

LIVING WITH DEMENTIA

JOURNEY MAPPING

FINAL REPORT

27 FEBRUARY 2026

This document provides the Australian Institute of Health and Welfare (AIHW) with a summary of the completed data collection phase of the *Journey Mapping Sub-Study* (Journey Mapping project) by the Centre for Ageing Research and Translation at the University of Canberra.

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SUMMARY

Dementia is a leading cause of disability and death in Australia, with a growing impact on the health and aged care system (Australian Institute of Health and Welfare [AIHW], 2025). Despite this, there remains limited direct evidence of the lived experience of people living with dementia as they navigate the time after receiving a diagnosis and post-diagnostic support. The Journey Mapping Sub-Study of the Living with Dementia Survey was undertaken to address this gap by interviewing people living with dementia across Australia to understand their experiences at key stages from awareness through to ongoing management.

A total of 46 people with dementia completed a journey-mapping interview, and 24 of them were supported by a care partner or family member. Participants included people with and without care partners and from a range of geographic areas. Interview questions asked participants to share their experiences of noticing early changes, seeking help and receiving a diagnosis, navigating life and supports after diagnosis, ongoing management of dementia, and reflecting on one key message about what it is like to live with dementia.

The findings are intended to inform service improvement and policy implementation, including actions under the National Dementia Action Plan 2024-2034, while recognising that experiences of dementia are non-linear and vary across individuals and contexts.

This report reveals the findings and key messages from interviews with people with dementia and care partners in Australia:

- **Early symptom recognition:** People with dementia often delay help-seeking until a significant event occurs, and misattribute symptoms of dementia to ageing, stress or other health issues.
- **Barriers when initially seeking help:** General practitioners (GPs) frequently dismissed concerns or attributed symptoms of dementia to other conditions (including ageing or other health issues), leading to delays in referral to specialists and diagnoses.
- **Challenges receiving a diagnosis:** Access to specialist assessments was challenging, with long wait times, inconsistent referral procedures, and confusion around the testing and assessment process.
- **Inadequate communication at diagnosis:** Most people with dementia did not receive a clear explanation of their condition, or it was provided in an abrupt and insensitive way. Written information on their condition or what to do next was also lacking. Information was usually limited to a flyer or verbal advice to contact Dementia Australia. The lack of tailored information and support at diagnosis was a key concern for many and compounded uncertainty in the period immediately following diagnosis.
- **Emotional impact and adjustment to living with dementia:** Initial reactions ranged from shock and grief to temporary relief. Adjustment was often prolonged and compounded by uncertainty about prognosis and a lack of structured, reliable support.
- **Difficulty navigating the system:** Government-funded supports, including My Aged Care (MAC), the Commonwealth Home Support Program (CHSP), Home Care Packages (HCP), and the National Disability Insurance Scheme (NDIS), were described as confusing and slow, with long wait times and inconsistent and unreliable processes. These complex systems were described as disproportionately

impacting people living with progressive cognitive impairment and negatively affecting care partners and families.

- **Challenges with ongoing management:** Progression of symptoms led to fatigue, falls, and social withdrawal and increasing impairment with activities of daily living. Driving cessation represented a major loss of independence, and people were poorly supported with alternatives. Most participants were not offered rehabilitation or reablement support to maintain their abilities for longer.
- **Unmet needs and system gaps:** People with dementia and care partners highlighted fragmented care, lack of psychosocial support, and lack of appropriate services for young-onset dementia. Several participants called for coordinated, person-centred pathways similar to those in cancer care.
- **Value of peer support and key people:** Peer groups and empathetic professionals (e.g., GPs, social workers, Dementia Australia dementia support specialists) were highly valued enablers for some participants, reducing isolation and helping navigate complex funding applications.

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BACKGROUND

Dementia is one of the leading causes of disability and loss of independence amongst older Australians. In 2024, an estimated **425,000 Australians were living with dementia** (AIHW, 2025), a number that is expected to grow as the population ages. Dementia has significant impacts not only on people with dementia, but also on the people who care for them, their families, communities and society. In 2023, dementia became the **leading cause of death in Australia**, with nearly 17,400 deaths attributed to the condition, accounting for almost 1 in 10 deaths that year (AIHW, 2025).

To respond to this growing challenge, the Australian Government Department of Health, Disability and Ageing developed the [National Dementia Action Plan for Australia 2024-2034](#). This ten-year plan, created in partnership with state and territory governments, sets out a national vision for an Australia that understands dementia and supports those living with the condition to have the best possible quality of life (AIHW, 2023). The plan also reflects Australia's commitment to the **World Health Organisation's (WHO) Global Action Plan on the Public Health Response to Dementia 2017–2025**.

The National Dementia Action Plan 2024-2034 has eight action areas, including three that are the central focus of this research report:

- [Improve dementia diagnosis, and post-diagnostic care and support](#)
- [Improve treatment, coordination and support for people living with dementia](#)
- [Support carers of people living with dementia](#)

Although several national surveys collect information on the experiences of older Australians and care partners, there remains a **significant gap in understanding the direct experiences of people living with dementia**.

To address this, the Living with Dementia Survey (LwDS) was established through a partnership between the Australian Institute of Health and Welfare (AIHW) and the University of Canberra's Health Research Institute (HRI) and Centre for Ageing Research and Translation (CARAT). The survey was open from May 2025 to January 2026 and collected information from people with dementia and their informal care partners about their experiences with health, aged care, and community services.

The **Journey Mapping project** is an additional part of this work. The project aimed to better understand the day-to-day needs and experiences of people with dementia and care partners over time, with a focus on informing improvements to the care they receive. Journey mapping is a research method used to understand a person's full experience of care, capturing the practical, emotional and administrative aspects of navigating health and aged care systems. It has been widely used to identify gaps in care by highlighting fragmented care pathways, knowledge limitations among care providers, poor communication and information sharing, and ineffective healthcare policies (Davies et al., 2023). Journey mapping research helps identify when and where people need the most support. For example, a recent Australian study

(Brookman et al., 2025) used this approach with informal care partners of people with dementia. The study identified three key periods of need: at diagnosis, initiating in-home care, and transition to residential care. Identifying that these time-sensitive needs are often foreseeable, journey mapping can inform the design of timely, staged supports across the dementia trajectory.

To our knowledge, in Australia, no journey mapping studies have focused on including the voices of people living with dementia. This project addresses that gap by examining experiences across key stages of the dementia journey to build a fuller picture of care over time and across settings (Hirschman & Hodgson, 2018; Ly et al., 2021).

OBJECTIVES & PURPOSE

The aim was to use journey mapping to better understand how people with dementia experience the health and aged care systems in Australia, from symptom awareness and diagnosis to post-diagnostic care and ongoing management. Journey mapping is a research approach which captures experiences at key transition points across a person's pathway through health services. It is designed to identify barriers, challenges and stress points rather than to represent average experiences. These findings are intended to complement quantitative data from the Living with Dementia Survey. The objectives of this project were to:

- Identify key transition points, challenges and gaps in dementia care and services;
- Describe the experiences of people with dementia and care partners when navigating the health and aged care systems; and
- Examine factors that enhance the overall experience of care across specific groups of people with dementia and their care partners.

The findings will help identify opportunities for system improvement to support better outcomes for people with dementia and those who care for them. The voices of people with dementia and their care partners are set forward in this report, highlighting areas for improvement in the health and aged care systems to inform the implementation of the National Dementia Action Plan 2024-2034.

METHODOLOGICAL FRAMEWORK

The Journey Mapping interviews were flexible, guided by three key ideas:

- **Navigating a winding path:** People with dementia and their care partners often encounter unexpected twists and turns when seeking support, and sometimes finding and accessing the right supports comes down to luck (Brookman et al., 2025; Alzheimer's Society, 2024). Our advisory group likened this to a

game of Snakes and Ladders, where Snakes are unexpected setbacks, and Ladders help move you forward.

- **Transitions and transition points:** For people with long-term health conditions like dementia, there are key moments and transition points across the dementia pathway, often when changing between health practitioners or care settings, or when support needs change as health conditions progress (Rojas-Smith et al., 2014).
- **Needs:** What people with dementia require for their health, comfort and wellbeing (Green & Kreuter, 1992) encompasses both needs they express directly and indirectly, and gaps in support or services they may not have identified themselves.

METHODS

Participants

The Journey Mapping project interviewed 46 people with dementia from across Australia who previously completed the Living with Dementia Survey and consented to further participation in research. Twenty-four participants chose to be interviewed alongside a care partner (usually a spouse or partner), who also shared their insights during the interview.

When selecting participants for Journey Mapping, we aimed to capture a broad range of experiences. To do so, we looked at participant responses to several LwDS questions relating to:

- Dementia diagnosis
- Post-diagnosis treatment/services
- Stigma
- Coordination of care

Participants were grouped based on their survey responses into those with challenging experiences, smooth experiences, and those with mixed experiences. As the purpose of the Journey Mapping project was to identify critical moments and opportunities for improvement within the health system, more participants with challenging experiences were prioritised for inclusion. The final sample included:

- **Twenty-three with comparatively challenging experiences;**
- **Thirteen with comparatively smoother experiences; and**
- **Ten with experiences that were mixed, or that were neither notably challenging nor smooth.**

Minimum quotas guided recruitment to ensure inclusion of people from different states and territories, age groups, and backgrounds, as well as people using different types of health and aged care services.

Participants had a range of dementia types, with Alzheimer's disease being the most common. The average age of participants was 74 years (range: 53-89), and eight participants were aged 65 or below. The sample included 24 women and 22 men. Participant quotas and characteristics are presented in Table 1.

