Understanding dementia from the perspective of people with a learning disability: preferences for the disclosure of dementia and care planning.

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A thesis submitted for the degree of Doctorate of Clinical Psychology

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Date of submission for examination April 2024

Acknowledgements

Firstly, thank you to everyone who participated in the research. It was a privilege to meet each of you and I am very grateful for the narratives you shared. I strive to honour the remarkable ideas you shared with me.

My sincere gratitude goes to Dr Alison Spencer and Dr Stephen Wood, my fantastic supervisors, for their continued support during the completion of my thesis. Thank you for your frequent words of encouragement and diligent guidance.

I thank my mum for never doubting my abilities to complete this thesis and her enduring prayers. To my wonderful partner, Sam, my phenomenal friends (especially Leve, Holly, Priyanka, Aaron, Babs, Milly, Tori and Shy) and of course, Milo - thank you for your love, patience, comfort and support. I am eternally grateful for the times you pushed me along when I thought I could not go any further.

I would like to give my gratitude to God, for without His grace and strength the completion of this thesis would not have been possible.

Finally, I would like to dedicate this thesis to my dear cousin, Ate Hope. Thank you for always making me laugh and for reminding me that people with learning disabilities should never be underestimated.

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Abstract

Background: Whilst it is known that people with learning disabilities are at increased risk of developing dementia, there is a paucity of research which focuses on this from the perspective of individuals with learning disabilities.

Literature review: A literature review was conducted to explore people with learning disabilities views about ageing, which revealed both positive and negative beliefs. However, a rapid review, focusing on dementia highlighted negative attitudes, stemming from its association with decline and loss of independence.

Aim and method: The study aims were to explore people with learning disabilities' understanding of dementia and their capacity to engage in discussions relating to dementia, the perceived dis/advantages of being told the diagnosis of dementia and their preferences for future dementia care planning. The study used a three-phase approach, conducted with 15 participants. This consisted of individual interviews, provision of psychoeducation on dementia and then the running of two focus groups. Data was analysed using reflexive thematic analysis.

Results: From the individual interviews, three themes emerged, based on whether participants had prior knowledge of dementia or not. Those without knowledge were more negative about the ageing process. From the focus groups, four themes emerged which emphasised dementia as a time of loss, the impact on families and carers, for dementia care to be compassionate and provide support to others in the person's support system.

Conclusion and implications: The findings showed that people with learning disabilities were able to actively engage in discussing ageing and dementia, despite these being sensitive and abstract topics. This study is unique because it captures the perspectives of people with learning disabilities. The findings provide concrete suggestions for enhancing dementia care for this group.

The provision of support for caregivers and the dissemination of accessible dementia information are two such examples.

Chapter 1: Introduction

Chapter Overview

This chapter will begin by discussing the historical understandings of learning disability, the shifts in societal perceptions and the evolution of learning disability care. It will then discuss the growth of the ageing population and provide an overview of the health inequalities experienced by people with learning disabilities. Following this, the concept of dementia will be explored, sharing historical and current understandings of the disease. This will include discussion about the assessment, diagnosis and treatment of the disease, the prevalence of dementia in the learning disability population and narratives of living well with dementia. Discourses of ageing well will be discussed along with the relevant theories of ageing well. Finally, the chapter will discuss the inaccessibility of ‘ageing well’ and ‘living well with dementia’ campaigns to people with learning disabilities.

Historical Understandings of Learning Disability and the Legacy of Discourses

The conceptualisation of learning disabilities has changed over time and varies between cultures and countries. This thesis therefore posits that learning disabilities are a socially constructed concept. How society defines disability has great psychological, social, economic and political importance for those with this diagnosis but also those who do not (Wendell, 1989; Atkinson, 2003). As such the language, used by organisations, policy makers, clinicians, the public and people with learning disabilities has great implications for the lived experiences of people with learning disabilities (Malli et al., 2018; Altermark, 2023). The following section explores how the language used towards people with learning disabilities has evolved over time and ends with an insight into the current understandings of learning disabilities.

The terminology since the 1800’s has evolved from phrases such as ‘idiots’, ‘mental defectives’, 'sub-normal' to now ‘People with Learning Disabilities’ and or ‘People with

Intellectual Disabilities' (Jarrett, 2015). The language used to describe people with learning disabilities is an indicator of the way in which they are perceived by society and also impacts how they are cared for by society. Prior to the 19th century, people with learning disabilities were referred to as 'idiots' and 'lunatics'. There was little differentiation between those with a learning disability and those with a mental health condition. This led to both groups being often transferred to a workhouse or prison (Langdon Down Museum of Learning Disabilities, 2023). Families with financial means would make private arrangements for their loved ones to be managed in a private 'mad house' and these were governed by the justices of peace, now known as magistrates (Smith, 2020). In these, private 'mad houses', individuals were managed by "moral treatment, gentle discipline and order" (Historic England, 2023. P. 1). Recognising the need to provide a similar structure people of a lower socioeconomic status, the County Asylums Act (1808) was created to motivate magistrates to create public asylums to house people with learning disabilities and those with mental health condition. There was slow progress towards this, which led to continued misplacement of these individuals into workhouses and prisons (Smith, 2020; Jarrett and Tilley, 2022). It was only until 1845, that public asylums became compulsory under the Lunacy Act and the County Asylums Act. While there was more responsibility for the state to establish and regulate asylums, the Lunacy Act showed little distinction between those with a diagnosis of a mental health difficulty and those with a learning disability. In this it stated that 'Lunatic shall mean insane person or any person being idiot or lunatic or of unsound mind' (Lunacy Act, 1845). This led to those with either a learning disability or a mental health condition being under the same care provision within asylums; restricted of their rights and segregated from society (Jarrett and Tilley, 2022; Langdon Down Museum of Learning Disabilities, 2023).

Andrew Reed, an independent minister and activist founded the Charity for the Asylum of Idiots in 1847 (Royal Hospital for Neuro-disability, 2024). This was following his correspondence with medical specialists in Paris regarding the treatment of ’mental disease’. During his period of learning, he visited several institutions caring for people with learning disabilities in France, Switzerland and Denmark where he noted the aim of the organisation was to not only care for people with learning disabilities but also educated the individual to allow engagement in leisure and work (The National Archives, 2024). This highlights the beginnings of a consciousness that positions people with a learning disability as able to contribute to society and have good quality of life. His efforts led to the establishment of four large scale asylums for individuals with learning disabilities by which admission were voluntary, but it is likely it would be the family of the person with a learning disability who encouraged admission rather than the person themselves (Atkinson, 2003; Social History of Learning Disability Research Group, 2023).

The Idiots Act of 1886, provided a distinction between those with mental health difficulties and a learning disability in legislation. This act permitted the detention of people with learning disabilities to asylums for education and care, however, it did not aim to provide long-term residential care for the individual (Bewley, 2008; Burrell and Trip, 2011). Despite this, the 1890 Lunacy Act did not make this distinction and encouraged those with a learning disability and those with a mental health condition to be admitted to a shared asylum (Burrell and Trip, 2011; Hilton, 2021). For many years, the disparity between legislations and confusion remained.

In 1907, the Eugenics Education Society was formed. This attempted to promote the ideology that the human race could be improved by encouraging couples deemed worthy to have children to have larger families and that society could control the reproduction of ‘unfit’ individuals (Atkinson, 2003; Burrell and Trip, 2011). Prior to the formation of the Eugenics society, ideas of this kind were already prevalent in Europe. In 1902, Mary Dendy's Sandlebridge Colony opened. Unlike the efforts of Andrew Reed, Dendy aimed to reduce crime and the passing on of genetics that may lead a child to have a learning disability therefore positioning people with learning disabilities as defected (Goodman, 2005; Reinders, Stainton and Parmenter, 2019).

The Report of Royal Commission on Care and Control of the Feeble-Minded (Dickinson, 1908) examined the policies and acts regarding people with learning disabilities and those with mental health difficulties and provided critique. In this, they stated that "there are numbers of mentally defective persons whose training is neglected, over whom no sufficient control is exercised, and whose wayward and irresponsible lives are productive of crime and misery" (Dickenson, 1908. Pg. 3). They comment on the lack of education that people with learning disabilities have and the repeated short sentences they serve in prison due to the lack of supervision in the community. They recommended the establishment of a board of control which would oversee local authority efforts to improve the well-being of the 'mentally defective'. This was a pivotal point in learning disability history, as now, organisational bodies were reflecting on the need for coordinated action to improve the wellbeing of people with learning disabilities.

Following this, a British neurologist and psychiatrist, Alfred Tredgold, wrote the first edition of 'Mental Deficiency' (1908) a textbook highlighting the causes of learning disabilities, how people with learning disabilities may present and intervention for those with a learning disability (Atkinson, 2003). Intervention included industrial and moral training and education on movement, intelligence and communication. In this text they highlighted that surgical treatment was not an effective strategy as well as stating that corporal punishment should be "avoided wherever possible" (Tredgold, 1908. P. 355). Despite this seemingly progressive position towards the care of people with learning disabilities, the text promoted sterilisation of people with learning disabilities and postulated that without this, "the community is inevitably doomed" (P 361). This textbook was used until 1958 in nurse training and thus the above narratives were common in society. During this period, 'mental defective' was the most common term for people with learning disabilities (Atkinson, 2003; Social History of Learning Disability Research Group, 2023).

The eugenics movement was at its peak between 1930-40 and the campaign for voluntary sterilisation was taking place. Alongside this, Lionel Penrose began research into learning disabilities and his Colchester Report (Penrose, 1938) looked at 1280 individuals with 'mental defect'. He concluded that learning disabilities were caused by genetic and environmental factors. This report, alongside Tredgold's textbook allowed improved and more accurate understandings of the origin of learning disabilities to be shared with society.

Contemporary Understandings of Learning Disability

Many have written about the impact of World War II in galvanising social change (Calder, 1971). After the Second World War, the eugenics movement was discredited but it's legacy and narratives were still evident in local and national policies. There seemed to be a great shift in how people perceived learning disability, with policies reflecting on how people with learning disabilities could contribute to society. The Disabled Persons' Act of 1944 is a prime example of this. For the first time, people with learning disabilities are seen to be capable of engaging in occupation and as having autonomy over their lives. The first paragraph of the act states "Most disabled people can take their place with others in the ordinary work of the country, with a careful choice of occupation". (The Disabled Persons Employment Act, 1944. Pg. 2). The evolution of attitudes towards people with learning disabilities is also illustrated by the creation of the National Association of Parents of Backward Children in 1946, which later became Mencap. The founder of Mencap was a mother of a child with learning disabilities who initially invited other parents to contact her to create a support network. It is reported that many expressed their “anger and sorrow at the lack of services for their children” (Mencap, 2023. P. 1.). At this point in history, there was a reduction in the stigma associated with being a parent of a child with learning disabilities.

When Bevan, health minister at the time, presented his National Health Service Bill to parliament, he stated “not only is it available to the whole population freely, but it is intended . . . to generalise the best health advice and treatment.” (National Health Service Bill, 1946. P. 1.). This included people with learning disabilities and led to the incorporation of the institutions and ‘colonies’ for people with learning disabilities into the newly established National Health Service (NHS) (Burrell and Trip, 2011). This illustrates that at this point in history, people with learning disabilities were being considered alongside the general population rather than being treated differently from them.

In 1953, almost half to the National Health Service’s beds were for ‘mental illness’ or ‘mental defect’. Concerns about the cost of inpatient admissions led the government to shift thinking towards care in the community (Burrell and Trip, 2011; Social History of Learning Disability Research Group, 2023). This prompted the introduction of the Mental Health Act (1959) which revoked the Mental Deficiencies Acts (1908). This supported ideas regarding the benefits of community care that advised inpatient admissions should be voluntary where possible unless the person was a risk to others or themselves. However, there was little funding to put this in place. The labelling used in the Mental Health Act to describe people with learning disabilities was ‘subnormal’ and ‘severely subnormal’ still implying that individuals with a learning disability were lacking in some way (Mental Health Act, 1959; Atkinson, 2003).

A pivotal point for mental health institutions took place in 1961. Enoch Powell was Health Minister and was faced with the assignment of reforming the country’s hospital services, paying special attention to the Mental Hospitals (Social History of Learning Disability Research Group, 2023). In his speech at the Annual Conference of the National Association for Mental Health, he told the public about the need for transition to community-based care, the implications of the changes and the finances required to fulfil this proposal (Powell, 1961). This lead to the development of ‘A Hospital Plan for England and Wales’ which outlined a 10-year plan for a movement towards community care. This gave rise to ideas of what community care for people with learning disabilities might look like, and in 1964, Tizard’s Community Services for the Mentally Handicapped argued for small residential units. Around this time, publications such as Segal’s ‘No Child is Ineducable’ (1967) recommended that children with learning disabilities should have the same rights as those without a learning disability. At this point in history, the learning disability community were beginning to experience integration with the general population across the lifespan.

While the planning for community care began in the 1960s, it was not until the 1970s White Paper ‘Better Services for the Mentally Handicapped’ that significant change was observed. This paper emphasised the need to integrate people with learning disabilities into the community with community-based support services and active support from families. They recommended that care should be provided on an individualised basis and that this should be guided by person-centred care plans. The paper recognised the importance of education and employment for the mental well-being of people with learning disabilities (Wardle, 1972).

This was a time where visible implementation of policies supporting the learning disability population was taking place, many group homes were being established nationally and inclusion of people with learning disabilities was growing on public agendas. In 1981, three residents of a learning disability specialist home successfully campaigned for the right to vote in general elections. In a local authority hearing, Irene McCabe a former resident stated “I have a right to vote. I am just as intelligent as the people outside. The people in Calderstones watch the news and know what is going on in the world.” (Mitchell, 2017). This act of resistance towards the silencing of people with learning disabilities was followed by the founding of the People First group in England in 1984. This was the first user-led, self-advocacy organisation governed by people with learning disabilities. This was an important political statement for people with learning disabilities, as prior to this, it had not been acknowledged that people with learning disabilities could be seated in professional positions. These self-advocacy groups were the first to adopt the term ‘People with Learning Disabilities’. However, it was only until 1990 that the Department of Health officially began to use the term. The development of this term corresponds to the movement towards person centred care in which the person is separate from their diagnosis.

In 2005, the Mental Capacity Act was created to protect the individuals’ ability to make decisions. In this it states that people, including those with learning disabilities, have the right to make their own decisions if they have the capacity to do so. This legislation protects the autonomy of vulnerable adults. It highlights that people with learning disabilities can and should have autonomy over their lives. The early 21st century was a time of hope for people with learning disabilities, as now society was working toward proper integration of this group into the general population and they were simultaneously being acknowledged as autonomous active agents in their lives (Clegg and Bigby, 2017).

As stated earlier in this section, the unfair treatment of people with learning disabilities was pervasive in society. This has continued since the establishment of the NHS and the impact of this on the health outcomes of people with learning disabilities has been quantified in the Mencap publication ‘Death by Indifference’ report (Mencap, 2007) which exposed the health inequalities leading to avoidable fatalities. In response to this, the Department of Health’s report ‘Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities’ highlighted the necessity for critical reform to improve care for people with learning disabilities.

Despite this report, little change was seen and the 2009 ‘Valuing People Now’ paper reiterated the need to reform care for people with learning disabilities and urged for prompt implementation of recommendations. Research has found improvements to learning disability care have been stunted due to austerity measures in the UK and cuts to public sector services which have led to burnt-out staff, ultimately impacting on quality care provision (Malli, 2018). Events revealing the abuse of people with learning disabilities in residential homes such as the Winterbourne View Hospital scandal, highlight the impact of underqualified, underpaid and burnt-out staff on the care provided to people with learning disabilities. Since the horrific events that took place at Winterbourne View Hospital, registering services for people with learning disabilities has become more stringent (NHS England, 2015).

Current Understandings of Learning Disability and the Impact on Inclusion

Currently, there are approximately 1.5 million people with a learning disability in the UK and 2000 of those individuals are detained in inpatient mental health hospitals (Mencap, 2023).

This is a dramatic shift to what was seen in the 19th century and shows the positive outcomes that community care makes possible. People with learning disabilities are also more integrated in society in comparison to the segregation they experienced historically. This is illustrated by the 23% of working age adults with a learning disability having a paid job and is compared to 76% of working age adults in the general population (Mencap, 2023). Advocates have highlighted that this percentage should be higher and that there are many barriers to people with learning disabilities accessing paid employment such as a lack of good quality support to get employment, employers attitudes and a lack of understanding as to what people with learning disabilities can do with the correct support (Mencap, 2023). While there has been improvement in the way people with learning disabilities are integrated into society, they continue to be discriminated against by people without learning disabilities. In Mencap's Big Learning Disability Survey 2022, 41.1% of people with learning disabilities said they did not leave the house because they were worried. Out of that proportion, 14.7% explained they were worried members of the public would bully them or call them names. As outlined, there has been great progress towards a society where people with learning disabilities are treated fairly, however there is much work to be done.

Currently in the UK, the terms learning disability and intellectual disability are used interchangeably, however the term learning disability is more commonly used in NHS services and by self-advocacy groups (Carr et al., 2016; Mencap, 2023). As this thesis aims to amplify the voices of people with learning disabilities, the term learning disability is used throughout this thesis to reflect the preferences of those with a learning disability and the language used in clinical practice.

The National Institute for Health and Care Excellence (NICE) advises that a learning disability is defined “by three core criteria: an IQ of less than 70 suggesting lower intellectual ability, significant impairment of social or adaptive functioning and onset in childhood” (NICE, 2015).

To measure IQ, a trained clinician utilises a standardised test of intelligence. In the UK, the most commonly used test is the Wechsler Adult Intelligence Scale fourth edition (WAIS-IV). A test of adaptive functioning should also be completed to identify challenges in daily functioning. However, intelligence is also a concept understood to be socially constructed due to its variation between cultures and time (Sternberg et al., 2001). As such, researchers in the field have queried the validity of the methods through which we diagnose learning disabilities (Webb and Whittaker, 2012). For the purpose of this thesis, the recruitment of participants is based on meeting criteria to access a specialist learning disability service.

Summary of Historical Context and Relevance to Current Study

Historical perspectives on learning disabilities have evolved significantly over time, reflecting changes in societal attitudes, terminology, and care practices. Initially, individuals with learning disabilities were often labelled with derogatory terms such as "idiots" or "mental defectives," leading to their marginalisation and mistreatment. The establishment of institutions and asylums in the 19th century aimed to provide care but often resulted in segregation and neglect. Efforts by activists like Andrew Reed in the mid-1800s began to challenge these norms, advocating for better care and recognition of the potential contributions of individuals with learning disabilities. However, it was not until the late 19th and early 20th centuries that legislation began to distinguish between mental health conditions and learning disabilities, although disparities continued in care and societal perceptions.

Throughout the 20th century, there was a gradual shift towards community-based care and inclusion, marked by significant legislative reforms and advocacy efforts. The post-World War Two era saw the establishment of policies emphasising the integration of people with learning disabilities into society. Despite progress, challenges remain, including disparities in healthcare access and societal discrimination. Contemporary understandings of learning disabilities emphasise person-centred care and autonomy, with a focus on inclusion and equal opportunities. However, ongoing efforts are needed to address barriers to ensure the rights and well-being of individuals with learning disabilities are upheld.

As stated in Malli et al. (2018), the lived experiences of people with learning disabilities are greatly influenced by the language used by society and these discourses are influenced by historical underpinnings. As such, to understand the current narratives of marginalisation in relation to learning disability and subsequent health inequalities, one must review historical understandings.

The Ageing Population and Health Inequalities Experienced by People with Learning Disabilities

Globally, the ageing population is rapidly increasing. The World Health Organisation estimates that between 2005 and 2050, the over 60s population will almost double from 12% to 22% (World Health Organisation, 2021). In the United Kingdom specifically, it is estimated that the percentage of people over the age of 75 years living in locales surrounding urban areas will increase by 25% by 2043 (Department of Health and Social Care, 2023). Due to advances in preventative health care, improved treatments for acute conditions and improved sanitation, people have a longer life expectancy. The Health Profile report (Public Health England, 2018) found that while people are living longer, there has been an increase in prevalence of health problems. Research has shown that as people age, the likelihood of receiving a diagnosis of a physical health condition increases. One study found that three-quarters of 75 year olds in the UK live with at least one long term health condition (NHS, n.d.). At 85 years of age, they found that this increased to 82%. The result of this is that our ageing population require more support to live safely and complete activities of daily living.

In conjunction with this, we have seen a dramatic increase in the life expectancy of people with learning disabilities (Baird and Sadovnick, 1988; Coppus, 2013; Glover et al., 2017). In the UK, approximately 1.5 million people have a learning disability (Mencap, 2023); 950,000 are adults over the age of 18 years. The life expectancy for people with learning disabilities in the 1930s was 18.5 years (Braddock et al., 2001), currently, people with learning disabilities have a life expectancy of over 60 years old (Hatton and Emerson, 2008; NHS England, 2023) which illustrates the significant strides made in healthcare. It is estimated that by 2030 the quantity of people with learning disabilities over the age of 70 using social care services will increase more than twofold (Foundation for People with Learning Disabilities, 2011). However, coexisting with this, is the persistent health inequalities that people with learning disabilities face. People with learning disabilities are more likely to experience multimorbidity across the lifespan (Kinnear et al., 2018) and research has shown that people with learning disabilities are more likely to experience conditions such as epilepsy, chronic obstructive pulmonary disease, asthma, hypertension and type II diabetes (NHS England, 2023).

A number of risk factors are associated with the poor health seen in people with learning disabilities. This includes obesity, lower grip strength and poor lung function (University of Essex, Institute for Social and Economic Research., 2023). From research in the general population, we know that obesity and poor lung function are strongly correlated to low socioeconomic status (Hegewald 2007; Anekwe et al., 2020) and with people with learning disabilities being less likely to be in paid employment (Mencap, 2023), it is unsurprising that they are exposed to these risk factors. People with a learning disability may also have risks associated with developmental difficulties (Evenhuis et al., 2001). For example, individuals with Down’s syndrome are at risk of congenital issues and Alzheimer’s disease due to genetic differences (Down’s Syndrome Association, 2021). It is reported that more than 60% of people with Down’s syndrome will develop dementia before they are 60 years old (Alzheimer’s Research UK, 2018). This is due to a genetic predisposition that causes overproduction of the amyloid plaque associated with Alzheimer’s disease (Janelidze et al., 2022). We also see an increased prevalence of dementia in older people with a learning disability not due to Down’s syndrome, in comparison to the general population (Alzheimer’s Research UK, 2018; Takenoshita et al., 2023).

The higher prevalence of health problems in the learning disability population correlates with the higher rates of hospital admission seen in people with learning disabilities when compared to the general population (Horridge, 2023). It has also been noted that people with learning disabilities are more likely to go to hospital with avoidable complications from long-term health conditions. One study found that for people with learning disabilities, eight out of every 100 admissions are emergencies that could have been prevented. This is compared to five out of every 100 admissions for the general population. While this difference is not statistically significant, the researchers did note that when people with learning disabilities were admitted to hospital it was 25% more likely to be an emergency (Glover, 2013). This suggests that currently, there is difficulty in managing the physical health care needs of people with learning disabilities in the community. Throughout their lives, people with learning disabilities experience more barriers to accessing services when compared to the general population. This is due to factors such as insufficient accessible transport options, limited understanding among staff regarding learning disabilities, difficulties in recognising signs of illness in people with learning disabilities and lack of collaboration between care providers (Allerton and Emerson 2012; Heslop et al. 2013; Tuffrey-Wijnes et al. 2013).

Historical Understandings of Dementia

As noted earlier in this chapter, with the population ageing there has been an increase in the prevalence of dementia. Prior to exploring current understandings of dementia, it is important to understand the definitions of dementia throughout history. Perceptions of dementia are shaped by socio-cultural and political factors, yielding diverse interpretations across various cultures. (Kane, 2000). Literature has commented on how the stigma and misconceptions associated with dementia has been influenced by how the condition has been socially constructed throughout history (Bosco et al., 2019; Ecoh et al., 2020; Werner and Kim, 2021).

Dementia has been part of human experience long before it was labelled. Around 2000 B.C., the ancient Egyptians noted the decline in memory function as individuals aged and that, for some, this was more severe (Signoret, 1991). Pythagoras, a Greek polymath from 570-495 B.C., categorised the human lifespan into six stages, with senescence (ages 63–79) and old age (age 80 or older) considered as a phase of mental and physical decline. Pythagoras also recognised that some individuals who live until this age were expected to experience a regression to an infant-like state. Hippocrates (460–370 B.C.) attributed cognitive disorders to brain injuries, while Plato (428–347 B.C.) believed that decline associated with old age itself was the primary cause of dementia (Yang et al., 2016). At this time, it was reported that treatment related to dementia was linked to Hippocrates' theory of the Four Humours (black bile, yellow bile, blood and phlegm) . In order to be healthy, one must balance the Four Humours through changing diet, lifestyle, occupation and climate (Bujalkova et al., 2001).

In contrast, Marcus Tullius Cicero, a Roman philosopher, argued that ageing did not necessarily lead to a decline in mental performance, except for individuals with weak willpower. He contended that dementia was not an inevitable consequence of ageing (Cicero, 1923; Yang et al., 2016). Aretheus, a 2nd-century A.D. doctor in Turkey, differentiated dementia into delirium (reversible acute cognitive disorders) and dementia (irreversible chronic disorders) (Habib et al., 1991). At this point in history, while distinctions were being made between typical ageing and dementia, there was significant stigma attached to the latter.

During the Middle Ages, the study of dementia was negatively impacted by the decline of the Roman Empire and the dominance of theocracy. Senility (dementia) was often viewed as a consequence of man's original sin (Albert and Mildworf, 1989). Society at this time believed dementia was punishment from the divine (Bosco et al., 2019). In the 17th century, William Shakespeare symbolically portrayed dementia in his play "King Lear" and since its inception, many actors research symptoms of dementia to prepare for their role. However in this play, there is a focus on the ‘madness of the king’ which illustrates the stigma associated with dementia symptoms at this time (Jones, 2014). In Shakespeare’s era, it was not uncommon for people who were deemed ‘mad’, including those with dementia, to be incarcerated, exorcised or killed (Elkin, 2017).

In the Modern Age, dementia as a diagnosis was initially accepted as a medical term in 1797 by Philippe Pinel (1745–1826), a doctor in France. He posited that there were four categories of ‘mental derangement’ one of which being dementia. To fall into this category, one must be deemed to have experienced thoughtlessness, ‘rebellious’ movement and forgetfulness

(Pinel, 1806). It was widely thought that due to this, dementia led to a loss of agency (Bosco et al., 2019). Jean Etienne Dominique Esquirol (1772–1840), a student of Pinel, described dementia as an experience of disability in understanding and intellect which over time, leads to reduced quality of life (Albert, 1989). Pinel developed the concept of 'moral therapy' in which he stated that the treatment for mental health conditions required "sympathy that is owned to suffering humanity" rather than the punitive treatment common at that time (Pinel, 1806. P. 35).

Otto Ludwig Binswanger (1852–1929), a Swiss researcher, introduced the term "presenile dementia" in 1894 during his study on neurosyphilis, a cause of dementia. From his study, he found that a group of patients with hypertension, reduction in mobility and progressive cognitive decline all had similar hardening of arteries (Yang, 2016). This later became known as Binswanger disease. At this point in history, dementia was not clearly distinct from mental health diagnosis such as psychosis. Therefore, often people with dementia were deemed 'insane' and this impacted the care they received with many being institutionalised (Bosco et al., 2019). During this time, people with dementia would have been housed in the same institutions as people with learning disabilities and mental health conditions described earlier in the chapter. However, people with dementia could not adhere to the norms of the asylums due to their fragility and confused state (Andrews, 2017). The treatment for dementia would have been largely focused on managing behaviours that challenge. In asylums, intervention for this would have been restraint via strait waistcoats and chains, with one social campaigner stating "we see chains and strait-waistcoats, three or four half-naked creatures thrust into a chamber filled with straw, to exasperate each other with their clamour and attempts at violence; or else gibbering in idleness or moping in solitude." (Martineau, 1834. P. 395).

Emil Kraepelin, a German doctor, believed that distinction between pathologies was an important way to advance knowledge in the medical field. To do this, he observed many individuals in his clinic and made attempts to notice patterns between people to create a classification of disorders. He classified dementia into senile and presenile dementia in 1910. In this, senile dementia accounted for people who had cognitive decline expected for their age, whereas presenile dementia accounted for those between the ages of 50-60 years of age showing similar decline (Holstein, 1997; Dahm, 2006).

