recruited to the study, the running and analysis of focus groups/interviews overly relied on participants' verbal communicative abilities. This restricted the involvement of people with more advanced dementia, for whom paralinguistic oriented analysis would be more appropriate to consider embodied forms of communications (Hydén, 2013). When people who had little verbal communication were included in focus groups (primarily in the working age dementia group), I was generally unable to consider their responses as my analysis orients around vocalizations, with the exception of PP's kiss in Chapter 4. As this moment was particularly striking and partly captured by her partner's reactions on the recorder, I could document it following the session. However, many more interactions were lost due to audio-only recording and being unable, through lack of resources and time, to properly attend to them. This particularly impacted people with more advanced dementia, but also applies to the paralinguistic communications of all participants, marking a promising area that is beginning to be explored (Morgner et al., 2019). Focusing on verbal-only communication also meant that certain voices dominated focus groups. As I discuss in Chapter 2, although carers' voices often dominated (which is in line with existing research; Davies et al., 2022; Dening, Jones and Sampson, 2013), the reality was much more complex and individualistic. This reflects that dementia is just one of many factors, including personality and group dynamics, that can influence the (im)balance of voices in focus groups (Smithson, 2000). Practical constraints particularly influenced the eventual imbalance of perspectives surrounding the linguistic stimuli (Figure 2.2), as this section was excluded on multiple occasions due to insufficient time.

Of course, these focus groups and interviews only depict one specific context and point in time. Neither method can claim to provide any 'authentic Voice of the People', being insurmountably constrained by not only processes of recruitment, conduct and analysis (Bloor et al., 2001: 15), but also by the fluctuating discursive identities of individuals and contextual influences on the expression (or suppression) of certain viewpoints during sessions (Barbour and Kitzinger, 1999). Moreover, as the researcher, I act as the overarching narrator who filters and organizes participants' complex perspectives and 'multiple truths' to produce the work you see before you (Macgilchrist, 2020: 5). This can only ever be a simplified retelling that foregrounds certain aspects above others and that is inescapably influenced by my own sociopolitical and affective standing (see Chapter 2 for details). Of course, this is true across academia, and qualitative research in particular 'embraces subjectivity', which is crucial to a researcher's ability to interpret participants' engagement with social phenomena empathetically and reflexively, thus transforming data into meaningful findings (Haven and Van Grootel, 2019: 234). By sharing and reflecting on my researcher positioning in Chapter 2, I attempt to constructively address the role of subjectivity in my research by contextualizing 'my voice' for readers.

All study decisions have implications, and often there are viable alternatives that are worth considering. For instance, when collecting participants' demographic data, I did not ask people to detail the type of dementia that they or loved ones had, nor to give an idea of timeframe or stage. As discussed in Chapter 2, such details often emerged spontaneously in conversation, with the rationale being to explore how people would choose to identify themselves rather than providing predetermined categories, which are themselves disputed within the research and medical community (Lock, 2013; Whitehouse and George, 2008). However, my generalized demographic dataset is in tension with the key emergent theme of recognizing diversity within the term dementia, since I cannot consider stage, timeframe nor type of dementia in relation to participants' responses unless they make this explicit in conversation.

Equally, my specific selection and arrangement of visual and linguistic stimuli determined much of participants' responses and conversations, and therefore the study findings. This is made explicit in Chapter 6 with: 'I would have only have thought that [about this image] because of the other ones [on the page]' (P7). Although selection was informed by existing guidelines and research, stimuli representativeness could be better ascertained through a more systematic, corpus-assisted selection process. However, whereas linguists can work with millions or even billions of words when conducting language-only dementia research (e.g. Bailey, 2019; Brookes, 2023), multimodal corpora are more difficult to analyse on such a large scale. In a dementia context, researchers have tended to rely on smaller multimodal datasets, such as eleven articles or ten picturebooks (Brookes et al., 2018; Caldwell, Falcus and Sako, 2021), although visual datasets can be larger, often with around 100–450 images (e.g. Ang, Yeo and Koran, 2023; Harvey and Brookes, 2019; Putland, Chikodzore-Paterson and Brookes, 2023). Larger scale multimodal corpus-assisted analyses provide a promising avenue for future research that could, among other things, inform the selection of more representative stimuli to discuss with participants.

Finally, this project would benefit greatly from involving people affected by dementia, not just as participants but as co-producers (or co-researchers). Through shared decision-making in the project's conception, development, management and analysis, the study's scope would expand beyond my own positioning to better address the needs and perspectives of individuals affected by dementia. To do so would require navigating study barriers, namely resources and time, and focusing on enablers for co-production (Bethell et al., 2018). This is a central recommendation for future research, reflecting the increasing recognition of people with dementia's leadership in research (Davies et al., 2022).

Returning to this chapter's central question, 'what now?', I would like to conclude this book by looking forward and considering how both the design and findings of this project present promising directions for future research. Firstly, there are many ways to expand the study's scope, including regarding stimuli and perspectives. As participants highlight at the end of Chapter 6, more dynamic representations of dementia exist, and future researchers could explore people's responses to video or theatrical representations of dementia, since films, theatre productions, TV programmes and video adverts increasingly explore dementia and can help shape public awareness of the condition (Schweda, 2019). There are also other facets of dementia that the stimuli do not address, such as the neoliberal 'healthist' discourse of individual self-responsibility for maximizing health (Slocombe, 2024), or situating dementia within disability and human rights discourses, which currently appear to be used primarily by advocates and researchers (Cahill, 2018; Davies et al., 2022; Shakespeare, Zeilig and Mittler, 2019).

Equally, there is much to be gained from engaging with the emerging work within Critical Dementia Studies, which challenges researchers and society alike to rethink taken-for-granted concepts and research approaches (Ward and Sandberg, 2023). There is great potential in widening the focus from 'a politically insulated concern with the person and their experience' of dementia to drawing on dementia to question wider social and political ideologies and conditions, such as humans' relationships with the world or the structuring of care in society (Ward and Sandberg, 2023: 263). This focus provides important opportunities to critically reflect on how dementia and those affected are positioned in contemporary society and on how counter-discourses could in turn inspire wider shifts in social thinking and action.

For instance, going beyond the human focus of this book, Jenkins and colleagues (2021) advocate for a 'multi-species' approach to dementia that challenges the hypercognitive notion of human exceptionalism by instead foregrounding the importance of interspecies relationships and the value inherent to living beings beyond humans (Jenkins, 2023). A multi-species approach can intersect with biomedical, psychosocial, structural/rights-based, embodied/relational and integrative approaches to dementia. For instance, a multi-species focus can include more inclusively conceptualizing 'personhood', acknowledging that animals too can experience dementia-like symptoms and fostering close relationships with animals more broadly (and thus challenging practices such as forcibly separating people entering residential care from their companion animals). It can also include supporting healthy microbiomes in our guts and intestines (which have the potential in turn to affect brain function and affective experiences, such as depression), and recognizing our mutual reliance on an increasingly ecologically degrading planet and acting accordingly (Jenkins, 2023; Jenkins et al., 2021).

As mentioned, the present study focuses on the perspectives of a particular group of people affected by dementia in a particular context and at a particular point in time. This, combined with how I have organized the analysis, inevitably presents a certain 'framing of "the person with dementia"' and of people otherwise affected, such as carers, which makes certain perspectives and discourses 'visible and intelligible while others are rendered invisible or unintelligible' (Ward and Sandberg, 2023: 6). Key areas for future research, then, include critically reflecting on who is currently made 'invisible or unintelligible' both in research and society more broadly within the already marginalized group of people with dementia (Innes, 2009; Tilsed, 2019), and working towards redressing this imbalance. Through this, further counter-discourses may emerge, including those that better recognize people with dementia as ‘intersectional beings’ (Hulko, 2009: 142). It is also important to consider the perspectives and (counter) discourses of other members of society, including health professionals, policymakers, communication professionals (such as journalists) and members of the public. Considering the role of discourses in not only reflecting but also *shaping* social behaviours and structures, further exploring discourses and counter-discourses across a range of social groups and contexts holds great potential for addressing dementia-related stigma at individual, community and structural levels (Alzheimer’s Disease International, 2024).

Building upon this work, a key next step is to focus on collaboratively creating alternative portrayals of dementia, with the aim of influencing wider discourses. This book demonstrates the attentiveness and creativity of people affected by dementia in (re)interpreting and countering current dementia discourses. Much more work should be done in this area, including producing new or revised imagery (and metaphors, language, etc.) led by people with dementia and their supporters. Focusing on imagery, there are multiple promising case studies that can be drawn upon for such work. For instance, Cathy Greenblat’s (2011, 2012, 2021) photography showcases aspects of ordinary life, activity and connection for people with dementia, thus offering a more normalizing, person-oriented and varied alternative to popular images that better aligns with participants’ recommendations. Equally, after the Centre for Ageing Better’s (2020) report recommended more diverse depictions of older adults, it responded by launching the first free age-positive image library to provide realistic and diverse alternatives to reductive visual stereotypes (Centre for Ageing Better, 2021). Elsewhere, Padfield and colleagues (2018) highlight the value of co-created photographic images that visualize invisible pain, which can strengthen agency for people in pain and help others without such experience to discuss pain. While their focus is on clinical encounters, such work shows how metaphorical co-produced images can help to navigate rifts in understanding between people with and without lived experience.

Alongside photographs, artwork created by people with lived experience of health conditions is recommended as a ‘highly impactful and relatable’ choice (Cochrane, 2020: 20). Although the value of supporting the creative self-expression of people with dementia is well documented (McFadden, Frank and Dysert, 2008; Swinnen, 2016), the educational potential of disseminating art by people with lived experience of dementia requires much greater attention. As Swaffer (2014) highlights, to be meaningful, such work must prioritize people with dementia and overcome some of the barriers that have thus far restricted the take-up of communication guidelines by professionals and media organizations alike. Clearly, stigmatizing and demeaning imagery is still used, often in conjunction with pejorative language, despite a wealth of language guidance. Future research, then, needs to go beyond providing visual and linguistic alternatives, to also examine the social uptake and impact of such imagery and language choices.