Table 1 – Journey mapping quotas and participant characteristics

CHARACTERISTIC		MINIMUM QUOTA	ACTUAL QUOTA
Gender	Male	15	22
	Female	15	24
Remoteness	MM1 Metropolitan areas	10	28
	MM2 Regional centre	5	7
	MM3 -MM7 Rural, remote and very remote	5	11
Service System Utilisation	Aged care (includes MAC/CHSP, HCP, Aged Care Assessment Service)	5	28
	NDIS	3	10
	Hospital (excluding outpatient) services	5	24
	Commonwealth-funded Dementia specific services (includes Dementia Australia, DBMAS, Staying At Home program)	5	38
State/ Territory	Other	5	42
	Primary Care (Includes GP, PHN)	5	46
	Care partner services	5	14
	New South Wales	10	13
	Victoria	7	9
	Queensland	7	9
	Western Australia	4	4
	South Australia	3	4
	Tasmania	3	4
	Northern Territory	3	1
Other	Australian Capital Territory	3	3
	Culturally and linguistically diverse background	10	6
	Aboriginal/Torres Strait Islander	5	3
	Participants with no care partner	10	10
Time elapsed since diagnosis	Without a formal diagnosis/Less than 6 months post diagnosis	5	5
	Between 6 months and 2 years post diagnosis	5	14
	2 or more years post diagnosis	5	27

Data Collection

Data collection for the Journey Mapping Sub-Study commenced on the 29 September 2025 and was completed on the 2 November 2025. Most interviews (35 of 46) were conducted in person at Dementia Australia offices or other locations, with the remainder (11 interviews) conducted online via Zoom. Interviews lasted an average of 69 minutes (range: 26-122 minutes), yielding a total of 52.7 hours of interview data. A conversational, semi-structured approach was used, guided by visual supports showing the dementia pathway and available supports. Participants were asked about their experiences at each stage of the dementia journey. We used four overarching questions to introduce each phase of the interview:

1. We'd like to begin by talking about your experience prior to receiving a diagnosis of dementia. What was it like when you first noticed changes/became aware that something had changed?
2. We would like to explore how you came to receive a dementia diagnosis and what this experience was like. Can you tell me about what this process was like for you?

3. Can you tell me about your experience following your diagnosis? How did you navigate this?
4. Can you tell me a bit about your experience with the ongoing management of dementia?

Before completing the interview, we asked: If there was one thing that you think people need to understand about what it's like to live with dementia, what would that be?

Data Analysis

Interviews were recorded and transcribed, reviewed and de-identified before analysis. The research team analysed the data to identify patterns in experiences, as well as key transitions, challenges, barriers and enablers across the dementia pathway. To ensure academic rigour, the research team used a framework analysis to organise findings by journey stage and by topic, with attention to the principles of credibility, transferability, dependability, and confirmability.

Findings were further validated at three feedback workshops with an advisory group of five members with lived experience and/or professional expertise relevant to the project. Advisory group members were selected to represent different stakeholder groups and to provide feedback on themes in the data, experiences, and proposed recommendations. Advisory group feedback was used to guide the project design and ensure interpretations were contextually accurate and aligned with their lived experience and expertise. This validation process strengthened the credibility, trustworthiness, and applicability of the findings.

RESULTS

The results section provides a comprehensive overview of the qualitative findings from the interviews and aligns with the journey-mapping graphical representation. Findings are presented under four overarching key stages: 1) Awareness; 2) Diagnosis; 3) Care after diagnosis; and 4) Ongoing management. Within each key stage, prominent themes from the data are summarised narratively to highlight common patterns. Illustrative quotes from people with dementia and their care partners are used to contextualise and enrich the findings, ensuring they remain grounded in lived experience and the nuance of individual journeys.

Key stages are presented chronologically; however, not all participants experienced them in the same order. There was considerable variability in the experiences of people living with dementia through these stages, particularly regarding accessing care after diagnosis and ongoing management. Many people living with dementia had multiple comorbidities or concurrent health conditions, meaning they simultaneously accessed health and support services to address other complaints. The progressive but variable nature of dementia meant that pathways were non-linear, and participants often moved between stages or revisited transitions as their symptoms progressed, resulting in variability in care journeys.

Awareness

This section explores how people first noticed changes in memory and thinking, and the factors influencing whether they recognised these changes as concerning and decided to seek help. The findings describe the early, often subtle signs that prompted awareness and how these were understood by people with dementia and the people supporting them.

Recognition of early signs and symptoms

Recognition of early signs and symptoms of dementia was generally gradual and involved noticing cumulative instances of difficulty with activities of daily living that were noticeably different from before. The most commonly reported early symptom was impaired memory or attention (n=30), whilst around a third of people with dementia experienced word-finding difficulties and/or executive functioning challenges.

The thing I noticed most was words, specific words, like sort of technical, musical words, because I was teaching music and using vocabulary that I've been using since I was about five. And I'd get to a point in an explanation or something to a class, and I just couldn't get the word. (Participant #24, female, 78 years)

Twenty-nine participants recalled early impairment in instrumental activities of daily living, with common concerns including managing appointments, finances and medication, and using technology. Eleven participants reported incidents whilst driving, ranging from minor difficulties with wayfinding to car accidents. Those who were still in the workforce at the time of symptom onset (n=11) reported that their

early symptoms noticeably impaired their performance at work. This was more common for those with young-onset dementia.

Early symptoms were rarely associated with the possibility of dementia and were rationalised as being related to other symptoms or other causes. Early symptoms were frequently misattributed by participants to other comorbidities, menopause, stress or being busy. Some participants (n=5) reported noticing changes but initially considered them a normal part of ageing. Those with a family history of dementia were more likely to consider that their early symptoms could be indicative of this.

I'd probably put it down to my age. That was my kind of excuse as such. And, you know, didn't worry about it. I'm getting older, I'm in my late 70s or what have you. Yeah, everyone forgets, at least I'm still alive. So that, I think, is the way I would kind of virtually dismiss it. (Participant #18, male, 80 years)

I didn't think I had a problem. I thought, you know, it's just, I'm forgetting things. I've got a lot on my mind. I was a busy man. I was making excuses. (Participant #44, male, 68 years)

Masking of early symptoms was commonly achieved through compensatory strategies such as note-taking, lists, or reliance on others, such as family members or work colleagues, to support memory. A small number of people with dementia (n=6) experienced initial symptoms affecting movement, gait, or balance, whilst others (n=7) experienced mood and personality changes, which were often noticed by those around them first.

The decision to seek advice on changes being experienced was instigated in various ways. Many reported that there was no single factor that precipitated help-seeking and that, over time, subtle cognitive changes and cumulative incidents crystallised into an awareness that something was wrong.

It's just this gradual sort of thing. And you need to sort of accept as you go, as life goes on, I guess. I didn't notice anything. There wasn't a light bulb moment that said to me, hey, you've got a problem. It's just been a gradual, gradual decline. (Spouse of participant #45, female)

Others reported they had not recognised early symptoms themselves but were prompted by an outside party, such as a family member. Several participants (n=10) reported a single incident that led to an acute moment of awareness, necessitating immediate discussion of their concerns or seeking advice, such as driving through a red light or experiencing an acute health episode, such as a fall, acute confusion, or changes in hearing.

What happened was, I suddenly had tinnitus, went to an audiologist, and after a few tests, he sent me for an MRI. (Participant #37, female, 83 years)

Initial help seeking

This section explores the early help-seeking process, focusing on initial contact with health professionals and the pathways they took when they initially sought help.

Initial discussions with a healthcare practitioner generally occurred during a GP appointment (n=43), whilst a minority (n=3) approached other health professionals, such as specialists or audiologists. This discussion

generally prompted the GP to conduct initial investigations, which typically included a clinical consultation and tests such as cognitive screening, medical imaging (e.g., a CT scan), and blood tests to rule out other causes. Most participants reported that the outcome of initial investigations through their GP was a referral to a geriatrician or neurologist.

I went to see the GP to get a referral, and he was a little bit like, well, you sound like you're perfectly normal. It doesn't sound like there's very much wrong with you. And I'm like, yeah, but you know in your head. And he's like, well, if you know in your head...I'll refer you to a neurologist. And he did. (Participant #29, male, 63 years)

Almost half of the people with dementia encountered delays in referral to an appropriate specialist assessment at this touchpoint (n=19) and, in turn, diagnosis. Several participants had early symptoms attributed to mental health issues like anxiety or depression (n=5), or to other health conditions such as cancer, chronic fatigue or menopause (n=5).

From a memory perspective, things were going downhill probably about two years ago. But we were told at that time by the doctor it was because of anaemia...And then she was diagnosed with bowel cancer...So that's what the doctor said was the reason for the memory issues. (Daughter of participant #13, female)

Whilst these explanations were generally considered reasonable, there was a lack of clear guidance around what to do if symptoms continued to progress or did not resolve with treatment. This led to waiting until symptoms worsened sufficiently for the person to re-attempt to seek an answer to their symptoms.

In some cases, a lack of holistic assessment contributed to delays in referral for further assessment. Some people with dementia reported that, as they had scored within normal range on brief cognitive screening, their concerns were dismissed without due consideration to the functional impairment they were experiencing. This was more common for those with young-onset dementia or people with high cognitive reserve, such as individuals with high educational attainment or who had worked in complex job roles. Others reported that, as their CT scan results did not detect an abnormality, no further investigation or follow-up was recommended.

I'd raised this with my GP, and I had the usual, it's probably menopause or your chronic fatigue syndrome. And then finally, that was taken a bit more seriously, and I did a cognitive test, and that was all okay. So away we went again, but I think my husband started to notice changes as well and he said, 'Look, I really think we need to push this a bit more'. (Participant #11, female, 59 years)

Repeated dismissal of concerns was often due to a provider's knowledge gap. In some instances, this led to significant delays in obtaining a diagnosis.

So that would have been in about 2019 and 2021. I got formally diagnosed in '21, but it took me two years with my doctor. They kept on saying...you're just getting old. (Participant #25, female, 69 years)

So eventually, I think the GP ordered a CT brain. And we were told...It was just part of ageing - nothing to worry about. So, we kept on going back to the GP, saying something's wrong, you know, his balance is off, he's losing his words. And again, we were reassured until a locum [GP] looked at the CT result

and said, 'what do you know about your stroke?' (Spouse of participant #3, female)

For those whose concerns were unheard, this was a distressing and frustrating experience and, in most instances, required strong advocacy or a change in medical practitioner to overcome gatekeeping.

Well, I was frustrated, I suppose. And I really wanted to clarify it. I wasn't worried about getting a diagnosis of something. I just wanted to know what was causing this uncertainty. (Participant #24, female, 78 years)

I do remember getting a bit angry at [the GP]. And he said, 'Look, let's just leave it and we'll, I'll get, you know, for a couple of weeks and come back and see me and we'll do some more tests.' (Participant #34, male, 65 years)

Diagnosis

This section outlines people's experiences of seeking and receiving a diagnosis after initial discussions with a health professional. This includes their pathway to accessing specialist services, how the diagnosis was communicated, information and support offered, and the emotional impact of receiving a diagnosis of dementia.

Accessing specialist services for diagnosis

Almost all people with dementia were referred to a specialist for further assessment. Those living outside metropolitan areas often had more difficulty accessing specialists, with referrals taking longer to obtain or requiring travel over long distances. Participants encountered variable wait times for a specialist appointment. Wait times were generally longer in the public system than in the private system, and some participants chose to go privately to avoid the public waitlist.