A student of Dr Kraeplin, Dr Alzheimer began interviewing a 50 year old woman, Auguste Deter. In 1906, a case study was written regarding her experience of cognitive decline including memory difficulties and changes in behaviour (Hippius and Neundorfer, 2003). Auguste experienced difficulties with her memory, reduced ability to communicate and changes to her behaviour. She was 50 years old, much younger than the other patients Dr Kraeplin and Dr Alzheimer had seen before. Auguste was admitted to an institution as the symptoms were not improving.

Auguste spent five years in the institution, during this time Dr Alzheimer interviewed her. He asked her questions about her life and questions to test her orientation to space and time. It was noted that she often struggled to respond and answered instead by saying “I have lost myself” (Maurer et al., 1997. Pg. 1548). Dr Alzheimer observed word finding difficulties and also a decline in functioning at night (Alzheimer, 1906; Maurer et al., 1997). Following her death, Dr Alzheimer requested access to her brain and clinical notes for study. He noted that the brain had shrunk, and discovered abnormal accumulations of protein, now known as plaques and tangles. Following his observations, more studies on people with a similar presentation were conducted and borne from this was Alzheimer’s disease (Alzheimer Society of Canada, 2023).

While Dr Alzheimer's research catalysed research into dementia, between the years of 1960 and 1970, less than 150 research articles on Alzheimer's disease were published. It was only in1976 when physician Dr Katzman wrote an editorial that included Alzheimer's as one of the world's greatest killers, that society became aware of this neurodegenerative disorder. Rather than it being positioned as a rare condition, society began to understand the prevalence of the disorder in the general population (Pincock, 2008). At this point in history, society understood dementia within the medical model. This was due to advances in research which showed the neurological underpinnings of the disorder which helped to distinguish dementia as a neurodegenerative disorder rather than a mental health difficulty (Busco et al., 2019). However, this seemed to perpetuate the objectification of people with dementia who were often reduced to their symptoms (Pinner et al., 2011). In response to this, various charities were set up to support families caring for a loved one with dementia and fund research into the disease. This includes the leading dementia charity in the UK, the Alzheimer's Society (Alzheimer's Disease International, 2023). At this point in history, there was a movement towards "developing programmes of care centred on well-coordinated community services" rather than long-term residential care for people with dementia. (Kay et al., 1966. P. 971).

In the late 20th century, the anti-psychiatry movement began to grow and many began to challenge the medical model of mental health difficulties. This coincided with the deinstitutionalisation movement noted earlier in this chapter. Part of this was an emphasis on the role of social, cultural and environmental factors in mental health and the importance of personal agency. The notion that neurological impairment could be exacerbated by malignant social psychology was proposed by Kitwood (Kitwood, 1997). Kitwood created the idea of Personhood which he defined 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.”. He stated that the personhood of the individual with dementia could be maintained via positive care relationships. This encouraged people with dementia to be placed at the centre of care. Since then, person-centred diagnosis and care has been regarded as the benchmark for dementia care (Nolan et al., 2006; Wilkins, 2021; NICE, 2023).

Current Understandings and Prevalence of Dementia

Currently, dementia is understood as an umbrella term for progressive diseases that cause a person to experience a deterioration in cognitive abilities leading to significant functional decline. Alzheimer’s disease is the most common disease that falls under this umbrella term, followed by vascular dementia and dementia with Lewy bodies. (Alzheimer’s Research UK, 2023). The World Health Organisation (WHO) provides the following definition:

> “Dementia is a syndrome that can be caused by a number of diseases which over time destroy nerve cells and damage the brain, typically leading to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing. While consciousness is not affected, the impairment in cognitive function is commonly accompanied, and occasionally preceded, by changes in mood, emotional control, behaviour, or motivation.” (WHO, 2023. P. 1.).

While this is a widely accepted definition of dementia, it is one that is medicalised and fails to describe dementia in a person-centred manner. Definitions that describe dementia from a humanistic perspective also include the impact decline has on functioning and the implications this has on the way an individual with dementia might relate to others. For example, this definition from the NHS, “Dementia symptoms may include problems with: memory loss, mental sharpness and quickness, language, difficulties doing daily activities...They may also find social situations difficult and lose interest in relationships and socialising... A person with dementia will usually need help from friends or relatives, including help with making decisions." (NHS, 2023. P. 1). Contemporary narratives of dementia discuss the experiences of "people *living* with dementia". This highlights a great shift in the perspectives of dementia whereby people can now imagine what it might be like to live alongside the condition rather than being overcome by it.

A survey conducted with 2,530 adults in the UK illustrated the evolving understandings of dementia (Alzheimer's Research UK, 2023). Half of the sample knew someone who was diagnosed with dementia, 65% understood that dementia is *not* part of normal ageing, 61% said that they would feel comfortable in telling people about a dementia diagnosis if they were diagnosed with the condition themselves and half of the sample reported that dementia is the health condition they fear most. This research highlights how society's understanding of dementia has increased and how stigma has declined. However, it also illustrates that despite the efforts of campaigners, the narrative of 'living well with dementia' is not present in public consciousness.

Research suggests that there are more than 944,000 people living with dementia in the UK (NHS Digital, 2024). Approximately 60% of these individuals will have a diagnosis of Alzheimer's disease, 20% will have vascular dementia and 10-15% will have dementia with Lewy bodies (Alzheimer's Research UK, 2023). Each of these differential diagnoses have distinguishing symptomology but for a dementia to be diagnosed in the UK, the following criteria from the Diagnostic and Statistical Manual of Mental Disorders (Fifth edition) (DSM-5) must be met: "Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual-motor, or social cognition)... The cognitive deficits interfere with independence in everyday activities" (American Psychiatric Association, 2022. No page number available due to being an exclusive online publication). While an American publication, the DSM-V is used in the UK to diagnose neurological disease and mental health difficulties.

As understandings of dementia have changed over time, so have the criteria for diagnosis and with this, there have been shifts in the prevalence of dementia over time. For example, the International Classification of Disease (ICD) 11th edition yielded the highest prevalence of dementia and ICD-10 the lowest. Early diagnostic manuals focused on deficits that might be observed in one's physical and cognitive profile whereas contemporary criteria also attends to functional decline and the impact of this on quality of life (Wetterberg et al., 2023). This is linked with societal shifts away from medical models which do not take a holistic view of health (NICE, 2024).

Assessment of Dementia

To assess whether a person meets the above criteria for dementia, the NICE guidelines suggest the following procedure: individuals who are suspected of having dementia should be referred by a GP to a memory clinic in which the individual will complete an initial assessment exploring onset of symptoms and deterioration and the impact this is having on their activities of daily living. It is helpful for the person to be accompanied by someone who knows them well to share their perspective. During this interview, it is recommended that risk factors for dementia should also be asked about, as well as comorbidities such as Parkinson's disease and stroke. Following this, it is suggested the individual suspected of having dementia should undergo physical examination to exclude other possible causes of symptoms and reversible causes of cognitive decline such as low blood sugar levels or urinary tract infections. In many cases, the individual will undergo a brain scan to assess brain structures for atrophy in the memory centres of the brain. Guidelines then suggest the person should complete a validated cognitive assessment tool. They note that clinicians should look holistically at the assessment and not assume that an individual does not have dementia because they have a normal score on cognitive testing (NICE, 2024).

Dementia and People with Learning Disabilities

For people with learning disabilities, the risk of developing dementia is much higher. Approximately 13% of people with learning disabilities in the 60-65 year old range will have a diagnosis of dementia, this is compared to only 1% in the general population (British Psychological Society and Royal College of Psychiatrists, 2015). In people with learning disabilities not due to Down’s syndrome, the same prevalence of subtypes of dementia is seen, ie. Alzheimer's disease being most common, followed by vascular dementia and dementia with Lewy bodies (Strydom et al., 2007). Causes for the increased prevalence of dementia in people with learning disabilities include genetics, such as the genetic profile mentioned regarding people with Down’s syndrome and health comorbidities, such as epilepsy which is known to increase a person’s risk of dementia (Tai X et al., 2023). One study explored modifiable risk factors for dementia in people with learning disabilities and found a significant correlation between duration of education, hypertension, depression, stroke and traumatic brain injury with onset of dementia (Takenoshita et al., 2023).

If we also look at the literature from the general population regarding the risk factors for dementia, it is widely acknowledged that a sedentary lifestyle and isolation increase a person’s risk for developing dementia (Alzheimer’s Society, 2023). For people with learning disabilities, these are commonly experienced risk factors with them being twice as likely to be inactive

(Mencap, 2019) and less likely to take part in social activity than their peers (Taheri et al., 2016; Merrells et al., 2018). As well as their increased risk of developing dementia, people with learning disabilities are more likely to experience a delay in receiving a diagnosis and thus delayed intervention (Alzheimer's Society UK, 2023). Many of the learning disability assessment tools do not have standardised data and lack defined cut off points for dementia. Instead, assessments have to be completed across time, thus causing delays (Elliot-King et al., 2016). Much of the diagnostics procedure for dementia relies on self-reported changes from the individual and those around them. This can make it more challenging to provide early diagnosis to those with a learning disability as symptoms may go unnoticed, misinterpreted or the individual themselves might have difficulties in communicating the changes themselves (Elliot etl al., 2003; Mencap, 2023). The literature also suggests that progression of the disease is more rapid in people with learning disabilities (Heslop et al., 2014; Strydom et al., 2013) and thus prompt diagnosis is even more important for people with learning disabilities.

The learning disability health check programme was recommended by NICE to reduce the health inequalities seen in people with learning disabilities. The regular annual health check that people with learning disabilities are offered includes monitoring of overall health and wellbeing. In this, clinicians should ask the individual or next of kin about any changes in cognition or behaviour that may suggest the need for a dementia assessment (National Institute of Clinical Excellence, 2024). For individuals with Down's syndrome, a baseline dementia assessment should be completed by the age of 30 years. Having a baseline test on record makes it easier for changes in behaviour and cognition to be noticed later in life (Alzheimer's Society, 2023) and thus make the process of diagnosing dementia easier and quicker.

Guidance from the British Psychological Society (BPS) and the Royal College of Psychiatry (RCP) entitled ‘Dementia and People with Intellectual Disabilities – Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.’ outlines the best practice for the diagnosis and treatment of dementia for people with learning disabilities. In this they note that the process of assessing dementia in people with learning disabilities should differ minimally from the assessments done in the mainstream population. Like the general population, people with a learning disability should have a clinical interview, physical examination and cognitive assessment. The only addition, is that greater thought must be taken when gaining consent to assess the person with learning disability and steps should be taken to make the information available accessible (BPS and RCP, 2014).

The intersection between learning disabilities and dementia complicates care needs, often requiring a multidisciplinary approach that includes expertise in both areas. Caregivers must navigate the complexities of supporting an individual who may already have significant cognitive and functional difficulty, now compounded by progressive decline associated with dementia. This places significant strain on caregivers and highlights the need for specialist training and resources to support them (Watchman et al., 2018). Alongside this, ethical considerations become more complex when people with learning disabilities develop dementia. Ensuring that individuals maintain their dignity and have a voice in care-planning is challenging but crucial (McCarron et al., 2014). Sitting within the intersection of having a learning disability and dementia also places the person at significant risk of further marginalisation. This means care providers and policy makers must be proactive in amplifying the voices of people with learning disabilities and improve access to services (Watchman et al., 2019).

Disclosing the Diagnosis of Dementia

The NICE guidelines for the disclosure of a dementia diagnosis recommend that clinicians should provide individuals with dementia and their support network with information relevant to their stage of dementia in written and oral format (NICE, 2018). In the guidelines, they suggest that by telling someone about their diagnosis of dementia, they can be involved in the care planning process. The specialist learning disability guidance from the BPS and RCP also suggests similar processes for people with learning disabilities. In this they also state that by becoming aware of their diagnosis, "This will also help them be involved as much as possible in decisions about their support and care and medical treatments, including concerning establishing their views and preferences about future care before their illness progresses." (BPS and RCP, 2015. Pg. 37).

Both guidelines, assume that the individuals with dementia would like to know about the diagnosis of dementia. This reflects the findings of research with people from the general population which shows that the majority of people with dementia and their support networks agree that it is helpful to know about the diagnosis (Bamford et al., 2004), however the research also highlights there is a percentage of people who do not want to know about a diagnosis of dementia (Merl et al., 2022; Glavind, 2023). For example, 7% (Thompsell and Lovestone, 2002), 11% (Bachman et al., 2000) and 30% (Marzanski, 2000) of people in each sample thought a dementia diagnosis should not be disclosed. There are clear benefits of telling a person with dementia about their diagnosis including the invitation for them to be an active participant in the planning of their care, validation of the difficulties they face and to exclude other causes. Although there is also reason against telling a person with dementia about their diagnosis including the absence of a cure, anxiety about deterioration, risk of the person with dementia becoming upset or not remembering and self-stigmatisation (Husband, 1999; Husband 2000;

Johnson et al., 2000; Holroyd et al., 2002). This raises the important question as to whether it is more consistent with person-centred care to ask individuals if they would like to know about a diagnosis of dementia, rather than to assume they would prefer to be made aware of their condition.

Treatments for Dementia

Currently there is no cure for dementia. However, there are psychosocial and medical interventions that can be useful in improving the individual's quality of life. One major advancement in dementia care is the use of medication to support the individual with memory and cognitive difficulties. NICE guidelines (2011) recommends donepezil (Aricept), galantamine (Reminyl), rivastigmine (Exelon) and memantine (Ebixa) as pharmological treatment for Alzheimer's disease. Research suggests that 1 in 10 people who take dementia medication experience benefits to their memory and cognition (Alzheimer's society, 2023) and that the effects of medication are more noticeable in those with mild to moderate dementia in comparison to those with severe dementia (Buckley and Salpeter, 2015). With 55% of people diagnosed with Alzheimer's disease being prescribed 'anti-dementia' drugs (Donegan et al., 2017), it is important to show curiosity around the benefits and consequences of such medication, especially for people with learning disabilities. One of the main difficulties being the way in which informed consent is sought from the person with a learning disability to be prescribed and encouraged to take medication. This includes, outlining the potential risks of medication and any side effects. Research has shown that often people with learning disabilities are not offered understandable information related to their medication but that with support they are able to make informed decisions about medication (Ferguson and Murphy, 2014). Another criticism of the use of medication is highlighted by the national NHS England work programme 'STopping

Over Medication of People with a learning disability (STOMP)’, people with a learning disability are frequently and inappropriately prescribed medication. As such, psychosocial interventions should be offered prior to medication. However, psychosocial interventions are often taxing on services’ workforce and short-term economy (National Collaborating Centre for Mental Health, 2015).

Psychosocial interventions seem to be based on Kitwood’s concept of personhood whereby the main aim of intervention is to maintain the person’s sense of self and dignity. In doing this, studies also report that there is an increase in implementation of person-centred care as staff are better able to acknowledge the individual as separate to the dementia (Cooney, 2019). NICE guidelines suggest that the person with dementia should be offered a range of activities to promote wellbeing that are tailored to the person’s preferences, cognitive stimulation therapy and reminiscence therapy (NICE, 2018). Cognitive stimulation therapy is widely promoted in the UK as an intervention for dementia. It is a group intervention where participants take part in group activities designed to improve memory, problem-solving skills and language ability (NHS, 2023). Research has shown that people who engage in a cognitive stimulation programme have improved scores on cognitive assessment tasks and improved quality of life in comparison to control groups (Spector et al., 2003; Aguirre et al., 2013). Other psychosocial interventions with a strong evidence base includes life story work. In this, individuals create a narrative of their lives to help maintain their sense of identity and promote person-centred care (McKinny, 2017). Research has also found that reminiscence therapy can improve mood, some cognitive abilities for people with dementia, self- acceptance and autonomy (Cotelli et al., 2012; Gonzales et al., 2015).

The research outlined above was completed with the general population. A comprehensive review of the evidence base for psychosocial interventions for people with a learning disability and dementia was conducted by MacDonald and Summers (2020). In this, they outline and assess the efficacy of psychosocial interventions for dementia with people with learning disabilities via a systematic review. They suggest there are three categories of psychological interventions: 1) behavioural interventions, 2) systemic interventions and 3) therapeutic interventions. All 21 studies included in this systematic review suggested that psychosocial interventions are beneficial for the person with a learning disability and dementia and the system supporting them. The authors also emphasise that the advances seen in psychosocial interventions for dementia in the general population are not seen in the learning disability population. For example, technology has not been used in life story work for people with learning disability and dementia whereas this can be observed as being efficacious in the general population. As such, access to equitable intervention in dementia is still an area of development in learning disability care.

Another domain that the BPS and RCP guidelines see as an area to intervene is environmental interventions (BPS and RCP, 2014). They propose that most individuals with learning disabilities presenting with behaviours that challenge due to dementia can be effectively managed through environment approaches (BPS, 2004). They explain that those supporting people with learning disabilities and dementia should create a ‘dementia-enabled’ environment. To do so, environments must be calm, predictable and make sense, familiar, suitably stimulating, safe and risk assessed (BPS and RCP, 2014. P. 57). Thus, their guidelines also state that the optimum place for people with learning disabilities and dementia to live and die is in their current home with appropriate adaptations. If this is not possible, they state that the compromise option is moving to a more specialist learning disability home where dementia can be managed better. The least preferred option would be for people to be referred out of learning disability services. While these guidelines hold good rationale and are clearly person-centred, the literature used in much of the paper does not consider the perspective of people with learning disabilities and relies on the clinical judgements of the authors and perspectives of caregivers.

Living Well with Dementia

The psychosocial interventions presented above are intended to support people to live well following the diagnosis of dementia (Guss et al., 2014). The title of the current British national dementia strategy, ‘Living Well with Dementia’ was co-produced by people with dementia and their families. In this, they acknowledge that while receiving a diagnosis of dementia can be catastrophic, with the right support at the appropriate time, individuals with dementia and their families can live well with dementia (Department of Health, 2009). As such, the strategy begins to dispute narratives that life for people with dementia and their families is hopeless. In the strategy, it outlines three areas in which the needs of people with dementia should be met. The areas being: improved awareness, earlier diagnosis and intervention and high-quality care (Department of Health, 2009). In 2012, we saw the Prime Minister’s first challenge on dementia. In this he outlined the government’s commitment to improving dementia care which included a drive to provide high quality care with financial incentives for hospitals able to achieve this, a commitment to create dementia friendly communities and to increase funding into dementia research (Department of Health, 2012). The Live Well pathway for dementia created by the NHS reflects these developments on a political and policy level, it conceptualises dementia care in a five step journey; preventing well, diagnosing well, supporting well, living well and dying well (NHS England, 2016). Core narratives regarding living well with dementia have also been adopted by campaigners and charities which has led to positive developments in the community (Alzheimer's Disease International, 2016).

In 2016, an updated Prime Minister's challenge on dementia was published (Department of Health, 2016), with an explicit aim for England to be the "best country in the world for dementia care, support, research and awareness." (Department of Health, 2016. P. 3). Building on the last challenge presented by the Prime Minister, this paper shares the government's commitment to accelerating this progress through coordinated action between key stakeholders. At present, we are awaiting an updated dementia plan for England which campaigners are urging government to publish. This plan was due to be published at the end of 2022 and is yet to be released (Hullah, 2023).

Despite this delay, historical strategies and clinical pathways continue to encourage positive attitudes towards living well with dementia. This is important as research into health outcomes in the geriatric population has shown that having positive attitudes towards ageing improves health and quality of life. The perception an individual has regarding their own ageing has been linked to quality of life outcomes and is therefore important to consider. Positive perceptions are linked to enhanced self-assessed health (Janekova et al., 2013), improved mental well-being (Polverino, 2010), improved performance on vision and hearing assessments (Kim et al., 2012), increased walking capabilities (Witham et al., 2006), decreased reliance on assistance for activities of daily living (Kim et al., 2012) and extended lifespan (Levy et al., 2002).

Negative perceptions of ageing have been associated with poorer self-assessed and physician-assessed health (Jang et al., 2004), reduced medication adherence (Polverino, 2010), heightened incidence of depressive symptoms (Han and Richardson, 2015), deterioration in physical function (Sargent-Cox et al., 2012), worse well-being (Bryant et al., 2012) and are recognised as a risk factor for future disability in activities of daily living (Moser et al., 2011). Additionally, Levy and Myers (2004) and Siebert et al. (2018) discovered that negative self-perceptions of ageing were significant predictors of development of mild cognitive impairment and dementia while controlling for health, genetic and socio-demographic variables. This is in line with Activity Theory (Havighurst, 1961) which posits adults who maintain their social roles and activities tend to have better physical and mental health. Research has shown that individuals with higher levels of self-efficacy are more likely to continue with established roles and activities in older age (Farmer et al., 2022). As such, when someone has more positive attitudes of ageing in which they believe themselves to be capable of engaging in activities they will experience better health outcomes.

Ageing Well and Marginalisation of People with Learning Disabilities in Research

Much of the progress seen in dementia care reflects the wider context of new ideas emerging as ‘Ageing Well’. Recognising the rate at which the population is ageing, the United Nations (UN) declared 2021 – 2030 as the Decade of Healthy Ageing (United Nations, 2020a). They aim to create more age-friendly environments, combat ageism, integrate health services and increase long-term care. This is a shift from the medically based model of ageing that focuses on physical health to instead the social aspects of ageing well. The UN (and policies mentioned earlier in this chapter) seem to be drawing from Havighurst's activity theory of ageing which suggests that optimal ageing takes place when the person continues to interact with significant others and engagement in activities continues (Havighurst, 1981). In support of this theory, Netuveli and Bane (2008) conducted a narrative review and found that cross-culturally, positive quality of life in the ageing population was based on the presence of social contacts, low dependency on others, good health, comfortable material circumstances and positive social comparisons.

The positive impact of improving the social environment on the wellbeing of the ageing individual may be linked with the way it preserves one's sense of identity. The changes that occur in ageing can threaten a person's sense of self and Identity Process Theory suggests that people maintain a dynamic balance between their sense of self and their experiences using a combination of processes (Sneed and Whitbourne, 2003). Identity assimilation is the process of interpreting experiences based on one's existing self-concepts, ensuring a consistent sense of self. Conversely, identity accommodation is the act of modifying one's identity in response to new experiences. When faced with experiences that do not align with their current identity, individuals first attempt identity assimilation. If this approach proves ineffective, they resort to identity accommodation. Striking a balance between these two processes enables individuals to adapt successfully to the challenges brought on by ageing (Snee and Whitbourne, 2003). To experience this process, one must continue to engage socially with the environment.

The UN's commitment to healthy ageing includes a plan of action which states that preventative health care is required to support people to age well (United Nations, 2020b). Related to dementia care, we saw the launch of the Alzheimer's Research UK campaign of 'Think Brain Health' in 2021. This aimed to increase public awareness of the ability to reduce risk of developing dementia through engagement in 'brain health' behaviours. They note that 40% of dementia cases are linked to risk factors related to lifestyle which we can change. They outline three areas to improve brain health: 1) Stay sharp – they recommend people should engage in cognitive stimulatory activities to have a reduced risk of dementia, 2) Keep connected – being social active is highlighted as an important factor in maintaining brain health, 3) Love your heart – they explain that research suggests behaviours good for the heart are also good for the brain e.g. exercising, balanced diet and not smoking.

Unfortunately, little of this work has been made accessible to people with learning disabilities which again highlights the health inequalities people with learning disabilities face. Noticing the lack of inclusion of people with learning disabilities in dementia policy, Dementia Action Alliance UK created a document called 'Hidden in Plain Sight – Dementia and Learning Disability' which outlines how "millions of people with learning disabilities have become invisible in national dementia strategy" (Dementia Action Alliance UK, 2018). They highlight how strategies and guidelines do not show targeted focus on people with learning disabilities and dementia. They raise concerns that without this, people with learning disabilities may not be provided with the best dementia care in a timely manner.

This disparity between the inclusion of the general population and the learning disability population is also seen in research. Much of the research in this chapter is based on non-learning disability samples and is at best from the perspectives of carers of people with learning disabilities. This includes the research mentioned in the BPS and RCP guidance, where despite their efforts to remain person-centred throughout, the guidance is lacking in the service-user perspective. The Valuing People White Paper (Department of Health, 2001) acknowledged the inequities and exclusion that people with learning disabilities are subject to and encourages researchers to include people with learning disabilities in research as main contributors. One study concluded that historically, people with learning disabilities were "tested, counted, observed, analysed, described and frequently pathologised, but never asked for their views" (Walmsey, 2001. P. 188). More recently, research has outlined the barriers to people with learning disabilities being included in research. These include difficulties in recruiting people with learning disabilities and working with people who are cognitively challenged within an intellectualised research framework (Lorito et al., 2018; Kuri and Schormans, 2022). Researchers have also doubted the capacity of people with learning disabilities to consent to participate in research and have expressed concern this may increase their vulnerability to being coerced (Dalton et al., 2004; Iacono, 2006). There appears to be a view that information gained from people with learning disabilities may be less reliable and thus less valuable. Another common assumption is that people with learning disabilities have reduced capacity to partake in conversations regarding more complex topics such as death (Tuffrey-Wijne et al., 2013; Wiese et al., 2014). This then leads to a reliance on carers or family members to describe how they believe the person with a learning disability perceives an experience. With the immense growth in the lifespan of people with learning disabilities, it is imperative to explore *their* perceptions of ageing and dementia especially when considering the literature correlating attitudes towards ageing and wellbeing.

Chapter summary

This chapter began by exploring the historical interpretations of learning disabilities, the shifts in societal attitudes, and the progression of care for individuals with learning disabilities. It outlined how historically, people with learning disabilities have been met with discrimination and how these perceptions impacted the policies relating to the learning disability population and the care available to this group. Currently, person-centred and compassionate understandings of learning disabilities are seen in society and reflected in services and legislation. The chapter then highlighted the increase in the elderly population and offered insights into the disparities in health experienced by those with learning disabilities. Subsequently, the concept of dementia was explored, including both historical perspectives and contemporary understandings of the condition. It outlined the evolution of understandings of dementia from it being perceived as a punishment from the divine to a more medicalised perception of the condition. Causes for the increased prevalence of dementia in the learning disability population were also discussed. The chapter also discussed narratives of ageing well and related theories. The literature highlighted a correlation between positive attitudes and ageing well. Lastly, the chapter addressed the inaccessibility of campaigns promoting ‘ageing-well’ and ‘living well with dementia’ for people with learning disabilities due to the lack of research with people with learning disabilities as the main contributors. The chapter concluded by stating the necessity for research into ageing and dementia from the perspectives of people with learning disabilities due to the link between attitudes towards ageing and wellbeing.

Chapter Two: Systematic Review

Chapter Overview

This chapter reviews the literature regarding how people with learning disabilities perceive ageing and dementia. As there were few papers that explored how people with learning disabilities perceived dementia, the researcher conducted a rapid literature review. Relating to the literature on how people with learning disabilities perceive ageing, the researcher conducted a qualitative systematic review using a meta-ethnographic approach. This chapter provides details on how both the systematic and rapid literature reviews were conducted, the themes generated and critique of the review.

Introduction

The previous chapter reviewed the impact of attitudes towards ageing on health outcomes in the non-learning disability population. A limited amount of research has emerged regarding the attitudes individuals with learning disabilities have towards ageing and dementia. However, this research has not been combined or analysed systematically. This review seeks to amalgamate existing studies to address the question, "What attitudes do people with learning disabilities have towards ageing and dementia?" By synthesizing this information, the goal is to gain insights into the depth of understanding that individuals with learning disabilities have regarding ageing and dementia. This, in turn, may promote future research that is more inclusive of the perspectives of individuals with learning disabilities and support the rationale for the aims of the present study.

Originally, this systematic review was interested in exploring how people with a learning disability perceive ageing *and* dementia. However, during the initial literature search, it became apparent that there were very few relevant papers. As such, a decision was made to exclude the four dementia papers from this systematic review and conduct a rapid review instead, which will be presented after this section.

Method

Design

Contemporary researchers have shown growing acceptance of qualitative research methodologies which has prompted the development of effective processes for synthesising such data (Britten et al., 2002). The objective of a meta-synthesis goes beyond traditional narrative and systematic literature reviews, involving a researcher's reinterpretation of the data. As Schreiber et al. (1997) describes, it entails bringing together, breaking down findings, examining them, identifying essential features, and, in some way, combining phenomena into a transformed whole.