As Sabat (2018: 58) states, there is no 'one size fits all' approach to understanding people's experiences of dementia. The same can be said for discourses and representational choices, which participants show need to better reflect the diversity and multiplicity of people with dementia and their experiences. With dementia looking set to remain both prevalent and incurable, there is a need to direct efforts towards better supporting people affected by the syndrome, including through addressing stigma and systemic inequalities. Within this, it is important to not only examine but consider how to best *contribute to* social discourses, acknowledging that any 'attempt to reconfigure existing perspectives necessitates the reconfiguration of available language' (Venkatesan and Kasthuri, 2018: 76). As well as having a history, dementia also has an 'array of potential futures' (Ward and Sandberg, 2023: 3), and it is in the present moment and its discursive choices that those future foundations will be defined.

Memory is 'like a bookshelf', and 'sometimes, it's on the shelf, other times it's, it's out' or 'miscatalogued'.

—Participants 21, 19 and 17, respectively

Figure 7.2 Memory is 'like a bookshelf' illustration (Josh Mallalieu, artist).

Appendix

Visual stimuli, ordered by page and position

Page 1

Image 1

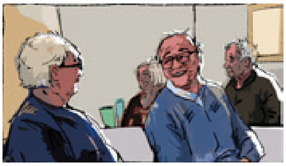


Image 3

Image 2

Five people participate in an organised activity by discussing large cards with photos that are scattered on the table. People in the background signal a community context.

Image 4

Image 1: iStock.com/KatarzynaBialasiewicz.

Image 2: iStock.com/dragana991.

Image 3: Artist's impression by Chris Chikodzore-Paterson, with permission from Alzheimer's Society.

Image 4: See A. Hill (31 August 2019), 'How football can spur reconnections for people with dementia', *The Guardian* (third image in the article). www.theguardian.com/society/2019/aug/31/how-football-can-spur-reconnections-for-people-with-dementia.

Page 2

Image 5

Image 7

Image 6

Image 8

Images 5 and 6: Artist's impression by Chris Chikodzore-Paterson, with permission from Alzheimer's Society.

Image 7: Sebastien Bozon/AFP via Getty Images.

Image 8: iStock.com/Handsome Bob.

Page 3

Image 9

Image 11

Image 10

Image 12

Image 9: PM Images/Stone via Getty Images.

Image 10: iStock.com/Siphotography.

Image 11: iStock.com/wildpixel.

Image 12: Andrew Bret Wallis/The Image Bank via Getty Images.

Page 4

Image 13 Photo shows a mid-distance shot of a couple in wedding outfits, smiling in their garden, which has been decorated for their (second) wedding.

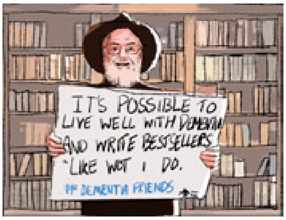
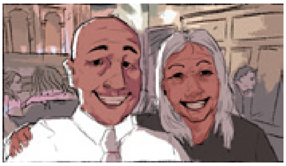


Image 15

Image 14



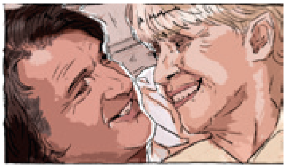


Image 16

Image 13: See M. Horne (23 August 2019), 'End dementia stigma, says Anne Duncan who "remarried" sufferer', *The Times* (first image in the article). www.thetimes.co.uk/article/end-dementia-stigma-says-anne-duncan-who-remarried-sufferer-rvkbt2sg5.

Image 14: Artist's impression by Chris Chikodzore-Paterson, with permission from Alzheimer's Research UK.

Images 15 and 16: Artist's impression by Chris Chikodzore-Paterson, with permission from Alzheimer's Society.

Page 5

Image 17

Image 19

Image 18

Image 20

Image 17: Andrew Brookes/Connect Images via Getty Images.

Image 18: John M Lund Photography Inc/DigitalVision via Getty Images.

Image 19: Artist's impression by Chris Chikodzore-Paterson, with permission from Alzheimer's Society.

Image 20: Artist's impression by Chris Chikodzore-Paterson, with permission from Alzheimer's Research UK.

References

Akram, M. A., Nanda, S., Maraver, P., Armañanzas, R. and Ascoli, G. A. (2018). 'An open repository for single-cell reconstructions of the brain forest'. *Scientific Data*, 5(1): 1–12.

Alejandro, A. (2021). 'Reflexive discourse analysis: A methodology for the practice of reflexivity'. *European Journal of International Relations*, 27(1): 150–74.

Alzheimer Europe (2013). 'The ethical issues linked to the perceptions and portrayal of dementia and people with dementia'. *Alzheimer Europe*. www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2013-The-ethical-issues-linked-to-the-perceptions-and-portrayal-of-dementia-and-people-with-dementia/Preface (accessed 19 May 2021).

Alzheimer Europe (2022). 'Guidelines for the ethical and inclusive communication about portrayal of dementia and people with dementia'. www.alzheimer-europe.org/sites/default/files/2023-01/Alzheimer%20Europe%20and%20European%20Working%20Group%20of%20People%20with%20Dementia%20Guidelines%20for%20the%20ethical%20and%20inclusive%20communication%20about%20portrayal%20of%20dementia%20and%20people%20with%20dementia.pdf (accessed 8 May 2025).

Alzheimer's Disease International (2019). *World Alzheimer Report 2019: Attitudes to Dementia*. London: Alzheimer's Disease International.

Alzheimer's Disease International (2024). *World Alzheimer Report 2024: Global Changes in Attitudes to Dementia*. London: Alzheimer's Disease International.

Alzheimer's Research UK (2022). *The Impact of Dementia on Women: How Women Are Disproportionately Affected across Their Lives and What Needs to Change*. Cambridge: Alzheimer's Research UK.

Alzheimer's Research UK (2023). *Dementia Attitudes Monitor*. Cambridge: Alzheimer's Research UK.

Alzheimer's Society (2017). 'Bookcase analogy'. *YouTube*. www.youtube.com/watch?v=kkvyGrOEIfA&ab_channel=Alzheimer%27sSociety (accessed 8 May 2025).

Alzheimer's Society (2018). *Positive Language: An Alzheimer's Society Guide to Talking about Dementia*. London: Alzheimer's Society.

Alzheimer's Society (2021). 'What is a dementia-friendly community?' www.alzheimers.org.uk/get-involved/dementia-friendly-communities/what-dementia-friendly-community (accessed 8 May 2025).

Alzheimer's Society (2024). 'The long goodbye: Our new advertising campaign'. www.alzheimers.org.uk/about-us/dementia-news-and-media/long-goodbye (accessed 8 May 2025).

American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM-5®)*. Washington, DC: American Psychiatric Association.

Ang, P. S., and Knox, J. (2023). 'Visualization of disability in news photographs: An analytical framework'. *Visual Communication*, 22(4): 600–22.

Ang, P. S., Yeo, S. L. and Koran, L. (2023). 'Advocating for a dementia-inclusive visual communication'. *Dementia*, 22(3): 628–45.

Aquilina, C., and Hughes, J. C. (2006). 'The return of the living dead: Agency lost and found?', in J. C. Hughes, S. J. Louw and S. R. Sabat (eds), *Dementia: Mind, Meaning, and the Person*. Oxford: Oxford University Press, pp. 143–61.

Archer, D., Iritani, B., Kimes, D. and Barrios, M. (1983). 'Face-ism: Five studies of sex differences in facial prominence'. *Journal of Personality and Social Psychology*, 45(4): 725–35.

Ashworth, R. (2014). 'More than just a cup of tea: Everyday cultural practices and interactions in research', *British Society of Gerontology: Generations Review*, 24: 4–10.

Atanasova, D. (2022). 'How constructive news outlets reported the synergistic effects of climate change and Covid-19 through metaphors'. *Journalism Practice*, 16(2–3): 384–403.

Baars, J. (2017). 'Human aging, finite lives and the idealization of clocks'. *Biogerontology*, 18(2): 285–92.

Bailey, A. (2019). *Discourses of Dementia in the British Press: A Corpus Linguistic Approach*. PhD thesis, University of Nottingham. http://eprints.nottingham.ac.uk/id/eprint/59481 (accessed 8 May 2025).

Bailey, A. (2020). 'Dementia and identity: A corpus-based study of an online dementia forum'. *Communication and Medicine*, 15(3): 249–60.

Bailey, A., Dening, T. and Harvey, K. (2021). 'Battles and breakthroughs: Representations of dementia in the British press'. *Ageing & Society*, 41(2): 362–76.

Baker, P. (2023). *Using Corpora in Discourse Analysis* (Second edition). London: Bloomsbury.

Baker, K., and Irving, A. (2016). 'Co-producing approaches to the management of dementia through social prescribing'. *Social Policy & Administration*, 50(3): 379–97.

Baker, P., Gabrielatos, C., KhosraviNik, M., Krzyzanowski, M., McEnery, T. and Wodak, R. (2008). 'A useful methodological synergy? Combining critical discourse analysis and corpus linguistics to examine discourses of refugees and asylum seekers in the UK press'. *Discourse & Society*, 19(3): 273–306.

Bangerter, L. R., Liu, Y., Kim, K. and Zarit, S. H. (2021). 'Adult day services and dementia caregivers' daily affect: The role of distress response to behavioral and psychological symptoms of dementia'. *Aging & Mental Health*, 25(1): 46–52.

Barbour, R. S. (2007). *Doing Focus Groups*. London: Sage.

Barbour, R. S. (2018). *Doing Focus Groups* (Second edition). London: Sage.

Barbour, R. S., and Kitzinger, J. (eds) (1999). *Developing Focus Group Research: Politics, Theory and Practice*. London: Sage.

Barthes, R. (1977). *Image, Music, Text*. Translated by Stephen Heath. London: Fontana Press.

Bartlett, R. (2014). 'Citizenship in action: The lived experiences of citizens with dementia who campaign for social change'. *Disability & Society*, 29(8): 1291–304.

Bartlett, R., and O'Connor, D. (2010). *Broadening the Dementia Debate: Towards Social Citizenship*. Bristol: Policy Press.

Bartlett, R., Windemuth-Wolfson, L., Oliver, K. and Dening, T. (2017). 'Suffering with dementia: The other side of "living well" '. *International Psychogeriatrics*, 29(2): 177–9.

Bartlett, T. (2018). 'Positive discourse analysis', in J. Flowerdew and J. E. Richardson (eds), *The Routledge Handbook of Critical Discourse Studies*. London: Taylor & Francis, pp. 187–204.