Participants underwent a range of assessments during the diagnostic process. Commonly, this included cognitive assessments and neuroimaging, such as computed tomography (CT), magnetic resonance imaging (MRI), and positron emission tomography (PET) scans. Some participants also underwent lumbar puncture, electroencephalogram (EEG), and neuropsychological assessment. The extent of assessment varied considerably. Some participants underwent multiple scans or repeat testing, whilst others had a more limited assessment process. Notably, as with initial screening, several commented on the inappropriate reliance on certain investigations to rule out a diagnosis of dementia. For example, the use of the Mini-Mental State Examination (MMSE), a brief cognitive screen to rule out cognitive impairment, was noted as too basic to capture their difficulties. Others reported that a lack of evidence on neuroimaging was used to exclude the possibility of dementia.

So, I've never been beyond that basic memory test, which is, I think, a 30-point test, and I usually score 27, 28, 29 out of 30 if not fully 30. I don't know if I ever actually made 30, but it was a very high score. They didn't feel there was any cause for concern, but I mean the MRI spoke for itself. (Participant #32, male, 70 years)

For some participants, the assessment process was well explained. Others reported a lack of clear communication about the purpose of assessments or the meaning of results. Some participants noted issues

with incorrect reporting or interpretation of investigations, and as a result, they were given premature reassurance that they did not have dementia, only to receive a diagnosis later. Cost was noted as a barrier to accessing some investigations. Delays due to COVID-19 were also reported.

The initial GP, after I had my CT scan, she got the results before the neurologist had seen them and then she rang me and told me there was absolutely nothing wrong. So, then I had an appointment lined up to see the neurologist to talk through the results and I assumed that he would be saying there's nothing wrong. So, I just took my nine-year-old grandson with me and went to see the neurologist who then says in front of this little boy, 'you have Alzheimer's' and you know, 'will have a survival rate of 8 to 10 years on average'. (Participant #20, female, 59 years)

Receiving the diagnosis and treatment

Variable experiences of diagnosis and treatment were reported, and these ranged from very positive experiences of diagnostic care and support, to abrupt, impersonal and distressing experiences. Regardless of the quality of care received, getting the diagnosis was usually confronting, and in some cases, this was compounded by poor communication from specialists. Participants often came away feeling unclear about their diagnosis and what that might mean for them.

A diagnosis of Mild Cognitive Impairment (MCI) was provided to some participants (n=8), either as a primary diagnosis, an interim diagnosis prior to receiving a formal diagnosis (n=4), or, in some cases, a revision of diagnosis after an initial formal diagnosis. The terminology was sometimes used interchangeably with dementia, which was confusing. More broadly, jargon and complex medical terminology posed challenges for participants, further complicating their understanding of their diagnosis and its implications.

[The specialist] sometimes talks about mild cognitive impairment, and then she'll talk about Alzheimer's, you know, interchangeably. And I sort of wonder how far is this going to go? (Participant #24, female, 78 years)

Nearly a third of participants (n=15) reported that the diagnosis was handled in a cold or clinical manner, without adequate compassion or emotional support. Discussions focused on the cause of the disease and often included a confronting estimate of life expectancy. Specialists explained that there are no curative treatments and that little could be done, aside from taking medication that might slow symptom progression in some cases. Many were advised to 'Get your end-of-life affairs in order' (Participant #40, female, 67 years) or given information on the legal implications of the diagnosis, such as its impact on driving. For many, the key takeaway from their diagnosis was that 'nothing can be done' (Participant #44, male, 77 years). This was a highly distressing experience for some, leading to feelings of helplessness and adding to the existing emotional shock of receiving the diagnosis.

[The specialist] said, yes, well, it looks like you've got early-onset Alzheimer's, and I'm going to prescribe this drug. And he got his registrar, and he started talking to his registrar, and then he walked out of the room. That was it. I'm like, I thought, did he just say that? Like, did he just do that? I was so distressed. (Spouse of participant #23, female)

So, the psychiatrist sitting here (participant mimed holding a folder up to her face and reading from this) 'Oh, you've had your MRI. Yes, yes, you've got Alzheimer's...and that was it, and I said, hang on

a minute. I think I'd better call my husband, who's out shopping... 'She said, yes, you obviously have Alzheimer's. Now you won't be able to drive anymore unless you do the following test.' We came down the stairs from the hospital, and I just sort of collapsed in an emotional heap. (Participant #21, female, 81 years)

A minority of participants had much more positive experiences. This included examples of diagnoses made through multidisciplinary diagnostic clinics, where the diagnostic process was perceived as holistic and well-coordinated. Participants commented on the compassion with which they were treated and reported feeling emotionally supported throughout the process. Additionally, sufficient time was allocated to explain the diagnostic process, the diagnosis, and the rationale.

The whole, from the time we got here, from the time we got the diagnosis, of course, we weren't expecting [a diagnosis], but from there right through to when we walked out of there later that afternoon, I got the feeling that we were being shepherded through and the feeling was that these people understand probably a good bit of what I was going through or what we're going through. It was heartwarming. (Participant #19, male, 80 years)

She is a very, very good doctor. I find her to be an exceptional person in being able to build trust...She had a very clear, like three-step plan. It was going to be this, and then we do that, then we do scans, and then we do this. (Participant #29, male, 63 years)

Pharmacological interventions were the predominant support offered, with most people with dementia (n=29) being provided with information on medication, including their limitations and possible side effects. A smaller number of participants recalled receiving other advice on slowing the progression of dementia, including lifestyle strategies like continued socialisation, exercise and mental stimulation. Souvenaid, an oral nutritional supplement, was also recommended to five participants, who were advised that it may have possible benefits to cognition.

Almost half of the participants who commenced on medication (n=13) reported significant side effects, and generally, the medication was ceased, although some experienced challenges in receiving timely advice or support on what to do. Inadequate explanation of possible adverse reactions to medication was highlighted as a challenge by some participants, with some not connecting these symptoms to the medication for some time.

He just put me on some medication, some tablets, and they were affecting me. I had real, I had really bad dreams and nightmares and things like that. And I rang up about four or five times to be able to finally get through to talk to him to find out what to do. (Participant #39, female, 71 years)

Information and support at diagnosis

A significant challenge for many (n=30) was inadequate information or support at diagnosis. People with dementia received inadequate information about their diagnosis, and they or their care partner felt there should have been additional support provided. The results of the investigations were often insufficiently explained, and participants were unsure how the diagnosis was determined. Variability in terminology or

the use of jargon during explanations of the diagnosis led to a lack of clarity about their specific diagnosis and unanswered questions or uncertainty about the aetiology of their dementia.

I thought, I wonder...what the geriatrician had said in the report back to the GP. So, I asked her, and she said, yes, it did state there that it was mixed dementia, that it was Alzheimer's and vascular. But we weren't actually told that by the geriatrician; she just said Alzheimer's. (Spouse of participant #35)

I think when I read the report, it said frontotemporal lobe, question mark, question mark, Alzheimer's...and nobody's actually sat her [down], I think, her GP has said, 'Look, you have got Alzheimer's'. But then from there... okay, where do you go to? And that's the journey we've been on. It's like, where do you go to get some help? (Spouse of participant #33)

Whilst the life-limiting and progressive nature of dementia was generally discussed, many participants wanted clearer information on how the condition was likely to progress and the speed with which changes may occur, which contributed to fear for the future. Some commented that a clearer explanation of what to expect or watch for in the immediate period that followed would have been beneficial. Most participants recalled receiving little or no information on post-diagnostic support or where to get further advice. When this was offered, it was generally limited to a flyer or verbal advice to contact a peak body organisation for further information, which was provided to nine out of the 46 participants.

Several ways to improve the diagnosis experience were suggested. Many participants commented that the immediate provision of further information on where to seek support post-diagnosis would have been beneficial. Being directly referred to Dementia Australia following the diagnosis, receiving written information at diagnosis, information on counselling or support groups, or a checklist of what to do from here. Others felt that a follow-up session a few weeks after the diagnosis, when they had had time to process it, would have helped. Some people with dementia (n=4) and care partners (n=3) had direct or indirect experience with cancer and compared their experience of the support offered following a dementia diagnosis with the support they had received following a cancer diagnosis, to highlight the disparity and inadequate support offered.

When I had breast cancer, best service ever. Couldn't ask for better service, truly. You know, people were there with the follow-up care, the ringing, the, yeah, dementia, zilch. Absolutely nothing. (Participant #43, female, 69 years)

Participants viewed their experience more favourably when the diagnosis was delivered in a strengths-based, person-centred manner. In these instances, the information provided focused not only on biomedical aspects but also on social and psychological factors, including non-pharmacological approaches to managing symptom progression, acknowledgement of the emotional impact of the diagnosis, and provision of information or advice on post-diagnostic support and practical matters.

Participants with positive experiences were also directly linked to a key person, such as a social worker, who helped navigate the transition from diagnosis to care. This assistance included supporting participants in applying for the NDIS or other Commonwealth-funded supports, referring them to other post-diagnostic support services, such as Dementia Australia, and providing emotional support to the person living with dementia and their families. Whilst information on the prognosis was provided, including that the diagnosis

was life-limiting, realistic hope was instilled by encouraging participants to maintain agency over their lives and to make the most of their remaining time through meaningful activities and a 'bucket list'.

She said because of his age, it's likely that he will die with it rather than from it, which is a bit of a comfort in a way because it's not a very fast-moving disease at his age [...]. And then the social worker that we saw, she said, maybe it's time for you to look at your bucket list [...] and do some of the things that you've always wanted to do. (Spouse of participant #19)

Impact of receiving the diagnosis

Many participants spoke of the emotional impact of diagnosis. Many reported feeling initial feelings of denial, disbelief, shock and grief at receiving the diagnosis (n=25). Whilst most participants were aware of the possibility of receiving a diagnosis, for some, this came as a complete surprise due to a lack of clear communication or explanation of the impetus for testing.

I suppose I'd been noticing symptoms for about 18 months before I had any testing. And even then, I hadn't tweaked it was for dementia testing. So, when I went for the follow-up after I'd had the MRIs and the neuropsych testing and so on, and my neurologist said, oh, well, it's good news, you haven't got Alzheimer's. And I was like, what? You've tested me for Alzheimer's? I didn't know that's what you were doing. (Participant #40, female, 67 years)

For some, the initial emotional impact of the diagnosis was one of relief (n=14). This was particularly common among those whose concerns were initially overlooked or dismissed, or who had experienced a protracted diagnostic process. Many of these participants spoke positively about the diagnosis, as it validated their concerns and provided an explanation for their symptoms. Often this initial relief was temporary and gave way to a period of adjusting to the diagnosis, and feelings of grief and loss.