Meta-ethnography, as proposed by Noblit and Hare (1988), is a specific form of meta-synthesis that extracts portions of a study and integrates them to provide a comprehensive view of the phenomenon of interest. They highlight that synthesis in meta-ethnography is interpretative rather than merely summative.

The seven-step process to conduct a meta-ethnography involves initiating the process, determining relevance to the initial interest, reading the studies, establishing the relationships between studies, translating the studies into one another, synthesizing translations, and expressing the synthesis (Noblit and Hare, 1988). This process was followed in the current meta-ethnography.

In contrast to other qualitative synthesis approaches like grounded theory, meta-ethnography allows the inclusion of various study designs instead of restricting to similar methodologies (Soilemezi and Linceviciute, 2018). Given the limited qualitative literature on the perspectives of people with learning disabilities, it was crucial that the chosen analysis approach did not further exclude papers from the synthesis. Meta-ethnography was chosen for its alignment with the synthesis goals and its capacity to include a broader range of papers. Unlike other approaches such as scoping reviews, meta-ethnography facilitates the creation of new interpretations from the synthesis, fostering a deeper understanding in a neglected research field.

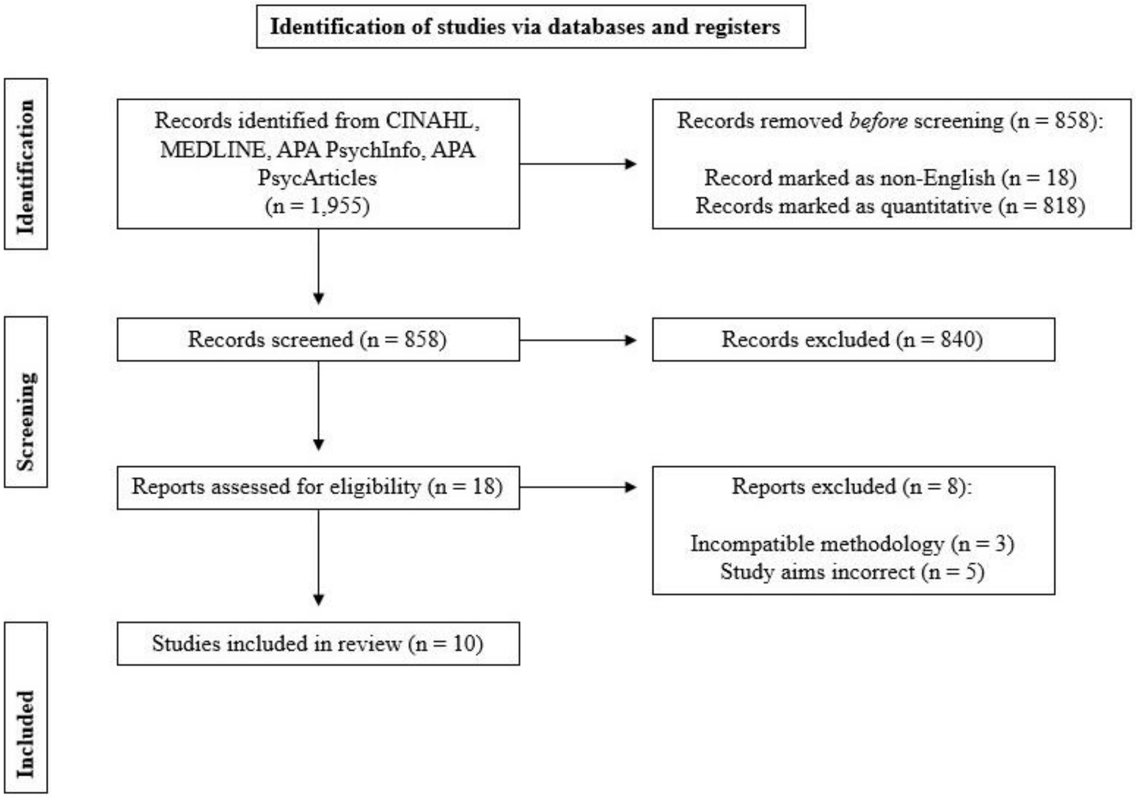
Article selection

A systematic review concerning how people with learning disabilities perceive ageing was conducted using the following electronic databases: CINAHL, MEDLINE, APA PsycInfo and APA PsycArticles. The subsequent search terms were used across the four databases using the option ‘select a field’ and the limiters ‘Peer Reviewed’ and ‘English’: [Experienc* OR perception* OR attitude* OR view* OR feeling* OR perspective* OR meaning* OR lived experience*] AND [Ageing OR ageing OR “old* adult*” OR “old* person*” OR elderly] AND [“Learning disab*” OR “intellectual* disab*” OR “mental* retard*” OR “learning difficult*” OR “special needs”].

Initially, 1,955 entries were identified across the four databases, reducing to 858 after articles marked as non-English and quantitative were removed. After title screening, 840 articles were excluded. Subsequently, 18 articles underwent full-text screening, with eight exclusions due to incompatible methodology or aim. This resulted in the inclusion of ten articles for review. The PRISMA flowchart in Figure 1 illustrates this process.

Figure 1.

PRISMA Flowchart for the Systematic Review.



A total of 10 papers were selected for review (Erickson et al., 1989; Thompson, 2002; Dew, 2006; David et al., 2015; Newberry et al., 2015; Kahlin et al., 2015; Mee Kim et al., 2020; Trip et al., 2020; Kim et al., 2021; Homgren, 2023).

Getting Started, Deciding What is Relevant, Reading the Studies

The first three stages of the meta-ethnography process begins with the creation of inclusion and exclusion criteria for papers to ensure relevance to the research question. Once papers have been selected, the researcher familiarises themselves with the papers by reading and re-reading the articles.

The research question for this systematic review focused on exploring what attitudes people with a learning disability have towards ageing. The specific inclusion and exclusion criteria are outlined in Table 1 and a summary of papers can be found in Table 2.

Studies that explored how individuals perceived ageing were included. For example, studies that asked participants to reflect on the positive and negative parts of the ageing process. Studies that focused on the reporting of experiences during the ageing process were excluded. For example, studies that were interested in detailing changes to health and living circumstance.

Table 1

Inclusion and Exclusion Criteria for the Systematic Review.

Inclusion Criteria	
Population	People with learning disabilities, worldwide.
Main focus	Attitudes towards ageing from the perspective of people with learning disabilities.
Methodology	Qualitative.
Language	Papers published in English.

Exclusion Criteria	
Population	Samples including people without learning disabilities.
Main focus	Studies reporting the experience of ageing in learning disability populations. Studies reporting how people with learning disabilities perceive the ageing of others.
Methodology	Quantitative research. Papers not subject to peer-review.
Language	Studies that were not published in English.

Determining how studies are related

Ten studies were analysed to identify relationships between studies, looking for similarities, differences, and patterns. The researcher categorised studies in a table based on their contributions to the overall understanding of the research question and initial themes were noted.

Translating the studies into one another

To translate the studies into one another, contributions and initial themes noted in the previous step were translated between individual studies to create a common set of themes. The themes created were: ‘slowing down, doing less.’, ‘life disrupted’, ‘uncertainty breeds fear’, ‘an unwanted experience’, ‘ageing does not discriminate’, ‘ageing as a social experience’, ‘the gifts of ageing’ and ‘life improves with age’. At this point, the researcher sought ways to understand the relationships between the themes.

Synthesising translations

Following Britten et al. (2002) the summary tables of the studies were compared with one another. It became apparent the studies related to each other reciprocally. The main concepts were then synthesised into three larger categories: 'The intrusive unsettling of ageing’, ‘Growing old, a journey with the other’ and ‘The golden years’. A model connecting the key concepts was then produced to create a line of argument synthesis.

Table 2

Summary of Papers Included in the Systematic Review.

Study	Participant details and country of origin	Study aim/purpose	Findings	Strengths/weaknesses
Erickson and Seltzer (1989)	47 individuals with learning disabilities, mean age of 62.38 (SD = 10.86). USA.	To explore the following questions 1) What significance do individuals with learning disabilities associate with ageing? 2) Is there a correlation between their perceptions of old age and their present employment, residence, and age? 3) Is there a connection between participants' definition for old age and their actual chronological age?	Participants anticipated deterioration to physical health and termination of work. They outlined benefits and consequences of ageing on social life. For example, they noted having more free time would be both welcomed and uncomfortable. Some expressed denial of ageing and the desire to remain young. Many associated ageing with death and low mood.	The study did not disclose full demographics of participants. It is unclear what level of learning disability participants had and they only included people with 'sufficient' language abilities.
Thompson (2002)	162 individuals with learning disabilities between 41-87 years old. UK.	To provide qualitative insight into the experiences of ageing of people with learning disabilities from the vantage point of their perceptions and memories.	Findings indicate that the physical changes linked to ageing do not seem to be a primary worry for older individuals with intellectual disabilities. More concerning are other changes, some of which are unrelated to ageing, such as alterations in services and family circumstances. The participants' candid descriptions of	Researchers used a snowball technique to recruit, meaning the sample is not likely to be representative. Despite this, a strength of this study is the big sample size.

			their lives also provide valuable insights into how straightforward interventions could enhance the quality of life for adults with intellectual disabilities as they age.	
Dew, 2006	13 women with learning disabilities were recruited between the ages of 55-82 years old. Australia.	To explore how individuals with learning disabilities perceive their lives as they age.	Analysis revealed the positive attitudes that participants had towards ageing. They saw it as a time to gain support from family and friends, which they enjoyed and also as a time where they were under less financial stress.	The majority of participants in this study were recruited from the same service, as such the commonalities in their responses may be due to their shared experiences in the service.
David et al. (2015)	19 women aged 50-64 years old with a mild to moderate learning disability. All participants lived in the community. Israel.	To delineate and examine the perspectives and significances that women with learning disabilities attribute to the process of ageing.	Ageing was seen to be largely linked with physical deterioration and conceptualised as a difficult time in life. To cope with age-related fear, participants seemed to create distance between themselves and ageing through denial.	The researchers used a novel and comprehensive process to seek consent, involving exploring this with participants through an open discussion. This study did not have a diverse sample with most participants from a middle class background and living in community housing.
Newberry et al. (2015)	Seven individuals with a mild learning disability aged between 60-81 years old. UK.	To investigate how individuals with learning disabilities comprehend the process of ageing.	Most participants had negative attitudes towards ageing which were based on the physical changes they attributed to ageing. Some individuals distanced themselves from ageing and conceptualised it as something the other experiences. Some shared their	The researcher noted that there was great variation in the length of interviews and attributed this to the variation in understanding that each participant had of the questions asked.

			concerns about becoming more dependent on others in old age and about the connection between ageing and death. Positive beliefs about ageing were also mentioned including narratives such as old age being a time of improved quality of life.	
Kahlin et al. (2015)	12 participants with mild to moderate learning disabilities. Aged 48-71 years old. Sweden.	To investigate how people with learning disabilities understand and articulate experiences of ageing.	The ageing process involves alterations in physical, psychological, and intellectual functioning, with a perceived decline in body function, loss of motivation, and apprehension. Participants observed reduced activity capacity in older adults, emphasizing the need for adaptive activities. Ageing was viewed as both inevitable and, for some, undesirable. It was associated with acquiring knowledge and experience, kindness, and wisdom, enabling individuals to align more closely with the non-learning disability population. The narrative also acknowledged death as a consequence of ageing.	Participants were allowed to use photographs to support their discussion. Interviewers utilised prompting to support discussions which may have led to biased lines of conversation.
Mee Kim et al. (2020)	28 individuals with learning disabilities aged	To investigate how individuals with learning disabilities perceive changes	Participants viewed ageing as a transformation into an undesirable self, accompanied by the fear of death and	The researchers employed questions that encouraged reflection on both the psychosocial and physical dimensions of

	between 40-50 years old. South Korea.	related to age in the lives of middle-aged people.	uncertainty about the future. They expressed concern about the potential need to relocate following the death of parents.	ageing. Individuals were recruited through service providers, potentially introducing bias to the sample.
Kim et al. (2020)	Six individuals with mild to severe learning disabilities aged between 39-51 years old. South Korea.	To investigate the lived experiences of middle-aged adults with learning disabilities in South Korea, exploring their outlook on life challenges, concerns, and coping strategies.	Individuals expressed concerns about ageing, particularly regarding changes in appearance and physical health, acknowledging the increasing proximity of death. When discussing ageing, they grieved the absence of significant life events such as marriage, employment, and children. Participants were conscious that reaching a certain age would prevent them from attending the day center, leading to worries about socialising.	The use of photovoice facilitated the inclusion of individuals with severe learning disabilities but non-verbal individuals were excluded from the research. The researcher's use of prompts in discussions might have influenced participants, potentially resulting in biased responses.
Trip et al. (2020)	19 individuals with learning disabilities aged 37-58 years old who live with family. New Zealand.	To investigate how individuals with learning disabilities perceive ageing and their future aspirations.	Some individuals acknowledged that a component of ageing involves cultivating independence through continuous learning and skill development. Changes in body appearance, such as weight loss and facial alterations, were associated with ageing. The perception of ageing included heightened support needs and memory loss. Ageing was also linked to envisioning future possibilities,	While employing photos aids to help individuals with learning disabilities to express their thoughts, it remains unclear whether they genuinely connected the images to the topic.

			expressing hope for forthcoming events. Some discussed alternative living arrangements due to ageing, while others found it challenging to envision the future.	
Homrgen, 2023	26 individuals with mild learning disabilities between the ages of 42-74 years old. Sweden.	To explore the ageing experiences of individuals with intellectual disabilities before undergoing an educational intervention.	Participants preferred to embrace the present to avoid contemplation of ageing. Many associated ageing with retirement, health issues, dependence on assistance in daily life, and the inevitability of death. Ageing often evoked concerns about loneliness and boredom resulting from social isolation after retirement. Positively, ageing was seen as an opportunity for wisdom, continued engagement in leisure activities with others, and the possibility of ongoing work.	Researchers relied on staff in a service to recruit participants they thought were appropriate for the study. They were concerned this would have made the sample biased.

Results

The intrusive unsettling of ageing

Slowing down, doing less. Across studies, people with learning disabilities understood ageing to be a process that leads to physical (Erickson and Seltzer,1989; David et al., 2015; Newberry et al., 2015; Kahlin et al., 2015; Trip et al., 2020; Kim et al., 2021) and cognitive decline (Kahlin et al., 2015; Trip et al., 2020). Some noted that the deterioration in these areas ultimately lead to death (Erickson and Seltzer, 1989; Newberry et al., 2015; Kahlin et al., 2015; Mee Kim et al., 2020; Kim et al., 2021).

When describing the specific physical and cognitive changes associated with ageing, many participants relied on stereotypical features such as sagging skin, greying hair, reduced mobility and memory loss (Newberry et al., 2015; Trip et al., 2020). Due to the impact some of these changes would have on the ageing person’s functioning, participants hypothesised that the aged person would require support from others (Dew, 2006; Kahlin et al., 2015; Newberry et al., 2015; Trip et al., 2020; Homgren 2023).

Participants reflected that when differences to functional abilities were observed, reflection on their mortality began (Trip et al., 2020). It seemed that because of this, for many individuals with learning disabilities, ageing was strongly linked to dying. It was also noted that reflection on death encouraged reflection on their life achievements or failure to meet society driven milestones (Newberry et al., 2015; Kim et al., 2021).

Kim et al. (2020) suggests that worries about declining health should be considered within a social context, it is emphasised that support from others and maintaining social contact play pivotal roles as facilitators of physical activity.

Life disrupted. Due to the reduced ability to function noted in the last theme, participants reported that it was necessary for older adults to adapt their activities or participate in primarily sedentary activities (Kahlin et al., 2015). It was noted that when adaptation is not possible, leisure or occupational activity would cease (Erickson and Seltzer, 1989; Trip et al., 2020). In cases where adaptation is possible, the hobbies and work would continue to be viable for individuals with learning disabilities (Homgren, 2023). Kim et al. (2020) outlined that for many individuals, there was a concern that when older, they would no longer be able to attend their current service in their old age.

The main caregivers for many participants within the studies were their parents. Many worried that ageing would include the experience of losing a parent. They acknowledged that this would then impact their residential status and led to concerns about how they would financially manage (Thompson, 2002; Mee Kim et al., 2020; Trip et al., 2020).

Uncertainty breeds fear. A common narrative seen in many papers was concern related to ageing (Kahlin et al., 2015; David et al., 2015). For many, this was a distinct fear and for others it was anxiety related to the uncertainty that ageing and the future brings (Mee Kim et al., 2020). This was more prominent in individuals who had limited awareness of the ageing process and encountered difficulty envisioning the future (Newberry et al., 2015; Trip et al., 2020). Some were anxious due to the prospect of changes to services and family circumstances that the future brings (Thompson, 2002). Some were concerned that the lack of services available to older adults would lead to them becoming bored and isolated (Homgren, 2023).

Mee Kim et al. (2020) concluded that individuals with learning disabilities comprehend ageing as characterized by fear, anxiety, and resistance, primarily stemming from a lack of concrete planning in which they are involved. The absence of plans contributes to the growth of anxious uncertainty.

The majority of studies highlighted that ageing for many people with learning disabilities is an anxiety provoking concept. Kim et al. (2020) concluded that it was the changes to the social aspects of life that created the most anxiety.

An unwanted experience. A considerable number of individuals with learning disabilities expressed a reluctance to undergo the ageing process (Kahlin et al., 2015) and the associated changes over time (Mee Kim et al., 2020). David et al. (2015) propose that unfavourable views of ageing stem from internalising stereotypes of frail and dependent elders.

To cope with potentially distressing and overwhelming thoughts of decline and mortality, some studies noticed that individuals at some level dissociated from ageing through distancing themselves from the experience. To do so, many would only describe ageing in the context of the other rather than something that they would experience themselves or deny the experience entirely (Erickson and Seltzer, 1989; David et al., 2015; Newberry et al., 2015).

Growing old, a journey with the other

Ageing does not discriminate. Individuals with learning disabilities characterised ageing as an "inevitable" phenomenon (Kahlin et al., 2015), an experience universally encountered by everyone (Trip et al., 2020). Trip et al. (2020) concluded that the universality of ageing encouraged people to be empathetic towards those ageing.

Ageing as a social experience. The ageing process was seen as a transformation through which individuals with learning disabilities gradually align more with the non-learning disability population. Kahlin et al. (2015) clarified that ageing serves as a normalizing phase, where disability and heightened support become shared experiences among all older adults.

Individuals recognised that the increased need for support common in old age brought connection with others. They saw this as a positive aspect to ageing especially when it was friends or family providing them with this support (Dew, 2006).

The golden years

The gifts of ageing. Despite many individuals holding negative perceptions of ageing, they also view it as a period for acquiring new skills and qualities. People with learning disabilities perceive older adults as possessing more knowledge, experience and thus competence in activities, and wisdom (Kahlin et al., 2015; Holmgren, 2023).

They also consider ageing as a time when they can attain increased independence through the development of knowledge and wisdom (Trip et al., 2020). The authors concluded that it is through this growing independence that they can contemplate future possibilities.

David et al. (2014) proposed that optimism and a positive attitude help individuals with learning disabilities cope with the challenges associated with ageing.

Life improves with age. The perception of ageing included the belief that it is a period when one's quality of life enhances. Some attributed this improvement to retirement, viewing it as an opportunity for happiness, relaxation, and enjoying life (Newberry et al., 2015).

Others contemplated ageing as a phase where they could experience reduced financial stress, due to receipt of pensions and inheritances (Dew, 2006).

Furthermore, ageing was associated with future possibilities, reflecting hope for upcoming events (Trip et al., 2020).

Line of argument synthesis

In a line of argument synthesis, studies uncover different aspects of the subject, creating a new interpretation (France et al., 2019). From this synthesis emerges a model describing varied perceptions of ageing in people with learning disabilities and how each relate to each other.

Studies consistently portray how people with learning disabilities view ageing, acknowledging both the accompanying loss and disruption, as well as positive aspects. People with learning disabilities perceive ageing similarly to the general population, associating it with disruption, loss, and stereotypical images of older adults. This existential anxiety prompts reflection on life experiences, leading to heightened awareness of unachieved life events and grief for lost possibilities.

In comparing themselves to societal norms, people with learning disabilities seek to understand key life events and notice similarities between ageing individuals with and without learning disabilities. In doing so, they observe that ageing creates less distance between the experiences of people with and without a learning disability. In older age, both share experiences of being cared for. Coping with disruption, they dissociate themselves from the concept of ageing through conceptualising it as a distant future process and by focusing on the personal growth and hope catalysed by ageing.

This proposed model suggests that people with learning disabilities perceive ageing through a multifaceted lens, exploring the potential connections between these diverse perceptions. It underscores the nuanced awareness often overlooked in discussions concerning people with learning disabilities.

Discussion

This review aimed to investigate the attitudes people with learning disabilities have towards ageing. Employing a meta-synthesis approach across ten studies using the meta-ethnographic method, the findings suggest that individuals with learning disabilities have nuanced attitudes towards ageing, similar to the non-learning disability population (Duay and Bryan, 2006; Bowling, 2008; Sargent-Cox et al., 2012). The synthesis, conducted through a line of argument approach, revealed that individuals with learning disabilities view ageing as an intrusive and unsettling process but also one that takes places in a social context and a time which some may perceive as the golden years. These themes collectively contribute to a comprehensive understanding of the attitudes individuals with learning disabilities have towards ageing.

Primarily, individuals with learning disabilities view ageing negatively, influenced by stereotypes portraying older individuals as frail and unwell. This perception may stem from a lack of information about the ageing process, leading to reliance on stereotypes. Stereotype embodiment theory (Levy, 2009) suggests that ingrained stereotypes can impact health and functioning, emphasising the importance of interventions providing accurate information to counteract such stereotypes.

Individuals with learning disabilities also perceive ageing as a process disrupting social experiences, acknowledging that the process of ageing is dependent on social factors. This aligns with Havighurst's Activity Theory of ageing (Havighurst, 1981), which highlights the need for caregivers and services to understand and optimise social aspects to improve the experience of individuals with learning disability as they grow older.

A recurring theme across studies is the idea that ageing is a universal phenomenon, prompting comparisons with others. This aligns with research by Lockwood et al. (2012), indicating that individuals compare themselves to others during life transitions for hope and to manage uncertainties. Festinger's model of social comparison (Festinger, 1954) further supports this, suggesting that such comparisons serve a function in self-assessment.

Contrary to assumptions about limited understanding of abstract concepts in people with learning disabilities, positive perceptions of ageing indicate a balanced and critical mindset. Optimism, identified as a mitigating factor for negative perceptions of ageing (Wurm and

Benyamin, 2014), highlights the importance of recognising and fostering positive attitudes towards ageing in people with learning disabilities.

The synthesis also challenges the exclusion of individuals with learning disabilities from discussions on future care planning. Past research noted their exclusion due to perceived lack of insight (Tuffrey-Wijne et al., 2013; Wiese et al., 2014). This synthesis highlights the depth of understanding in people with learning disabilities and advocates for their active involvement in open dialogues about ageing, aligning with government guidelines.

Given the impact of the attitudes a person has on health outcomes (as discussed in the first chapter), future research could delve into how people with learning disabilities perceive dementia. While there is existing research exploring the attitudes and perceptions people with learning disabilities have toward dementia, it is limited. The existing literature regarding how people with learning disabilities perceive dementia will be summarised below.

Limitations

The studies underwent critical appraisal using the Critical Appraisal Skills Programme checklist and were assessed against the four key validation criteria in qualitative research outlined by Whittemore, Chase, and Mandle (2001). These criteria include 1) credibility - ensuring accurate representation of voices; 2) authenticity - inclusion of diverse voices; 3) critical reflection on methodology; and 4) integrity - self-critical examination by researchers. The extent to which studies included in this review met the aforementioned criteria will be discussed and a table overview has been included in Appendix A.

In the majority of the studies, interviews were led by researchers (Kahlin et al., 2015; Newberry et al., 2015; Mee Kim et al., 2020; Kim et al., 2021; Trip et al., 2020). Researchers acknowledged the power differentials between them and participants, recognizing the potential for implicit coercion. While this concern was critically addressed in the limitations section of the papers, limited efforts were made to mitigate this issue, compromising the credibility of participant responses.

Certain studies employed triangulation in data collection methods (Kahlin et al., 2015; Kim et al., 2020; Trip et al., 2020). The use of photographs to enhance communication not only increased the quality of discussions but also allowed for the generation of thick descriptions of participants' perspectives. Lincoln and Guba (1985) have emphasized that thick descriptions enhance the credibility of qualitative studies, providing a richer understanding of the participants' viewpoints.

All participants in the studies lived in the community and had access to various services and support. As previously discussed, anxiety related to ageing often stems from experiences of disruption and loss (Kim et al., 2021). It is essential to question the potential differences in responses from participants lacking similar stability, thus limiting the generalisability and authenticity of these findings.

All papers included good critical reflection on the methodologies used, however, there was no inclusion of self-reflexivity and the impact this might have on the work. While it is not uncommon for qualitative researchers to reflect on their identity and the impact it may have on the work, it would have been useful for researchers of the included studies to share the impact of the intersection between their identities and the research. This would bring better awareness of the context in which findings were established.

The generalizability of this synthesis is constrained by exclusion criteria that omitted non-English studies. Investigating perceptions of ageing in non-English countries would be valuable, considering cultural differences in elder care. Although the author utilized tools such as the Critical Appraisal Skills Programme checklist for critical appraisal, the absence of co-researchers limits perspectives. Additionally, despite a rigorous search process, some relevant studies might have been overlooked.

Conclusion

This meta-synthesis investigates the attitudes people with learning disabilities have towards ageing. Contrary to societal beliefs, the findings indicate that individuals with learning disabilities possess nuanced attitudes towards ageing. They view ageing as a period involving intrusive and unsettling experiences, a journey with the other and an opportunity to experience the golden years. Recognising the attitudes people with learning disabilities have towards ageing is crucial, given the substantial influence that perceptions can have on health outcomes.

Rapid literature review: the attitudes people with learning disabilities have towards dementia

A rapid literature review serves as an expedited alternative to the systematic literature review (Smela et al., 2023). This was used to identify and summarise papers available relevant to the research question: 'what attitudes do people with learning disabilities have towards dementia?'

A rapid literature search of the following electronic databases was conducted: CINAHL, MEDLINE, APA PsycInfo and APA PsycArticles. The following search terms were used across the four databases using the option 'select a field' and the limiters 'Peer Reviewed' and 'English': [Experienc* OR perception* OR attitude* OR view* OR feeling* OR perspective*] AND ["Learning disab*" OR "intellectual* disab*" OR "mental* retard*" OR "learning difficult*" OR "special needs"] AND [Dementia OR demented OR "Alzheimer's disease" OR Alzheimer's OR "vascular dementia" OR "dementia with lewy bodies" OR "lewy bodied dementia" OR "mixed dementia"]. The inclusion and exclusion criteria for papers are outlined in Table 3.

Initially, 1,024 entries were identified across the four databases, reducing to 56 after articles marked as non-English and quantitative were removed. After title screening, 49 articles were excluded. Subsequently, 7 articles underwent full-text screening, with 4 exclusions due to incompatible methodology or aim. This resulted in the inclusion of three articles for rapid review. The PRISMA flowchart in Figure 2 outlines this process.

Table 3.