Basting, A. D. (2009). *Forget Memory: Creating Better Lives for People with Dementia*. Baltimore, MD: Johns Hopkins University Press.

Beard, R. L. (2016). *Living with Alzheimer's: Managing Memory Loss, Identity, and Illness*. New York: New York University Press.

Beard, R. L., Fetterman, D. J., Wu, B. and Bryant, L. (2009a). 'The two voices of Alzheimer's: Attitudes toward brain health by diagnosed individuals and support persons'. *The Gerontologist*, 49(S1): S40–9.

Beard, R. L., Knauss, J. and Moyer, D. (2009b). 'Managing disability and enjoying life: How we reframe dementia through personal narratives'. *Journal of Aging Studies*, 23(4): 227–35.

Beaulieu, A. (2000). *The Space Inside the Skull: Digital Representations, Brain Mapping and Cognitive Neuroscience in the Decade of the Brain.* PhD thesis, University of Amsterdam.

Beaulieu, A. (2002). 'Images are not the (only) truth: Brain mapping, visual knowledge, and iconoclasm'. *Science, Technology, & Human Values*, 27(1): 53–86.

Bednarek, M., and Caple, H. (2012). ' "Value added": Language, image and news values'. *Discourse, Context & Media*, 1(2–3): 103–13.

Bednarek, M., and Caple, H. (2014). 'Why do news values matter? Towards a new methodological framework for analysing news discourse in critical discourse analysis and beyond'. *Discourse & Society*, 25(2): 135–58.

Bednarek, M., and Caple, H. (2017). *The Discourse of News Values: How News Organizations Create Newsworthiness*. New York: Oxford University Press.

Bednarek, M., and Caple, H. (2019). *News Discourse*. London: Bloomsbury.

Behuniak, S. M. (2010). 'Toward a political model of dementia: Power as compassionate care'. *Journal of Aging Studies*, 24(4): 231–40.

Behuniak, S. M. (2011). ‘The living dead? The construction of people with Alzheimer’s disease as zombies’. *Ageing & Society*, 31(1): 70–92.

Bell, A. (1991). *The Language of News Media*. Oxford: Blackwell.

Ballenger, J. F. (2000). ‘Beyond the characteristic plaques and tangles: Mid-twentieth century U.S. psychiatry and the fight against senility’, in P. J. Whitehouse, K. Maurer and J. F. Ballenger (eds), *Concepts of Alzheimer Disease: Biological, Clinical and Cultural Perspectives*. London: Johns Hopkins University Press, pp. 83–103.

Besley, S., Kourouklis, D., O’Neill, P. and Garau, M. (2023). *Dementia in the UK: Estimating the Potential Future Impact and Return on Research Investment*. OHE Contract Research Report. London: Office of Health Economics.

Bethell, J., Commisso, E., Rostad, H. M., Puts, M., Babineau, J., Grinbergs-Saull, A., Wighton, M. B., Hammel, J., Doyle, E., Nadeu, S. and McGilton, K. S. (2018). ‘Patient engagement in research related to dementia: A scoping review’. *Dementia*, 17(8): 944–75.

Billig, M. (2008). ‘The language of critical discourse analysis: The case of nominalization’. *Discourse & Society*, 19(6): 783–800.

Biro, D. (2010). *Listening to Pain: Finding Words, Compassion, and Relief*. London: W. W. Norton.

Birt, L., Griffiths, R., Charlesworth, G., Higgs, P., Orrell, M., Leung, P. and Poland, F. (2020). ‘Maintaining social connections in dementia: A qualitative synthesis’. *Qualitative Health Research*, 30(1): 23–42.

Blakeley, G., and Quilter-Pinner, H. (2019). *Who Cares? The Financialisation of Adult Social Care*. London: Institute for Public Policy Research.

Bloor, M., Frankland, J., Thomas, M., Stewart, K. and Robson, K. (2001). *Focus Groups in Social Research*. London: Sage.

Boller, F., and Forbes, M. M. (1998). ‘History of dementia and dementia in history: An overview’. *Journal of the Neurological Sciences*, 158(2): 125–33.

Bös, B., and Schneider, C. (2022). ‘“Typing with dementia”: Online self-positioning of people living with dementia’. *Journal of Interactional Research in Communication Disorders*, 12(2): 212–33.

Bould, E. (2018). *Dementia-Friendly Media and Broadcast Guide: A Guide to Representing Dementia in the Arts, Culture and Popular Discourse*. London: Alzheimer’s Society.

Boyle, G. (2017). ‘Revealing gendered identity and agency in dementia’. *Health & Social Care in the Community*, 25(6): 1787–93.

Breeze, R. (2011). ‘Critical discourse analysis and its critics’. *Pragmatics: Quarterly Publication of the International Pragmatics Association*, 21(4): 493–525.

Brinkmann, S., and Kvale, S. (2018). *Doing Interviews* (Second edition). London: Sage.

Brooker, D., and Kitwood, T. (eds) (2019). *Dementia Reconsidered Revisited: The Person Still Comes First* (Second edition). London: Open University Press.

Brookes, G. (2023). ‘Killer, thief or companion? A corpus-based study of dementia metaphors in UK tabloids’. *Metaphor and Symbol*, 38(3): 213–30.

Brookes, G., and Collins, L. (2024). *Corpus Linguistics for Health Communication: A Guide for Research*. Oxon: Routledge.

Brookes, G., Harvey, K., Chadborn, N. and Dening, T. (2018). '"Our biggest killer": Multimodal discourse representations of dementia in the British press', *Social Semiotics*, 28(3): 371–95.

Brookes, G., Putland, E. and Harvey, K. (2021). 'Multimodality: Examining visual representations of dementia in public health discourse', in G. Brookes and D. Hunt (eds), *Analysing Health Communication: Discourse Approaches*. London: Palgrave Macmillan, pp. 241–69.

Brossard, B. (2017). 'Reactions to discredit in memory consultation: A sociological perspective to cognitive assessment in the elderly'. *Journal of Contemporary Ethnography*, 46(1): 30–50.

Bryden, C. (2016). *Nothing about Us, without Us! 20 Years of Dementia Advocacy* (Illustrated edition). London: Jessica Kingsley.

Bryden, C. (2019). 'Foreword', in D. Brooker and T. Kitwood (eds), *Dementia Reconsidered Revisited: The Person Still Comes First* (Second edition). London: Open University Press, pp. xi–xiii.

Bryden, C. (2020). 'Challenging the discourses of loss: A continuing sense of self within the lived experience of dementia'. *Dementia*, 19(1): 74–82.

Buggins, S.-L., Clarke, C. and Wolverson, E. (2021). 'Resilience in older people living with dementia: A narrative analysis'. *Dementia*, 20(4): 1234–49.

Burr, V. (2015). *Social Constructionism*. London: Taylor & Francis.

Caddell, L. S., and Clare, L. (2011). 'I'm still the same person: The impact of early-stage dementia on identity'. *Dementia*, 10(3): 379–98.

Cahill, S. (2018). *Dementia and Human Rights*. Bristol: Policy Press.

Caldwell, E. F., Falcus, S. and Sako, K. (2021). 'Depicting dementia: Representations of cognitive health and illness in ten picturebooks for children'. *Children's Literature in Education*, 52(1): 106–31.

Cameron, D. (2001). *Working with Spoken Discourse*. London: Sage.

Cap, P. (2023). 'Taking stock of critical discourse research: Current work and new directions'. *Heteroglossia*, 14: 155–78.

Caple, H. (2018). 'Analysing the multimodal text', in C. Taylor and A. Marchi (eds), *Corpus Approaches to Discourse: A Critical Review*. Milton: Taylor & Francis, pp. 85–109.

Caple, H., and Bednarek, M. (2013). 'Delving into the discourse: Approaches to news values in journalism studies and beyond'. *Reuters Institute for the Study of Journalism*. https://ora.ox.ac.uk/objects/uuid:1f5c6d91-bb1f-4278-a160-66149ecfb36b (accessed 8 May 2025).

Caple, H., and Bednarek, M. (2016). 'Rethinking news values: What a discursive approach can tell us about the construction of news discourse and news photography'. *Journalism*, 17(4): 435–55.

Carel, H., Kidd, I. J. and Pettigrew, R. (2016). 'Illness as transformative experience'. *The Lancet*, 388(10050): 1152–3.

Carmody, J., Traynor, V. and Marchetti, E. (2015). 'Barriers to qualitative dementia research: The elephant in the room'. *Qualitative Health Research*, 25(7): 1013–19.

Castaño, E. (2020). 'Discourse analysis as a tool for uncovering the lived experience of dementia: Metaphor framing and well-being in early-onset dementia narratives'. *Discourse & Communication*, 14(2): 115–32.

Castaño, E. (2023). 'Blogging through dementia: Reworking mainstream discourse through metaphor in online early-onset dementia narratives'. *Dementia*, 22(1): 105–24.

Centre for Ageing Better (2020). *An Old Age Problem? How Society Shapes and Reinforces Negative Attitudes to Ageing*. Centre for Ageing Better. https://ageing-better.org.uk/publications/old-age-problem-how-society-shapes-and-reinforces-negative-attitudes-ageing (accessed 8 May 2025).

Centre for Ageing Better (2021). 'Age-positive image library launched to tackle negative stereotypes of later life'. www.ageing-better.org.uk/news/age-positive-image-library-launched (accessed 8 May 2025).

Chang, C. Y. M., Baber, W., Dening, T. and Yates, J. (2021). ' "He just doesn't want to get out of the chair and do it": The impact of apathy in people with dementia on their carers'. *International Journal of Environmental Research and Public Health*, 18(12): 6317.

Chang, E.-S., Kannoth, S., Levy, S., Wang, S-Y, Lee, J. E. and Levy, B. R. (2020), 'Global reach of ageism on older persons' health: A systematic review'. *PLoS One*, 15(1): 1–24.

Chappell, N. L., Przydatek, M. E., Dujela, C. and Smith, A. (2015). 'Caregivers to those with dementia; fears for the future'. *The Gerontologist*, 55(2): 862.

Cheek, J. (2004). 'At the margins? Discourse analysis and qualitative research'. *Qualitative Health Research*, 14(8): 1140–50.

Chelberg, K. (2023). ' "Brainwork practices": Responsibilisation of dementia prevention in Australian aged care discourse'. *Ageing & Society*: 1–26.