I was so happy that at last I'd had an answer to what was happening initially [...]. I thought, oh, thank God, you know, I know what it is, you know, because for me, it's knowing, it is important. And then I can move forward from there. [The specialist and neuropsychologist] they were sad to tell me, but I was so happy to be told [...]. It wasn't until probably 18 months later that I felt devastated. (Participant #43, female, 69 years)

The diagnosis could be experienced as simultaneously empowering and disempowering. Having a label for the changes they were experiencing could allow for planning and access, whilst also creating concern around autonomy and identity.

Care after diagnosis

This section explores participants' experiences in the immediate period following diagnosis, including emotional adjustment, efforts to obtain information, post-diagnostic support, and navigating services.

Adjusting to the diagnosis

Following the diagnosis, participants largely described a period of significant challenge and adjustment, during which they both contended with the emotional impact of the diagnosis and the practical challenges of obtaining further support in planning for the future. A majority of participants reported that this was a

time in which they were coming to terms with their condition and experiencing feelings of grief and loss, fear for the future and uncertainty about how to navigate the post-diagnosis period.

I was scared because, you know, I knew it happened with my parents, in particular, my father. But it was more like...There was no pathway. Where do you go? Where do you go now? And if you don't go that way, what happens. (Participant #34, male, 65 years)

The challenges of this period were compounded by limited knowledge of dementia and the lack of intervention or support offered at diagnosis. Many participants (n=23) reported turning to 'Doctor Google' to get more information, with varying levels of success. For many, this was the avenue through which they discovered dementia-specific supports, such as Dementia Australia. Locating support was often difficult, with many reporting that although they found some information online, it was not always relevant to their circumstances. Many participants noted that once they found a service that met their needs, it served as a springboard to other sources of information and support.

Once we got in touch, once I'd made contact with Dementia Australia, that sort of showed us the way and things that, different things that you could clock into and get help and whatever. (Spouse of participant #35)

Accessing supports after diagnosis and planning for the future was a non-linear process that participants revisited over time as dementia progressed, and was most stressful and demanding in the initial period following diagnosis, or when a significant change in function occurred.

Dementia Specific Support Organisations

Dementia-specific support organisations were frequently the first service to which participants were connected, either through their healthcare providers or, more commonly, through internet searches. Experiences of using these services were mostly positive. For some participants, it was a significant source of information and support. For others, it did not meet their needs, or they felt overlooked. Some reported that programs and resources were geared primarily towards care partners rather than people with dementia, or that the advice offered did not reflect their circumstances. A lack of rehabilitation support and of specific offerings for people with young-onset dementia was also viewed as a gap.

Positive experiences were often linked to individual staff members. Several participants described workers who were empathetic, proactive, and available when needed. Counselling was valued by several participants, particularly when accessible at the right time. The Dementia Australia Living with Dementia short course enabled some participants to meet others in similar situations and feel less alone. Memory Lane Cafés were also valued by many, though two participants highlighted the infrequency of these meetings as an issue. The Dementia Australia advocates program was also raised by five participants, some of whom reported significant benefits from involvement, including a sense of purpose, agency, and identity. Participants were able to access information, education, and programs directly through contacting these organisations and did not describe particular challenges with access, however, the support offered appeared to vary based on location and was sometimes inconsistent.

I think I lost my self-esteem, my self-worth [...] And it was [advocacy program worker] who kind of like, slowly, supported me [to become an advocate]. [the organisation] in itself, right, who lifted me

up, you know, unravelled all those insecurities and what happened to me. And I sprouted again; you know what I mean? (Participant #31, female, 53 years)

Conversely, three participants had less positive opinions; one with no prior involvement in the program reported that she was unable to access certain supports unless she became an advocate, and the other two, with current or former advocate program involvement, perceived that the scheme exploited some participants.

There's some major issues with how charities, in particular, and private businesses use not just the voices of, but the intellectual property of people with dementia and give them one, no credit and two, no payment. (Participant #40, female, 67 years)

Applying for Commonwealth-funded Aged and Disability supports

Participants reported that for Aged and/or disability supports, participants needed to go through an assessment process to determine their eligibility for Government-subsidised support before they could receive a service. Most people with dementia (n=45) had applied, or re-applied for Commonwealth-funded Aged (MAC, CHSP, HCP) and/or Disability (NDIS) support. More than three-quarters of these encountered difficulties with the application process, with both people with dementia and care partners describing the process as confusing, exhausting, and overwhelming. People with dementia relied heavily on care partners or formal supports to manage this process for them due to the cognitive demands of navigating the system. Several participants reported that the support application process was punitive and excessively bureaucratic, whilst a small sample reported receiving assistance with applying for Aged Care or Disability support, and without this assistance, they would not have been able to complete the process successfully.

[You] go through hell to actually get it - and I don't see why it should be that complicated. And the fact that it is, probably means a lot of people won't bother or won't even know where to start. I was just lucky that the occupational therapist was interested and prepared to continue to help us get it. (Spouse of participant #16)

A common challenge was significant waiting periods for an initial assessment (n=19), and then a further wait to receive funding (n=16). The opacity of the system regarding wait times was a source of concern. Whilst this occurred, participants entered a holding pattern in which little progress was made in navigating care after diagnosis. Some participants experienced significant functional deterioration whilst waiting for assessments or funding approvals. One care partner described their experience of trying to access a reassessment following a deterioration in function, only to be told that they had been deemed as not requiring support.

We came back, and his condition deteriorated. And I thought I can't cope with this...I then got on to My Aged Care, and I rang them and...they said, 'Oh, he's regarded as someone who doesn't need further care.' I said, excuse me? And they said, 'No, he doesn't require any care because in March he said he didn't need any care'. (Spouse of participant #26)

We got the... assessment after assessment and after assessment. We did about four or five of those bloody things where they gave us a number and then [...] we go on the list sort of thing. (Participant

#4, male, 77 years)

The assessment experience also varied significantly for those applying for Commonwealth-funded Aged Care. A lack of person-centeredness during assessments was reported, with several participants feeling stigmatised or belittled during the process, whilst others reported that their support needs were not effectively assessed.

They [Aged Care Assessor] make you feel ashamed and they treat you as if... you're like a criminal. I felt so embarrassed. Whereas, I mean, there wouldn't be too many people around who'd want to go through all that. There's better ways of making money than that. (Participant #8, male, 74 years)

I was quite annoyed and even more so in retrospect with mum having an accident [...] I felt like from an ACAT perspective, they should have been asking a lot more questions around 'can you please show me where your medication's kept? How many pills do you take?' [...] she said to me, 'My God, we get people all the time like you that are just too worried about their relatives and they just basically need to let them live their life'. So, I kind of went away from that going, oh, I just need to, back off a bit and let mum be independent. So that was a big one for me that in hindsight I look back on when I was really angry with that assessment. (Daughter of participant #13)

Assessors did not always account for the needs of the person with dementia and the care partner collectively, and some dyads reported instances where the care partner was excluded from the process of assessment or decisions around support. This was a significant stressor for some care partners when the person they cared for did not have full insight into their care needs and the level of informal support that was provided.

The very first time My Aged Care was set up to come and assess, I wasn't even here. Like, I wasn't even invited to anything to ask for the family's perspective, you know, how it is, so only his opinion was taken. So, for years, we haven't used anything. (Spouse of participant #7)

Several participants found the application process smooth and reported that the system was responsive, though some expressed surprise that this was the case. These people often attributed their smooth experience with this to having formal or informal support, with knowledge of the system.

[I was supported to apply] through a dementia specialist. she's no longer here, but she was amazing. [...] My doctor, GP, proactive, filled out her part, amazing, and then I had my part. And we did that and it was like, right, okay, we couldn't do any more. Okay, let's just put it in. We did that and I don't believe it was that long. You know what I mean? But I received a letter saying, hey, you've been accepted. So, and people, when I told them, they were just so surprised because it's so hard to get the NDIS. (participant #31, female, 53 years)

And we have had other people say, 'Oh, it took a year for us to get a response' [from My Aged Care], and every time we applied to something within a fortnight, something was happening, so that that also surprised me. And that might say there's a fault in the system, that it identifies people at present with some degree of intellect that allows them better access (participant #27, male, 79 years)

Using Commonwealth-funded Aged and Disability supports

Once the assessment process was completed and Commonwealth-funded services were in place, this was a significant relief and enabled participants to move from a holding pattern of waiting for support to re-engaging in meaningful activities. Most participants used their funding to support direct care, respite, or engagement in leisure activities, while a small number also accessed allied health services.

For the time that I was waiting for the aged care process to commence, I found that I just had to find alternative ways. I just had to stop my own personal things that I was doing, so that I could be home to look after him. You know, I had to plan...Everything had to be planned. Until we've now got the [HCP] up and running effectively. We've got some sort of semblance of life now, haven't we? (Spouse of participant #26)

However, for others, ongoing challenges remained in accessing and using supports, even after funding was approved and allocated. Accessing CHSP, HCP, and NDIS services without support to coordinate this was highlighted as challenging.

You've got to fill out an application form, you've got to talk to My Aged Care, you've got to get codes, 14 digit codes by the way, and then you've got to somehow or rather, then My Aged Care appoints an outfit called Indigo [...], and Indigo then ring you up out of the blue and say I'm from Indigo. Then you've got to get an explanation from them about what the hell is your role in this chain and how do I get the [personal alarm] (Spouse of participant #16)

Some participants had not accessed any support after funding for an HCP or NDIS support plan, as they were unsure how to do so. For others, excessive bureaucracy or regulatory barriers led to suboptimal utilisation of funding and services. Setting level policies from providers also created additional challenges, with a lack of consistency in the process apparent. Participants reported variability among service providers in bureaucratic and administrative requirements.

But I found the repetition of filling in the same forms, like for the incontinence pads and everything, I'd already filled all that information in. You know, I've been to the doctor, I've had seven letters from the doctor to support things for the package. [The provider requests] 'Can you get a letter from the doctor to say that he needs physio?' So, I pay to see the doctor. (Spouse of participant #5)

Knowledge of dementia varied widely across the workforce, with many people experiencing poor communication and inconsistent guidance about what support was available. The findings highlight a strong need for increased dementia-specific training across the healthcare workforce.