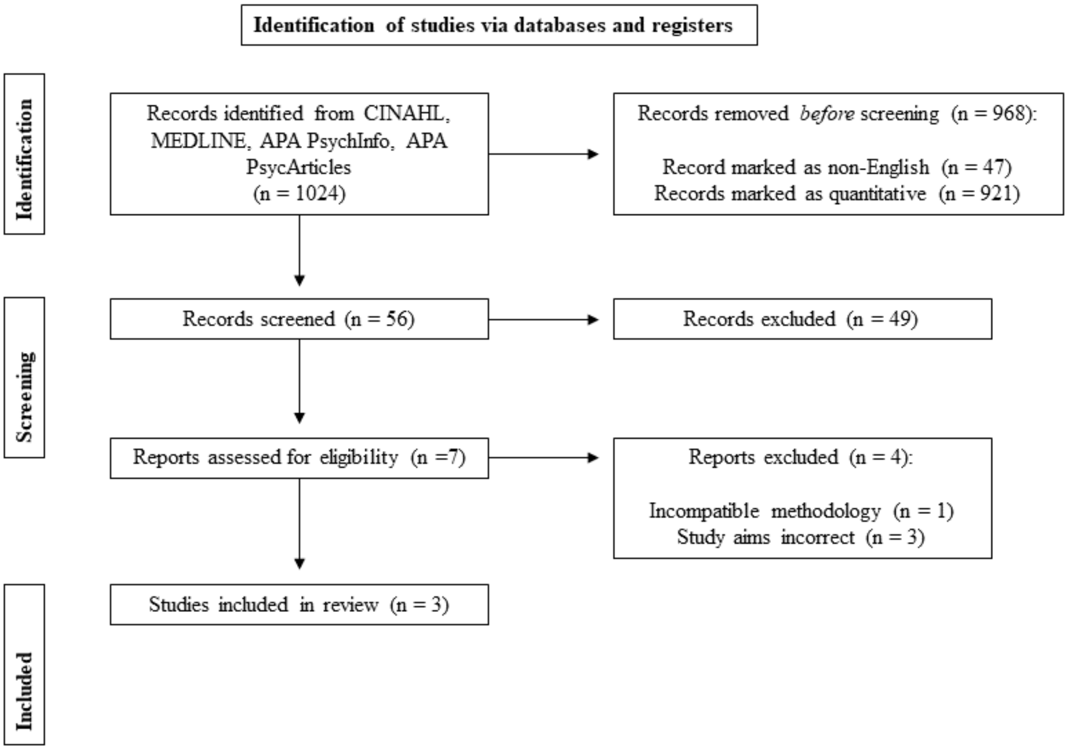
Inclusion and Exclusion Criteria for the Rapid Literature Review.

Inclusion Criteria	
Population	People with learning disabilities.
Main focus	Attitudes towards dementia from the perspective of people with learning disabilities.
Methodology	Qualitative.
Language	Papers published in English.

Exclusion Criteria	
Population	Samples including people without learning disabilities.
Main focus	Studies reporting the experience of dementia in learning disability populations.
Methodology	Quantitative research.
	Papers not subject to peer-review.
Language	Studies that were not published in English.

Figure 2.

PRISMA Flowchart for the Rapid Literature Review.



A total of three papers met the above criteria (Lloyd et al., 2007; Forbat and Wilkinson, 2008; Watchman et al., 2020). All papers were critically appraised using the CASP checklist and all were deemed to be of good quality. A table overview of the extent to which studies met this criteria has been included in Appendix B. Themes from the papers relevant to the research question: ‘what attitudes do people with a learning disability have towards dementia?’ are presented in Table 4.

Table 4.

Overview of Studies and Relevant themes.

Study	Participant details and country of origin	Study aim/purpose	Findings
Lloyd et al., 2007	Six individuals with learning disabilities between the ages 49-59. UK.	To investigate the perspectives and subjective experiences of six individuals with both Down’s syndrome and dementia.	Many of the themes were related to the person's experience of dementia however, the study also illustrated the attitudes people with Down's syndrome have towards dementia. They shared understandings of dementia as a process whereby individuals experience a decline in memory, functioning and activities. They also saw it as a time where they are unable to do what they want and showed nostalgia for a time where they had more independence. Some participants perceived dementia to be linked to death.
Forbat and Wilkinson, 2008	Eight individuals with a learning disability who have lived with someone diagnosed with dementia or are diagnosed with dementia. Two participants had a diagnosis of dementia.	To explore best practice in providing support to people with learning disabilities and dementia in their homes. To do so, research exploring how people with a learning disability understand dementia was undertaken.	Participants shared their understanding of dementia. This included it being perceived as a time of confusion, forgetfulness, wandering, compromised health and safety, an experience shared between the patient and their support system and as a condition that affords the person with dementia 'special privileges'. While participants held mostly negative attitudes towards dementia, some examples of 'special privileges' were offered allowing people to live well with dementia.

Watchman et al., 2020	Five individuals with learning disabilities were recruited as co-researchers.	To record the narratives individual with learning disabilities have about dementia through photovoice methodology.	Dementia was viewed as an experience where people experience a decline to memory, changes to behaviour and uncertainty due to these changes. This meant people perceived dementia as a threat. They noted dementia requires care from friends, family and support staff. They shared concerns that if someone has dementia, they must be supported in residential care.

Findings

Across the three studies, participants perceived dementia to be a process in which people experience a decline to their cognition characterised by memory loss (Lloyd et al., 2007; Forbat and Wilkinson, 2008; Watchman et al., 2020). They reflected on the impact this has on an individual's functioning and thus ability to engage in activities. Overall participants had negative attitudes towards dementia and saw it as a threat (Watchman, et al., 2020).

Participants acknowledged that dementia brings a reduction to independence due to the increased support people with dementia require. They also noted that the increased need for support amplifies the importance of connection with friends and families and the positive experience of 'special privileges'. For example, participants noted that people with dementia have more choice when choosing where to sit in the dining room (Forbat and Wilkinson, 2008), however it was also noted in this study that it seemed participants did not realise that this was due to sensory needs rather than favouritism.

The studies highlight that generally, people with a learning disability have negative attitudes towards dementia (Lloyd et al., 2007; Forbat and Wilkinson, 2008; Watchman et al., 2020). There was minimal discussion on how one might live well with dementia and many participants correlated dementia with death and dying (Lloyd et al., 2007). The fear of dementia that participants experienced seemed to be connected with the unpredictable nature of dementia. It is possible that people with learning disabilities might hold less fear-based attitudes towards dementia if they understood dementia to a greater extent.

This rapid literature search highlights the ways in which people with learning disabilities can engage in research about dementia and the need for more research in this area. Therefore, this study aims to explore the following: 1) people with learning disabilities' understanding of dementia, 2) their capacity to engage in discussions relating to dementia, 3) their perceived dis/advantages of being told the diagnosis of dementia and 4) discuss their preferences for future care planning in the context of dementia.

Chapter Three: Methods

Chapter Overview

This chapter will share a detailed account of how the study was conducted. It will start by outlining the rationale for the chosen qualitative methodology, paying special attention to the philosophical underpinnings of the study. It will then explore the ethical considerations. Following this, the chapter outlines the procedure for the study, including the recruitment of participants and chosen method of analysis. Finally, the chapter discusses avenues for the dissemination of the findings.

Epistemological positioning and justification of methodology

Academics have long engaged in discussions related to the utilisation of qualitative and quantitative methodologies. The debate here is based in the fundamental differences in the epistemological and ontological position of each approach (Braun and Clarke, 2013). The positivist philosophy that underlies quantitative methodology emphasises objectivity, assuming that knowledge is acquired through experimental methods to identify consistent relationships between variables and establish causality (Haig, 2014). Quantitative research typically addresses questions related to 'what', 'where', and 'when'. Historically, quantitative methodologies have received more favourable opinion in social sciences in comparison to qualitative methodologies (Millsap and Maydeu-Ovlivares, 2009). This perpetuates the longstanding assumption that quantitative approaches offer greater rigour, robustness, and legitimacy, with statistics allowing replicability and generalisability (Boutillier et al., 2001).

Despite this, qualitative research allows a methodological framework for exploring subjective, in-depth, and personal experiences, an area where quantitative methods fall short (Braun and Clarke, 2013). In comparison to quantitative methodologies, interpretivist philosophy underpinning qualitative methodology challenges ideas of an objective reality that can be understood, positing that instead researchers should aim to understand the various social constructions of meaning and knowledge of phenomenon (Willig and Rogers, 2017).

Both qualitative and quantitative research is moulded by the underlying beliefs and assumptions concerning the development of knowledge. This is conceptualised as ontology, which pertains to the nature of reality, and epistemology, which concerns the nature of human knowledge (Ritchie et al., 2014). These two aspects are depicted on a continuum with opposing ends: positivism and interpretivism. To have a cohesive and uniform methodology and procedure the researcher should identify their own ontological and epistemological stances (Braun and Clarke, 2013. Pg. 26). As such, parts of this section are presented in the first person.

I posit the existence of an objective reality, recognising that it has been shaped by "psychological, social, historical and cultural factors" (Ritchie et al., Pg. 13). As such, regarding my ontological standpoint, I position myself midway along the continuum, adopting a critical realist stance. In the context of this study, it is crucial to adopt a realist perspective on dementia, acknowledging the tangible nature of the atypical deterioration seen in the brain. However, it is also important to recognise that individuals may perceive and interpret dementia differently based on their own experiences. I am also mindful of the inherent subjectivity in qualitative research, understanding that my personal beliefs will influence the interpretation of the data.

Aligning with my ontological standpoint, I place myself in the middle of the epistemological spectrum. I embrace a perspective situated in contextualised constructionism, asserting that all knowledge is contingent upon context (Ritchie et al., 2014). This perspective suggests that a single phenomenon might have multiple meanings, which resonates with the focus of the current study – investigating the range of perspectives from various individuals with learning disabilities regarding dementia. To explore the participants views and experiences, and to provide insightful recommendations for clinicians and guidance, the study employed a qualitative methodology.

Consultation from an expert by experience

In the last 30 years, governments have emphasised the need to include service users in the planning and delivery of healthcare services. This includes the involvement of service users, (also referred to as ‘experts by experience’ if not accessing a service) in research preceding service development (House of Commons Health Committee, 2007; Omeni et al., 2014). The National Institute of Health Research provides recommendations on the various levels at which experts by experience may be involved in research: for example, devising questions, research design and dissemination of research (NIHR, 2021). Through their experiential expertise, it is believed that engagement of experts by experience enhances the quality of the research by reinforcing connections between practice and research (Pandya-Wood et al., 2017). Subsequently, this highlights areas of research that would benefit service users the most (Hewlett et al., 2006; Staniszewska et al., 2007) and increases validity of the study as experts by experience have been observed to correct researchers when misinterpreted (Savage et al., 2006; Blackburn et al., 2018).

Recognising the lack of attention given to the views of individuals with learning disabilities and the researcher’s epistemological position, it was deemed crucial to include experts by experience in the development of the research. The researcher met with a Mencap Research Champion to collaborate on the creation of the interview schedule. The Mencap Research Champion is a person with a learning disability who has learnt research skills and methods to support involvement in research projects (Mencap, 2024). The Research Champion reviewed initial research questions and provided feedback. This included the addition of prompts when asking participants about the ageing process and reminding participants consistently that they were not diagnosed with dementia to reduce anxiety.

The researcher also consulted with a professional with extensive experience in the field of learning disability care and research. The researcher met with a Clinical Psychologist who has led pioneering qualitative and quantitative research in the field of dementia and learning disabilities. In this consultation, the researcher explored barriers the senior clinician had experienced during research with people with learning disabilities especially regarding the ethics procedure. The senior clinician advised that recruiting younger participants would be most ethically sound as they were at less risk of dementia due to their age. The researcher of the current study also sought feedback regarding the creation of previous psychoeducational material in which the senior clinician emphasised the benefits of using pictures and storytelling.

Research environment

The present study took place in a community day centre for adults with learning disabilities in the East of England. Specific details of the day centre are withheld to protect anonymity. This service offers day services to adults with learning disabilities and related needs. Emphasising healthy lifestyle and community inclusion, the programme provides a diverse range of activities for more than one hundred individuals daily. In line with their mission of community inclusion for people with learning disabilities, they frequently participate in research projects.

Ethics

In 2021, the British Psychological Society updated their code of human research ethics which set out “to help psychology researchers to engage actively in identifying, analysing and addressing the range of ethics issues that are pertinent for their particular projects.” (BPS, 2021. P. 4). The current study was conducted in line with the guidance outlined in this document.

Valid consent and informing participants

As stated in the BPS guidelines (2021), prospective participants should have substantial information to make an informed decision regarding their consent for participation in a study. This information should be presented in a format that meets the accessibility requirements of the individuals and therefore making it understandable for them. To meet this requirement, participants were provided with a detailed participant information sheet (Appendix C). The information sheet outlined the purpose of the research, what would be required of the individual if they were to participate, how their data would be stored and used and their right to withdraw at any point. The BPS code states that "Psychologists should ensure that participants from vulnerable populations where understanding [may] be more difficult are given ample opportunity to understand the nature, purpose and anticipated outcomes of any research participation, so that they may give consent to the extent that their capabilities allow." (BPS, 2021. P. 15). As such, participants were given the easy-read information sheet prior to the first meeting with the researcher and again prior to signing the consent form. They were supported by day centre staff to read the information sheet. The researcher also asked the prospective participant if the information sheet required any clarification or if they had any questions about the research. The researcher ensured that all queries were answered and verbalised the main points in the participant information sheet to ensure the participant could make an informed decision.

After participants had provided verbal confirmation of comprehension of the information sheet, they were asked to complete a consent to take part form (Appendix D). Informed consent was constantly reviewed and participants were asked to confirm their consent at each phase of the study. This included verbal confirmation once the audio recording started has and a reminder of their right to withdraw at any time. The researcher was also attuned to verbal and physical cues which might suggest the participant felt uncomfortable in the interview. If the researcher observed anxiety, apprehension or distress in the participant, the researcher would ask the participant if they were okay and whether they wanted to continue.

Risk

The BPS code (2021) states that identification and assessment of all possible risks and the development of protocols to manage these risks are important steps in the research process. It also notes that research with vulnerable groups such as those lacking mental capacity or individuals in a dependent relationship would be considered as involving more than minimal risk. While all participants in this study were deemed to have mental capacity to consent to participate in research, a common experience in the learning disability population is reduced mental capacity to make major decisions (Foundation for People with Learning Disabilities, 2024). As such, extra care was taken when assessing risk of the research study.

As qualitative research is interested in the experiences of participants, there was a risk that the research topic would provoke distress in participants. As dementia is a neurodegenerative disease, there were concerns that this would increase anxiety in participants of the study. The researcher was also mindful that the participants may have family or friends with dementia. To mitigate this, staff who had knowledge of the potential participants were involved in the recruitment process and participants were invited to reflect on their wellbeing after each interview to monitor any distress. Throughout the data collection period, it was agreed that the researcher would notify a member of staff at the day centre if a participant became distressed. There was also the option for the researcher to gain the consent of participants to refer them to the local community learning disability services for additional support if this was needed.

Although participants in the study did not display signs of distress, one participant disclosed that they were experiencing low mood and agitation. In this case, the interview was terminated and the member of staff present in the interview provided the individual with support and notified the individual's key workers.

Ethical approval

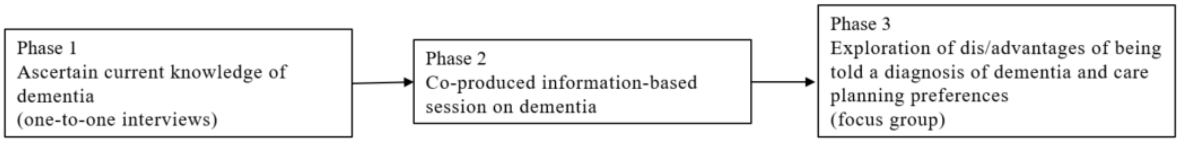
Ethical approval was sought from the University of Essex and due to the participation of individuals with learning disabilities, the research was subject to sub-committee approval from the Arts and Humanities research institute at the University. The ethical approval number from the University of Essex Ethics Committee was ETH2122-1218 (Appendix E). Following this, the researcher sought approval to undertake the study from the day centre manager and commissioners (Appendix F). The day centre and commissioning group did not have their own ethical approval processes and were satisfied by the decision of the University of Essex's ethical panel.

Materials

Study overview

To aid understanding of the following section, a brief overview of the study procedure will be provided. The study was divided into three phases. This three phase process is depicted in figure 3 and each phase of the study will be described in depth later in this chapter. Phase one was created to support the production of resources for phase two (information-based session about dementia). Participation in phase two ensured that participants had sufficient knowledge about dementia to engage in the focus group (phase three) which explored preferences relating to the diagnosis and care planning processes. All three phases were completed at the day service to reduce attrition.

Figure 3.
Three Phase Study Approach.



Interview and focus group topic guides

Given the critical realist position of the research and the sample of participants, one-to-one interviews and focus groups were used. Semi-structured interviews are an approach in which the researcher prepares an interview guide prior to the interview but does not strictly adhere to it. Instead the researcher is permitted to deviate from the precise wording of the question stated in the interview guide and may change the order in which questions are asked (Braun and Clarke, 2013). This enables rich narratives and contextual information to emerge which would not typically be possible when using standardised interview formats (Willig and Rogers, 2017). One-to-one semi-structured interviews allowed the researcher to build rapport and trust with the participant in phase one of the study. Nind (2008) suggests that by doing so, people with a learning disability will feel more confident to share their experiences and opinions. Ritchie et al., (2014) also proposes that good rapport between the researcher and participants leads to high quality qualitative research. They also suggest that “A good working relationship is achieved where the researcher seeks to put the participant at ease and to create a climate of trust” (Ritchie et al., 2014. Pg. 143.). Due to this, the researcher of the current study utilised one-to-one interviews to facilitate this in phase one of the research.

Focus groups are a group discussion in which participants share their own perspectives but also listen to the perspectives of others. They “listen, reflect on what is said and in the light of this consider their own standpoint further” (Ritchie et al., 2014. P. 215). As such, the discussion grows from the responses heard. Focus groups were utilised in phase three as they have been found to increase the depth of information produced in research with people with learning disabilities due to the collective voice that emerges (Bollard, 2003). This was pertinent for phase three of the study due to the complex matter of dementia that participants discussed. Both semi-structured interviews and focus groups have proven effective in prior studies involving people with learning disabilities (Hoole and Morgan., 2011; Lewis et al., 2016; Skelly et al., 2021; Scherer et al., 2023).

To facilitate this, topic guides for the one-to-one interviews and focus groups were created and can be found in Appendix G. Considering the recommendations from the expert by experience and relevant literature on interviewing adults with learning disabilities, the first part of each topic guide offered participants a foundation for the rest of the discussion. For the one-to-one interviews, this involved asking the participants about their understanding of growing old and their awareness of dementia. This included prompts encouraging participants to think about various aspects of a person's lived experience such as, physicality, mentality and relationships. Following this, the interview delved into more specific questions about the difference between ageing without dementia and ageing with dementia. The one-to-one interviews concluded with a debrief, in which the researcher assessed the participant's wellbeing and explained that they would meet again for phase two and three of the study.

For the focus groups, the topic guide involved asking participants about their understanding of ageing and dementia again to ascertain their understanding of information shared in phase two. Following this, the interview explored participants' preferences in the diagnostic process and care planning for people with learning disabilities and dementia. To encourage shared discussion, the researcher would ask specific participants for their views if they had not engaged in the discussion for some time. The focus group ended in a debrief where the research again assessed the participant's wellbeing and invited participants to join a learning session on lifestyle changes that reduce the risk of dementia.

Previous research examining understandings of dementia in non-learning disability populations highlighted areas of interest that should be included in the schedule (Cowan, 2021; Zhao et al., 2021; Thelu et al., 2022). A common measure used in historical literature was the Dementia Attitudes Scale (O'Connor and McFadden, 2010) which the researcher of the current study used to identify areas to explore with participants when discussing understandings of dementia. The researcher also reviewed the literature related to service user involvement in service development and care related decision-making within the learning disability population (Hoole and Morgan, 2010 and Webb et al., 2020) to inform the schedule. Furthermore, the researcher reviewed the BPS and RCP guidance for people with intellectual disabilities and dementia (2015) to identify aspects of the dementia care-planning process for participants of the current study to share their opinions on.

Recruitment

Inclusion and exclusion criteria

Individuals qualified to participate in the current study if they met the following criteria. Eligible participants had to be service users of the day service and thus registered as having a learning disability. The age requirement was 18 and above, with no upper age limit. Additionally, participants needed to be capable of engageing in the interviews and focus groups. As such, participants were required to be able to express themselves verbally and comprehend the information discussed in both the one-to-one interviews and focus groups. To determine these capabilities, the researcher relied on the experience of day centre staff and their knowledge of each potential participant.

Participants were also required to have capacity to consent to participate in the study. This was guided by the day service's knowledge of the individual prior to asking the individual if they wanted to participate in the study. It was also guided by the individual's understanding of the participant information sheet. The researcher used their clinical experience to apply principles from the Mental Capacity Act (MCA, 2005) to assess whether an individual had capacity to consent to participate. This act suggests that we should assume a person has capacity unless proven otherwise.

Individuals with a diagnosis of dementia were excluded from participating in the present study as well as those whose mental health was of concern. This was to safeguard the wellbeing of participants as the researcher acknowledged that discussion of dementia may lead participants to become distressed, especially in the context of lived experience of dementia.

Sampling

Participants were recruited from a day centre in the East of England. Voluntary response sampling was employed for participant recruitment following gatekeeper permission. The day service staff had a shared gatekeeper role, in this they supported the recruitment of appropriate participants. The researcher met with the day service manager to discuss the study to highlight the social value of the study which Denny et al., (2015) found to be important in gaining the support of gatekeepers in research.

The researcher aimed to recruit between 12-15 participants as this is deemed a large enough sample for saturation in qualitative research (Hennick and Kaiser, 2022). Saturation in qualitative research can be observed when consistent themes are noticed between participants during interviews or focus groups (Ritchie et al., 2014).

Procedure

Recruitment

The University of Essex has a longstanding working relationship with the day service contributing to the Doctorate in Clinical Psychology Learning Disability module. The academic supervisor facilitated initial contact between the researcher and the day service manager. The researcher shared a copy of the study leaflet (Appendix H) with the service manager to share with prospective participants and for this to be displayed on the day centre notice board. Following this, the researcher attended the day centre to meet with the day service manager and some of the potential participants to answer questions about the study. The service manager then shared the participant information sheet with the participants prior to phase one of the study.

Phases one to three

As mentioned earlier in the chapter, the study was divided into three phases and each phase will be described in depth below. All three phases were completed at the day service to reduce attrition.

Phase One. Phase one was used to explore the current knowledge each participant had of dementia. A one-to-one semi-structured interview was used to elicit the participant's current understanding of dementia. This was audio recorded and then analysed using reflexive thematic analysis.

The information provided at this stage informed the information-based session about dementia in phase two. For example, the researcher noted how the participants often compared people with dementia to those without to construct a narrative around experiences often seen in people with dementia. The researcher also observed that participants often employed storytelling to share their observations of people with dementia. As such, the research used a narrative approach when creating the resources for the information-based session on dementia.

Phase Two. Phase two was an information-based session about dementia created from co-produced material gathered in phase one. To allow adequate time for any questions to be answered, participants were placed into two groups. Phase two was implemented to ensure all participants had a clear understanding of what dementia is. Without this, some members would have found it challenging to engage in the group discussion that occurs in the phase three focus group.

The phase one interviews allowed the researcher to understand the level of comprehension individuals had about dementia and thus guided what the researcher included in the educational session. While the information-based session was largely based on the discussions had in phase one, material was also adapted from pre-existing resources such as Jenny’s Diary (Watchman, 2015) and About my Friend (Dodd, Turk and Christmas, 2005). These resources were referred to due to their prominent use in learning disability services as a psychoeducational tool about dementia for people with dementia. In the information-based session, the following topics were covered: What happens when we age? What happens when someone gets dementia? How does memory ability impact the support a person requires? This information was presented in a story to mirror the dialogue used by participants in phase one, resources created by Watchman (2015) and Dodd, Turk and Christmas (2005) and advice from the senior clinician the researcher consulted with prior to the study.

The story included two characters, a person ageing without dementia and a person ageing with dementia. This reflected the conceptualisation of dementia demonstrated by individuals who had pre-existing knowledge of dementia. In phase one, these individuals held dichotomous views regarding the experiences of people ageing with versus without dementia. The resource shares a narrative of how a person with dementia might navigate activities of daily living and then compares this to how one might engage with the same activities without dementia. The resource highlights that with dementia, an individual will experience significant changes to functioning. This is compared with the smaller changes to functioning seen in those ageing without dementia. The resource then explores what support each character might need to engage in daily activities. The resource can be found in Appendix I. To ensure participants understood the content, the researcher presented the story to participants, paused frequently to assess understanding and offered clarification.

Phase Three. In phase three, the participants remained in their two groups and participated in a focus group interview. This was audio recorded and then transcribed for analysis. The topic guide referred to in the materials section was used to explore the perceived dis/advantages of being told a diagnosis of dementia. The group then discussed what they thought the process of diagnosis disclosure and care planning in the context of dementia should include.

Data analysis

Transcription

The interviews were recorded on a Dictaphone were transferred to the researcher’s computer and subjected to encryption. Due to time constraints, the researcher utilised a transcription service to support with transcribing. The transcription process followed an orthographic approach, capturing spoken words and features such as laughter and pauses. Minimal punctuation was used to replicate the language spoken. To ensure the researcher did not omit the familiarisation phase of the six phased approach to reflexive thematic analysis (Braun and Clarke, 2006), the researcher listened to the audio recordings while reading the transcripts. This also ensured all transcripts were true to the recordings. Following transcription, the next step involved anonymising the transcripts by assigning researcher-selected pseudonyms, and any identifiable information was either redacted or completely removed. The finalised transcripts were then imported into Microsoft Word for further analysis.

Qualitative data analysis

Various analytic methods aim to reveal patterns and themes within qualitative data, such as grounded theory (GT) or interpretative phenomenological analysis (IPA). However, both GT and IPA are constrained by theoretical frameworks. IPA aligns with a phenomenological epistemology, focusing on understanding individuals' everyday subjective experiences to understand the phenomenon under study (Braun and Clarke, 2013). This method was deemed less suitable for the current study due to its highly interpretative nature and the focus on individual participant characteristics *and* patterns of meanings across participants (Willig and Rogers, 2017). Given the absence of existing literature on understandings of dementia from the perspective of people with learning disabilities, the researcher thought that at this stage it would be more appropriate to obtain a larger sample and concentrate on commonalities across participants.

While GT exists in various forms (Willig and Rogers, 2017), the objective of the analysis is to systematically explore research data to generate a plausible and useful theory of the phenomenon (Braun and Clarke, 2013). GT seeks to identify and provide a detailed account of contextualized social processes; in the context of this study, it would aim to develop a theory about the underpinnings of understandings of dementia in the learning disability population. As such, GT’s focus generation does not align with the study’s aims.

Thematic analysis

Thematic Analysis (TA) is a widely used concept, tool, process, method, or approach for examining qualitative data. Despite its widespread use, it is frequently inadequately defined and performed (Braun and Clarke, 2022). Unlike GT and IPA, TA lacks attachment to a specific theoretical framework or epistemological position, making it applicable to various theoretical approaches, including critical realism (Braun and Clarke, 2022). TA is a method “for developing, analysing and interpreting patterns across a qualitative dataset” (Braun and Clarke, 2022. P. 4).

In alignment with the philosophical position of this study, TA maintains consistency between its epistemology, methodology, methods, and data analysis (Crotty, 1998). This study, with its focus on meaning, depth and the complex understandings of dementia from the perspective of people with learning disabilities, found TA to be a robust analytic tool. Following an inductive, semantic, and critical realist approach to TA, as suggested by Braun and Clarke (2006), the analysis remained data-driven. The semantic approach involved identifying themes from the explicit meanings of the data, contrasting with latent-level analyses that delve into underlying concepts influencing what people verbalise. For the current study, analysis used a semantic approach as researchers have been directed to this approach when exploring an under-researched topic (Braun and Clarke, 2006).

Braun and Clarke (2022) propose that there are three types of thematic analysis: Coding Reliability, Codebook and Reflexive. These methodologies can be situated along a spectrum, ranging from coding reliability at one end to reflexive approaches at the other. Coding reliability thematic analysis is considered a ‘small q’ qualitative analysis where the researcher uses a qualitative method with a positivist position, valuing reliability and replicability (Braun and Clarke, 2022). In reflexive thematic analysis, the researcher assumes an active role, engaging reflectively and reflexively with the data and analysis (Braun and Clarke, 2013) and strongly adheres to qualitative research values.

Considering these factors, reflexive thematic analysis was deemed suitable for the current research, consistent with the critical realist standpoint. This method permits the generation of themes from the data, enabling a nuanced comprehension of the perceptions of dementia among adults with learning disabilities.