Cheston, R., Christopher, G. and Ismail, S. (2015). 'Dementia as an existential threat: The importance of self-esteem, social connectedness and meaning in life'. *Science Progress*, 98(4): 416–19.

Clare, L., Rowlands, J. M. and Quin, R. (2008). 'Collective strength: The impact of developing a shared social identity in early-stage dementia'. *Dementia*, 7(1): 9–30.

Clare, L., and Shakespeare, P. (2004). 'Negotiating the impact of forgetting: Dimensions of resistance in task-oriented conversations between people with early-stage dementia and their partners'. *Dementia*, 3(2): 211–32.

Clarke, C., and Wolverson, E. (2016). *Positive Psychology Approaches to Dementia*. London: Jessica Kingsley.

Clarke, J. N. (2006). 'The case of the missing person: Alzheimer's disease in mass print magazines 1991–2001'. *Health Communication*, 19(3): 269–76.

Clarke, V., and Braun, V. (2017). 'Thematic analysis', *Journal of Positive Psychology*, 12(3): 297–8.

Cochrane (2020). 'Choosing images for sharing evidence: A guide'. https://uk.cochrane.org/choosing-images-sharing-evidence-guide (accessed 16 September 2021).

Cohn, S. (2004). 'Increasing resolution, intensifying ambiguity: An ethnographic account of seeing life in brain scans'. *Economy and Society*, 33(1): 52–76.

Cohn, S. (2010). 'Picturing the brain inside, revealing the illness outside: A comparison of the different meanings attributed to brain scans by scientists and patients', in J. Edwards, P. Harvey and P. Wade (eds), *Technologized Images, Technologized Bodies*. Oxford: Berghahn Books, pp. 65–84.

Cowdell, F. (2006). 'Preserving personhood in dementia research: A literature review'. *International Journal of Older People Nursing*, 1(2): 85–94.

Culley, L. (2006). 'Transcending transculturalism? Race, ethnicity and health-care'. *Nursing Inquiry*, 13(2): 144–53.

Curry, A. L., and Hammonds, K. H. (2014). *The Power of Solutions Journalism. Report on the Engaging News Project*. Austin: The University of Texas at Austin. https://mediaengagement.org/research/solutions-journalism/#identifier_18_1195 (accessed 8 May 2025).

Dahl, R. ([1988] 2016). *Matilda*. China: Puffin.

Davies, J. C. (2011). 'Preserving the "us identity" through marriage commitment while living with early-stage dementia'. *Dementia*, 10(2): 217–34.

Davies, T., Houston, A., Gordon, H., McLintock, M., Mitchell, W., Rook, G. and Shakespeare, T. (2022). 'Dementia enquirers: Pioneering approaches to dementia research in UK'. *Disability & Society*, 37(1): 129–47.

Davis, D. (2007). 'Help! My body is being invaded by an alien! Open peer commentaries'. *American Journal of Bioethics*, 7(4): 60–1.

DEEP (2013). 'Choosing a dementia-friendly meeting space'. http://dementiavoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Choosing-a-meeting-space.pdf (accessed 8 May 2025).

DEEP (2014). *Dementia Words Matter: Guidelines on Language about Dementia*. The Dementia Engagement and Empowerment Project. https://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf (accessed 8 May 2025).

DEEP (2024). 'What is DEEP? The Dementia Engagement and Empowerment Project'. www.dementiavoices.org.uk/wp-content/uploads/2019/07/What-is-DEEP-A5-Booklet.pdf (accessed 8 May 2025).

Dementia UK (2024a). 'We live with dementia'. www.dementiauk.org/we-live-with-dementia/ (accessed 24 October 2024).

Dementia UK (2024b). 'Young onset dementia facts and figures'. www.dementiauk.org/about-dementia/young-onset-dementia/about-young-onset-dementia/facts-and-figures/ (accessed 20 October 2024).

Dening, K. H., Jones, L. and Sampson, E. L. (2013). ‘Preferences for end-of-life care: A nominal group study of people with dementia and their family carers’, *Palliative Medicine*, 27(5): 409–17.

Department for Constitutional Affairs (ed.) (2007). *Mental Capacity Act 2005: Code of Practice*. London: The Stationery Office.

Derksen, E., Vernooij-Dassen, M., Gillissen, F., Olde Rikkert, M. and Scheltens, P. (2006). ‘Impact of diagnostic disclosure in dementia on patients and carers: Qualitative case series analysis’. *Aging & Mental Health*, 10(5): 525–31.

Devlin, E., MacAskill, S. and Stead, M. (2007). ‘“We’re still the same people”: Developing a mass media campaign to raise awareness and challenge the stigma of dementia’. *International Journal of Nonprofit and Voluntary Sector Marketing*, 12(1): 47–58.

Dewing, J. (2008). ‘Process consent and research with older persons living with dementia’. *Research Ethics*, 4(2): 59–64.

Dewing, J. (2019). ‘On being a person (commentary)’, in D. Brooker and T. Kitwood (eds), *Dementia Reconsidered Revisited: The Person Still Comes First* (Second edition). London: Open University Press, pp. 17–23.

Donnellan, W. J., Bennett, K. M. and Soulsby, L. K. (2019). ‘How does carer resilience change over time and care status? A qualitative longitudinal study’. *Aging & Mental Health*, 23(11): 1510–16.

Dörnyei, Z. (2007). *Research Methods in Applied Linguistics: Quantitative, Qualitative, and Mixed Methodologies*. Oxford: Oxford University Press.

Dowling, E. (2021). *The Care Crisis: What Caused It and How Can We End It?* London: Verso.

Downs, M. (2013). ‘Embodiment: The implications for living well with dementia’. *Dementia*, 12(3): 368–74.

Dumit, J. (1999). ‘Objective brains, prejudicial images’. *Science in Context*, 12(1): 173–201.

Dumit, J. (2003). ‘Is it me or my brain? Depression and neuroscientific facts’. *Journal of Medical Humanities*, 24(1): 35–47.

Dumit, J. (2004). *Picturing Personhood: Brain Scans and Biomedical Identity*. Oxford: Princeton University Press.

Enright, J., O’Connell, M. E., Branger, C., Kirk, A. and Morgan, D. (2020). ‘Identity, relationship quality, and subjective burden in caregivers of persons with dementia’. *Dementia*, 19(6): 1855–71.

Entman, R. M. (1993). ‘Framing: Toward clarification of a fractured paradigm’. *Journal of Communication*, 43(4): 51–58.

Erol, R., Brooker, D. and Peel, E. (2016). ‘The impact of dementia on women internationally: An integrative review’. *Health Care for Women International*, 37(12): 1320–41.

Evans, S. C. (2018). ‘Ageism and dementia’, in L. Ayalon and C. Tesch-Römer (eds), *Contemporary Perspectives on Ageism*. Cham: Springer Open, pp. 263–75.

Fairclough, N. (2010). *Critical Discourse Analysis: The Critical Study of Language*. London: Taylor & Francis.

Fairclough, N., Mulderrig, J. and Wodak, R. (2011). 'Critical discourse analysis', in T. A. van Dijk (ed.), *Discourse Studies: A Multidisciplinary Introduction*. London: Sage, pp. 394–417.

Featherstone, M., and Wernick, A. (1995). 'Introduction', in M. Featherstone and A. Wernick (eds), *Images of Aging: Cultural Representations of Later Life*. London: Taylor & Francis, pp. 1–14.

Finlay, L. (2002). ' "Outing" the Researcher: The Provenance, Process, and Practice of Reflexivity'. *Qualitative Health Research*, 12(4): 531–45.

Fletcher, J. R. (2019a). 'Destigmatising dementia: The dangers of felt stigma and benevolent othering'. *Dementia*, 20(2): 1–10.

Fletcher, J. R. (2019b). 'Negotiating tensions between methodology and procedural ethics'. *Journal of Gerontological Social Work*, 62(4): 384–91.

Fletcher, J. R. (2020a). 'Distributed selves: Shifting inequities of impression management in couples living with dementia'. *Symbolic Interaction*, 43(3): 405–27.

Fletcher, J. R. (2020b). 'Mythical dementia and Alzheimerised senility: Discrepant and intersecting representations of cognitive decline in later life'. *Social Theory & Health*, 18(1): 50–65.

Fletcher, J. R. (2020c). 'Renegotiating relationships: Theorising shared experiences of dementia within the dyadic career'. *Dementia*, 19(3): 708–20.

Fletcher, J. R. (2021a). 'Black knowledges matter: How the suppression of non-white understandings of dementia harms us all and how we can combat it'. *Sociology of Health and Illness*, 43: 1818–25.

Fletcher, J. R. (2021b). 'Unethical governance: Capacity legislation and the exclusion of people diagnosed with dementias from research'. *Research Ethics*, 17(3): 298–308.

Fletcher, J. R. (2024). 'Pathologisation, (bio)medicalisation and biopolitics', in J. R. Fletcher and A. Capstick (eds), *A Critical History of Dementia Studies*. Oxon: Routledge, pp. 13–26.

Fletcher, J. R., Lee, K. and Snowden, S. (2019). 'Uncertainties when applying the Mental Capacity Act in dementia research: A call for researcher experiences'. *Ethics and Social Welfare*, 13(2): 183–97.

Flick, U. (2018). *An Introduction to Qualitative Research* (Sixth edition). London: Sage.

Flowerdew, J., and Richardson, J. E. (2018). 'Introduction', in J. Flowerdew and J. E. Richardson (eds), *The Routledge Handbook of Critical Discourse Studies*. London: Taylor & Francis, pp. 21–33.

Fontana, A., and Smith, R. W. (1989). 'Alzheimer's disease victims: The "unbecoming" of self and the normalization of competence'. *Sociological Perspectives*, 32(1): 35–46.

Forceville, C. (1996). *Pictorial Metaphor in Advertising*. London: Taylor & Francis.

Forceville, C. (2002). 'The identification of target and source in pictorial metaphors'. *Journal of Pragmatics*, 34(1): 1–14.

Forceville, C. (2008). 'Metaphor in pictures and multimodal representations', in R. W. Gibbs (ed.), *The Cambridge Handbook of Metaphor and Thought*. London: Cambridge University Press, pp. 462–82.

Forceville, C., and Urios-Aparisi, E. (2009). *Multimodal Metaphor*. Berlin: De Gruyter.

Foucault, M. (1972). *Archaeology of Knowledge*. Translated by A. M. Sheridan Smith. London: Routledge.