The catchphrase is, we're living well with dementia. How can you live well with dementia if you've been diagnosed and you're not given accurate information, if you're not given compassion, if you're not given... if they're not following up, and they're not training their staff properly? (Participant #36, female, 58 years)

Ongoing management

This section explores participants' experiences of the longer-term aspects of living with dementia. This included managing symptom progression over time, planning for the future, and the psychological processes of acceptance and adjustment to the condition.

Managing progression of symptoms and their impact on day-to-day life

As symptoms progress, people living with dementia experience growing impacts on daily activities, confidence, independence, and social engagement.

In our sample, these changes brought ongoing challenges and the need to continually adapt daily activities and routines (n=39). Many reported experiencing increasing difficulties with recall, word-finding, executive functioning, and concentration, which, in turn, increasingly affected daily activities. Many participants spoke of becoming increasingly disoriented and less confident.

I can't find my glasses, my phone, my keys. And if I shut my eyes and visualise it, it's right there in front of me, you know? People next door haven't stolen it, the ghosts and the spirits haven't come in and moved it. (Participant #42, female, 80 years)

Fatigue was commonly reported and had become more pronounced over time, progressively limiting participants' ability to engage in activities such as exercise and travel. Several participants also reported worsening balance and an increase in falls. Day-to-day fluctuations in symptoms were difficult to manage, leading to uncertainty about what would come next. The cumulative effect of these changes led many participants to gradually withdraw from social activities and previously enjoyed activities. Difficulties with communication and word finding had become particularly distressing for those who had previously been highly social.

But I'm finding the fatigue makes it really difficult if I've got time and I often just feel I need to just rest. Tried jigsaw puzzles, but it's the same thing. I'm just finding it increasingly hard to get the energy to do stuff. (Participant #22, female, 78 years)

Participants described feeling increasingly lost, frustrated, and isolated as their symptoms progressed. Care partners observed these changes and described their own growing frustrations. These included the need to repeat information more often, cope with mood or behavioural changes, and take on increasing care responsibilities. Some care partners noted a growing lack of insight or social awareness, which further complicated support. Several expressed frustrations with the lack of practical strategies that services provide to address these evolving challenges.

The effects of dementia on driving were a significant concern for many people with dementia (n=26) and had major implications for independence. Participants approached the issue of driving in various ways. Some participants voluntarily ceased driving, motivated by a desire to take control of their situation and avoid having this decision made for them, or by concern for their own safety or that of others.

Because I could have [continued] driving but I thought, what if my judgment went? And I was thinking I was all right and I wasn't. I thought, no, it's not safe. It's not fair to anybody. (Participant #30, female, 89 years)

Cessation of driving, particularly for those who had not voluntarily made this decision, was a source of distress. Several participants described being advised to stop driving immediately following diagnosis, or to cease driving until they had undergone an occupational therapy driving assessment. For some, this was the most challenging moment in their post-diagnosis experience. The loss of driving was perceived as a significant reduction in independence and leisure, with participants needing to rely on formal services, care workers, or family members for transport. Many found this transition difficult.

It plays on my mind even now. Not being able to get in the car so you can go to Bunnings or go da da da. It's a real pain. Yeah. I find that hard. (Participant #18, male, 80 years)

Some participants reported that they continued to drive following diagnosis, in some cases with a restricted licence. Whilst they acknowledged ongoing challenges, particularly around wayfinding and fatigue when driving long distances, they also recognised the importance of driving for maintaining independence. This was especially the case for those living in rural areas. Concerns were raised about the cost of future driving assessments and uncertainty about how long they would be able to continue driving. Some participants had undergone driving assessments and passed, whilst others remained uncertain about what the future would hold.

Anticipating needs and future planning

Planning for future needs emerges as an important and often iterative process as people living with dementia and care partners reflect on how to prepare for the progressive nature of dementia. Participants described making and revisiting decisions about legal, financial, housing, and care as important for retaining a sense of control and reducing the impact on their families.

Around two-thirds of participants (n=30) spent time following their diagnoses, planning for the future, and preparing for anticipated needs. This process was often iterative, and for those with a care partner, it was usually collaborative, led by the care partner. Housing was a focus for many, with some moving to downsize, be closer to family or services, or enhance safety or independence. One dyad moved from an urban centre to a small regional town. Whilst this was positive for the continued independence of the person with dementia in remaining engaged in the community, it came with trade-offs regarding the accessibility of healthcare and support. Several moved into retirement villages, which were seen as beneficial in providing both a safe home environment and opportunities for social connection and continued engagement in leisure activities.

We're in an over-50s village. It's very nice...there's a lot of community get-togethers and things like that, so you never feel like you're at home, and you can't go anywhere or whatever. There's always people around. I didn't want to move there, but [husband] thought it was the best thing for us, and he was right. (Participant #28, female, 63 years)

One dyad, who were renting and who faced housing insecurity due to the financial implications of the dementia diagnosis, had applied for public housing; however, they reported that the wait list for this was a significant concern. Many made legal and financial preparations by creating or updating wills, appointing an Enduring Power of Attorney or Guardian, and creating advanced care directives. Several participants had also planned for their funerals.

I've nearly finished an end-of-life directive. And certainly, when we were doing all the legal stuff, I was being prodded to get on with it. It's important. I know it's important. (Participant #1, female, 75 years)

Once future plans were in place, this provided comfort, and many were motivated to make life easier for their care partners or families. For example, a small number stating they wished to avoid burdening their family in the event they required a high level of care, or to ensure that their family was prepared to manage

their future needs. Many participants also applied for Commonwealth-funded aged care or disability services to enable future planning, such as obtaining funding approvals for residential respite or permanent care.

I don't want my kids to go through this, where suddenly, you know, you're doing a fairly high-level job, and the next thing, you know, you can't remember where anything is in the house. (Participant #20, female, 59 years)

I want to be in charge. I'm not going to drift and say somebody else will organise it. I want things my way and my children know the way I would like it to be. I know there would be a point, if I live long enough, when I will not be able to make decisions anymore. (Participant #30, female, 89 years)

Despite these efforts, planning for the future was accompanied by considerable anxiety and uncertainty. Many participants expressed deep fears about the progression of their symptoms, including the prospect of hallucinations, further memory loss and inevitable cognitive decline. The unpredictability of dementia left many feeling unable to adequately prepare, even when plans were in place. Participants wanted to remain in their own home for as long as possible, and the prospect of requiring residential aged care in the future was a source of distress for both people with dementia and care partners.

In general, I'm pretty okay. But there's it's like the end is near. And... I just came out of one week respite in a nursing home. When I see all the other people there, they're worse off than I am, and it's like a cocoon. Is what are they there for? You know, they eat, they sleep [...] Nothing else is happening. There's, there's no, no joy. We sat at the dining room and there's that eerie silence, everybody staring at nothing [...] (Participant #3, male, 75 years)

Adapting, coping and acceptance

Participants described strategies they use to adapt to and cope with dementia while maintaining independence (n=43). Having a positive attitude and being proactive were integral to “keep the brain going”. Several participants emphasised pushing back against stigma by being open about their dementia diagnosis. Proactive engagement encompassed health, emotional, and social activities to adapt to living with dementia, as well as health-promoting behaviours, such as exercise, to maintain function. Meaningful activities including reading, puzzles, music, gardening, creative pursuits and volunteering provided cognitive stimulation, purpose and renewed identity.

Keep it out there - and I've told everybody, I don't care. If you think that someone with Alzheimer's is bad in some way, that's your problem and not mine. (Participant #29, male, 63 years)

'Well, the thing is, you still have to keep active. That's my opinion. You can't sit still and do nothing. So I try to do my best to do whatever I need to do. And that's why it's good that I can contact you and that can help a little bit more. We're going to the Memory Lane cafe and all that sort of thing, my hobbies and things and exercises. I do it as much as I can.' (Participant #38, male, 88 years)

The most common strategies used were compensatory strategies for memory changes (n=29) such as developing consistent daily routines; writing lists and using cues to compensate for memory difficulties; using diaries, calendars, and cue cards to assist with recall; and journaling. Participants embraced living in the moment to maintain happiness and retain self-dignity despite symptoms.

So, I just sort of mugged on myself, really, and tried to be positive and made routines and strategies and things like, for instance, I was forgetting to go to the toilet before I went out, so I left the keys in the bathroom, that sort of thing, and made lists, bloody lists everywhere. (Participant #37, female, 83 years)

Human connection with spouses, family, and social relationships was highly valued in adapting to and coping with dementia (n=13). For some, dementia brought new opportunities, such as giving and receiving peer support and volunteering, which provided a sense of purpose and fulfilment. Approximately one-third of participants (n=15) considered support from not-for-profit organisations (e.g., Dementia Australia and care partner support providers), health professionals, and psychological services important for adapting to dementia. Being well-informed about dementia and available services provided reassurance.

Yeah, be positive. Get counselling. You need a lot of counselling. And it was like, bring your family, get counselling. But be honest with your family, how you're feeling, how it makes you feel. Don't speak up for them. Don't talk for them. ... Label the house so they know where the cups are. Give them instructions on how to make this or that. Don't take over. (Participant #21, female, 81 years)

Closely intertwined with these adaptive strategies was acceptance, which participants described as both something they worked towards and something that enabled them to move forward. Acceptance involved reframing dementia, and recognising that life with dementia could still be meaningful, even if it looked different to what they had expected. For some, acceptance was fostered through engaging with services for counselling and education, which helped them to feel ready to access supports and develop strategies for managing day-to-day. For others, acceptance developed over time through the process of staying active, engaging in meaningful activities

Within certain constraints, dementia... My experience of dementia is not limiting to the life that I lead. I don't have to be in cotton wool. I don't have to sit at home. I can take part in things as much as I choose. (Participant#19, male, 80 years)

I thought I'd turn into, you know, a head down, sort of sitting in a nursing home within a couple of years. And I didn't realise there was life after a diagnosis and a rich life after a diagnosis. And also, if you regard it as an illness, you think you're not going to be well. But in fact - I can't say I've never been fitter because I've run a lot of marathon - but, you know, my doctors... delighted with me. (Participant #21, female, 81 years)

Challenges and opportunities

This section examines key challenges raised by people with dementia in the journey mapping analysis, which, if addressed, present opportunities to improve experiences for people with dementia and their families. These were present across multiple chronological time points reported above and are also shown in Table 1.