An inductive reflexive thematic analysis was conducted, informed by Braun and Clarke's (2006) six-stage process:

1. Familiarisation with the data and dataset. This involved reading and re-reading each interview transcript whilst listening to the recordings. The researcher made notes on each transcript to facilitate familiarisation of the transcripts. The researcher also reflected on their own responses to the data and their biases which may impact the interpretation of the data.
2. Coding. The researcher coded at the semantic and latent levels of meaning. To do so, the researcher highlighted segments of data relevant to the research question and applied code labels to them using the ‘add comment’ function in Word. To ensure equality in coding the researcher dedicated the same amount of time to coding each transcript. The code labels were then collated in an Excel spreadsheet.
3. Generating initial themes. This involved the grouping of similar codes into themes. Each theme had a key central organising concept, capturing shared patterns of meaning to address the research question. To do so, the researcher grouped codes into their respective candidate themes on another sheet in the Excel spreadsheet.
4. Developing and reviewing themes. To assess the fit of themes to the overall dataset and thus validity of the analysis, the researcher reflected on whether themes made sense in relation to the coded extracts and then the full dataset. In response to this assessment, the researcher merged themes together or removed themes where necessary. Following this, the themes were finalised.

5. Refining, defining, and naming themes. The researcher attempted to fine-tune the analysis through reflection on whether themes were centred around clear concepts and had a strong meaningful narrative promoting understanding of the research question. The researcher found this to be an evolving process which took place even during the write up process. To do so, the researcher triangulated information from their reflective log with the transcripts. An example of the reflective log can be found in Appendix J.
6. Writing up. The write up was informed by discussions within thesis supervision and reviews of draft versions of the results. To validate accuracy of themes, the researcher brought themes and relevant quotes to supervision. Supervisors then supported the researcher to finalise themes based on their ability to capture the meaning of the data set.

Evaluating the quality of research

The researcher aimed to conduct high quality research and utilised Yardley's (2000) criteria for the assessment of qualitative research in the healthcare field:

1. Sensitivity to context: This encompasses being attuned to and comprehending the existing research literature within the topic area, as well as the socio-cultural context surrounding the research.
2. Commitment and rigour: This fosters a commitment to actively engage with the subject, proficiency in research techniques, and thorough immersion in the study's data. Rigour pertains to comprehensive data collection and analysis.
3. Coherence and transparency: Coherence relates to the alignment with the research question and the philosophical framework and methodology employed. Transparency entails providing detailed information to enable replication of the study, along with acknowledging the researcher's own impact on the research process.

4. Impact and importance: This is in relation to the impact and utility of the research in academia and in practice on a clinical and policy level.

An evaluation of the research in relation to these criteria is discussed in Chapter Four.

Storing and protecting the data

Confidentiality involves safeguarding the privacy of the participant and their information, while anonymity ensures that any identifiable information is removed or replaced to guarantee the participants cannot be identified. Consent forms and demographic information were scanned and stored as password-protected documents on the researcher's computer.

Interview recordings were transferred to a personal computer and encrypted. Participants were informed that the interviews would be audio recorded, and the recordings would be deleted afterward. Transcriptions were done promptly, and all identifiable information was removed. Once anonymized, the transcripts were securely stored for analysis on the researcher's laptop. The transcripts will be deleted from the researcher's personal computer once the study is complete. All data from the research project will be stored by the University of Essex until the study is complete, after this the data will be destroyed. The study's confidentiality and anonymity procedures adhere to the requirements of the General Data Protection Regulations (EU) (GDPR) from the Data Protection Act 2018 (DPA, 2018).

Dissemination

This thesis will be accessible via the University of Essex online library following the completion of the Doctorate in Clinical Psychology. The researcher will also present the findings of the study at the day centre for the participants and staff. This accessible presentation will also be shared with the Growing Old with a Learning Disability group to circulate to members of the public who have a learning disability. The researcher intends to submit the research for publication to journals such as: the British Journal of Learning Disabilities, Advances in Mental Health and Learning Disabilities, Tizard Learning Disability Review, Ageing and Mental Health or the International Journal of Geriatric Psychiatry. Additionally, a poster and/or presentation will be submitted for consideration at one of the following conferences: Faculty for People with Intellectual Disabilities Annual Conference (BPS), Annual International Academy for Research in Learning Disabilities conference and British Institute of Learning Disabilities (BILD) conference.

Chapter Four: Results

Chapter Overview

This chapter will present the findings of the study. First, a description of the study sample will be provided to contextualise the results. The results from phase one will then be shared, followed by the results from phase three of the study.

Study Sample

The study participants' ages ranged from 23-67 years old with a mean age of 42 years. There were eight females and seven males. One participant stated they were of mixed heritage (Brazilian/Russian) and another participant was of South African heritage. The remaining 13 participants were White British. Table 5 can be used to aid understanding of the sample.

Participant Pseudonym	**Gender**	**Age**	**Phase completed**
Lauren	Female	31	1,2,3
Kelly	Female	50	1,2,3
Sarah	Female	26	1
George	Male	28	1,2,3
Richard	Male	50	1
Lucy	Female	54	1,2,3
Charlotte	Female	52	1
Lizzie	Female	30	1,2,3
Andrea	Female	67	1
Will	Male	37	1,2,3
Aaron	Male	48	1,2,3
John	Male	23	1

Tim	Male	35	1,2,3
Brenda	Female	23	1,2,3
Brian	Male	49	1,2,3

As shown in the above table, five participants did not complete phase two and three of the study. The main reason for this was due to them being absent on the day of these phases. One participant was excluded from phases two and three due to a disclosure they made in phase one. This was regarding their mental health and therefore they were withdrawn from the rest of the study in line with the inclusion criteria and ethics form. The exclusion from further participation in the study was explained to the participant by the researcher with the support of day centre staff. The participant understood the rationale for this and was agreeable to the plan.

Analysis of Phase One

Information gathered from the one-to-one interviews were used to inform the psychoeducation included in phase two. The one-to-one interviews also yielded themes and subthemes relevant to the study aims and are shown in Table 6 and 7. Themes were developed using thematic analysis (Braun and Clark, 2006).

In phase one, nine out of the 15 participants reported that they knew what dementia was. As such, this organically divided the cohort into two groups – those who were aware of dementia as a concept versus those who did not. All of the respondents who recognised the term dementia reported that they knew someone with dementia, either a resident living in their shared accommodation, friends or family. During the coding phase of analysis, there was a difference between how the two groups understood normal ageing. Those who were knowledgeable about dementia had a nuanced understanding of typical ageing processes in addition to an understanding of what dementia is.

Due to this distinction between the two groups, themes can be best understood when sorted under headings - ‘Participants without knowledge of dementia’ and ‘Participants with knowledge of dementia’. As individuals with learning disabilities are likely to present with communication difficulties, the participants of this study often answered questions in short sentences. This meant that the researcher had to combine their responses to illustrate a point. Due to this, some themes will be supported by multiple short quotes from various participants.

Table 6.

Phase One Themes from Participants Without Knowledge of Dementia.

Theme	Subtheme
The older you get, the more you lose, the more you need.	To lose To be cared for

Theme One: The Older You Get, the More You Lose, the More You Need

Participants with a learning disability who were not aware of dementia strongly attributed two experiences to the typical ageing process (without dementia) – loss and being cared for. Described in the first subtheme, *to lose*, participants explained that ageing is a process of loss whereby the ageing individual loses cognitive and physical abilities. They perceive these losses to be catastrophic and seemed to be implicitly associated with symptoms of dementia. Due to this, the ageing individual requires increased levels of support which participants discuss in the second subtheme. Participants reflected on the various levels of care an individual might need as they age and this is outlined in the subtheme *to be cared for*.

To lose. All participants attributed loss to the typical ageing process and spent a significant amount of time discussing the memory loss that they expect an ageing individual to experience. Participants discussed how an older adult may forget information required to complete mundane tasks. Andrea explained that “[older people] forget to see what they’ve got in the freezer when they do shopping. Home number, phones numbers. And her shopping list”. There was also a sense that older adults lacked insight into their memory difficulties with one participant stating that “They lose their memory... they repeat themselves over and over again.” (Charlotte).

Participants described how the loss of memories would impact on the individual’s ability to orientate themselves to the present. There was a narrative that difficulties in remembering recent events would lead individuals to return to memories of the past. One participant shared this point by stating that “They might repeat themselves or go back in time” (Brian).

The level of memory loss described by participants is not in line with the actuality of what would be observed in the typical healthy ageing population. It seems that participants who were unknowledgeable about dementia were implicitly associating symptoms of dementia with typical ageing leading them to hold skewed attitudes about ageing.

There were coherent ideas across the group of the appearance ageing adults. Many referred to the changes that would be seen to the skin and hair, providing examples such as, “They lose [their] hair, it falls out...skin goes brittle” (Brian). The descriptions suggested that the ageing adult loses their youthful appearance and suggests that there is a universal experience of physical deterioration over time.

Participants also suggested that the body of an aged person is one that is frail and at high risk of illness. One participant stated that “their body, it shuts down” (Andrea). Due to the individual's perception of ageing as a process of deterioration, they noted that an ageing person would become weak, vulnerable to illness and experience reduced mobility. Participants explained that older adults, "they can't walk...they can't talk" (Lauren), and that "they need help lifting [the shopping]" (Charlotte). When asked "What happens when someone gets old?" Tim responded by saying "Generally being quite ill.".

The image of growing old that participants described was one of fragility and loss. This subtheme highlights the negative attitudes towards ageing that this group held and is encapsulated by this quote from Lauren "It must be hard though...getting old".

To be cared for. Participants thought widely about how these cognitive and physical losses would impact the ageing individual. They all shared the narrative of older adults requiring support and the majority explained that this support would come from staff. Andrea explained that "old people go to the nursing home... because to get- so people can look after them. Like staff". Similarly, Lauren stated that "old people go to a care home". It is important to note that during these discussions, respondents did not reflect on how the ageing individuals might continue to care for themselves in their own home with partial support. Participants held dichotomous views of the care available to older adults and while this could be related to polarized thinking seen in the learning disability population, it also speaks to the attitudes they may hold towards youth and older adulthood. It echoes how participants perceive older adulthood as negative and restrictive and thus youth as positive and freeing.

Other participants discussed how they thought older people required specific care for physical health needs. This emphasises the ideas posited in the first subtheme regarding participants' association of ageing with vulnerability to illness. Lauren explained that "the hospital looks after them to make them feel better from being poorly". The respondents in this group did not discuss the potential for independence in older age or the ability to age well. It seems that those in this group who were unknowledgeable about dementia held limited ideas about the ageing process.

Table 7.

Phase One Themes from Participants With Knowledge of Dementia.

Theme	Subtheme
Growing old, slow and steady.	Manageable loss
	Embracing rest
Dementia as total loss	Loss of functioning and control
	"It's like a prison...when they've got dementia"
	Loss of life worth living

Theme Two: Growing Old, Slow and Steady

Similar to the group of participants who were not knowledgeable about dementia, this group also acknowledged the losses an individual might experience as they age. However, participants discussed loss alongside adjustment and optimisation of activities which positioned older adults as competent in managing the losses. This is discussed in the subtheme *manageable loss*. Outlined in the second subtheme, the respondents reflected on how these losses would impact on an individual's pace of life. They shared that while life would become slower, this would be welcomed and that we might see older adults *embracing rest*.

Manageable loss. Many participants explained that ageing will impact a person's cognitive, physical, functional and relational capacity. All participants thought that older adults would experience memory loss with some respondents also acknowledging that significant memory loss may be a symptom of dementia: “Well sometimes it’s becoming a sign of dementia, for example. Yeah. But sometimes they can forget things.” (Lizzie).

When discussing memory loss, individuals in this group being knowledgeable about dementia, provided more nuanced understanding of how memory loss associated with typical ageing would impact an individual’s functioning. For example, Sarah highlighted that memory loss would change the way an older adult engages in conversation:

> “Because the first thing they can do is like talk, and then they're gonna stop halfway. And say what was I thinking? What was I saying? Like all that like, thinking about where they want to go and everything, and then they stopped and go- 'What was I thinking about? What, what was I doing?'”

Participants also acknowledged that changes would be seen in other areas of an ageing individual’s cognition. A common narrative in the group was that the ageing adult will experience a reduction in the speed at which they think, for example some participants stated that “It takes [older adults] a long time to think” (John) and that “They make decisions slowly” (Sarah).

While the participants held an understanding that cognition would change over time, they understood that the ageing individual will continue to hold the ability to engage in cognitive processes albeit at a reduced speed. Some participants compared this to people with dementia stating that “when compared to dementia [people ageing without dementia] can think more” (Lucy). This illustrates that amongst people with learning disabilities who were knowledgeable about dementia, there was a more nuanced understanding of the ageing process. They showed understanding that ageing would change an individual’s cognitive capacity but not eradicate it entirely and not to the extent of decline seen in dementia presentations.

Respondents also shared their expectations for the body to deteriorate in older age. However, different to the responses in the group unknowledgeable about dementia, the group here, also discussed ways an older adult might have to adjust in order to optimise their functioning. For instance, participants shared that ageing adults might use walking aids or seek help from those around them. Some participants explained that older adults need to shift their way of being rather than employing a singular adaptation to cope with age related deterioration. For example, a participant suggested that the ageing individual needs to be more cautious in their interactions with the environment to cope with frailty.

> “Walking ability goes, they can have walking frame or walking sticks” (Richard)
>
> “Things gets too heavy. Sometimes they can’t pick it up and they need the stronger person to do it sometimes” (Lucy)
>
> “Skin goes thin, the bones get brittle and you have to take more care” (Richard).

It was also noted that individuals with a lower severity of learning disability were better able to discuss ways to optimise and compensate for age related loss. This may indicate that level of learning disability also mediates the attitudes one holds towards the process.

Outside of the physical and cognitive losses that participants described, they also shared their insights into how ageing might lead to relational loss. Will explained that “people get anxious when they get old, it ruins [relationships], get frustrated”. It seemed that older age was associated with increased experience of mental distress which was then anticipated to impact relationships. Some participants thought there would be a difference between how ageing impacted romantic relationships and friendships. When asked about the impact of ageing on relationships Andrea stated, “[Romantic relationships] breakdown sometimes… but friendships are very good”. In this group, participants reflected that ageing is a process that impacts the individual but also those around them.

Embracing rest. Participants reflected on the impact of the aforementioned changes on the life of an ageing adult. The reduced cognitive, physical and relational abilities were associated with reduced engagement in activity. They noted that older age would bring a reduction in the number of activities one might engage in, however they seemed to hold an understanding that people in their older age would welcome this period of rest. For example, “They probably just retire or something or stay at home and spend time with family... If some people don’t have dementia they just um live an easy- live an easy life so yeah.” (Lucy)

Similar to Lucy’s response, others also held positive attitudes towards ageing if there was an absence of dementia. Richard explained that “without dementia, well they still do things” and Brenda shared that “normal ageing like for me because I haven’t got dementia, I’ll live a happy life and not be grouchy”. Through these statements, respondents illustrated their clear understanding of the distinction between dementia and ageing without dementia.

Theme Three: Dementia as Total Loss.

In this theme, participants described the ways they understood dementia. During the interviews, these participants answered affirmatively when asked if they knew what dementia was. For the majority, this knowledge came from an experience of a friend or a relative having dementia. Participants explained that a key aspect of dementia was *loss of functioning and control* due to a decline in cognition and physical deterioration. In the second subtheme *It’s like a prison...when they’ve got dementia*, respondents share their perspectives on how individuals with dementia become isolated due to difficulty in relating to others. After outlining the catastrophic losses associated with dementia, participants shared narratives regarding a ‘loss of life worth living’. In this subtheme, participants share their thoughts on how dementia impacts on one’s quality of life and their understanding of it as a terminal illness.

Loss of functioning and control. Participants discussed the various levels of memory loss, ranging from forgetting information about one’s identity to the ability to access prospective memory. They acknowledged that global memory loss due to dementia was different to the isolated instances of forgetfulness seen in older people without dementia. The main difference here is that the memory difficulties experienced by people with dementia had a direct effect on the individual’s sense of self.

> “When you forget things like your name, when you're born, where things are, partners name. Um what day it is, what's happening next week.”(Will)
>
> “They can’t remember who- who they are and don’t know what they’re doing and miss all sorts of things” (Richard)

Participants shared that for people with dementia, memory is impacted severely and that this will become a barrier to functioning and lead to a regression in the individual’s presentation. Richard explained that “Dementia is...deterioration in the brain can't remember. Taking things out, dirty clothes in the refrigerator. ...'cause they're almost like a kind of child like a child's memory like five year old”.

There was also a shared narrative regarding the lack of control individuals with dementia have over their bodies. Participants frequently referred to the incontinence experienced by people with dementia suggesting lack of control over their physical body. Sarah shared her observations of a friend with dementia and said “They can dance for a little while then they stopped because they couldn't- they can't help- because they need to go to the toilet...Like they wee- they wee themselves and they can't help it.”.

They also suggested that due to the significant cognitive decline that people with dementia experience, they will have difficulty in making decisions. In this case, participants suggested that “if they can’t make decisions for themselves, then it’s up to the family” (Lucy). This points to the reduced control individuals with dementia might have over their lives.

The functional loss described to be observed in people with dementia was strongly related to the changes in communication. Many participants noted that people with dementia will mumble or forget words. Respondents thought that due to this, communicating with others becomes difficult and their ability to access services reduces.

> “Can be slurred. It’s a bit like having a stroke but not not having a stroke” (Lizzie)
>
> “Because they can become really ill, and you wouldn't know, because they can't tell you.” (Lizzie)
>
> “You can't understand what they're trying to say.” (Lucy)

The reduced ability to communicate that people with dementia experience reinforces the loss of control as they can no longer communicate their desires.

“It’s like a prison...when they’ve got dementia”. Participants shared that people with dementia exhibit significant changes to their personality and that they engage in aggressive behaviours. Kelly explained that “they don’t smile at you” and Lizzie shared that people with dementia are a “bit argumentative. A bit blunt and sharp”.

The aggressive perception of people with dementia came from experiences participants had with people with dementia. Participants noted experiences of physical and verbal aggression.

> "They seem to shout when they walk around" (John)
>
> "She kept getting moody and saying 'get out the way'" (Tim)
>
> "Sometimes they can get violent" (Melissa)

Participants were unsure as to why people with dementia presented in this way and it is important to consider that uncertainty increases an individual's experience of threat.

Across the participants there was a sense that they did not want to be around people with dementia explaining that "they sort of lose touch" (Lizzie).

Other participants shared the expectation that people with dementia would be rejected by their support system. Some participants shared that individuals with dementia would experience breakdowns in their romantic relationships. Another shared idea was that following rejection from their support system, people with dementia would become lonely. It seemed to suggest that participants also held a view that individuals with dementia would not be able to create new connections with others.

> "He (referring to a friend with dementia) had a girlfriend but his girlfriend just didn't want him anymore, and it was a bit too hard for him. And he's a bit he was so sad and that was just horrible for him" (Sarah)
>
> "Being lonely. It's like if you have family around you and one of us had dementia another person would just turn around and walk out." (Lizzie)

There was a sense that due to the changes to personality and increased levels of perceived aggression, people with dementia become isolated with one participant stating "It's like a prison for people when they've got dementia" (Richard).

Loss of life worth living. Participants shared that due to the losses discussed in the earlier subthemes, they perceived the lives of people with dementia as lacking in quality. One participant explained that people with dementia “they have a miserable life” (Lauren) and another shared that “because [she hasn’t] got dementia, [she’ll] live a happy life” (Brenda). It is also important to reflect on the absence of reflection on the ability to live well with dementia and to continue with valued activities. The explicit quotes and implicit meanings gained from the lack of discussion around the possibility of living well with dementia illustrate how participants held strong negative attitudes towards dementia.

Individuals reflected on how people with dementia would ultimately lose their lives to the disease. Many of the participants demonstrated their understanding of dementia by acknowledging it as an incurable, terminal disease. Some participants explained that prior to dying, people with dementia spend a significant amount of time thinking about death.

> “Because it's like the end of life thing. Because with dementia is not curable. It's an illness that you can't cure. I know quite a lot of people had it. And I know a lot people that died of it as well.' (Lizzie)
>
> “They’re thinking about the end in the sky” (Kelly).

Summary of Findings from Phase One

Analysis of the one-to-one interviews in phase one generated a total of three themes which were best understood when organised under the two headings - “Participants without knowledge of dementia” and “Participants with knowledge of dementia”. Participants without knowledge of dementia described ageing as a process in which individuals experience loss which leads to loss of functioning and ultimately results in the need for increased support. These narratives were discussed in the theme 'The older you get, the more you lose, the more you need.’. Participants with knowledge of dementia described ageing as a time when the individual experiences some deterioration but that this would be manageable. They also described ageing as a pleasant time in which one might be able to rest. These ideas were captured in the theme 'Growing old, slow and steady'. When thinking about dementia, this group described it as a process in which individuals lose control and the ability to function, thus affecting relationships and their quality of life. This was discussed in the theme 'Dementia as total loss'.

Analysis of Phase Three

The information that emerged from the one-to-one interviews was used to develop the resources used in the psychoeducational session on dementia in phase two.

Following on from the psychoeducational session on dementia (phase two), two focus groups took place (phase three). The information that emerged was analysed using thematic analysis. Table 8 illustrates the themes and subthemes from the focus groups.

Table 8.

Phase Three Themes.

Theme	Subtheme
Dementia as a losing game	Reduced abilities in people with dementia People with dementia as vulnerable Dementia as a terminal illness
Dementia does not occur in a vacuum	Impact of dementia diagnosis on the system Carer burden in people caring for someone with dementia
Dementia care to be compassionate and patient-led - 'because they care'	Dignified / person centred diagnostic procedure and care provision

	Including the system during the process of diagnosis and care planning
Dementia care should take a birds eye view	Dementia carers to meet physical and emotional needs of client Dementia clinicians to support family members as well Preventative action is important in dementia

Theme One: Dementia as a Losing Game

All participants recognised dementia as a process of loss. There was frequent mention of reduced cognitive ability and mobility in people with dementia which is discussed in the first subtheme *reduced abilities in people with dementia*. This subtheme also discusses the perceived impact the loss of these skills will have on the individual's functional ability. As the conversation progressed, participants of the focus group began to reflect on how reduction in functional ability would impact the person with dementia and the way they relate to the world. These ideas are illustrated in the subtheme *people with dementia as vulnerable.* It describes how people with dementia are at increased risk of harm and that this risk will have greater consequences in comparison to those without dementia. Participants seemed to also reflect on the cumulative effects of reduced functioning and increased vulnerability. The third subtheme *dementia as a terminal illness* depicts the perceived finality of a dementia diagnosis and speaks to the ultimate loss of life. Many participants shared anecdotes of experiences with someone with learning disability and dementia to illustrate their points.

Reduced abilities in people with dementia. Participants in both groups reflected on the cognitive and physical deficits they expected people with dementia to have. Many described changes to their memory and gave specific examples of what they thought a person with dementia might forget, stating that “They forget names and phone numbers and address” (Lizzie) and will often be observed “Forgetting to lock the door” (Brenda).

When thinking about changes to mobility, two participants shared that they thought a person with dementia would “need to use wheelchair because they cannot walk” (Lizzie) and that support would be needed if the person with dementia wanted to go shopping because they would find it difficult to lift the bags. Participants also acknowledged that people who do not have dementia will experience changes to mobility as they age.

For some respondents, the cognitive changes were more prominent in their understandings of dementia. Some respondents discussed how dementia might make it difficult for people to remember and recognise faces. One participant described how she would approach a friend who has dementia and how she would manage the interaction:

> “If you did go up to him, you just have to go up and just say to him - Hello, Steven. This is Lauren. And sometimes he does recognise- like he does think oh, he does remember sometimes and then sometimes he just doesn't remember.” (Lauren)

Participants appeared to perceive people with dementia as unable to truly connect with their environment not only because of their difficulty in recognising familiar faces but also due to the difficulty in comprehending what is happening in the moment. Many hypothesised that the person with dementia would be confused. One participant evoked an image of a person with dementia being stuck in their own internal world stating that “She gets confused in her head. Going round and round” (Tim).

Not only did participants speak of the loss of cognitive and physical abilities in people with dementia, they also reflected on the impact this would have on the individual’s overall functioning. All participants made suggestions of the practical tasks individuals with dementia would need help with, such as, “Like cooking. Cleaning? Hoovering.” (Brenda).

For many, the functional decline seen in people with dementia was perceived as catastrophic and this is depicted by the totalising language used by respondents:

“They need help- they need help, with everything.” (Kelly)

“[They] can’t do anything.” (Brenda)

“They wouldn’t know what to do. So maybe someone should be there at all times” (Lizzie)

In the learning disability sphere, functional independence is held in high esteem because education and care systems focus on supporting individuals to reach their full potential. As such, the additional help required for people with dementia may be perceived as more troubling to people with learning disabilities.

People with dementia as vulnerable. Conversations about the loss in functional ability a person with dementia may experience led to a shared perception of people with dementia as vulnerable. Many participants noted that even mundane activities could lead to serious harm due to reduced physical ability, with one participant sharing that “Sometimes they (people with dementia) go to the toilet and fall go to hospital” (Tim).

Some participants thought that cognitive limitations would pose the greatest risk to people with dementia. In their responses, they share that despite being physically able to complete an activity, the cognitive difficulties a person with dementia faces may be the biggest hindrance. For example, Lizzie states, “Sometimes they can forget what's on the hob and that and what's in the oven. Bam. Fire.”.

This subtheme is also supported by points in the previous section whereby the participants state people with dementia require high intensity support. Respondents seem to perceive people with dementia as incapable of assessing risk independently and thus dependent on others due to this vulnerability.

Dementia as a terminal illness. Participants in the group who knew someone with dementia would often reflect on the finality of the diagnosis:

> “My grandad had dementia and then he passed away” (Lauren)
>
> “When it gets worse they just think they can just plan for when when it does happen and when they do die and they can plan for like the funeral” (Kelly)

When thinking about life after receiving a diagnosis of dementia, participants showed awareness of the prognosis but omitted how a person with dementia might live well with the condition. Participants’ reflections were overwhelmingly focused on what one might lose if they were to receive such a diagnosis and suggests they hold largely negative attitudes towards dementia.

Theme Two: Dementia Does Not Occur in a Vacuum

Many of the participants discussed dementia within a social context. They described the ways in which the disclosure of a dementia diagnosis may impact those supporting the individual with dementia and the way in which the person with dementia is perceived. These concepts are explored in the first subtheme *impact of dementia diagnosis on the system.* Participants acknowledged the impact a dementia diagnosis would have on the lives of those supporting the individual with dementia which is discussed in the subtheme *carer burden in people caring for those with dementia.*

Impact of dementia diagnosis on the system. Participants reflected on the emotional impact a dementia diagnosis would have on the system. They spoke about how initial feelings of sadness would then be compounded by anxiety. George shared that "It upsets [the family] and then they get worried” and Lucy explained that “There’ll be tears”.

Some respondents shared that some families might find it difficult to adjust to life with a loved one with dementia, stating that “They’ll be devastated and angry” (Lucy). To manage these emotions, participants explored the utility of professional support for caregivers, suggesting that “Support from counselling will help them feel better” (Lizzie).

Some explained that a person with dementia might be feared by some individuals in their support system. Respondents shared perceptions that people with dementia are dangerous and reflected on fears of being around a person with dementia:

> “I know a lot of people with dementia can swear and that and lash out. So you've got to be careful” (Brenda)
>
> “If they were to lash out, then that's the only one way they can calm them down. Sectioning them and then putting them on a special ward.” (Lauren)

Overall, there was a strong narrative that being diagnosed with dementia affects more than just the individual. Respondents acknowledged the emotional response the support system may have towards the person with dementia including feelings of fear. The responses also highlight how people with learning disabilities acknowledge the dynamic range of emotions individuals supporting people with dementia may experience.

Carer burden in people caring for those with dementia. Participants explained that due to the reduced ability to function in people with dementia, family members and carers would have to support the individual. When individuals spoke about this, they alluded to the sense of duty one might have to look after their family member. One participant shared their family's experience of caring for a loved one with dementia, "Because if it's a family member, like my mum, she always did shopping for my grandad and always did his washing" (Lizzie).

Respondents assumed that family would have to care for the individual with dementia. Often suggesting that "if they're parents, they can live with their kid" (George). There was no suggestion of carers having a choice to step into this position, but rather a narrative of expectations for family to fulfil a role.

Respondents also noted that it takes effortful coordination between people in the system to support the individual with dementia. Respondents suggested that the individual with dementia had to be supported within a network of people and for this network to function correctly, planned coordination must take place. Lizzie shared her family's experience of having to coordinate care for a loved one with dementia and the need for this to be shared between the support system - "Because there'd be no one else to help. My uncle would be working with my auntie. And it'd be only my dad that was free because my brother's in Scotland and it's harder.".