Fox, P. (1989). 'From senility to Alzheimer's disease: The rise of the Alzheimer's disease movement'. *Milbank Quarterly*, 67(1): 58–102.

Galtung, J., and Ruge, M. H. (1965). 'The structure of foreign news'. *Journal of Peace Research*, 2(1): 64–91.

Gamson, W. A., and Modigliani, A. (1989). 'Media discourse and public opinion on nuclear power: A constructionist Approach'. *American Journal of Sociology*, 95(1): 1–37.

García-Castro, F. J., Alba, A. and Blanca, M. J. (2021). 'The role of character strengths in predicting gains in informal caregivers of dementia'. *Aging & Mental Health*, 25(1): 32–7.

George, D. R., and Whitehouse, P. J. (2014). 'The war (on terror) on Alzheimer's'. *Dementia*, 13(1): 120–30.

George, D. R., and Whitehouse, P. J. (2021). *American Dementia: Brain Health in an Unhealthy Society*. Baltimore, MD: Johns Hopkins University Press.

Gerritsen, D. L., Oyebode, J. and Gove, D. (2018). 'Ethical implications of the perception and portrayal of dementia'. *Dementia*, 17(5): 596–608.

Getty Images (2019). 'Human brain dissolving into squares representing data'. www.gettyimages.co.uk/detail/photo/brain-data-royalty-free-image/460689423 (accessed 8 May 2025).

Gilleard, C. (2018). 'Suffering: The darker side of ageing'. *Journal of Aging Studies*, 44: 28–33.

Gillies, A. (2009). *Keeper: Living with Nancy – A Journey into Alzheimer's*. London: Short Books.

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice-Hall.

Goodley, D. (2020). *Disability and Other Human Questions*. Bingley: Emerald.

Górska, S., Forsyth, K. and Maciver, D. (2018). 'Living with dementia: A meta-synthesis of qualitative research on the lived experience'. *The Gerontologist*, 58(3): e180–96.

Greenblat, C. (2011). 'Changing images, changing visions, changing practices'. *International Psychogeriatrics*, 23(9): 1361–3.

Greenblat, C. (2012). *Love, Loss, and Laughter: Seeing Alzheimer's Differently*. Guilford, CT: Lyons Press.

Greenblat, C. (2021). 'Dementia'. *Cathy Greenblat Photography*. www.cathygreenblatphotography.com (accessed 15 December 2021).

Gwyn, R. (2002). *Communicating Health and Illness*. London: Sage.

Hall, S. (1997). 'The work of representation', in S. Hall (ed.), *Representation: Cultural Representations and Signifying Practices*. London: Sage, pp. 13–74.

Halliday, M. A. K. (1978). *Language as Social Semiotic*. London: Edward Arnold.

Halliday, M. A. K. (1985). *An Introduction to Functional Grammar*. London: Edward Arnold.

Halliday, M. A. K., and Matthiessen, C. M. I. M. (2013). *Halliday's Introduction to Functional Grammar*. London: Taylor & Francis.

Hamilton, H. E. (2019). *Language, Dementia and Meaning Making Navigating Challenges of Cognition and Face in Everyday Life*. Cham: Palgrave Macmillan.

Hamilton, H. E., and Hamaguchi, T. (2015). 'Discourse and aging', in D. Tannen, H. E. Hamilton and D. Schiffrin (eds), *The Handbook of Discourse Analysis* (Second edition). Oxford: Wiley-Blackwell, pp. 705–27.

Hamilton-West, K., Milne, A. and Hotham, S. (2020). 'New horizons in supporting older people's health and wellbeing: Is social prescribing a way forward?', *Age and Ageing*, 49(3): 319–26.

Harris, P. B. (2013). 'Dementia and friendship: The quality and nature of the relationships that remain'. *International Journal of Aging and Human Development*, 76(2): 141–64.

Harvey, K., and Brookes, G. (2019). 'Looking through dementia: What do commercial stock images tell us about aging and cognitive decline?' *Qualitative Health Research*, 29(7): 987–1003.

Harvey, K., and Koteyko, N. (2013). *Exploring Health Communication: Language in Action*. London: Taylor & Francis.

Haven, T. L., and Van Grootel, L. (2019). 'Preregistering qualitative research'. *Accountability in Research*, 26(3): 229–44.

Heap, C. J., and Wolverson, E. (2020). 'Intensive interaction and discourses of personhood: A focus group study with dementia caregivers'. *Dementia*, 19(6): 2018–37.

Hengelaar, A. H., Wittenberg, Y., Kwekkeboom, R., Van Hartingsveldt, M. and Verdonk, P. (2023). 'Intersectionality in informal care research: A scoping review'. *Scandinavian Journal of Public Health*, 51(1): 106–24.

Herskovits, E. (1995). 'Struggling over subjectivity: Debates about the "self" and Alzheimer's disease'. *Medical Anthropology Quarterly*, 9(2): 146–64.

Hickman, H., Clarke, C. and Wolverson, E. (2020). 'A qualitative study of the shared experience of humour between people living with dementia and their partners'. *Dementia*, 19(6): 1794–810.

Higgs, P., and Gilleard, C. (2016). 'Interrogating personhood and dementia'. *Aging & Mental Health*, 20(8): 773–80.

Hillman, A., Jones, I. R., Quinn, C., Nelis, S. M. and Clare, L. (2018). 'Dualities of dementia illness narratives and their role in a narrative economy'. *Sociology of Health & Illness*, 40(5): 874–91.

Holdsworth, K., and McCabe, M. (2018). 'The impact of younger-onset dementia on relationships, intimacy, and sexuality in midlife couples: A systematic review'. *International Psychogeriatrics*, 30(1): 15–29.

Horne, M. (2019). 'End dementia stigma, says Anne Duncan who "remarried" sufferer'. *The Times*. www.thetimes.com/article/f3ae21fe-c528-11e9-9b38-47c3100effef (accessed 8 May 2025).

Hughes, J. C. (2011). 'A situated embodied view of the person with dementia: Where does the spiritual come in?', in A. Jewell (ed.), *Spirituality and Personhood in Dementia*. London: Jessica Kingsley, pp. 198–206.

Hughes, J. C. (2014). *How We Think about Dementia: Personhood, Rights, Ethics, the Arts and What They Mean for Care*. London: Jessica Kingsley.

Hulko, W. (2009). 'From "not a big deal" to "hellish": Experiences of older people with dementia'. *Journal of Aging Studies*, 23(3): 131–44.

Hydén, L.-C. (2013). 'Storytelling in dementia: Embodiment as a resource'. *Dementia (London, England)*, 12(3): 359–67.

Hydén, L.-C., Lindemann, H. and Brockmeier, J. (2014). 'Introduction', in L.-C. Hydén, H. Lindemann and J. Brockmeier (eds), *Beyond Loss: Dementia, Identity, Personhood*. New York: Oxford University Press, pp. 1–8.

Innes, A. (2009). *Dementia Studies: A Social Science Perspective*. London: Sage.

Jenkins, N. (2023). 'Multi-species dementia studies: How moving beyond human exceptionalism can advance dementia's more critical turn', in R. Ward and L. J. Sandberg (eds), *Critical Dementia Studies: An Introduction*. Routledge: London, pp. 72–82.

Jenkins, N., Gorman, R., Douglas, C., Ashall, V., Ritchie, L. and Jack-Waugh, A. (2021). 'Multi-species dementia studies: Contours, contributions and controversies'. *Journal of Aging Studies*, 59: 100975.

Jewitt, C. (ed.) (2014). *The Routledge Handbook of Multimodal Analysis* (Second edition). London: Routledge.

Johnstone, M.-J. (2013). 'Metaphors, stigma and the "Alzheimerization" of the euthanasia debate'. *Dementia*, 12(4): 377–93.

Jones, N., and Corrigan, P. W. (2014). 'Understanding stigma', in P. W. Corrigan (ed.), *Stigma of Disease and Disability: Understanding Causes and Overcoming Injustices*. Washington, DC: American Psychological Association, pp. 9–34.

Katsuno, T. (2003). 'Personal spirituality of persons with early-stage dementia: Is it related to perceived quality of life?' *Dementia*, 2(3): 315–35.

Katz, S., and Leibing, A. (2023). ' "Lost in time like tears in rain": Critical perspectives on personhood and dementia', in R. Ward and L. J. Sandberg (eds), *Critical Dementia Studies: An Introduction*. London: Routledge, pp. 57–71.

Kelly, P. (2019). 'The role of the media: Help or hinderance?', in Alzheimer's Disease International (ed.), *World Alzheimer Report 2019: Attitudes to Dementia*. London: ADI, pp. 95–6.

Kenigsberg, P.-A., Aquino, J-P., Bérard, A., Gzil, F., Andrieu, S., Banerjee, S., Brémond, F., Buée, L., Cohen-Mansfield, J., Mangialasche, F., Platel, H., Salmon, E. and Robert, P. (2016). 'Dementia beyond 2025: Knowledge and uncertainties'. *Dementia*, 15(1): 6–21.

Kessler, E.-M., and Schwender, C. (2012). 'Giving dementia a face? The portrayal of older people with dementia in German weekly news magazines between the years 2000 and 2009'. *Journals of Gerontology: Series B*, 67B(2): 261–70.

Keuck, L. (2018). 'Diagnosing Alzheimer's disease in Kraepelin's clinic, 1909–1912'. *History of the Human Sciences*, 31(2): 42–64.

Keyes, S. E., Clarke, C. L., Wilkinson, H., Alexjuk, E. J., Wilcockson, J., Robinson, L., McClelland, S., Corner, L. and Cattan, M. (2016). ' "We're all thrown in the same boat …": A qualitative analysis of peer support in dementia care'. *Dementia*, 15(4): 560–77.

Khan, O. (2015). 'Dementia and ethnic Diversity: Numbers and trends', in J. Botsford and K. Harrison Dening (eds), *Dementia, Culture and Ethnicity: Issues for All*. London: Jessica Kingsley, pp. 21–34.

King, A. (2022). 'Queer futures? Forget it! Dementia, queer theory and the limits of normativity', *Journal of Aging Studies*, 63: 1–8. https://doi.org/10.1016/j.jaging.2021.100993.

Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.