Unmet needs in the health and aged care system

People with dementia and their families described a fragmented, reactive system that left them navigating post-diagnosis care alone, with major gaps in psychosocial support, coordination, and age-appropriate services, especially for young-onset dementia. Participants wanted a coherent, compassionate pathway similar to cancer care, with clear information, skilled professionals who know them, and timely access to peer

support, rehabilitation, and practical help to stay connected and maintain their autonomy. Where participants experienced a smoother pathway, it was typically due to a particular individual within the system who went beyond their role to proactively connect people with dementia to relevant services, make referrals, and guide them through an otherwise fragmented system. These key people played a pivotal role in improving navigation of the system for people with dementia and carers, often providing informal care coordination in the absence of a formalised support pathway.

That [NDIS] was daunting and difficult. And I'm like, I think I'm absolutely certain we would have abandoned even getting onto a NDIS plan if it wasn't for [key person]. (Person with dementia #29, male, 63 years)

Fragmented system, lack of continuity of care, and poor coordination

Across interviews, people (n=31) described fragmented care characterised by multiple providers, poor care coordination and limited follow-through. They faced long wait times, referral loops, and confusion, often learning about supports through self-advocacy or chance rather than structured pathways. Care partners often felt abandoned after diagnosis, receiving only basic information, with limited guidance, follow-up, or case management for service, financial, or planning decisions. Continuity of care with providers was perceived as particularly valued but was often not possible due to service capacity issues or staff turnover. The inability to establish this continuity led some to disengage with supports.

[...] the last 10 years, I haven't seen the same... except for this last 12 months, I've never seen the same GP any more than twice. [...] You go out, oh they're booked out till next week, you know. You get to a stage where you couldn't care less [...], and until this last 12 months with this new doctor, yeah, it's not worthwhile. To me, it's not worthwhile. (Participant #7, male, 85 years)

Participants wanted trusted health professionals, especially GPs, who understood their medical and personal circumstances and could coordinate care effectively throughout the course of the disease.

But also, for dementia, I think there has to be something like a nurse calling because sometimes it's scary. I may have read up about my diagnosis, but most likely at some point I'll forget all that. So, if I have a nurse to call and say, this is how I'm feeling today, what is it? And then they'll ask a few more things as a nurse. And they will say, don't worry about it, this is the progression that's normal for this type of illness at this stage. (Participant #41, female, 74 years)

Several wanted checklists or practical roadmaps, and proactive referral to dementia-specific supports, rather than piecing together aged, disability, and community services themselves. They described this as a human rights issue and systemic failure to recognise dementia as a condition requiring comprehensive, person-centred support, not episodic medical care.

We need disability assessment and support, that we should receive rehabilitation, speech therapy, physio, neurophysio, EPs, you name it, mindfulness, counselling, loss and grief support. Nobody tells you about that. (Participant #40, female, 67 years)

Gaps in psychosocial and peer support

Participants (n=17) reported various gaps in psychosocial and peer support, such as limited emotional support and opportunity for cognitive stimulation, delivered by staff with dementia-specific training.

Mainstream services did not adequately address emotional adjustment, grief, or identity change, forcing families to seek informal counselling or peer groups for advice. Many participants sought out connections with empathetic peers or trained professionals to ease adjustment and reduce isolation. They viewed peer support as essential rather than optional. While Memory Lane Cafes met this need for some, others, particularly those with young-onset dementia, struggled to find suitable peer support. Participants suggested linking peer groups with trained care navigators to facilitate access to services over time. Several wanted peer connections soon after diagnosis to build mutual support and engagement rather than withdrawal due to stigma and fear.

Being put in touch with someone to sort of talk about the process [...] But, yeah, I sort of think sometimes just having someone to... who is in a similar situation, or a therapist of some sort to just talk through could have been and could still be very helpful. (Participant #9, female, 74 years)

Unmet needs in young-onset dementia

Those who had been diagnosed with young-onset dementia (n=11) found few suitable peer programs or meaningful activities. Some contrasted cancer care's structured, proactive models (e.g., specialist nurses, care pathways) with the absence of equivalents for young-onset dementia, despite life-changing impacts on work, finances, and family roles. Several faced isolation, age-inappropriate programs, and rigid eligibility rules that limited access or delayed funding.

And I just thought, why am I here? Everybody's much older than I am, like, kind of scared. I just thought, why would they send me here? That's all I could remember. (Participant #15, female, 61 years)

People with young-onset dementia described delays and confusion accessing NDIS and other supports and wanted a single contact who understood their needs and could help streamline processes. One dyad spent substantial personal funds on equipment and home modifications before discovering they were eligible for funding, expressing regret at having to navigate the system during emotional upheaval.

*[I needed] some financial advice or someone steering me in the right direction. Cause I mean, now I've got **** all left, you know, and I'm almost completely reliant on my pension. You know, we don't have a house anymore. (Participant #34, male, 65 years)*

Information, prognosis, and communication

People with dementia (n=24) and care partners wanted clear, staged, condition-specific information on their prognosis, tailored to dementia subtype and circumstances, and incorporating advice on driving, work, and occupational roles. The clinician's communication style strongly shaped how sensitive information was received. Participants valued encouragement, practical strategies, and strengths-based messaging that promoted continued participation rather than deficit framing. They also wanted proactive, evidence-based advice on managing their symptoms and maintaining social connections. Many were unaware of available options, such as rehabilitation or reablement, because health professionals rarely discussed them.

Goodness me, everything that I found out myself, someone could have printed on a bloody leaflet, you know, about all the things you can do. (Participant #25, female, 69 years)

When we got the diagnosis, we got a couple of different brochures and things. I think we were introduced to Dementia Australia and a few others. Like, that was probably it. There was no referring back to the doctor. There was no, like, there was no, these are the next steps...This is what it's going to look like. This is how, you know, every dementia journey is different. But statistically, these are the, this is the process of what it will look like. There was none of that. So, we didn't really - we're basically just out the door and you feel your way through. (Daughter of participant #17)

Allied health, rehabilitation and reablement

Participants described a variety of experiences with allied health services (n=28). Occupational therapy was valued for practical strategies to maintain independence, and home modifications, while physiotherapy and exercise physiology were beneficial for preventing falls and maintaining mobility. However, gaps were evident in the provision of tailored, dementia-specific support. Memory-related interventions were often not offered, and dementia-specific needs were often not addressed, with clinicians focusing on addressing other health conditions. A small number of participants self-advocated for rehabilitation with allied health clinicians or paid out of pocket to access additional allied health support to enable them to maintain their independence for longer. Also, several participants called for better access to dementia rehabilitation and highlighted this as a gap. Whilst only a few (n=3) had accessed structured dementia rehabilitation programs, they were found to be deeply positive.

Dementia rehabilitation in the home... That was the best thing we've ever done. (Spouse of participant #5)

Driving and participation

Loss of a driver's license disrupted social life, work, family roles, and access to meaningful activities, often amplifying isolation. Despite the known impact of driving cessation on a person's life space, there was limited to no guidance to help plan alternative transport to maintain engagement. This transition exposed broader gaps in access to rehabilitation, respite, and community engagement supports.

I didn't realise, they don't pick me up from home, and I've given them my ID code, and now I can't give it to anyone else...it's useless. So I've got [...] community transport, but all they do is to pick me up and take me on bus trips, whereas the [...] people have got a big centre where you can go and do things, but it's too far away, I can't get there, it's in Woollahra, which would take me two buses. It would have been alright if I was still driving, but I don't anymore. (Participant #42, female, 80 years)

End-of-life concerns

A small number of people with dementia (n=5) raised end-of-life preferences as an area of concern. Legislation precluding people with dementia from undergoing voluntary assisted dying was stated as a gap, and some felt practitioners involved in their care were uncomfortable discussing this topic with them. Participants wanted services that respected their agency and informed decision-making from diagnosis through end-of-life care. They called for open, non-judgmental conversations about risks, values, and choices, integrated across health, disability, and aged care systems, to preserve dignity, connection, and self-determination.

If you had cancer, you can go down that road and you get the little thing on the table and you can decide and that can be reasonable. For me, it's how do you get to that end-of-life place that's reasonable and compassionate and caring? (Participant #29, male, 63 years)

Impact of stigma

The negative impact of stigma on people with dementia in the study was also raised by around two-thirds of participants (n=32). This included direct, overt experiences of being stigmatised, reports of subtle discrimination, and the fear or anticipation of stigma, all of which shaped how people navigated their diagnosis or engaged with others. Participants felt they were treated differently following their diagnosis due to negative stereotypes, and a lack of awareness in the community, meaning participants felt they were treated differently following their diagnosis.

Around one-third of participants reported negative changes to social relationships following disclosing their diagnosis, including social exclusion and loss of friendships (n=14). Several participants chose not to disclose their diagnosis due to fear of prejudice or upsetting reactions from others (n=5). There was a view that stigma was predominantly driven by a lack of community awareness about dementia (n=12), and several people highlighted the role of education in breaking down stigma, with some noting they previously held similar beliefs before diagnosis.

People don't know enough about it. I mean, to be honest, I didn't know anything about it. I had to read up on it. I thought Alzheimer's was when they put you in a home, you know? But it's not that at all. And that's why I think there's that stigma about it, because people don't understand. (Participant #28, female, 63 years)

Experiences of stigma and discrimination from health professionals and service providers were also reported (n=8). Some participants reported being treated as a "non-person" by health professionals. Two people with young-onset dementia described experiencing stigma from a peak body organisation. Another reported being told by their GP not to tell anyone about their diagnosis. Negative stereotypes and misconceptions about dementia also presented a barrier to diagnosis, with one person with dementia describing their struggle to be taken seriously by medical professionals because she didn't "look like" someone with dementia.

I started trying to get some information, with not a very high level of success. Mostly, the medical people that I spoke to just thought I was making a joke, which I didn't think it was very funny myself, but they just sort of said, oh, it couldn't be possible. (Participant #24, female, 78 years)

I feel [...] since the diagnosis, I feel we've been left. He's a man with dementia, but they're just leaving to die. Doing nothing, nobody, no hope, no nothing, nowhere I can call on. There's no help... there's no help. It's just like they've left him to die from dementia. Is that what they do with demented people? (Spouse of participant #4)

Once diagnosed, other assumptions emerged. Several participants described professionals bypassing the person with dementia to speak only to the care partners, having made presumptions about the person with dementia's capability to understand information about their condition.