Throughout both focus groups, it became clear that participants perceived dementia as a diagnosis that impacts wider networks and that in response to this, support must also be provided to the family/carers of the person with dementia.

Theme Three: Dementia Care to be Compassionate and Patient-led - 'Because They Care'

This theme explores what participants thought should be included in high quality dementia care. Participants spoke about the diagnostic procedure and care provision, noting that both should be person-centred. This is discussed in depth in the subtheme *dignified / person centred diagnostic procedure and care provision.* Also, discussed in this subtheme, is the impact this approach to care will have on the therapeutic relationship between patient and clinician. In the second subtheme, *including the system during the process of diagnosis and care planning,* the participants build on discussion regarding dementia being best understood in a social context. They explore the need to include support systems from diagnosis to care.

Dignified / person centred diagnostic procedure and care provision. The group spoke about the importance of face-to-face appointments and eye contact. It seemed that through this, participants felt that patients would experience the clinician as caring and that information would be conveyed more accurately. Many participants stated that face-to-face appointments supported comprehension of information and often related this to their own experiences in online and face-to-face appointments. Participants also acknowledged a dementia diagnosis disclosure appointment, is one of great seriousness and thus requires a proportionate level of support.

> “it’s easier. I can understand.” (Aaron)
>
> “It’s a big appointment, the doctor just needs to tell them face to face. Slowly and clearly because they care” (Lizzie)
>
> “If it was over the phone, they can't tell you that for all information over the phone. But especially if you go in they can tell you properly.” (Tim)

They also noted the need for attention to differences between patients, such as, clinicians using the individual’s preferred name and preferred communication style.

> “And about how you want them to say your name because some names can be shortened. But a lot of people don't know how people shorten their names” (Will)
>
> “Like when they’re told something, maybe a Makaton picture will be helpful” (Aaron)

Participants in this sample seemed to be particularly attuned to the various methods of non-verbal communication such as Makaton. This knowledge is unique to the learning disability population as alternative forms of communication are common in this group. They highlighted that all patients will have varying preferences, but that every patient should lead the care planning process as much as possible. When asked about who might help the patient make decisions, one respondent said “the person can choose for themselves” (George).

Most respondents thought the person should be told about the diagnosis of dementia. Some discussed the risk that some patients might not want to know about their diagnosis of dementia. For example, Will stated “I’m not sure if they’d want to know, it might upset them mightn’t it?”.

This highlights the need to reduce reliance on assumptions based on mainstream practices, in order to promote truly person-centred care in dementia. However, this proposes an ethical dilemma which historically has caused much debate between dementia clinicians and researchers.

Including the system during the process of diagnosis and care planning. Despite the emphasis on person-centred care, the participants of the focus groups acknowledged that some individuals may find it hard to make decisions themselves or find it difficult to communicate their decision. In these cases, they suggest that if the person with dementia cannot lead the care planning process, then a family member or carer who knows them well should be involved and make decisions on their behalf. This was highlighted when Lizzie stated “They should make decisions or if they can’t, then it's up to their families', and was reinforced by Lauren’s comment- “or their carers can”.

One participant noted that because of their learning disability, if they were to get dementia, they would prefer for staff to help them with a care plan. Participants seem to relate this to their own experiences of appointments and find it more comfortable when staff answered on their behalf.

> "I would want my carer help me with my care plan, it's actually ea- easier for me because I don't know what to put in my care plan." (Will)
>
> "I find it difficult so my staff do it for me and help" (Lauren)

These insights are particularly unique to people with learning disabilities who are familiar with systems of care and the ways in which staff might support an individual with limited capacity.

Participants also explained that it would be beneficial to have family and staff in appointments and part of the care planning process. For example, Aaron stated that "They should share it with family and friends. If your don't tell anyone, how would they know?". Their rationale for this was due to the involvement these individuals would have in the ongoing care of the person with dementia. Lauren explained that professionals should "Tell the family the plan plan so they can give them support".

These subthemes highlight the nuanced understanding people with a learning disability have regarding the care planning process. They hold in mind the need for it to be individualised and person-led but that for some this will not be possible. They suggest that in these cases, individuals should be supported by those who know them best.

Theme Four: Dementia Care Should Take a Bird's Eye View

This theme discusses the wider perspective that participants thought should be taken when considering dementia care. Summarised in the subtheme *dementia carers to meet physical and emotional needs of client* participants shared that people supporting individuals with dementia should pay attention to all aspects of the individual and not dismiss their mental wellbeing. The participants also acknowledge that due to the impact dementia has on the system around the individual with dementia, clinicians should also offer support to family and carers. These ideas are discussed in the subtheme *dementia clinicians to support family members*. In the final subtheme, *preventative action is important in dementia*; the respondents discussed the importance of proactive care in dementia and how learning about it empowers individuals to protect themselves against the condition.

Dementia carers to meet physical and emotional needs of client. Individuals seemed to reflect on their own experiences with carers and highlighted the need for carers to be kind, empathetic and respectful in order to meet the physical *and* emotional needs of the individual.

The majority of participants were confident in discussing the support people with dementia would require concerning activities of daily living and physical health. All participants suggested that individuals with dementia would require support getting to appointments, cleaning and doing grocery shopping. When asked about the role of carers for people with dementia, participants statements included the following, “Cooking. Cleaning?” (Lizzie) and “Hoovering ... making beds because they find that difficult... One of my carers, when they first get me up in the mornings, they’ll do it” (Lauren).

When engageing in this part of the discussion, many participants like Lauren, used their own experiences of care as a person with a learning disability to inform what support they thought people with dementia would require.

Participants shared that they would want a carer who values being kind to their clients and works in a person centred manner. They reflected on the specific qualities a carer of someone with dementia would require to maintain the wellbeing of people with dementia, such as the need to be empathetic while the individual with dementia presents with behaviours that challenge. They also shared that it would be important for carers to treat individuals with dignity and respect. These findings highlight the ability of people with learning disabilities to retain information about dementia and utilise it to reflect on care needs.

> "Who likes being helpful, kind, flexible" (Lizzie)
>
> "Maybe [carers] need a bit more like empathy? For when people with dementia lash out?" (Lauren)
>
> "Treat them with just a bit of like respect and just make sure not to rush them" (Will)

They also discussed the need for the care-plan to be inclusive of the individual's physical, functional and emotional needs with one participant stating that "the care plan's got to be a full package" (Lizzie). Again, due to the participants' lived experience of being 'cared for', they showed familiarity with terms such as 'care plan' which the non-learning disability population may not be familiar with.

They spoke about the need for specialist dementia training for the carers to allow them to be competent in supporting the individual in all domains. One participant drew from observations of the staff at her home supporting someone with dementia, they said "all the staff have got that training. So they all know about dementia. So how- they can help them and everything" (Lauren). Another participant shared that carers being knowledgeable about dementia would improve the care provided to the individual with dementia "Carer need to know about dementia to better help the person who has dementia" (Aaron).

They suggested training should be based on the needs of the client rather than only providing generic training to all staff. They discussed how staff might ask the person with dementia how they would like care to be provided and that if this was not possible then staff should ask someone who knows the individual well.

> "So if, for example, if I had dementia, and I'll show you how to do it, they will know from us or if I if I didn't know from us, then they will know from family and stuff like that." (Lizzie).

This highlights the person-centred approach that people with learning disabilities think is necessary for people with dementia.

Dementia clinicians to support family members as well. Due to the impact of the diagnosis on the system, the group suggested that the system supporting the person with dementia may also need support. One participant said that "It's good for [carers] to go to the appointment. To help them get to the doctors so they can have help as well" (Aaron). This quote highlights how participants thought the family and carers would be inherently impacted by the diagnosis of dementia.

Other participants suggested that counselling would be helpful for families so that they have "someone to talk to" (Lauren) or that families "could call the care home for support" (Lizzie). These quotes suggests that carers need an outlet for the burden of caring for someone with dementia. It seems that respondents were able to take a solution-focused position as discussions developed in the focus groups.

Preventative action is important in dementia. Many spoke about the need to care plan in advance. They suggested that this should happen before a person is diagnosed with dementia. Participants acknowledged the impact dementia would have on the individual's ability to make or communicate preferences. For example, one participant said the care-plan would "tell [carers] that they need to they probably just have to plan of what they need to do when [the person] get dementia' (Brenda). They also suggested that this should take place prior to any crises and before the dementia progresses to the mid to late stages of the condition, another participant suggested that the plan should happen "before they get worse” (Will).

The participants explained that they enjoyed learning about dementia and that by being provided with information on it, they could decide whether they wanted to engage in further learning about the condition. They shared that learning about dementia would provide individuals with understanding of what to do if they were to be diagnosed with the condition.

> 'It's important to know. So you know what's going on... So you can read it. Or you can print it off and read it. Or you know, you can mark off what it means and that.' (Brenda).
>
> ‘to get some information, so if the person has dementia they know what to do.’ (Lizzie).

Understanding dementia led to a curiosity of how to prevent the disease. All participants answered affirmatively when asked if they would like to learn about how to prevent dementia. The researcher noted that during the information session based on co-produced material all participants were engaged. They continued to contribute to discussion and asked questions about the material.

Summary of Findings from Phase Three

Following the psychoeducation group on dementia, focus group discussions took place. Analysis of the focus groups in phase three generated a total of four themes. Participants discussed new understandings of dementia in which they perceived people with dementia as vulnerable, lacking in functional ability and reflected on the terminal prognosis of the disease. These narratives were explored in the theme ‘Dementia as a losing game’. Individuals also discussed how dementia might impact the individuals supporting the person with dementia. These ideas were captured in the theme ‘Dementia does not occur in a vacuum’. When thinking about dementia care, participants explained that care should be taken to include the person’s support system and be provided in a dignified and compassionate manner. This was explored in the theme ‘Dementia care to be compassionate and patient-led - ‘because they care’’. Finally, participants shared that dementia care should be provided in a holistic manner to the individual with dementia and for the support system. Participants also discussed the positive impact of preventative care. This was discussed in the theme ‘Dementia care should take a bird’s eye view’.

Chapter Five: Discussion

Chapter Overview

This chapter aims to provide a concise overview of the research findings and discuss how these findings relate to the main research aims. Then the quality of the research will be assessed, followed by ideas for future research. The chapter will then outline implications of the research for clinicians and policymakers. Then the personal reflections from the researcher will be shared. The chapter will end by exploring avenues for dissemination of the research.

Research Aims

This research aimed to explore the following: 1) people with learning disability's understanding of dementia and explore their capacity to engage in discussions relating to dementia, 2) their perceived dis/advantages of being told the diagnosis of dementia and 3) discuss their preferences for future care planning in the context of dementia. A total of 15 participants engaged in phase one of this research and ten of those went on to complete phase two and three of the study. Through reflexive thematic analysis, eight themes (three themes relating to phase one and four relating to phase three) were generated in response to the research aims stated above. These themes showed that people with a learning disability have the capacity to understand the concept of dementia if they have been in contact with someone with dementia or if they have been supported to learn about dementia. They shared understandings of dementia as a process of loss which can also impact on those supporting the individual with dementia. When thinking about dementia care, participants suggested that clinicians should work in a compassionate manner while working holistically. All participants emphasised the need for care to be patient-led, which included conversations regarding the benefits of being told the diagnosis of dementia. They also suggested that preventative care is important in the context of dementia.

Phase One

Phase one of the research was completed to inform phases two and three of the study but also yielded findings relevant to the research aims.

The older you get, the more you lose, the more you need./ Normal ageing – a slower pace of life/ Ageing leads to partial but manageable loss / dementia as total loss. The difference between the theme generated by the participants who did not know anyone with dementia ('The older you get, the more you lose, the more you need.') and the themes generated by participants who knew someone with dementia ('Normal ageing – a slower pace of life', 'Ageing leads to partial but manageable loss', 'Dementia as total loss') highlight how public health information regarding dementia has not been made accessible to people with learning disabilities. Participants who knew about dementia due to personal experiences of a family member or friend having the condition were better able to distinguish symptoms of normal ageing from symptoms of dementia. Whereas the remainder of participants implicitly related symptoms of dementia to normal ageing. This led to people without knowledge of dementia to perceive ageing as a catastrophic process where good quality of life is not possible. The themes generated illustrate the capacity of people with learning disabilities to engage in these conversations and indicates a need to increase sharing of information to this group regarding dementia.

In chapter one, the researcher discusses how perceptions of ageing are important for quality of life outcomes. Literature discussed in earlier chapters illustrate how positive attitudes towards ageing means improved self-rated health (Janekova et al., 2013), improved psychological well-being (Polverino, 2010), better performance on vision and hearing tests (Kim et al., 2012), increased walking distances (Witham et al., 2006), a reduced need for support with activities of daily living (Kim et al., 2012) and increased lifespan (Levy et al., 2002). The themes generated following phase one suggest that people with learning disabilities have skewed views of the ageing process. If the learning disability population have skewed perceptions of the normal ageing process and implicitly confuse symptoms of dementia as typical stages in older age, then we might assume from previous research that they will have negative attitudes towards ageing and potentially worse health outcomes. Also discussed in earlier chapters is the idea that the ageing learning disability population have worse health outcomes such as increased experience of multimorbidity (Kinnear et al., 2018) and increased prevalence of epilepsy, chronic obstructive pulmonary disease, asthma, hypertension and type II diabetes (NHS England, 2023). While social disparities play a large role in this, we might hypothesise that negative misperceptions of ageing also play a role.

The one-to-one interviews utilized in phase one supported participants to discuss understandings of dementia freely and did not require support from family and/or carers. They were able to show capacity for consent to participation in research. This shows that through thoughtful application of research methodology, participants can be empowered in systems where they have been historically silenced. It refutes ideas that people with learning disabilities are not credible sources of information in research due to their susceptibility to coercion and difficulties in engaging in complex topics (Dalton et al., 2004; Iacono, 2006).

Phase Three

The data from phase three was gathered after the information-based session about dementia from co-produced material obtained in phase one. As such, the knowledge base that participants held while engaging in discussions had shifted. At this point in the study, all participants had engaged in learning about dementia and those who were not aware of dementia prior to the study now reported differences between normal ageing and dementia. This indicates that participants may have developed a clearer understanding of dementia and aging as distinct concepts through this learning process.

Four themes were generated from the discussions in phase three: ‘Dementia as a losing game’, ‘Dementia does not occur in a vacuum’, ‘Dementia care to be compassionate and patient-led – ‘because they care’’ and ‘Dementia care should take a bird’s eye view’. These will be discussed in relation to existing research and the implications for policy and clinical work will be reflected upon.

Dementia as a losing game. People with learning disabilities understood dementia as a condition that reduces an individual’s functional abilities, leading them to be vulnerable. They perceived it as an illness that ultimately leads to death.

Participants of the study showed good understanding of the impact of dementia. For example, they noted the loss of memory, reduced recognition of others, confusion, reduced cognition and mobility. They then reflected on the wider impact this would have on the individual’s functioning and discussed the effects this would have on activities of daily living. Participants also thought about the ways in which reduction in functional ability would increase vulnerability in people with dementia. Participants of this research conceptualised dementia as a dynamic process acknowledging the various losses that people with dementia experience and the ultimate loss of life.

Participants showed good understanding of the symptoms of dementia and reflected on the wider impact these changes would have on the person’s life. However, despite these interesting and nuanced reflections, participants did not explore any narratives of living well with dementia.

This differs from the research outlined in chapter two in which individuals with learning disabilities have engaged in discussion around the negative *and* positive aspects of ageing. It may be that for some, the concept of dementia was new and seen as a threat due to the uncertainty of the condition. This reflects the natural human inclination to remember threatening and negative information rather than positive information. In early history, individuals who remembered negative information such as threats and danger would be more likely to survive (Cacioppo et al., 2014). Additionally, those who knew of dementia prior to the study witnessed people dying in the latter stages of dementia. Being witness to the symptoms associated with late stages of dementia may make it difficult to reflect on the possibility of living well with dementia.

The themes generated in this study, replicate the findings of the rapid literature review that was conducted in Chapter Two (Lloyd et al., 2007; Forbat and Wilkinson, 2008; Watchman et al., 2020). Similarly, participants in this study viewed dementia as a process of loss and overall held negative attitudes towards the condition.

The findings mirror what is seen in research related to diabetes in the learning disability population. In this literature, people with learning disabilities see living with a chronic condition as life-limiting, with little room for positive experience (Dysch et al., 2011; Maine et al., 2018).

The findings may also indicate the wider social context whereby ideas of ‘Living well with dementia’ have not been fully integrated into dementia narratives and/or shared with the learning disability population in an accessible way. This supports the pre-existing literature on the attitudes people with learning disabilities have towards dementia and suggests more needs to be done to make campaigns of ‘Living well with dementia’ more accessible.

Dementia does not occur in a vacuum. Participants discussed dementia in a social context and reflected on the way dementia would impact the system supporting the individual diagnosed with dementia and how others perceive the person with dementia. They also acknowledged the burden carers might experience when supporting someone with dementia.

Participants thought about the emotional experience of family and carers and the ways it might be difficult to accept and adjust to life with a loved one with dementia. Respondents acknowledged that due to this, family and carers might need support from professionals.

Carer burden seemed to be conceptualised as an experience that happens due to the 'duty of care' families may feel for their loved one with dementia, despite not having the emotional, financial, practical capacity. The burden also came from the need to engage in effortful coordination with other people and organisations supporting the individual. While previous research (Lloyd et al., 2007; Forbat and Wilkinson, 2008; Watchman et al., 2020), has acknowledged the need for support from friends and family, it had not explored the impact this would have on support systems.

The current research found that people with learning disabilities perceive dementia as an experience best understood within a social context. This links to the United Nations' movement away from a medically based model of ageing that focuses on physical health to one that acknowledges the social aspect of ageing mentioned in chapter one.

In the guidance from the British Psychological Society (BPS) and the Royal College of Psychiatry (RCP) entitled 'Dementia and People with Intellectual Disabilities – Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.' (2015), it states that family and professional carers should receive psychoeducation on dementia and emotional support post-diagnosis. It mentions the use of a carer burden questionnaire to assess the individual's level of dependence on others but does not go further to explore the long term challenges of caring for someone with dementia. In future guidance, it may be helpful to elaborate on this, as carer burden has been shown to reduce the quality of care provided (Malli, 2018).

Dementia care to be compassionate and patient-led - 'because they care'. This research found that participants wanted person-centered experiences of diagnosis and onward care. To do this, they explained approaches that maintain an individual's dignity was important. Participants explained that dignified care was created through clinicians displaying their investment in caring for people with dementia and allowing the person with dementia to be part of all decisions. This also included the decision of whether to be told about the diagnosis or not and for communication aids to be used in appointments.

Despite emphasising the need to have person-centered dementia care, participants of this research acknowledged that individuals in the late stages of dementia would require support to make decisions. The respondents suggested that another individual who knew the person well should make decisions on their behalf. Some participants also explained that because of their learning disability they would want staff to be present in appointments to support with forms and answering questions. This outlines that individuals with learning disabilities would like future care planning to be compassionate, person-led and inclusive of people they care about.

Throughout the BPS and RCP guidance (2015), especially in the chapter on 'Philosophy of Care', it states that services should be person-centred, however, it did not highlight what this might look like in practice. The present research provides clinicians with service-user led, specific approaches that may be used in dementia care.

In the same guidance it also states that it is national guidance to tell people with a life limiting condition their diagnosis, but this present study encourages us to reflect on whether we should allow individuals to choose whether they would like to know about the diagnosis following assessment. For instance, three participants reflected on the consequences of telling someone they have dementia. This would show further investment of services into dignified care, where every person is included in every decision of their care. Findings suggest that clinicians should consult with the individual with dementia at all stages and that when this is not possible, they should consult with someone who knows the person well.

This replicates findings from a study carried out with people with learning disabilities with diabetes. In this clinicians, found that inclusive care that involved the person and their support system improved health outcomes (Ng, 2023).

Dementia care should take a bird's eye view. This theme explores how participants believed it to be important for dementia care to consider the wider context of the individual. This included discussion around the need to care for the individual's physical and emotional needs, thinking about what support might be needed for those caring for someone with dementia and about preventative care.

Participants of this study discussed their own experiences of care as people with learning disabilities and utilised this to inform their contributions to the focus groups. For example, participants were knowledgeable on aspects of care planning which people from the general population might not be aware of. They highlighted that often physical care needs are prioritised and that that carers should also manage the emotional needs of a person with dementia. This is a unique strength of completing this research with this particular population.

Participants also acknowledged that the family of people with dementia would require support and made suggestions as to where this care might come from. Some suggested counselling while others shared that the dementia specialist should offer support. This current research echoes what is suggested in the BPS and RCP guidance (2015), which states that staff should provide holistic support and that early intervention should be provided.

Respondents also shared that preventative action is important. When talking about care planning, the group highlighted the importance for this to take place before any crises happened.

All respondents showed interest in learning about dementia and some expressed a wish to go on and learn more about the condition. There was a curiosity around how to prevent the onset of the disease.

This theme not only highlights the preferences for care but also highlights potential benefits of being told about the diagnosis. For example, this would allow people to engage in interventions that may slow the progression of the disease and assist with care planning. This mirrors the findings seen in wider health literature in which is states that early identification of disorders such as cancer and heart disease, allows the individual to engage in proactive measures to slow progression of the disease (Tuffrey-Wijne et al., 2009; Mcilfatrick et al., 2011; Young et al., 2012). This supports ideas presented in the ‘Think Brain Health’ campaign by the Alzheimer’s Society UK which highlights the importance of preventative care. The current research highlights the curiosity that people with learning disabilities hold in regard to this and provides further rationale for ideas regarding the concept of brain health to be developed in an accessible way.

The research also reflects aspects seen within the framework of ‘Personhood’ (Kitwood, 1997) thereby focusing on the maintenance of the person’s sense of self and dignity thought holistic care.

Due to the researcher’s training as a Psychologist, they often allowed participants to deviate from the topic of conversation. While this meant that there were parts of the data set that were not relevant to the study aims, it meant that rapport developed between participants and researcher. This was seen to be beneficial for the ongoing discussion and allowed participants to feel more comfortable in sharing their thoughts. The researcher also acknowledges that due to their clinical experience, they are more sensitive to shifts in emotions which would have impacted the interpretation of data and thus generation of themes. For example, the researcher may have overinterpreted the emotional impact of dementia for participants.

Strengths and limitations

People with learning disabilities and their understandings of dementia and preferences for care planning process

This research adds to the very limited literature exploring dementia from the perspectives of people with learning disabilities. Much of the previous research focused on understandings from the perspective of people without learning disabilities or sought understandings from the caregivers of those with learning disabilities and dementia.

Despite the novel explorations of the current research, it does not illustrate the understandings of lived experience of learning disability and dementia. Future research could expand on ideas seen in the present research by using a sample of people with learning disabilities and early stages of dementia to ascertain their views on dementia and preferences for care.

Research Paradigm and Methodology

Consulting with an expert by experience. In the past, as highlighted in the first chapter, learning disability research has followed a positivist approach. This method involved the objective study of people with learning disabilities, resulting in the establishment of oppressive legislation and policies. Unfortunately, their voices have been noticeably absent from both research literature and society at large.

This largely motivated the researcher of this study to apply a critical realist position to underpin the research. This position emphasises the importance of subjectivity and context while understanding the perspectives of people with learning disabilities regarding dementia.

A strength of this study is the use of consultation with an expert by experience in creating the research paradigm. By including a person with a learning disability, the research inherently empowers those with a learning disability to be involved in a field they are often maginalised in.

The expert by experience also held expertise in understanding the impact participating in research might have for individuals with a learning disability and ways to make the research accessible to them. The expert by experience has an increased sensitivity to ethical considerations that the researcher was not aware of due to their position as someone without a learning disability. For instance, the consultant explained that people with learning disabilities may think they have dementia by being included in the research and thus encouraged consistent reminders throughout the research process that they did not have dementia. The consultant also supported the researcher to construct interview questions in a way that was accessible to people with learning disabilities.

While this study aimed to empower and amplify the experiences of the learning disability population through the methodology, sample and involvement of an expert by experience, it could have gone further within a co-production framework. Future research could include people with learning disabilities as co-researchers on the project, thus involving them from beginning to end. However, this would have required significantly more time, and individuals would need to be paid for their input which is beyond the scope of a Professional Doctorate.

Three phase approach to research. The present study used a novel and unique approach to research with people with learning disabilities. The three stage approach ensured that when participants engaged in phase three, they had sufficient knowledge of dementia to join the focus group and to share their perspectives about dementia care.

The information-based session (phase two) created from co-produced material gathered in phase one was another means for people with learning disabilities to be empowered in research. Through this, the researcher acknowledges that some participants have preexisting ideas and knowledge about dementia which dismantles the power differentials often seen between researcher and participants. Using the information gathered from the one-to-one interviews in phase one also allowed for the content of the information-based session to be relevant to participants and presented to them in an accessible way.

A criticism of this method is that the responses heard in phase three are likely to have been influenced by the information shared in phase two. Due to this, critics may argue that responses are biased; however, had this approach been omitted and focus groups used on their own, several of the participants would have struggled to contribute. This would have created another form of bias in which only those with personal experience of dementia would have the ability and/or knowledge to participate.

One-to-one semi-structured interviews. Using one-to-one semi-structured interviews with participants allowed the researcher to build rapport with the sample in preparation for phase three. It also allowed the researcher to assess the capacity of the participants to consent to research and for questions about the research to be answered in a tailored manner. The researcher also gained an insight into the communication needs of participants. This was then considered in all other parts of the study. For example, the researcher noted that pictures were a valuable tool when communicating with participants and that many communicated through anecdotes. As such, imagery and storytelling were heavily relied upon in phase two.

The use of semi-structured interview allowed for exploration of the unique perspectives of each participant and allowed the researcher to be flexible with the questions asked and the manner in which those questions were asked. For example, meeting the communication needs of each participant.

The researcher reflected on the limitations of using semi-structured interviews. Semi-structured interviews lack the strict standardisation of structured interviews. This means it is likely there was some variation in the questions that were posed. The researcher may have influenced the way in which participants responded due to their presence, the type of question asked and the way in which the question was asked. However, due to the sample, flexibility in communication was vital in maintaining rapport and supported participants to engage in dialogue. Using semi-structure interviews was resource intensive and time consuming, however, this process was deemed necessary due to the depth of information and rich data it elucidates.

Focus groups. Using focus groups allowed participants to build on each other's ideas but also invited space for debate, which again supported the development of rich narratives.

The make up of the focus group helped to reduce the power differentials between the researcher and participants, as participants were familiar with each other from the day centre. It was felt that through this, the participants felt more comfortable in answering questions about an unfamiliar concept.

The researcher also considered the limitations of using focus group interviews. It may have been that the more outspoken members of the group directed discussion and may have coerced other members in the group to answer in a specific way. Some members of the group may have been more agreeable in discussions as they wanted to be seen as part of the group, however the researcher made an effort to include all members of the group within the discussions as far as possible.

Study Sample and Sample Size. There are no definitive criteria for the adequate sample size for qualitative research. It has been recommended that a sample size of 12-15 participants is acceptable (Hennick and Kaiser, 2022). This study recruited 15 participants but saw some attrition between phase one and two. Of the five participants who did not complete the full study, three were unavailable on the dates phase two took place, one preferred to engage in another activity at the day centre and one experienced difficulties with mental health meaning it was not appropriate for them to participate in phases two and three. The three phase approach of this study increased the likelihood of attrition but given the difficulties accessing the client group, it was still possible to attain a representative and appropriate sample.

As all participants were recruited from the same day centre, the sample may be limited in its diversity of participants. The majority of participants were White British and cis gendered. Participants of the study all communicated verbally and based on the researcher’s clinical judgement, presented with a learning disability within the mild to moderate range. While qualitative research does not aim to be generalisable, it would be helpful to carry out this research with a more diverse sample in a different setting to develop our understanding of learning disability and dementia. There may also be differences in care planning preferences for people from an individualistic culture versus those from a collectivist culture. Similarly, it would be interesting to explore any differences between those who communicate verbally versus non-verbally.

Yardley's Criteria of Quality Assessment

Yardley's Criteria of Quality Assessment (2000) is often used to evaluate the methodological rigour and overall quality of qualitative studies. It has been used to further evaluate the quality of this research due to it being an established standardised framework offering a comprehensive evaluation. It considers multiple dimensions of research quality including sensitivity to context, commitment and rigour, coherence and transparency, and impact and importance. Each of these criteria will be discussed in relation to the current study below.