Kitzinger, J. (1993). 'Understanding AIDS: Researching audience perceptions of acquired immune deficiency syndrome', in J. E. T. Eldridge (ed.), *Getting the Message: News, Truth and Power*. London: Routledge, pp. 271–304.

Kitzinger, J., and Barbour, R. S. (1999). 'Introduction: The challenge and promise of focus groups', in R. S. Barbour and J. Kitzinger (eds), *Developing Focus Group Research: Politics, Theory and Practice*. London: Sage, pp. 1–20.

Koncul, A., George Onyedikachi, E. and Bartlett, R. (2024). 'A semiotic analysis of meanings of dementia around the world', in J. R. Fletcher and A. Capstick (eds), *A Critical History of Dementia Studies*. Oxford: Routledge, pp. 86–104.

Kontos, P. (2003). ' "The painterly hand": Embodied consciousness and Alzheimer's disease'. *Journal of Aging Studies*, 17(2): 151–70.

Kontos, P. (2004). 'Ethnographic reflections on selfhood, embodiment and Alzheimer's disease'. *Ageing and Society*, 24: 829–49.

Kontos, P. (2006). 'Embodied selfhood: An ethnographic exploration of Alzheimer's disease', in A. Leibing and L. Cohen (eds), *Thinking about Dementia*. London: Rutgers University Press, pp. 195–217.

Kontos, P., and Grigorovich, A. (2018). 'Rethinking musicality in dementia as embodied and relational'. *Journal of Aging Studies*, 45: 39–48.

Kontos, P., Miller, K.-L. and Kontos, A. P. (2017), 'Relational citizenship: Supporting embodied selfhood and relationality in dementia care'. *Sociology of Health & Illness*, 39(2): 182–98.

Kress, G. (2000). ‘Design and transformation: New theories of meaning’, in B. Cope and M. Kalantzis (eds), *Multiliteracies: Literacy Learning and the Design of Social Futures*. London: Taylor & Francis, pp. 149–57.

Kress, G., and van Leeuwen, T. (2001). *Multimodal Discourse: The Modes and Media of Contemporary Communication*. London: Arnold.

Kress, G., and van Leeuwen, T. (2006). *Reading Images: The Grammar of Visual Design* (Second edition). Oxon: Routledge.

Kress, G., and van Leeuwen, T. (2021). *Reading Images: The Grammar of Visual Design* (Third edition). Oxon: Routledge.

KYN, Innovations in Dementia, Batchelor, A., Rook, G., King, G., Dunn, L., Kennedy, S., Hayden, J., Davies, T. and Hare, P. (2023). ‘How we talk about dementia: Good practice guidelines for language and images’. www.kyn.co.uk/assets/files/uploads/kyn-lets-talk-about-dementia-guidelines.pdf (accessed 8 May 2025).

Laceulle, H., and Baars, J. (2014). ‘Self-realization and cultural narratives about later life’. *Journal of Aging Studies*, 31: 34–44.

Lakoff, G., and Johnson, M. (1980). *Metaphors We Live By*. Chicago: University of Chicago Press.

Lakoff, G., and Turner, M. (2009). *More than Cool Reason: A Field Guide to Poetic Metaphor*. Chicago: University of Chicago Press.

Lane, H. P., McLachlan, S. and Philip, J. (2013). ‘The war against dementia: Are we battle weary yet?’ *Age and Ageing*, 42(3): 281–83.

Langdon, S. A., Eagle, A. and Warner, J. (2007). ‘Making sense of dementia in the social world: A qualitative study’. *Social Science & Medicine*, 64(4): 989–1000.

Latimer, J. (2018). ‘Repelling neoliberal world-making? How the ageing–dementia relation is reassembling the social’. *Sociological Review*, 66(4): 832–56.

Lawless, M., Augoustinos, M. and LeCouteur, A. (2018). ‘ “Your brain matters”: Issues of risk and responsibility in online dementia prevention information’. *Qualitative Health Research*, 28(10): 1539–51.

Ledin, P., and Machin, D. (2018a). ‘Doing critical discourse studies with multimodality: From metafunctions to materiality’. *Critical Discourse Studies*, 16(5): 497–513.

Ledin, P., and Machin, D. (2018b). *Doing Visual Analysis: From Theory to Practice*. London: Sage.

Leone, C., Winterton, R. and Blackberry, I. (2023). ‘Media discourses on the socio-spatial rights of older people living with dementia and their carers’. *Dementia*, 22(1): 161–79.

Lerner, B. H. (2006). *When Illness Goes Public: Celebrity Patients and How We Look at Medicine*. Baltimore, MD: Johns Hopkins University Press.

Levy, B. (2009). ‘Stereotype embodiment: A psychosocial approach to aging’. *Current Directions in Psychological Science*, 18(6): 332–6.

Liu, J., Wang, L. and Tian, J. (2012). ‘Recognition of dementia in Ancient China’. *Neurobiology of Ageing*, 33(12): 2948.e11–e13.

Livingston, G., Huntley, J., Liu, K. Y., Costafreda, S. G., Selbæk, G., Alladi, S., Ames, D., Banerjee, S., Burns, A., Brayne, C., Fox, N. C., Ferri, C. P., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Nakasujja, N., Rockwood, K., Samus, Q., Shirai, K., Singh-Manoux, A., Schneider, L. S., Walsh, S., Yao, Y., Sommerlad, A. and Mukadam, N. (2024). 'Dementia prevention, intervention, and care: 2024 report of the *Lancet* standing commission'. *Lancet*, 396: 413–46.

Lock, M. M. (2013). *The Alzheimer Conundrum: Entanglements of Dementia and Aging*. Princeton, NJ: Princeton University Press.

Low, L.-F., and Purwaningrum, F. (2020). 'Negative stereotypes, fear and social distance: A systematic review of depictions of dementia in popular culture in the context of stigma'. *BMC Geriatrics*, 20: 1–16.

Low, L.-F., Swaffer, K., McGrath, M. and Brodaty, H. (2018). 'Do people with early stage dementia experience Prescribed Disengagement®? A systematic review of qualitative studies'. *International Psychogeriatrics*, 30(6): 807–31.

Luke, A. (2002). 'Beyond science and ideological critique: Developments in critical discourse analysis'. *Annual Review of Applied Linguistics*, 22: 96–110.

Macgilchrist, F. (2007). 'Critical approaches to discourse analysis across disciplines'. *Critical Approaches to Discourse Analysis across Disciplines*, 1(1): 74–94.

Macgilchrist, F. (2020). 'When discourse analysts tell stories: What do we "do" when we use narrative as a resource to critically analyse discourse?' *Critical Discourse Studies*, 18(3): 387–403.

Machin, D. (2013). 'What is multimodal critical discourse studies?' *Critical Discourse Studies*, 10(4): 347–55.

Machin, D. (2014). 'Multimodality and theories of the visual', in C. Jewitt (ed.), *The Routledge Handbook of Multimodal Analysis* (Second edition). London: Routledge, pp. 181–200.

Machin, D., and Mayr, A. (2023). *How to Do Critical Discourse Analysis: A Multimodal Introduction* (Second edition). London: Sage.

Machin, D., and van Leeuwen, T. (2007). *Global Media Discourse: A Critical Introduction*. Florence: Taylor & Francis.

Malik, N. (2008). 'Defining charity and charitable purposes in the United Kingdom Europe'. *International Journal of Not-for-Profit Law*, 11(1): 36–50.

Manthorpe, J. Samsi, K., Campbell, S., Abley, C., Keady, J., Bond, J., Watts, S., Robinson, L., Gemski, A., Warner, J., Goodman, C., Drennan, V. and Iliffe, S. (2011). *The Transition from Cognitive Impairment to Dementia: Older People's Experiences*. London: NIHR Service Delivery and Organisation Programme.

Mason, C., Andrews, M., Ferguson, R., Bingham, J., Batchelor, A., King, G., Davies, T., Hayden, J. and Mitchell, W. (2024). 'Language about people with dementia', in J. R. Fletcher and A. Capstick (eds), *A Critical History of Dementia Studies*. Oxon: Routledge, pp. 41–54.

Mautner, G. (2005). 'For-profit discourse in the nonprofit and public sectors', in G. Erreygers and G. Jacobs (eds), *Language, Communication and the Economy*. Amsterdam: John Benjamins, pp. 25–44.

Mautner, G. (2010). *Language and the Market Society: Critical Reflections on Discourse and Dominance*. London: Taylor & Francis.

McCabe, L., Robertson, J. and Kelly, F. (2018). 'Scaffolding and working together: A qualitative exploration of strategies for everyday life with dementia'. *Age and Ageing*, 47(2): 303–10.

McFadden, S., Frank, V. and Dysert, A. (2008). 'Creativity in the "now" of advanced dementia: Glimpses of the lifeworld through storytelling and painting'. *Journal of Aging*: 135–49.

McIntyre, K., and Gyldensted, C. (2018). 'Positive psychology as a theoretical foundation for constructive journalism'. *Journalism Practice*, 12(6): 662–78.

McParland, P., Kelly, F. and Innes, A. (2017). 'Dichotomising dementia: Is there another way?', in P. Higgs and C. Gilleard (eds), *Ageing, Dementia and the Social Mind*. Hoboken, NJ: John Wiley & Sons, pp. 83–94.

McShane, K. (2018). 'Loving an unfamiliar world: Dementia, mental illness and climate change'. *Ethics and the Environment*, 23(1): 1–16.

Mental Health Foundation (2015). *Dementia, Rights, and the Social Model of Disability*. London: Mental Health Foundation.

Mills, S. (1997). *Discourse*. London: Routledge.

Milne, A. (2010). 'The "D" word: Reflections on the relationship between stigma, discrimination and dementia'. *Journal of Mental Health*, 19(3): 227–33.

Mishler, E. (1984). *The Discourse of Medicine: Dialectics of Medical Interviews*. New York: Ablex.

Mitchell, W. (2018). *Somebody I Used to Know*. London: Bloomsbury.

Morgan, J. (2018). 'Living well with dementia'. *Lancet Neurology*, 17(4): 306–7.

Morgner, C., Hazel, S., Schneider, J. and Tischler, V. (2019). 'Conduct in dementia: Video analysis of arts interventions'. *Sociological Research Online*, 24(4): 514–40.

Mullay, S., Schofield, P., Clarke, A. and Primrose, W. (2018). ' "They're just who they've always been": The intersections of dementia, community and selfhood in Scottish care homes'. *Ageing and Society*, 38(5): 1063–82.