And also, when we go and see the geriatrician, he talks to me [...] he said, 'and how's he been?' I said, well, he's sitting here, ask him. You know, he's not a dummy. I'm not the ventriloquist, for goodness sake. (Spouse of participant #23)

Some people reported a perception that people with dementia are undervalued by service providers or automatically seen as old, frail, or incapable.

I've never contacted the [specialist] since. Why would I? See, because they think dementia is something that you get when you're 70 that turns you into a pumpkin, a vegetable, within moments, almost. (Participant #21, female, 81 years)

While not the majority of participants, these experiences of stigma in healthcare settings were particularly damaging and had a lasting impact on trust in healthcare and support services for those who did experience them.

Key person on the journey

For many people living with dementia (n=28), encountering a single key person during or after diagnosis was a catalyst for smoother condition management. Often, this was an existing, long-term patient-provider relationship, such as with a GP. Still, there were also examples of immediate impact from specialists who provided clear, person-centred information without making patients feel rushed.

Skilled dementia support specialists from a peak body organisation were highlighted for their ability to navigate Commonwealth-funded support and documentation, particularly for people with young-onset dementia. These case workers absorbed some of the practical and emotional load of navigating complex application processes, providing relief at a critical time of profound stress and confusion. Similar comments were made about counsellors and nurses who helped with acceptance of dementia and practical strategies for managing the condition.

Yeah, it was like she was a godsend, you know. She took the pressure. I didn't know. I didn't understand why it was happening, like going to the NDIS and everything. And I was crying. I was basically on my own doing that. I didn't have no family support. I didn't have no one...She says, 'right, you need to get on the NDIS'...She just, she was magic. She knew what to do. She was trained. She was great. (Participant #15, female, 61 years)

Several participants were grateful to their GPs, who went above and beyond by providing supporting letters to assist with applications for Commonwealth funding, with some even considering them "like family". Others mentioned both experienced and esteemed specialists and young geriatricians who were knowledgeable and strong advocates for their clients. Several participants said they would have felt lost and abandoned without their practitioner's information.

My GP is very good. She's really thorough, and if I ask her something, she'll be dogged in pursuit of it until she can give me an answer. (Participant #1, female, 75 years)

Effective multidisciplinary teams can also fulfil the role of a key person, providing coordinated care and a seamless handover of information, enabling team members to build upon each other's expertise in a way that feels continuous and coherent to people with dementia and care partners. Two participants reflected

on receiving coordinated, compassionate, respectful, expert dementia care in a public health clinic, and two others were diagnosed at the ISLAND clinic in Hobart, Tasmania, a full-day memory assessment service. Notably, the ISLAND clinic's collaboration with Dementia Australia ensured that timely support, information about available groups and services, and follow-up were integrated into the experience of receiving a diagnosis, exemplifying how a well-coordinated team approach can replicate the functions of a key person.

You're in their hands, and you have a whole day of assessment there by a whole range of health professionals...I think I appreciated that it was a holistic assessment. So it was, you know, cognitive testing, physical testing, your gait, how you walked. It was really comprehensive. (Participant #11, female, 82 years)

Two participants also reflected on the influence of Kate Swaffer's book "What the hell happened to my brain?", which helped people accept their diagnosis and self-advocate for better care. This validation and hope illustrate that meaningful guidance and empowerment from outside the health and aged care system, from someone with lived experience, can have a profound impact on people with dementia.

Benefits of peer support

Social connection and peer support were central to how people described living well with dementia (n=29). Finding people with similar or shared lived experiences, as well as practical help with everyday activities, were seen as benefits of peer support and connection. This occurred through conversations with others, information sharing, and large-group activities, thereby engaging people with dementia and fostering a sense of belonging to something bigger than themselves. One example is the Memory Lane Cafes run by Dementia Australia and comparable memory cafes, which were seen as opportunities to connect with others experiencing similar circumstances, share knowledge and resources, and receive advice on navigating services and everyday challenges. Some felt that the Memory Lane Cafes were not frequent enough, whereas a Forget-me-not cafe in Western Australia was appreciated for its weekly schedule.

We go to one that's luckily weekly rather than monthly. Yeah. Awesome, isn't it - what we find out there and the people that we meet there. You [person with dementia] didn't want to go to that either, but [...] said, I'm going to take you up. Another girlfriend said, I'll take you up for coffee. And now we hardly want to miss it. And it started like 8, 10 people, and now there's like 20, 30 people. Yeah, it's been given a big thumbs up from everybody who's been going. (Spouse of participant #8)

Despite this, participants highlighted persistent gaps and barriers in accessing suitable peer support programs. Finding the "right" peer connections often took time and luck, especially when looking for people at a similar life stage or with comparable levels of independence. Mobility limitations, transport issues, and lack of funding for dementia-inclusive groups restricted some people's ability to attend in-person activities, even when they recognised how much they and others could benefit. Despite these challenges, both in-person and online connections with others "who get it" were experienced as highly meaningful, offering mutual emotional support, shared humour, and a sustaining sense of connection.

Hospital experiences

Hospital care for people with dementia (n=10) was portrayed as highly variable, ranging from neglectful to respectful. Several accounts from participants recounted staff with a limited understanding of dementia,

leading to people being left alone, labelled as “difficult” or managed without clear explanations to the person or their families. In contrast, several encounters were described as coordinated, compassionate care in which staff welcomed input from care partners, communicated clearly, and ensured effective care transition. In several cases, hospitalisation became the moment when dementia was recognised, but not always sensitively communicated, with informal diagnoses and family members stepping in to fill gaps in basic care.

Hospital stays were frequently triggered by frightening, acute events or the need for surgery, often leading to prolonged rehabilitation to restore mobility or manage daily tasks. People with dementia and their families encountered both structural and interpersonal barriers: long waits in emergency departments, indecision and delay around procedures such as pacemaker insertion, and chaotic environments where basic needs like eating, hygiene, and infection prevention were not reliably supported. Family members reported becoming de facto care staff, taking on personal care, medication monitoring, and advocacy, while some nurses were described as going above and beyond, reinforcing how respect, clear communication, and inclusion of care partners could transform distress into a sense of safety and satisfaction even when hospitalisation was lengthy or complex.

Before the pandemic...I would at least receive a conversation with one of the either the doctor or nursing staff and kind of a list with what sort of happened, what was the diagnosis, what was the outcome, what have they fixed. After the pandemic, nothing. And it's still now, usually when he goes in and comes back out, there is no communication with me. It's like they tell him, and I made it known the last time that I'm not quite happy with that because when I then pick him up and ask him, he can't remember...I'm left with nothing, like I have no information whatsoever, you know, what was it, what did they fix, what did they change, and sometimes I'm getting presented with a new list of medication, where I already can see looking at it, this is a medication we tried five years ago, and it's spun out all his current medication and made him worse off within two weeks. (Spouse of participant #19)

Taken together, a tension exists between system-driven, risk-averse care and person-centred approaches that recognise the person with dementia’s perspective, involve families, and provide continuity from hospital through to life back at home.

DISCUSSION: SUMMARY OF STAGES, TRANSITIONS IN CARE, AND CRITICAL MOMENTS

In this section, findings from the interviews are synthesised to identify and describe key transition points and moments in the dementia journey where people with dementia and care partners experienced vulnerability, change, or opportunities for improved support.

The discussion situates the journey mapping findings within the policy context of the National Dementia Action Plan (2024-2034) (NDAP). The NDAP contains eight priority action areas (briefly outlined in Figure 1)

to guide national efforts to improve outcomes for people living with dementia, their care partners, and the broader community. The stages, transitions in care, and critical moments identified in our analysis intersect with multiple NDAP priority action areas, in particular, they speak directly to timely diagnosis and post diagnostic care (Action 4) and treatment, coordination and support (Action 5), whilst also providing evidence relevant to tackling stigma and improving awareness (Action 2), equity of access (Action 1), carer support (Action 6) and workforce capability (Action 7). By mapping living experiences across the dementia journey, this section highlights where the health and aged care systems can be improved to align with NDAP actions to inform targeted strategies which may have the greatest impact.



Figure 1. National Dementia Action Plan priority areas

Journey mapping is increasingly adopted as an approach to understanding how individuals navigate complex health systems (Davies et al., 2023); however, it remains a relatively new field, and there is a lack of standardised terminology and reporting guidelines. To ensure clarity in this report, we have distinguished between:

- 1. Stages:** Pre-determined chronological phases that characterise the dementia experience over time; Awareness, Diagnosis, Care after diagnosis and Ongoing management.
- 2. Sub-stages:** Specific periods or processes within each stage that people move through, potentially more than once.
- 3. Transitions in care:** Movement of people with dementia between providers, settings, or levels of care.
- 4. Critical moments:** Pivotal points within care settings where the quality of the response internally, rather than the movement between care settings or providers, shaped the outcome or experience.

Stages provide the overall structure of the journey, whilst transitions and critical moments represent specific junctures at which opportunities for system improvement arise, and can occur within, between or across stages. They were identified as recurring patterns during the framework analysis, particularly where barriers or enablers had a disproportionate impact on subsequent outcomes or the person's trajectory. The findings from our study revealed multiple sub-stages within the four stages, three formal transitions in care and five critical moments that shape the dementia journey from symptom recognition to ongoing management, where timely information, support, or care coordination could meaningfully alter people's experiences, and are moments where timely interventions could have the greatest impact. The summary of these stages, key transitions and critical moments is displayed visually in Figure 2 and described in detail below.

It is important to note that most people with dementia's experience of care is non-linear. People with dementia may revisit earlier stages as symptoms progress, go through multiple transitions in care or experience critical encounters at various points. An effective, context-focused assessment of needs is crucial for determining next steps and ensuring timely interventions are delivered where they can have the greatest impact.