Sensitivity to context – Yardley (2000) describes sensitivity to context as an awareness and understanding of the current research in the area of study. The researcher reflected on the literature relevant to each aspect of the study. For example, literature about the historical understandings of learning disabilities and dementia was discussed as well as research about attitudes towards ageing and dementia and dementia care. The researcher also reflects on their own context which inevitably impacts the creation of the study and analysis of the data. The researcher's context will be discussed in depth later in this chapter.

Commitment and rigour – Commitment and rigour is related to the commitment of the researcher to engagement in the topic, competence in rigorous research skills and immersion in the study data (Yardley, 2000). The researcher showed their commitment to the research by immersing themselves in the data through reflexive thematic analysis whereby they conducted and transcribed the interviews and analysed the data. In regard to rigour, the rich data collected has answered the aims of the study and is supported by the sample size of 15 which is considered sufficient for qualitative research. Overall, the research can be seen as good quality.

Coherence and transparency – Yardley (2000) suggests coherence relates to the alignment with the research question and the philosophical framework and methodology employed. Transparency entails providing detailed information to enable replication of the study, along with acknowledging the researcher's own impact on the research process.

There is good coherency between the researcher’s epistemological stance of critical realism and the research question exploring unique perceptions of people with learning disabilities regarding dementia and dementia care. The thesis also provides clear direction as to how this study may be replicated in the future, indicating transparency of methodology.

Impact and importance – Impact and importance is related to the impact of the research in academia and practice on a clinical and policy level (Yardley, 2000). This current study contributes to the research base and has clear clinical and policy implications. These will be discussed in the next section.

Further research

While the present study highlights the understandings people with a learning disability have of dementia and their views on good dementia care, an in-depth examination is warranted to comprehend the distinct experiences and care-needs of people with learning disabilities who have a diagnosis of dementia. Research in this domain could shed light on the specific communication barriers, coping mechanisms, and care preferences that individuals with learning disabilities and dementia encounter. Understanding these intricacies is vital for the development of targeted interventions and person-centered care approaches that accommodate the dual impact of learning disabilities and dementia. However, any research of this nature will be difficult. Due to difficulties in noticing the early symptoms of dementia in people with learning disabilities, many are not diagnosed until the mid to late stages of the condition. As such, they often have lost the cognitive ability and insight to be involved in research.

The NHS long-term plan states that it will improve its understanding of the needs of people with learning disabilities and improve their health and wellbeing. The current research supports this, and future research should endeavor to do the same by exploring the preferences for disclosure and care planning in the context of other long-term health conditions, such as diabetes, cardiovascular diseases, or respiratory disorders. Investigating similarities and differences in the experiences and preferences across various health conditions can deepen our understanding of the broader healthcare needs of the learning disability population. It may also illustrate patterns that inform the development of more inclusive and person-centered care strategies tailored to individuals with learning disabilities facing diverse health challenges. This approach holds the potential to contribute significantly to the refinement of healthcare policies and practices, fostering a more holistic and sensitive approach to supporting people with learning disabilities in managing their health. The health inequalities that the learning disability population face, such as increased mortality rates in comparison to the general population, further highlights the urgent need for research.

Previous literature has shown attitudes towards ageing impacts quality of life. Future research could explore connections between the perceptions of dementia and the subsequent impacts on the quality of life and health outcomes for people with learning disabilities. This research could involve a comprehensive examination of how the awareness, understanding, and attitudes towards dementia influence the overall well-being of this population. It may be that to do this, a longitudinal methodology is employed.

In the context of advancing inclusive and comprehensive research methodologies, it is crucial that future studies actively include people with learning disabilities. By engaging people with learning disabilities in research, researchers can establish a more inclusive and equitable knowledge base. This will address the existing gaps in understanding the unique challenges and strengths associated with this population. Future research should prioritise the development of methodologies that are accessible and accommodating, fostering meaningful participation and ensuring the voices of people with learning disabilities are heard. This will allow the creation of better informed and responsive interventions, policies, and support systems tailored to the diverse needs of people with learning disabilities.

Clinical Implications, Policy Recommendations and the Researcher's Reflections

Clinical Implications

This research was created and facilitated by a researcher who has worked clinically in learning disability and older adult services. As such, the researcher is sensitive to the clinical implications of this study and has observed three areas in which this research is relevant to clinical work: the dementia diagnosis procedure, dementia care and care-planning and preventative care.

The themes from this study suggest that professionals should include people with learning disabilities and their support system during the diagnosis procedure. Participants also suggested that clinicians should conduct appointments in an accessible way through using communication aids and support from speech and language therapy if necessary. Services should improve methods of communication with people with learning disabilities. It may be that services are encouraged to train in languages such as Makaton which may support people with learning disabilities to be included in the diagnosis process.

When reflecting on the nature in which dementia is diagnosed, participants emphasised that medical professionals disclosing the diagnosis should do this in a dignified manner. To do so, they stated that professionals should prioritise patient views and show compassion for all involved. Services should encourage patient led care through actively asking for their perspectives at all stages and not assume that their understanding is limited due to their learning disability. Findings suggest that professionals should reflect on the impact a dementia diagnosis may have on other residents if the person with learning disabilities is living in a residential home. Services may find it beneficial to have access to support and resources that inform and normalise experiences of living with someone with dementia. The resource created for phase two of the study could be used to inform people with learning disabilities about dementia, should someone in their home be diagnosed. As such, another clinical implication of this project is the potential for the psychoeducation resource to be published for use in services.

The findings of this research suggest that in the context of dementia care and care planning, the person with dementia should be included as much as possible. Often people with learning disabilities and dementia are not included in care planning due to the delay in receiving a diagnosis of dementia. As such, for people with learning disabilities to be included in care planning, improvements must be seen in the processes involved in the diagnosis of dementia. Participants shared that professionals should support people with dementia in a holistic manner, holding in mind their mental wellbeing as well as their physical health. This suggests that dementia services should continue to employ health care professionals from all backgrounds and not solely focus on the physical health care needs of people with dementia. Services should also include thought about the needs of carers and the presence of carer burden.

The findings of this study highlight the need for services to work proactively in preventative care within the field of dementia. This will be beneficial in two domains, firstly to acknowledge the benefits of brain health behaviours in preventing dementia. Policies and services should support people with learning disabilities to learn about dementia prior to any concerns about cognitive decline, to encourage them to engage in brain health behaviours. Secondly, dementia services should begin care planning in a preventative manner, prior to a crisis.

Policy Recommendations

While there are many policies and guidelines that aim to protect people with learning disabilities and ensure good quality care, there is often a discrepancy between this and what is seen in practice.

Policies such as the NHS Long Term Plan, National Dementia Strategy, the Prime Minister's Challenge on dementia (2016) and the 'Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.' (BPS, 2015) may benefit from the findings of the current study, when updates are made. While much of what has been found in this thesis has been alluded to in aforementioned policy and guidelines, previous documents have not used research with people with learning disabilities to inform their guidance and policies. Previous documents have also used terms like 'person-centred care' without highlighting specifically how this might be achieved. The current study has presented specific ways in which dementia care could be improved for people with learning disabilities from the perspective of people with learning disabilities. This includes the need for person-centred, holistic dementia care in learning disability services. Attention should be brought to Standard Operating Procedures of services to ensure the care for people with learning disabilities and dementia is based on research and relevant documents. The findings of this study highlight the need to involve people with learning disabilities in the creation of dementia policy. Current policy does not reflect on the lived experience of people with learning disabilities and dementia, so it is important for documents to include this if they are to be written from a person-led perspective.

This thesis highlights the need for policies and guidelines to incorporate remedies for the impact dementia has on the carers and/or families of those with dementia. As such, more time and effort should be spent on including guidance on how these individuals might be supported in dementia policies and campaigns.

Researcher's Reflections

The position of the researcher is important to reflect upon to make sense of the research findings and the impact of the researcher's identity on the generation of themes. The position of the researcher includes, race, gender, age, sexual orientation, education, religion and ability (Burnham, 2012).

During the write up of this thesis, I identify as a 26-year-old, heterosexual cis-gendered woman who is of mixed origin (Filipino/British) and raised in the South-East of England. I have a Bachelor of Science in Psychology and have worked in the care sector for six years prior to training. During my undergraduate degree, I completed a placement completing dementia assessments with people who have Down's syndrome. Prior to my Professional Doctorate in Clinical Psychology, I worked predominantly with people with dementia and individuals with learning disabilities and autism.

During my Professional Doctorate in Clinical Psychology, I have had more experience working with people with learning disabilities and people with dementia in a clinical capacity. I also have personal experience of caring for a loved one with dementia and I have a cousin who has Down's syndrome. These professional and personal experiences have highlighted the power imbalances within services and society for people with learning disabilities, people with dementia and their families. I also believe it motivated me to include people with learning disabilities as the main contributors to this research in view of the lack of existing research from their perspective. Due to my personal and professional experiences alongside people with learning disabilities, I was confident they would be able to engage in this research and that their insights would be valuable for the field.

Throughout the process of conducting this research, I engaged in regular reflection regarding the impact of my own beliefs on the interpretation of data. I hoped that by doing so I would become more aware of the presence of any personal bias that may have affected the research and the generation of themes.

During the ethical approval process of this thesis, the research was subject to secondary review by an ethics panel. I recall feeling frustrated as while I could understand the need to safeguard people with learning disabilities, I also felt this was an overcautious approach which could pose a barrier to including people with learning disabilities in research. Also, I contemplated whether this undermined principles of the Mental Capacity Act, which states that everyone should be assumed to have capacity unless proven otherwise.

I also reflected on the learning opportunities I experienced while completing this thesis that will aid my career as a Clinical Psychologist. While the obvious learning opportunities relate directly to my role in service development, completing this thesis also provided me with opportunities to develop as a clinician. Reflecting on ethical dilemmas while creating this research and engaging in ethical approval processes will help me to reflect on similar ethical dilemmas in my clinical work and improve my ability to support supervisees through the research process.

Through regular supervision, I developed skills in discussing my research and justifying key decisions. This will benefit my ability to present decisions made in the context of research and clinical work paying special attention to the rationale leading to these decisions.

Through the inclusion of people with learning disabilities in this research and working alongside an expert by experience with a learning disability, my ability to work with people with learning disabilities has improved. More specifically, I have seen improvements in my ability to communicate and engage with people with learning disabilities and how to adapt resources to make them accessible to this population.

As Clinical Psychologists, we are expected to use evidence-based treatment modalities. Completing this thesis has reinforced ideas of the importance of evidence-based practice especially when the research is service-user led. Using service-user led research to inform practice empowers patient groups who are often silenced. Good quality research reflects on the historical evidence base and steers future research and guidance. This ensures that new interventions and guidance are well thought out and take previous learnings into account.

Practicing thematic analysis which is often used in Clinical Psychology literature has improved my ability to critique papers that use this approach. This helps me to acknowledge when a paper is of good quality and will support me to use thematic analysis again confidently. If required, I believe I would be able to support others, such as future supervisees, in using thematic analysis.

Conclusion

To conclude, the present research has a novel and significant impact on the understanding of how people with a learning disability perceive dementia and their preferences for the diagnosis procedure and care-planning process. The findings highlight that people with learning disabilities hold nuanced understandings of dementia and that compassionate, patient-led care should be prioritised in dementia care. The findings also outline how dementia care should take a wider perspective, engageing in preventive care and providing support to the care network around the person with dementia. The study demonstrates that individuals with a learning disability can participate in research and provide valuable contributions to research. This research advocates for the voices of people with learning disabilities to be amplified and heard in research and clinical spheres. Through this, the inequalities experienced by people with learning disabilities will be addressed and their needs prioritised.

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Appendices

Appendix A.

Critical Appraisal Skills Programme Checklist for the Systematic Review.

		Study									
Section and Question		Erickson et al., 1989	Thompson, 2002	Dew, 2006	David et al., 2015	Newberry et al., 2015	Kahlin et al., 2015	Mee Kim et al., 2020	Kim et al., 2020	Trip et al., 2020	Holmgren, 2023
Section A: Are the results of the study valid?	Q1: Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	Q2: Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	Q3: Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	Q4: Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	Q5: Was the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	Q6. Has the relationship between researcher and participants been adequately considered?	N	N	N	Y	Y	Y	Y	Y	N	N
Section B: What are the results?	Q7: Have ethical issues been taken into consideration?	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
	Q8: Was the data analysis sufficiently rigorous?	N	Y	Y	N	Y	Y	Y	Y	Y	Y
	Q9: Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Section C: Will the results help locally?	Q10: How valuable is the research? (Was this considered by the researchers?)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note. Y = Yes; N = No; U = Unclear

Appendix B.

Critical Appraisal Skills Programme Checklist for the Rapid Literature Review.

Section and Question		Study		
		Lloyd et al., 2007	Forbat and Wilkinson, 2008	Watchman et al., 2020
Section A: Are the results of the study valid?	Q1: Was there a clear statement of the aims of the research?	Y	Y	Y
	Q2: Is a qualitative methodology appropriate?	Y	Y	Y
	Q3: Was the research design appropriate to address the	Y	Y	Y
	Q4: Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y
	Q5: Was the data collected in a way that addressed the research issue?	Y	Y	Y
	Q6. Has the relationship between researcher and	N	N	Y
Section B: What are the results?	Q7: Have ethical issues been taken into consideration?	Y	Y	Y
	Q8: Was the data analysis sufficiently rigorous?	Y	Y	Y
	Q9: Is there a clear statement of findings?	Y	Y	Y
Section C: Will the results help locally?	Q10: How valuable is the research? (Was this considered by the researchers?)	Y	Y	Y

Note. Y = Yes; N = No; U = Unclear

Appendix C. Participant Information Sheet.

University of Essex

Introducing the Researcher

This is Sharon-Lin Harwood.

She is a Trainee Clinical Psychologist.

She is in her second year of training.

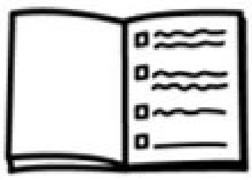
She learns at the University of Essex 2 days a week.

NHS

She works in the NHS on Wednesdays, Thursdays, and Fridays.

She will do a research project for her course.

Research is when we ask people questions find out new information.



She would like to ask if you want to take part in her research project.

This form will tell you information about her research project to help you decide if you want to take part.

This project will ask people with learning disabilities about dementia and how they think people with a learning disability and dementia should be treated.

Don't worry if you do not know what dementia is, we will learn about it together.

You will meet Sharon-Lin at your daycentre 3 times. She will bring someone from her work to help her.

What will happen?

You will complete a form that asks for information about you, for example your age and ethnicity

You will do a recorded interview with Sharon-Lin. Only your voice will be recorded. This will take 45 minutes. Sharon-Lin will delete the recording once she has written down what was said.

2

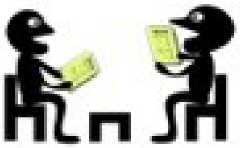
You will join a group to learn about dementia. This will take 90 minutes / 1 and a half hours.

3

In a group, you will talk about dementia and how you think people with a learning disability and dementia should be treated. This will be recorded. This will take 60 minutes / 1 hour.

Talking about dementia might be upsetting. Your team can help you if you are upset or need someone to talk to.

Sharon-Lin will keep anything you tell her safe and private. Once the research has finished, Sharon-Lin will keep this information until July 2024.



Alison and Stephen, who are teachers at the University of Essex, will help Sharon-Lin with her project. Another person will write down what was said in the recordings, they are called a transcriber. Only Sharon-Lin, Alison, Stephen and the transcriber will hear what you told Sharon-Lin.

University of Essex

Sharon-Lin will do a report on what she finds out. Sharon-Lin will use what you have said in the report.

MY NAME

✖

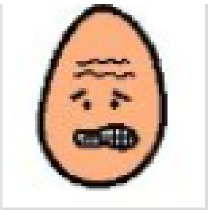
However, Sharon-Lin will not use your name. This means no one will know that you said anything.

If you decide to take part in the project, Sharon-Lin will tell you what she finds out. Sharon-Lin will also tell other people with learning disabilities, carers and professionals what she finds out. She will use journals and conferences.

You can stop doing the research at anytime. You do not have to give a reason. This is ok. It will not change the service you receive from Project 49.

University of Essex

Information about the Research Project
Reporting Concerns and Complaints



If you have any concerns or complaints about the study you or someone who supports should follow these steps.

1. the first person to contact is the researcher, Sharon-Lin Harwood by email: sh21580@essex.ac.uk

2. If you are still not happy, please contact the University's Research Governance and Planning Manager, Sarah Manning-Press by email.

Sarah's email: sarahm@essex.ac.uk

OR my teacher Alison: as16018@essex.ac.uk

University of Essex

Information about the Research Project

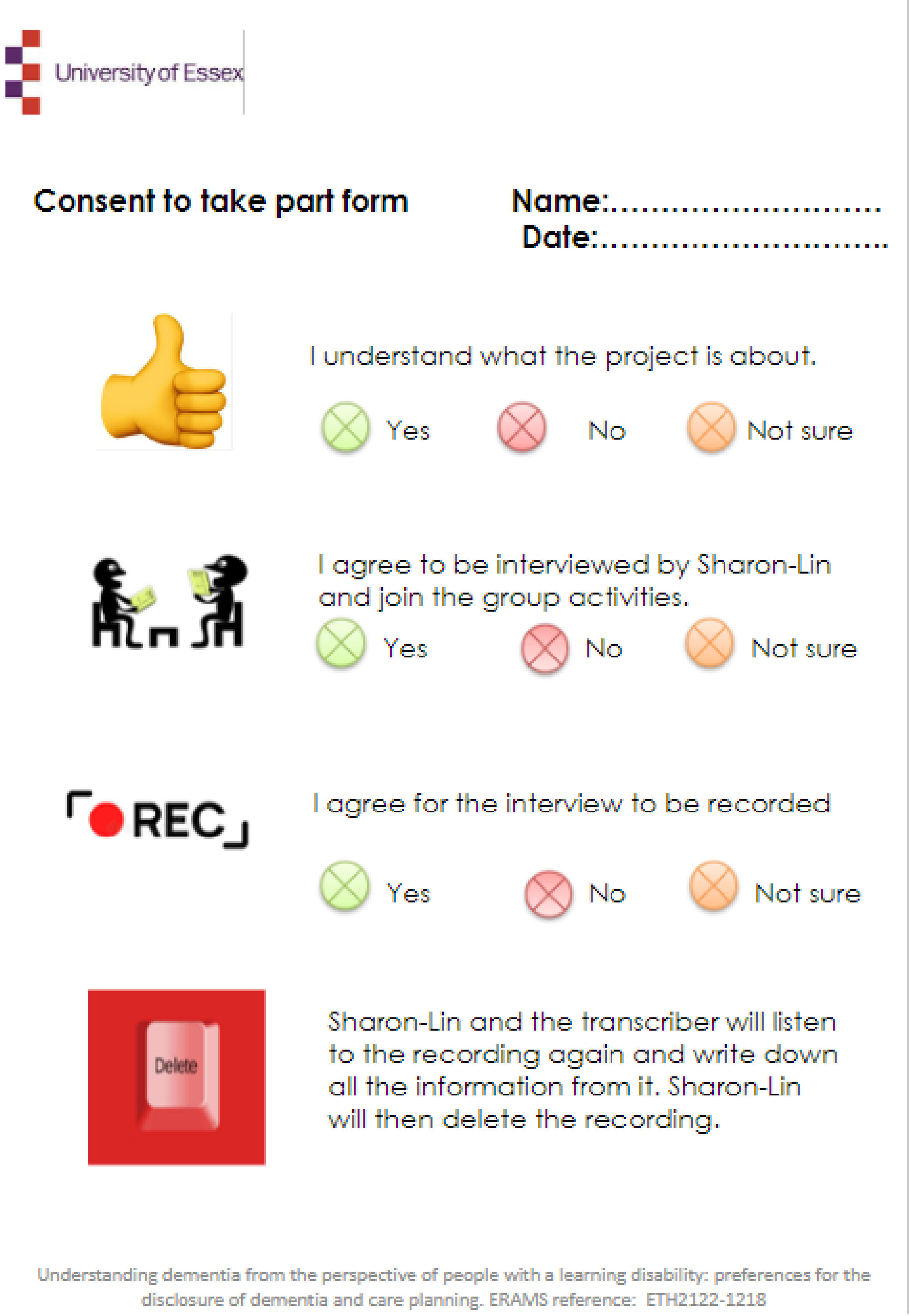
Name............................. **Date...........................**

I understand what the project is about.

⊗ Yes ⊗ No ⊗ Not sure

You will receive a copy of this form

Appendix D. Consent to Take Part Form.



University of Essex

Consent to take part form

Name:..........................
Date:............................

I understand what the project is about.

⊗ Yes ⊗ No ⊗ Not sure

I agree to be interviewed by Sharon-Lin and join the group activities.

⊗ Yes ⊗ No ⊗ Not sure

I agree for the interview to be recorded

⊗ Yes ⊗ No ⊗ Not sure

Sharon-Lin and the transcriber will listen to the recording again and write down all the information from it. Sharon-Lin will then delete the recording.

Understanding dementia from the perspective of people with a learning disability: preferences for the disclosure of dementia and care planning. ERAMS reference: ETH2122-1218

University of Essex

Consent to take part form

Name:..........................
Date:...........................

I understand that all the information I give will be kept safe and private. Sharon-Lin, Alison, Stephen and the transcriber will not share it with anyone else.

⊗ Yes ⊗ No ⊗ Not sure

MY NAME
✖

I agree that anything I say can be used in the report. My name will not be used.

⊗ Yes ⊗ No ⊗ Not sure

Sharon-Lin will use a secret name for me. This means no one will know I said anything. It is like wearing a disguise. I can pick my own secret name.

My secret name is:

____

⊗ Not sure ⊗ Sharon-Lin can choose

Appendix E. Ethical Approval from the University of Essex.

University of Essex

22/12/2022

Miss Sharon-Lin Harwood

Health and Social Care

University of Essex

Dear Sharon-Lin,

Ethics Committee Decision

Application: ETH2122-1218

We are pleased to inform you that the research proposal entitled "Understanding dementia from the perspective of people with a learning disability: preferences for the disclosure of dementia and care planning." has been reviewed by the Ethics Sub Committee 2, and, based on the information provided, it has been awarded a favourable opinion.

The application was awarded a favourable opinion subject to the following **conditions**:

Extensions and Amendments:

If you propose to introduce an amendment to the research after approval or extend the duration of the study, an amendment should be submitted in ERAMS for further approval in advance of the expiry date listed in the ethics application form. Please note that it is not possible to make any amendments, including extending the duration of the study, once the expiry date has passed.

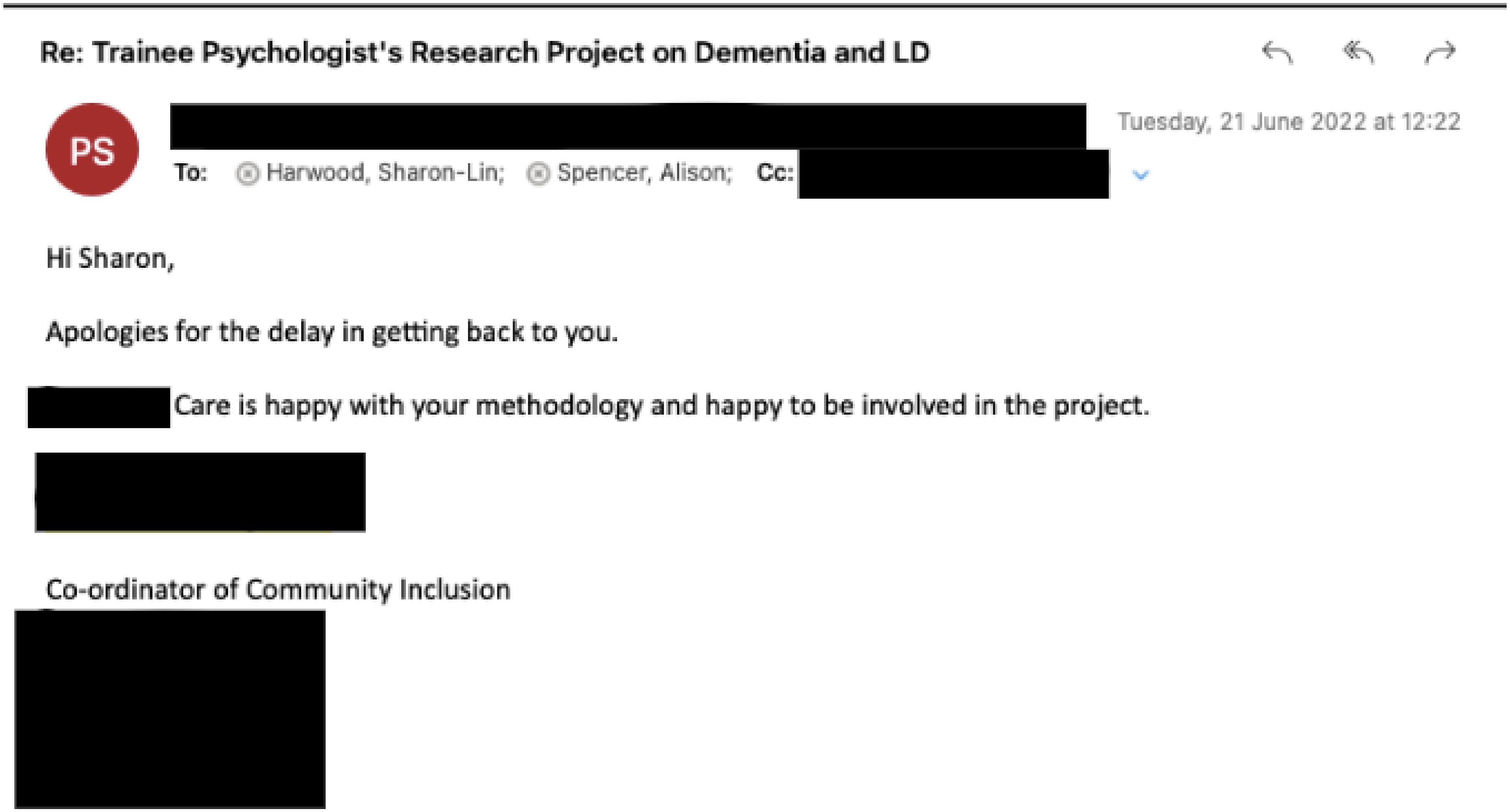
Covid-19:

Please note that the current Government guidelines in relation to Covid-19 must be adhered to and are subject to change and it is your responsibility to keep yourself informed and bear in mind the possibility of change when planning your research. You will be kept informed if there are any changes in the University guidelines.

Yours sincerely,

REO Research Governance team

Appendix F. Approval from the Day Centre Manager and Commissioners.



Re: Trainee Psychologist's Research Project on Dementia and LD

PS [redacted] Tuesday, 21 June 2022 at 12:22

To: Harwood, Sharon-Lin; Spencer, Alison; Cc: [redacted]

Hi Sharon,

Apologies for the delay in getting back to you.

[redacted] Care is happy with your methodology and happy to be involved in the project.

[redacted]

Co-ordinator of Community Inclusion

[redacted]

Wed 18/01/2023 11:23
[redacted]
RE: Research enquiry [redacted]
To Harwood, Sharon-Lin
Cc [redacted]
You forwarded this message on 18/01/2023 11:52.

Hi Sharon-Lin
Now that we have had confirmation that the prize draw offer has been removed, I can confirm that our senior management team for Adults has approved this research. As such it can go ahead.
If you need anything else, please let me know.
Kind regards,
[redacted]

From [redacted]
Sent: 18 January 2023 09:11
To [redacted]
Subject: FW: Research enquiry [redacted]

Hi [redacted] please see below from Sharon for a response

[redacted] – Team Manager – CTPLD
[redacted]

From: Harwood, Sharon-Lin <sh21580@essex.ac.uk>
Sent: 18 January 2023 08:59
To [redacted]
Subject: RE: Research enquiry [redacted]

Hi [redacted]

Apologies for the delayed response, I was trying to access additional funding. At this point in time, it will not be possible to reimburse all participants. As such, I will remove the prize draw for participants.

Would it be possible to get written confirmation that [redacted] council have approved the research? This could be in the form of an email.

Bw,

Sharon-Lin

Appendix G. Topic Guides for the One-to-One Interviews and Focus Groups.

Topic Guide for Phase One: One-to-One Interviews.