Murray, M. (2000). 'Levels of narrative analysis in health psychology'. *Journal of Health Psychology*, 5(3): 337–47.

National Institute on Aging (2024). 'What happens to the brain in Alzheimer's disease?' www.nia.nih.gov/health/what-happens-brain-alzheimers-disease. (accessed 8 May 2025).

Nguyen, T., and Li, X. (2020). 'Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature'. *Dementia*, 19(2): 148–81.

Nikunen, K. (2016). ‘Media, passion and humanitarian reality television’. *European Journal of Cultural Studies*, 19(3): 265–82.

Norrick, N. R. and Chiaro, D. (2009). *Humor in Interaction*. Amsterdam: John Benjamins.

O’Malley, M-P., Shortt, O. and Carroll, C. (2022). ‘Representations of the experiences of people with dementia in Irish newspapers’. *Dementia*, 21(4): 1343–62.

O’Shaughnessy, M., Lee, K. and Lintern, T. (2010). ‘Changes in the couple relationship in dementia care: Spouse carers’ experiences’. *Dementia*, 9(2): 237–58.

Ovenden, I., Dening, T. and Beer, C. (2019). ‘ “Here everyone is the same”: A qualitative evaluation of participating in a Boccia (indoor bowling) group: Innovative practice’. *Dementia*, 18(2): 785–92.

Padfield, D., Omand, H., Semino, E., de C Williams, A. and Zakrzewska, J. M. (2018). ‘Images as catalysts for meaning-making in medical pain encounters: A multidisciplinary analysis’. *Medical Humanities*; *London*, 44(2): 74–81.

Pan, Z., and Kosicki, G. M. (1993). ‘Framing analysis: An approach to news discourse’. *Political Communication*, 10(1): 55–75.

Parveen, S., Barker, S., Kaur, R., Kerry, F., Mitchell, W., Happs, A., Fry, G., Morrison, V., Fortinsky, R. and Oyebode, J. R. (2018). ‘Involving minority ethnic communities and diverse experts by experience in dementia research: The Caregiving HOPE study’. *Dementia*, 17(8): 990–1000.

Parveen, S., Oyebode, J. R. and Downs, M. (2014). ‘New perspectives and approaches: A multi-faith/cultural view’, in S.-M. Bamford, G. Holley-Moore and J. Watson (eds), *New Perspectives and Approaches to Understanding Dementia and Stigma*. London: ILC-UK, pp. 37–40.

Paul, L. A. (2014). *Transformative Experience*. Oxford: Oxford University Press.

Peel, E. (2014). ‘ “The living death of Alzheimer’s” versus “Take a walk to keep dementia at bay”: Representations of dementia in print media and carer discourse’. *Sociology of Health & Illness*, 36(6): 885–901.

Peel, E., and Harding, R. (2014). ‘ “It’s a huge maze, the system, it’s a terrible maze”: Dementia carers’ constructions of navigating health and social care services’. *Dementia*, 13(5): 642–61.

Perel-Levin, S. (2019). ‘Stigma, dementia and age’, in Alzheimer’s Disease International (ed.), *World Alzheimer Report 2019: Attitudes to Dementia*. London: ADI, pp. 90–1.

Pesonen, H.-M., Remes, A. M. and Isola, A. (2011). ‘Ethical aspects of researching subjective experiences in early-stage dementia’. *Nursing Ethics*, 18(5): 651–61.

Peterson, N., and Schicktanz, S. (2021). ‘The experts’ advice: Prevention and responsibility in German media and scientific discourses on dementia’. *Qualitative Health Research*, 31(11): 2005–18.

Post, S. (2000a). ‘The concept of Alzheimer disease in a hypercognitive society’, in P. J. Whitehouse, K. Maurer and J. F. Ballenger (eds), *Concepts of Alzheimer Disease: Biological, Clinical, and Cultural Perspectives*. Baltimore, MD: Johns Hopkins University Press.

Post, S. (2000b). *The Moral Challenge of Alzheimer's Disease: Ethical Issues from Diagnosis to Dying* (Second edition). London: Johns Hopkins University Press.

Prasantha, D. S. (2019). 'Neuron forest: Journeys to the brain'. *Stroke Carer*. www.strokecarer.com/neuron-forest-journeys-to-the-brain-8/ (accessed 8 May 2025).

Pratchett, T. (2008). 'Foreword', in *Dementia: Out of the Shadows*. London: Alzheimer's Society, pp. vii–xi.

Pratt, R., and Wilkinson, H. (2001). *'Tell Me the Truth': The Effect of Being Told the Diagnosis of Dementia from the Perspective of the Person with Dementia*. London: Mental Health Foundation.

Pritchard-Jones, L. (2017). 'Ageism and autonomy in health vare: Explorations through a relational lens'. *Health Care Analysis*, 25(1): 72–89.

Proctor, G. (2001). 'Listening to older women with dementia: Relationships, voices and power'. *Disability & Society*, 16(3): 361–76.

Prorok, J. C., Horgan, S. and Seitz, D. P. (2013). 'Health care experiences of people with dementia and their caregivers: A meta-ethnographic analysis of qualitative studies'. *CMAJ: Canadian Medical Association Journal*, 185(14): E669–80.

Putland, E. (2022). 'The (in)accuracies of floating leaves: How people with varying experiences of dementia differently position the same visual metaphor'. *Dementia*, 21(5): 1471–87.

Putland, E., and Brookes, G. (2024a). 'Dementia stigma: Representation and language use'. *Journal of Language and Ageing Research*, 2(1): 5–46.

Putland, E., and Brookes, G. (2024b). 'Visualizing dementia and stigma: A scoping review of the literature'. *Visual Communication*: 1–31.

Putland, E., and Brookes, G. (in press). 'Dementia, death and discourse', in D. Galasiński and J. Ziółkowska (eds), *The Bloomsbury Handbook of Language and Death*. London: Bloomsbury.

Putland, E., Chikodzore-Paterson, C. and Brookes, G. (2023). 'Artificial intelligence and visual discourse: Multimodal critical discourse analysis of AI-generated images of "dementia"'. *Social Semiotics*: 1–26.

Putland, E., Chikodzore-Paterson, C. and Brookes, G. (in press). '"We no longer recognized her as a human being": A critical discourse analysis of AI-generated character descriptions of men and women with dementia'. *Journal of Language and Discrimination*, Special Issue. Edited by Laura Coffey-Glover.

QSR International (2018). *NVivo*. www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home (accessed 8 May 2025).

Rahman, S. (2015). *Living Better with Dementia: Good Practice and Innovation for the Future*. London: Jessica Kingsley.

Rayment, G., Swainston, K. and Wilson, G. (2019). 'Using photo-elicitation to explore the lived experience of informal caregivers of individuals living with dementia'. *British Journal of Health Psychology*, 24(1): 102–22.

Read, S. T., Toye, C. and Wynaden, D. (2017). 'Experiences and expectations of living with dementia: A qualitative study'. *Collegian*, 24(5): 427–32.

Sabat, S. R. (2002). 'Selfhood and Alzheimer's disease', in P. B. Harris (ed.), *The Person with Alzheimer's Disease: Pathways to Understanding the Experience* (Illustrated edition). Baltimore, MD: Johns Hopkins University Press, pp. 88–111.

Sabat, S. R. (2014). 'A bio-psycho-social approach to dementia', in M. Downs and B. Bowers (eds), *Excellence in Dementia Care: Research into Practice*. New York: Open University Press, pp. 107–21.

Sabat, S. R. (2018). *Alzheimer's Disease and Dementia: What Everyone Needs to Know®*. New York: Oxford University Press.

Sabat, S. R. (2019). 'How personhood is undermined (commentary)', in D. Brooker and T. Kitwood (eds), *Dementia Reconsidered Revisited: The Person Still Comes First* (Second edition). London: Open University Press, pp. 59–63.

Samsi, K., and Manthorpe, J. (2020). *Interviewing People Living with Dementia in Social Care Research: Methods Review*. London: NIHR School for Social Care Research.

Schweda, M. (2019). 'Medical gazes and meteorological metaphors: Representations of dementia in contemporary motion pictures'. *Israel Journal of Health Policy Research*, 8(18): 1–8.

Semino, E. (2008). *Metaphor in Discourse*. Cambridge: Cambridge University Press.

Semino, E., and Demjén, Z. (eds) (2016). *The Routledge Handbook of Metaphor and Language*. Florence: Taylor & Francis.

Semino, E., Demjén, Z. and Demmen, J. (2018). 'An integrated approach to metaphor and framing in cognition, discourse, and practice, with an application to metaphors for cancer'. *Applied Linguistics*, 39(5): 625–45.

Semino, E., Demjén, Z., Demmen, J., Koller V., Payne, S., Hardie, A. and Rayson, P. (2017). 'The online use of violence and journey metaphors by patients with cancer, as compared with health professionals: A mixed methods study'. *BMJ Supportive & Palliative Care*, 7(1): 60–6.

Serafini, G., Calcagno, P., Lester, D., Girardi, P., Amore, M. and Pompili, M. (2016). 'Suicide risk in Alzheimer's disease: A systematic review'. *Current Alzheimer Research*, 13(10): 1083–99.

Šestáková, A., and Plichtová, J. (2020). 'More than a medical condition: Qualitative analysis of media representations of dementia and Alzheimer's disease'. *Human Affairs: Postdisciplinary Humanities & Social Sciences Quarterly*, 30(3): 382–98.

Shakespeare, T., Zeilig, H. and Mittler, P. (2019). 'Rights in mind: Thinking differently about dementia and disability'. *Dementia*, 18(3): 1075–88.

Shannon, G., Jansen, M.,Williams, K., Cáceres, C., Motta, A., Odhiambo, A., Eleveld, A. and Mannell, J. (2019). 'Gender equality in science, medicine, and global health: Where are we at and why does it matter?' *The Lancet*, 393(10171): 560–9.

Skills for Care (2023). *The State of the Adult Social Care Sector and Workforce in England*. Leeds: Skills for Care.

Slocombe, F. (2024). *Understanding Identity and Representations of Dementia: A Conversation Analytic and Discursive Analysis*. PhD thesis, Loughborough University.

Smith, J. A., Larkin, M. H. and Flowers, P. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.

Smithson, J. (2000). 'Using and analysing focus groups: Limitations and possibilities'. *International Journal of Social Research Methodology*, 3(2): 103–19.