- What happens to people when they get older?
    - Prompt: what happens to people’s thinking? What happens to people’s memory? How would the help a person needs change day-to-day
- Do you know what dementia is?
    - What does it mean? Have you known anyone with dementia?
- What is difference between normal old age and dementia?
- What happens to people with dementia?
    - What happens to their thinking? What happens to their memory? How would the help a person needs change day-to-day?

Topic Guide for Phase Three: Focus Groups.

- From our learning session earlier, what can you tell me about dementia?
- What’s the difference between dementia and normal ageing?
- Should people with learning disabilities be told if they have dementia?
    - Prompts: Why / why not? What would be helpful about knowing about dementia? What would NOT be helpful about knowing about dementia?
- Who else should know about dementia if someone gets it?
    - Friends? Family? Carers? Why?
- If someone did want to know about their dementia, how should they be told?
    - Prompt: How should they be told eg. Pictures, written? Who should go to the appointment with them?
- If a someone got dementia, how do you think they would you like to be cared for?
    - Prompt: Where might they want to live? Who might they want to live with them?
- What would be important for carers to know when supporting people with learning disabilities and dementia?
- Do you think other people with a learning disability should learn about dementia?
    - Why / why not?

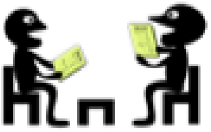
Appendix H. Study Leaflet.

University of Essex

RESEARCH PARTICIPANTS NEEDED!

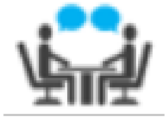
This project will ask people with learning disabilities about dementia and how they think people with a learning disability and dementia should be treated.

Don't worry if you do not know what dementia is, we will learn about it together.



You will meet the researcher at your daycentre 3 times. She will bring someone from her work to help her.

1 The researcher will talk to you by yourself.

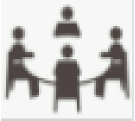


↓

2 You will learn about dementia in a group.

↓

3 You will talk about dementia in a group.



Tell a member of staff if you would like to join in.
The researcher will contact you.

Understanding dementia from the perspective of people with a learning disability: preferences for the disclosure of dementia and care planning. ERAMS reference: ETH2122-1218

Appendix I. Psychoeducation Resource about Dementia.

HELEN AND ANN

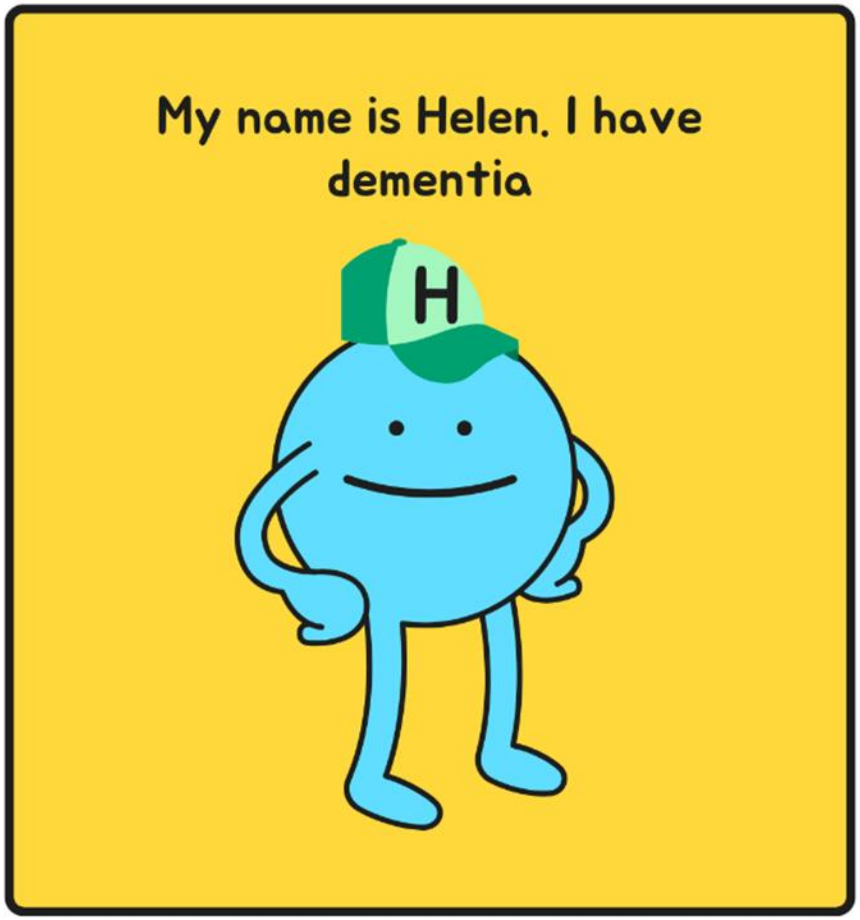
Helen and Ann are 60 years old and have been friends for many years.

Helen has been told by a doctor that she has dementia. Ann is ageing normally.

They enjoy walking, shopping and going to bingo together.

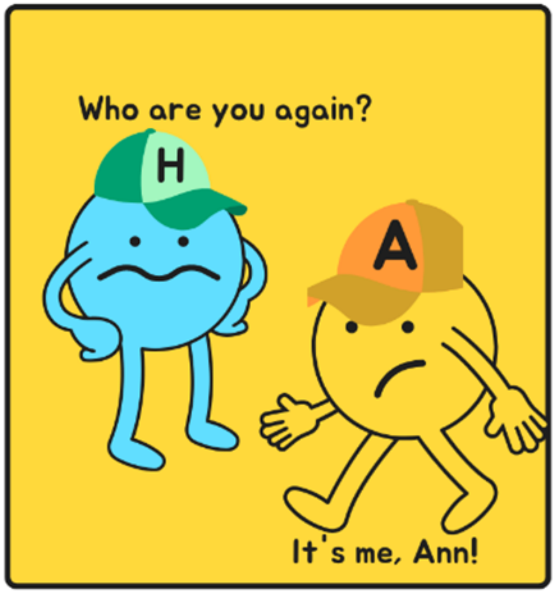
Let's join them on some activities to see what the difference is between dementia and normal ageing.

HELEN'S DAY OUT



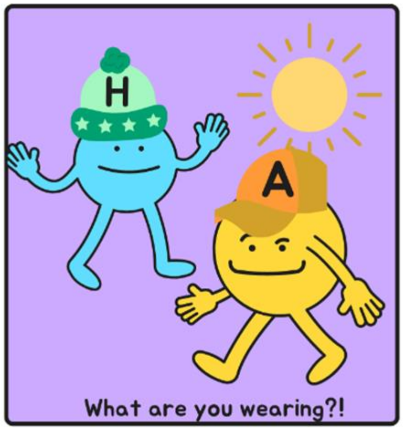
HELEN GOES FOR A WALK

Every morning, Helen and Ann go for a walk. Helen forgets where she is. This is dangerous because sometimes she gets lost.



Helen can forget who Ann is, even though they have been friends for many years. This makes Ann sad and Helen feels confused.

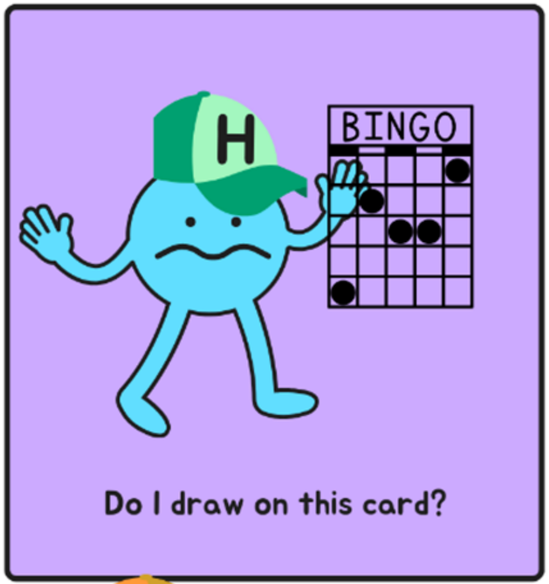
HELEN GOES SHOPPING



Helen and Ann go shopping together and it's very sunny outside. Helen decides to wear a big coat, fuzzy hat and gloves even though it's very warm. Ann thinks this is a bit strange.

When they are at the shops, Helen finds it difficult to plan what food she needs for the week. She ends up buying too much food.

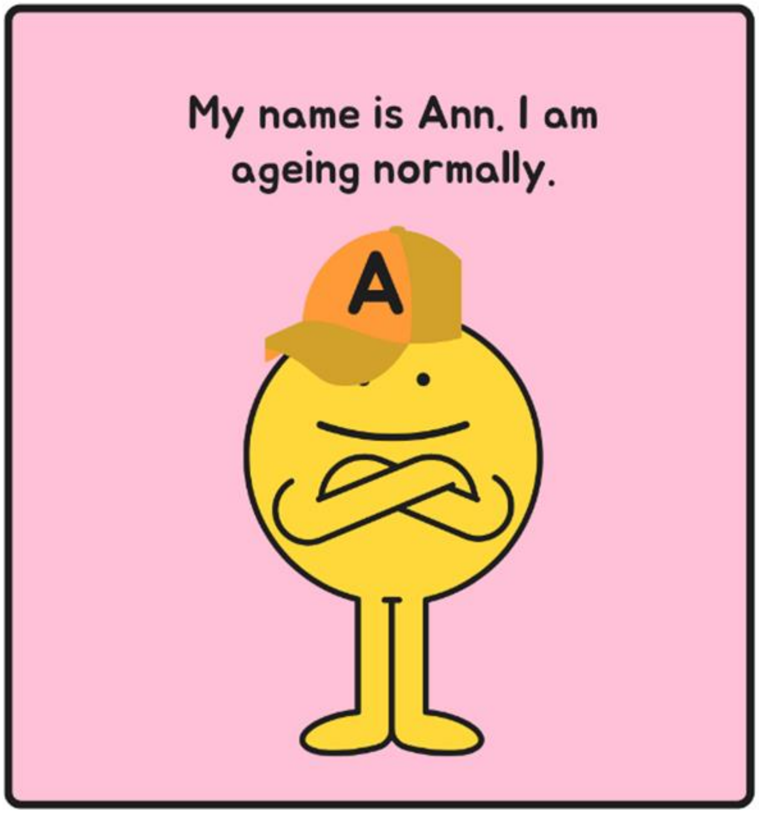
HELEN GOES TO BINGO



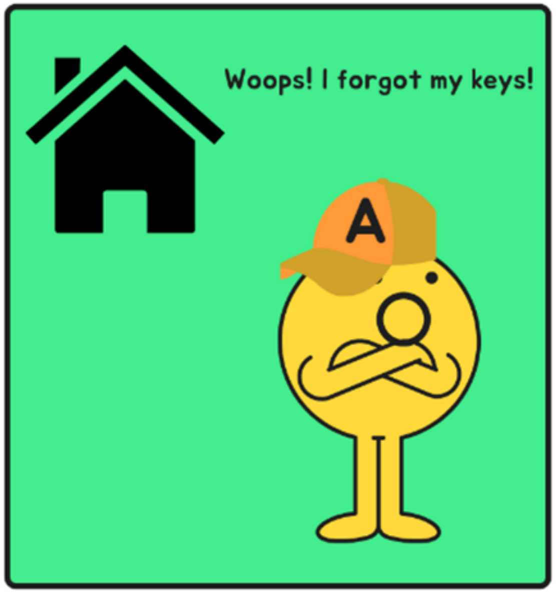
When they go to bingo, Helen gets confused about what she needs to do with her bingo card.

Helen decides to leave early. She does not enjoy bingo anymore. Ann finds this strange because Helen has always loved bingo.

ANN'S DAY OUT



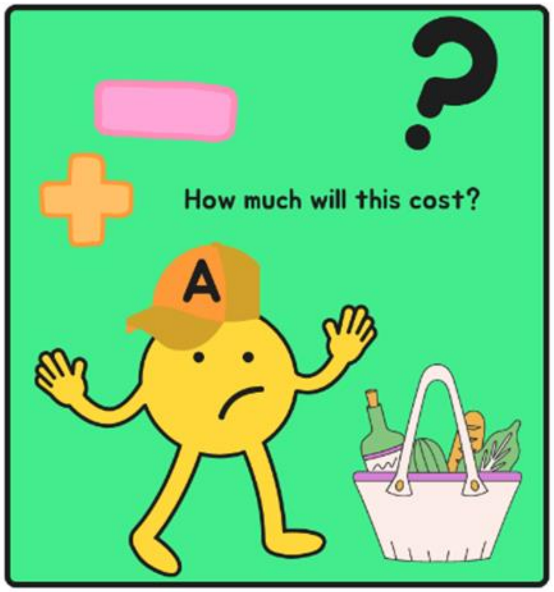
ANN GOES FOR A WALK



When they go for a walk, Ann sometimes forgets her keys at home. A common mistake we all make!

Ann sometimes struggles to find words when chatting to Helen. This does not bother Ann too much, because she can always find another word to use.

ANN GOES SHOPPING

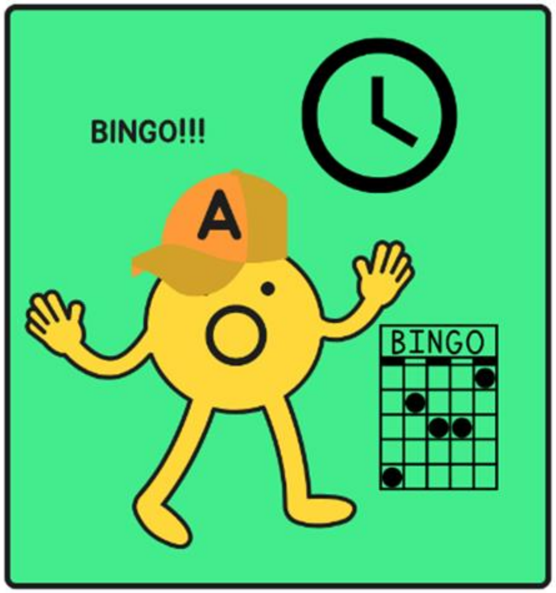


Ann used to be quick at maths when she was younger. Now it takes her longer to work out how much her shopping costs.

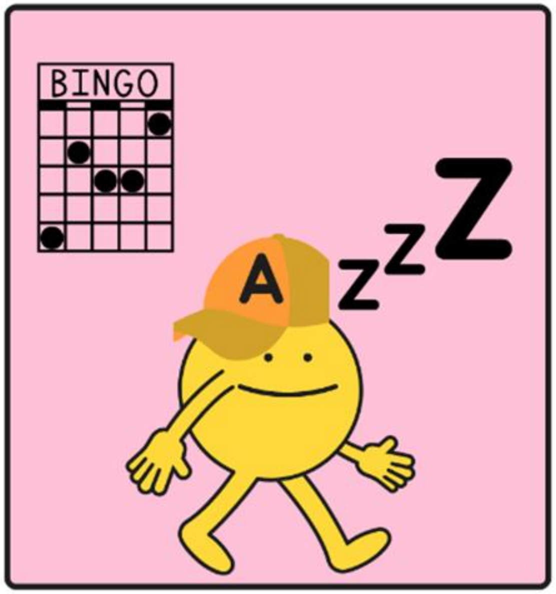
Ann tries to use her new smartphone to work out the price of the shopping. The new phone is hard to use.

Ann is able to follow instructions from the shop assistant who tells her how to use the phone.

ANN GOES TO BINGO

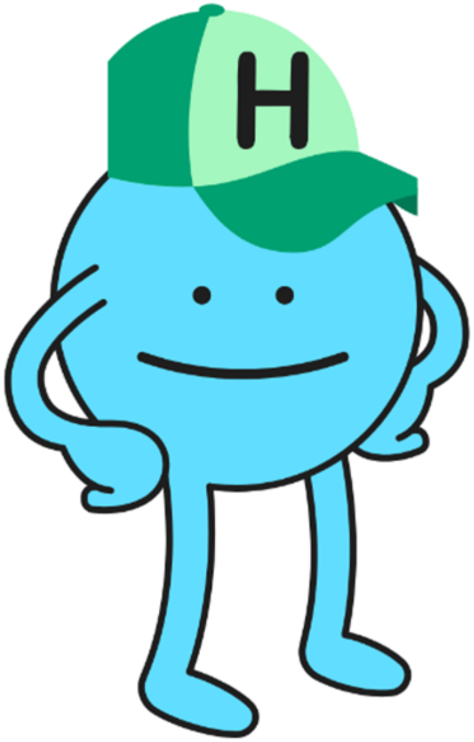


At bingo, Ann has noticed that she takes longer to realise she has a won.



Ann decides to leave bingo early because she is feeling tired. She still enjoys playing bingo.

WHAT IS THE DIFFERENCE BETWEEN HELEN AND ANN?



Dementia means BIG changes.

Normal ageing means small changes.

WHAT HELP DOES HELEN NEED?

Because Helen has dementia. She needs more support.

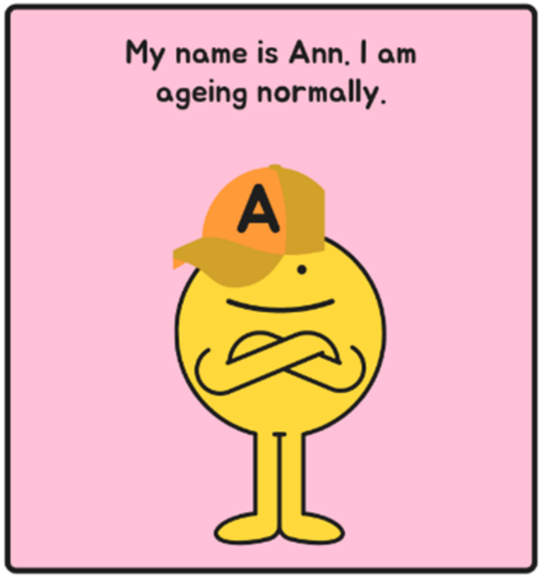
Someone like Helen, might need someone to be with them when they leave the house so that they do not get lost.

Someone like Helen, might need help to get dressed to make sure they are wearing the right clothes.

Someone like Helen, might need help with cooking and cleaning because planning is hard.

Someone like Helen might stop doing their hobbies because they are confused and their personality has changed.

WHAT HELP DOES ANN NEED?



As we age, we all need more support. This is very normal.

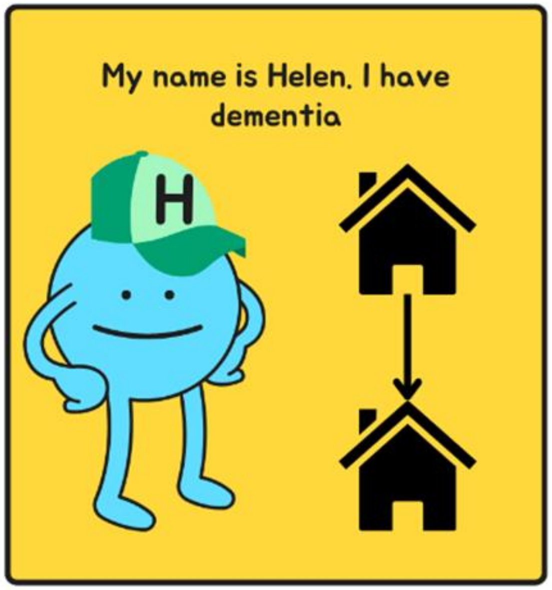
Someone like Ann, might keep her keys in a special place so she does not forget them.

Someone like Ann, might ask friends to be patient with her when she forgets words.

Someone like Ann, might need more time to think about difficult questions.

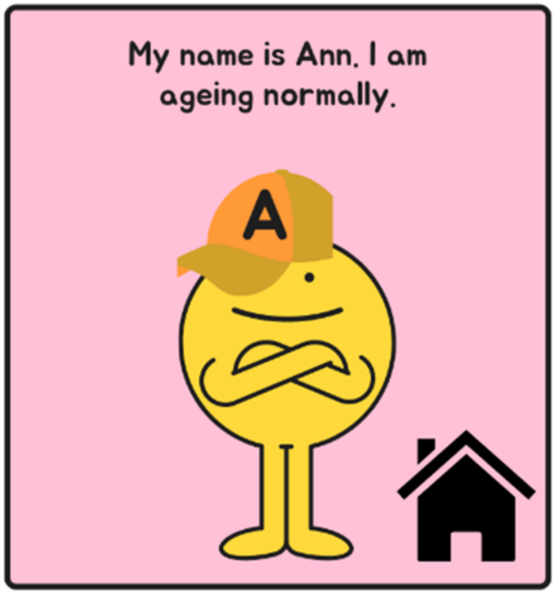
Someone like Ann, might enjoy the same hobbies but have to leave earlier because they are tired.

WHAT HELP DOES HELEN NEED?



Because dementia gets worse over time and there is no cure for it yet, a lot of people like Helen move to a care home. This means they have special support, day and night.

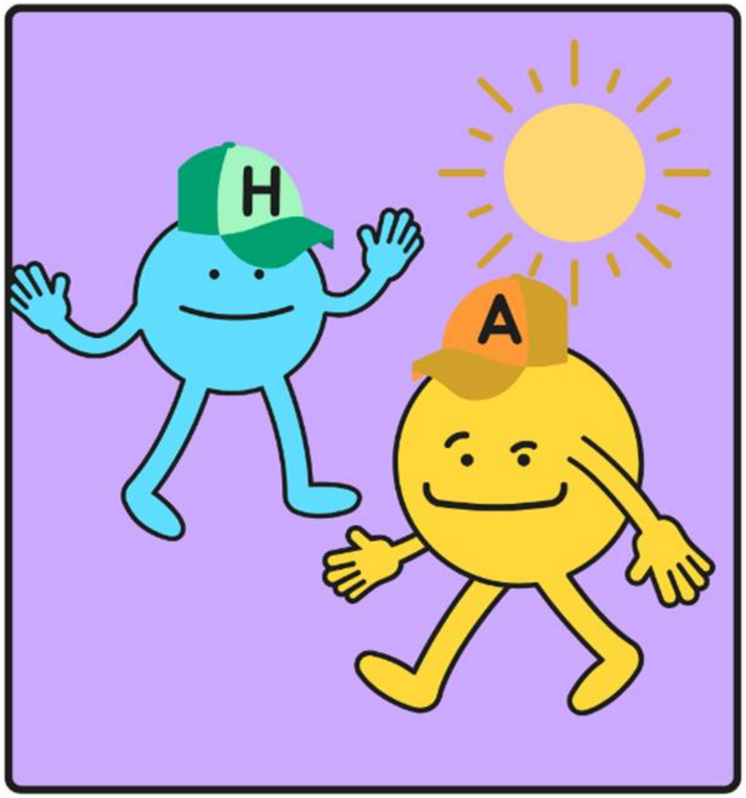
WHAT HELP DOES ANN NEED?



When people age normally, they only need a little bit more support.

This means they can live at home.

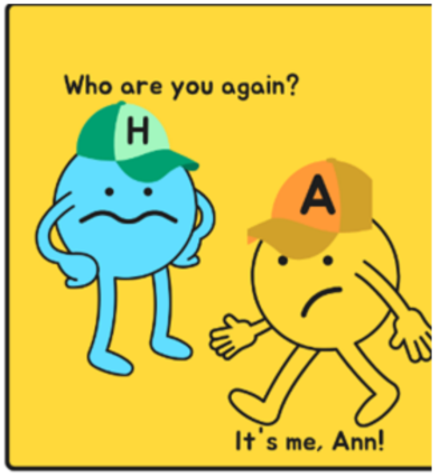
HELEN AND ANN ARE STILL FRIENDS



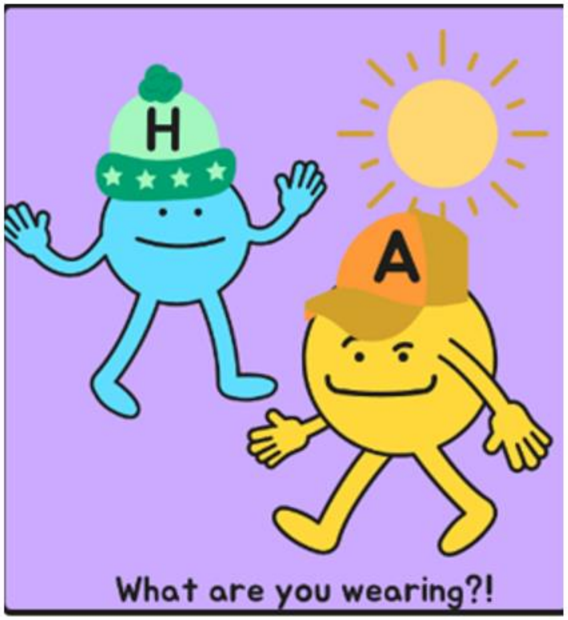
Even though Helen has dementia, her and Ann are still good friends. They still walk, shop and play bingo together. Ann helps Helen when she is struggling.

RECAP: DEMENTIA

Getting lost in places they know well

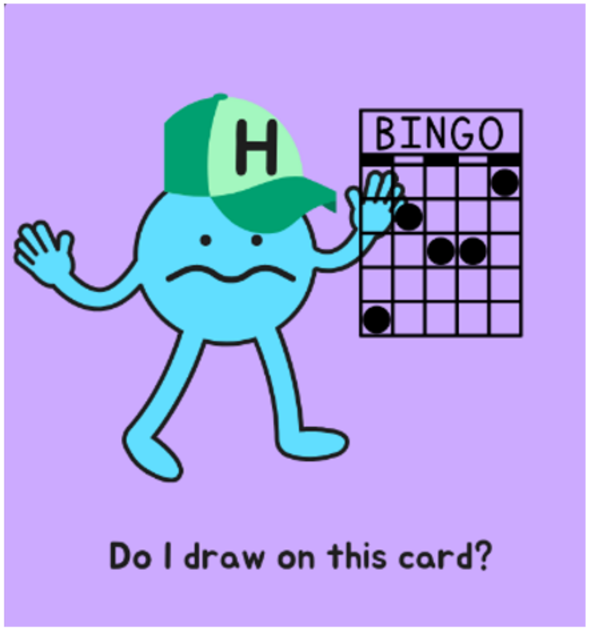


Forgetting who people are

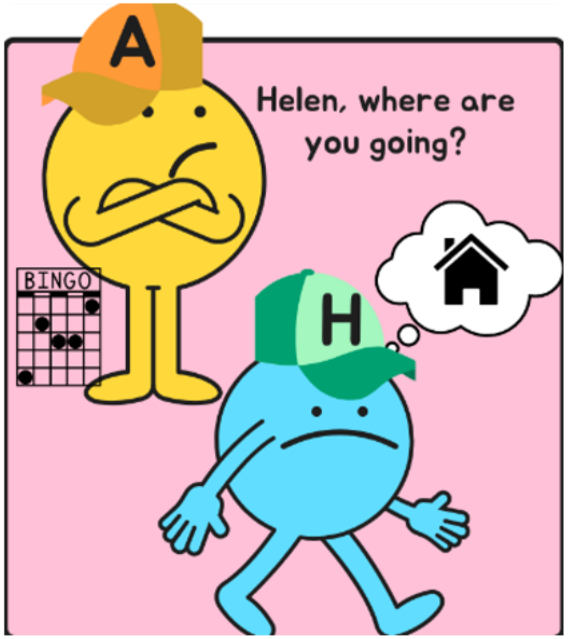


Might need help getting dressed, using the phone or brushing teeth.

Planning becomes difficult



Forgetting how to do things and talk to people



Changes to what they like and don't like

Appendix J

07/03/2023

Reflections from AM interviews

- Understanding of dementia seems to differ between people who have known someone with dementia vs those who have never observed someone with dementia.
- Physical changes of ageing more apparent.
- When doing psychoed group think about common tasks that might change over time eg. Making tea.

21/03/2023

Reflections from PM interviews

- A few people didn't turn up. Curiosities around why
  - Reliance on other people bringing them to appointments
  - Not realising or able to retain how many sessions there was going to be?
- Interesting common feature to other interviews eg. Know someone with dementia increases understanding.

25/05/2023

Focus group reflections

- Good retention of information learnt from psychoed session. What were the barriers to them learning before? Lack of LD friendly information.
- Dementia as a worst-case scenario, no narrative around living well with dementia. Room seemed low energy, more solemn when talking about dementia.
- When talking about care planning process for dementia everyone really engaged, had lots of information about this process. Probably different to general population.
- When talking about dementia care usually spoke about how it would impact multiple people. "everyone needs to" "they'll all want". Suggesting systematic impact of dementia.