#SocialCareFuture (2024). 'Another world is possible'. https://socialcarefuture.org.uk/noticeboard/another-world-is-possible/ (accessed 8 May 2025).

Sontag, S. (1979). *Illness as Metaphor*. London: Allen Lane.

Spreadbury, J. H., and Kipps, C. (2019). 'Measuring younger onset dementia: What the qualitative literature reveals about the "lived experience" for patients and caregivers'. *Dementia*, 18(2): 579–98.

Steele, L., Phillipson, L., Swaffer, K. and Fleming, R. (2023). 'Segregation and incarceration of people living with dementia in care homes: Critical disability and human rights approaches', in R. Ward and L. J. Sandberg (eds), *Critical Dementia Studies: An Introduction*. London: Routledge, pp. 151–67.

Steeman, E., Godderis, J., Grypdonck, M., De Bal, N. and De Casterlé, B. D. (2007). 'Living with dementia from the perspective of older people: Is it a positive story?' *Aging & Mental Health*, 11(2): 119–30.

Stubbs, M. (1997). 'Whorf's children: Critical comments on critical discourse analysis (CDA)', in A. Ryan and A. Wray (eds), *Evolving Models of Language*. Clevedon: Multilingual Matters, pp. 100–16.

Sunderland, J. (2004). *Gendered Discourses*. London: Palgrave Macmillan.

Swaffer, K. (2014). 'Dementia: Stigma, language, and dementia-friendly'. *Dementia*, 13(6): 709–16.

Swaffer, K. (2016). *What the Hell Happened to My Brain? Living beyond Dementia*. London: Jessica Kingsley.

Sweeting, H., and Gilhooly, M. (1997). 'Dementia and the phenomenon of social death'. *Sociology of Health & Illness*, 19(1): 93–117.

Swinnen, A. M. C. (2016). 'Healing words: A study of poetry interventions in dementia care'. *Dementia*, 15(6): 1377–404.

Swinnen, A., and Schweda, M. (eds) (2015). *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*. Bielefeld: Transcript Verlag.

Swinton, J. (2012). *Dementia: Living in the Memories of God*. London: SCM Press.

Swinton, J. (2021). 'Re-imagining personhood: Dementia, culture and citizenship'. *Journal of Religion, Spirituality & Aging*, 33(2): 172–81.

Talbot, C. V., O'Dwyer, S. T., Clare, L., Heaton, J. and Anderson, J. (2020). 'How people with dementia use Twitter: A qualitative analysis'. *Computers in Human Behavior*, 102: 112–19.

Talja, S. (1999). 'Analyzing qualitative interview data: The discourse analytic method'. *Library & Information Science Research*, 21(4): 459–77.

Tannen, D., Hamilton, H. E. and Schiffrin, D. (eds) (2015). *The Handbook of Discourse Analysis* (Second edition). Oxford: Wiley-Blackwell.

Taylor, A., and Yardley, C. (2014). 'Advocacy, education, and the role of not-for-profit organizations in Lewy body dementias'. *Alzheimer's Research & Therapy*, 6(59): 1–5.

Taylor, E. (2022). 'All you need to know about brain scans and dementia'. *Alzheimer's Research UK*. www.alzheimersresearchuk.org/news/all-you-need-to-know-about-brain-scans-and-dementia/ (accessed 8 May 2025).

Taylor, J. (2008). 'On recognition, caring, and dementia'. *Medical Anthropology Quarterly*, 22(4): 313–35.

Taylor, J., Sims, J. and Haines, T. P. (2012). 'The influence of protection, palliation and costs on mobility optimization of residents in nursing homes: A thematic analysis of discourse'. *International Journal of Nursing Studies*, 49(11): 1364–74.

Thelker, C. (2018). 'Walking through the neuron forest … called dementia'. *Dementia Alliance International*. www.dementiaallianceinternational.org/tag/walking-through-the-neuron-forest-called-dementia-by-christine-thelker/ (accessed 22 February 2022).

Tilsed, S. (2019). 'From seldom heard to seen and heard: Why communities should not be viewed as hard to reach', in Alzheimer's Disease International (ed.), *World Alzheimer Report 2019: Attitudes to Dementia*. London: ADI, pp. 160–1.

Tuchman, G. (1978). *Making News: A Study in the Construction of Reality*. New York: Free Press.

van Corven, C. T. M., Bielderman, A., Wijnen, M., Leontjevas, R., Lucassen, P., Graff, M. J. L. and Gerritsen, D. L. (2021). 'Defining empowerment for older people living with dementia from multiple perspectives: A qualitative study'. *International Journal of Nursing Studies*, 114: 1–11.

van Dijk, T. A. (2009), 'Critical discourse studies: A sociocognitive approach', in R. Wodak and M. Meyer (eds), *Methods of Critical Discourse Analysis* (Second edition). London: Sage, pp. 62–86.

van Gorp, B., and Vercruysse, T. (2012). 'Frames and counter-frames giving meaning to dementia: A framing analysis of media content'. *Social Science & Medicine*, 74(8): 1274–81.

van Gorp, B., Vercruysse, T. and Van den Bulck, J. (2012). 'Toward a more nuanced perception of Alzheimer's disease: Designing and testing a campaign advertisement'. *American Journal of Alzheimer's Disease & Other Dementias*, 27(6): 388–96.

van Leeuwen, T. (2008). *Discourse and Practice: New Tools for Critical Analysis*. New York: Oxford University Press.

van Wijngaarden, E., Leget, C., Goossensen, A., Pool, R. and The, A.-M. (2019). 'A captive, a wreck, a piece of dirt: Aging anxieties embodied in older people with a death wish'. *OMEGA: Journal of Death and Dying*, 80(2): 245–65.

Venkatesan, S. and Kasthuri, R. R. (2018). '"Magic and laughter": Graphic medicine, recasting Alzheimer narratives and Dana Walrath's aliceheimer's: Alzheimer's through the looking glass', *Concentric: Literary and Cultural Studies*, 44(1): 61–84.

Vermeer, Y., Higgs, P. and Charlesworth, G. (2022). 'Selling surveillance technology: Semiotic themes in advertisements for ageing in place with dementia'. *Social Semiotics*, 32(3): 1–22.

Vidal, F. (2009). 'Brainhood, anthropological figure of modernity'. *History of the Human Sciences*, 22(1): 5–36.

Villar, F., Serrat, R. and Bravo-Segal, S. (2019). 'Giving them a voice: Challenges to narrative agency in people with dementia'. *Geriatrics*, 4(20): 1–9.

Walsh-Childers, K. (2017). *Mass Media and Health: Examining Media Impact on Individuals and the Health Environment*. New York: Routledge.

Ward, R., Howorth, M., Wilkinson, H., Campbell, S. and Keady, J. (2012). 'Supporting the friendships of people with dementia'. *Dementia*, 11(3): 287–303.

Ward, R., and Sandberg, L. J. (eds) (2023). *Critical Dementia Studies: An Introduction*. London: Routledge.

Ward-Griffin, C., Bol, N. and Oudshoorn, A. (2006). 'Perspectives of women with dementia receiving care from their adult daughters'. *Canadian Journal of Nursing Research Archive*, 38(1): 120–46.

Watchman, K., Janicki, M. P., Udell, L., Hogan, M., Quinn, S. and Beránková, A. (2019). 'Consensus statement of the International Summit on Intellectual Disability and Dementia on valuing the perspectives of persons with intellectual disability'. *Journal of Intellectual Disabilities*, 23(2): 266–80.

Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M.-J. and Antoine, P. (2017). 'Do spouse caregivers of persons with early- and late-onset dementia cope differently? A comparative study', *Archives of Gerontology and Geriatrics*, 69: 162–8.

Waxer, P. H. (1997). 'Nonverbal cues for anxiety: An examination of emotional leakage'. *Journal of Abnormal Psychology*, 86(3): 306–14.

Werner, P., and Heinik, J. (2008). 'Stigma by association and Alzheimer's disease'. *Aging & Mental Health*, 12(1): 92–9.

Whiffin, C. J., Ellis-Hill, C., Bailey, C., Jarrett, N. and Hutchinson, P. J. (2019). 'We are not the same people we used to be: An exploration of family biographical narratives and ident'. *Neuropsychological Rehabilitation*, 29(8): 1256–72.

Whitehouse, P. J. and George, D. R. (2008). *The Myth of Alzheimer's*. New York: St. Martin's Griffin.

Widdowson, H. G. (1998). 'Review article: The theory and practice of critical discourse analysis'. *Applied Linguistics*, 19(1): 136–51.

Wilkosz, P. A., Seltman, H. K., Weamer, E. A., Lopez, O. L., DeKosky, S. T. and Sweet, R. A. (2010). 'Trajectories of cognitive decline in Alzheimer's disease'. *International Psychogeriatrics*, 22(2): 281–90.

Wittenberg, R., Hu, B., Barraza-Araiza, L. and Rehill, A. (2019). *Projections of Older People with Dementia and Costs of Dementia Care in the United Kingdom, 2019–2040*. London: London School of Economics and Political Science.

Wodak, R., and Meyer, M. (eds) (2009). *Methods of Critical Discourse Analysis* (Second edition). London: Sage.

World Health Organization (2017). *Global Action Plan on the Public Health Response to Dementia*. Geneva: World Health Organization.

World Health Organization (2023). 'Dementia'. www.who.int/news-room/fact-sheets/detail/dementia (accessed 29 March 2025).

Wu, Y.-T., Clare, L., Rees Jones, I., Martyr, A. Nelis, S. M., Quinn, C., Victor, C. R., Lamont, R. A., Rippon, I. and Matthews, F. E. (2018). 'Inequalities in living well with dementia: The impact of deprivation on well-being, quality of life and life satisfaction—Results from the improving the experience of dementia and enhancing active life study'. *International Journal of Geriatric Psychiatry*, 33(12): 1736–42.

Zeilig, H. (2014a). 'Dementia as a cultural metaphor'. *The Gerontologist*, 54(2): 258–67.

Zeilig, H. (2014b). 'Gaps and spaces: Representations of dementia in contemporary British poetry'. *Dementia*, 13(2): 160–75.

Zimmermann, M. (2017). 'Alzheimer's disease metaphors as mirror and lens to the stigma of dementia'. *Literature and Medicine*, 35(1): 71–97.

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