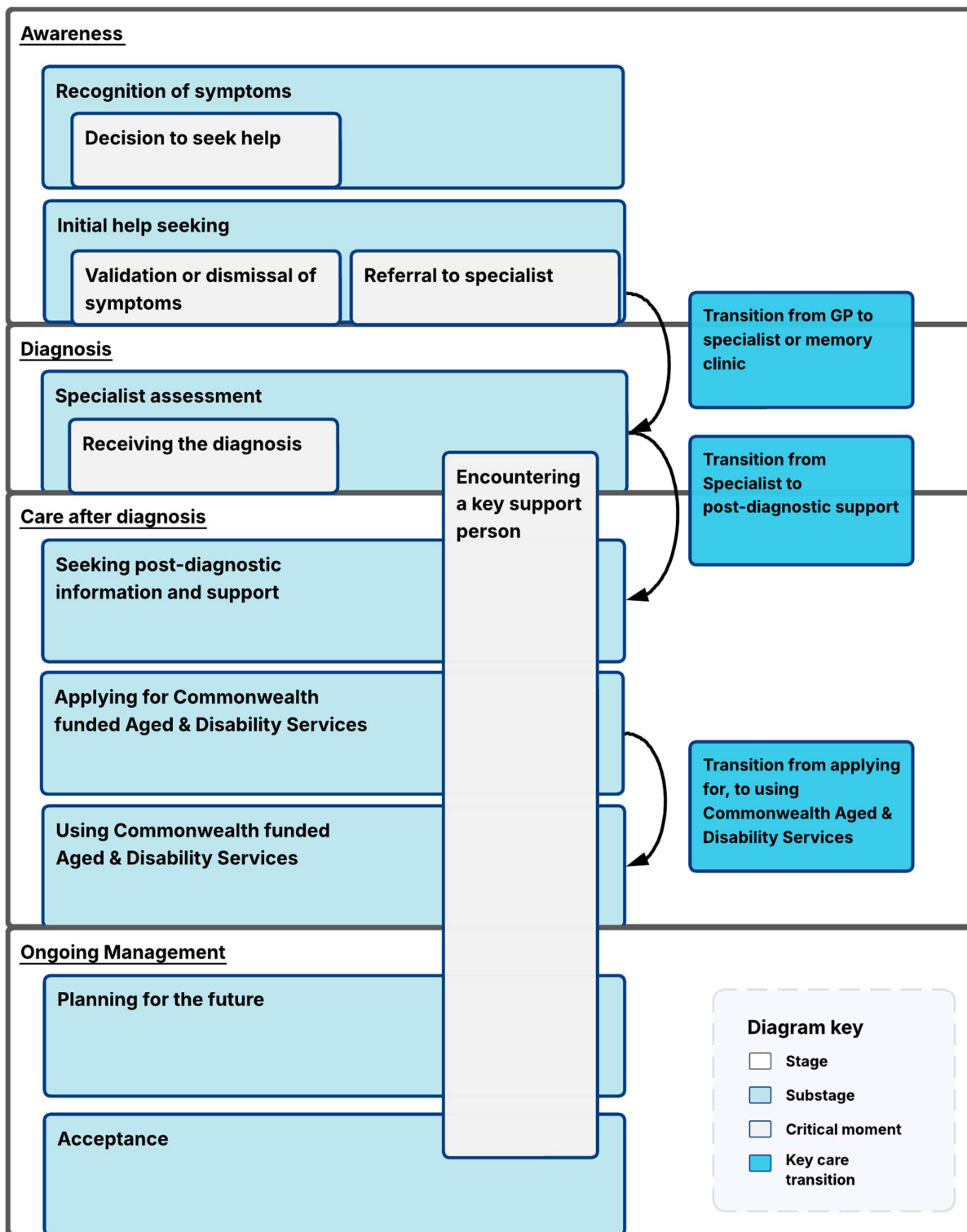


Figure 2. Summary of stages, transitions in care and critical moments

Stage 1: Awareness

The awareness stage encompasses how subtle and cumulative changes are often normalised or misattributed, often due to stigma and inconsistent approaches in primary care, which contribute to delays in help-seeking and referral. These early encounters, when symptoms present, influence the pathway to a diagnosis and can either enable timely diagnosis or contribute to diagnostic delay and subsequent access to services or supports.

Recognition of early symptoms

Participants reported that symptom recognition typically began with either subtle changes in memory, mood, or function observed by the person themselves, family, friends, or colleagues. Often, changes came into focus through a significant event, such as a driving or health incident. Recognition reflected participants' awareness that their cognitive performance had declined in comparison to the past, but these early symptoms were rarely associated with dementia and were often explained away.

The symptom recognition delays found in this study reflect broader patterns identified in national data. They are central to NDAP Priority 1, which aims to improve community awareness and understanding of dementia as a medical condition rather than a normal part of ageing.

- **Critical moment 1: Decision to seek help for symptoms**

Even after recognising that something had changed, most waited until symptoms reached a certain threshold of concern before raising the issue with a healthcare practitioner. The decision to approach a GP, typically the first point of contact, required participants to overcome fear, stigma, and uncertainty about whether symptoms warranted medical attention.

These hesitations reflect widespread public misunderstanding of dementia. The AIHW Dementia Awareness Survey (2024) found that only one in three Australians feels confident in their knowledge of dementia, one in five mistakenly believes dementia is a normal part of ageing, and two in three hold stereotypical views about how people with dementia may present. Low public awareness of dementia as a medical condition, rather than a normal part of ageing, appears to contribute to delays in help-seeking (Feldman et al., 2017). Internationally, stigma and denial have been identified as major barriers to diagnosis (Parker et al, 2020). In Australia, these barriers translate into an average delay of more than 6 months between first noticing symptoms and raising concerns with a GP or specialist (Black et al., 2020). These collectively lead to significant delays in diagnosis and in access to supports that help the person live well and independently.

Initial help seeking

Most participants initially raised concerns with their GP, who typically conducted screening before referring to a specialist. However, this early help-seeking stage contained two critical moments at which a person's experience could diverge profoundly: the point at which their concerns were either validated or dismissed by their GP, and the referral decisions made around specialist referral.

- **Critical moment 2: Validation or dismissal of concerns**

In this study, many participants reported that symptoms and concerns were initially dismissed or that screening was insufficient to detect the real impairments they were experiencing. This point represents

a critical moment where a person can be diagnosed quickly or face ongoing uncertainty while experiencing an undiagnosed neurodegenerative condition.

Primary care has been identified as a bottleneck in dementia diagnosis. GPs are the preferred source of help for 89% of Australians with symptoms of dementia, yet around half of all cases remain undiagnosed (AIHW, 2024). Barriers include time constraints, diagnostic uncertainty, and low confidence in detecting and managing dementia (Casey et al., 2020; Crombie et al., 2024). These barriers may be exacerbated in rural areas (Crombie et al., 2024). Brief cognitive screening tools such as the MMSE have limited sensitivity for detecting early changes, particularly in highly educated individuals, who may perform within normal ranges despite meaningful decline from baseline (O'Bryant et al., 2008). There are existing pathways and guidance for GPs on dementia screening, assessment and diagnosis (e.g. Primary Health Network Dementia Pathways). Yet participants' experiences suggest these are not consistently implemented in primary care. Participants' experiences suggest gaps in knowledge and awareness among primary care staff, as well as structural barriers, such as limitations in the current Medicare Benefit Schedule (MBS), that constrain the time available for a comprehensive assessment.

- **Critical moment 3: Getting an appropriate specialist referral**

Following initial GP screening, the next critical moment is whether the person receives an appropriate and timely referral to specialist assessment. In the journey mapping sample, referrals were often made at the request of the person with dementia or care partner. Participants were usually referred to a geriatrician, a memory clinic, or a neurologist.

Referral decisions are often shaped by multiple factors: GPs' confidence and level of dementia awareness, local specialist availability, whether the person can advocate for further testing and investigation, and the person's ability to pay. Australian Memory and Cognition Clinic Guidelines recommend that high-priority clients be seen for an initial assessment within 30 days, and normal-priority clients within 90 days (Australian Dementia Network, 2024). However, wait times to access a specialist varied dramatically across our sample, ranging from 1 week to 12 months; therefore, prompt referral reduces time to diagnosis and the subsequent initiation of support or other treatment. Geographic location significantly affects referral outcomes. Many participants in rural or regional areas experienced increased delays due to limited specialist availability, and some travelled hundreds of kilometres to access services. This geographic inequity has been well documented, with people in regional, rural, and remote areas encountering limited specialist availability, travel burdens, and reduced access to dementia-specific services (AIHW, 2024). The dependence on patient or family advocacy to obtain referrals raises equity concerns. Priority populations that already face barriers to equitable access, such as people from culturally and linguistically diverse (CALD) backgrounds, may face additional delays as a result.

Transition in care 1: From GP to Specialist/Assessment Service

The transition from GP to specialist or memory clinics, either public or private, is a pivotal step towards receiving a formal diagnosis, which typically involves specialised cognitive testing and brain imaging. The time to receive a referral can vary dramatically. In the journey mapping sample, referrals were often requested by the client or their family, and the referral was typically made to a geriatrician, a memory clinic, or a neurologist.

SUMMARY: AWARENESS

Key insights:

- Early symptoms are subtle and are rarely attributed to the possibility of dementia (Relevant to: Action 2).
- People delay discussing symptoms with a medical practitioner due to a lack of awareness and stigma (Relevant to: Actions 2 & 3).
- People with dementia often face barriers at the GP level, which delay referral for diagnosis, including dismissal, misdiagnosis and unclear referral pathways for further assessment (Relevant to: Actions 3, 4 & 7).
- Wait times for specialist assessment vary, with rural and regional participants experiencing increased barriers to access and travel burden (Relevant to: Actions 1 & 4).

Stage 2: Diagnosis

Undergoing specialist assessment

Following referral, diagnosis was a process that could extend from weeks to months or even years, involving multiple clinical assessments and appointments. Long wait times for an initial appointment in the public system prompted some to opt for private services. Participants underwent highly variable assessment pathways, with some accessing multidisciplinary memory clinics, whilst others may have seen only a single specialist. Assessment usually involved cognitive testing, neuroimaging (CT, MRI, or PET scans), and some also underwent lumbar puncture, EEG, or neuropsychological assessment. As with the GP point-of-contact, some participants were concerned about overreliance on screening tools or a lack of comprehensive assessment. Communication about the purpose of assessments or results was inconsistent.

Often, testing occurred across multiple appointments, with months-long wait times between appointments. Due to this protracted process, reducing wait times for an initial consultation is critical to receiving a timely diagnosis and, subsequently, to people with dementia getting on a pathway towards a clear plan for services and supports, either as soon as possible or to prepare for the future.

Time to diagnosis for people with dementia in high-income countries is typically reported as 2 to 4 years from symptom onset, increasing to between 5 and 7 years for people with atypical dementias or young-onset dementia (Draper et al., 2016). The Australian Dementia Network Memory and Cognition Clinic Guideline (2024) provide a framework for multidisciplinary assessment standards that could inform implementation. However, increased resourcing would likely be required to achieve consistent application across services.

Critical moment 4: Receiving the diagnosis

Receiving the diagnosis was a life-changing and emotionally draining event for people with dementia and their families. In our sample, a careful and considered explanation directly influenced the likelihood of engaging with services and the willingness to engage in future planning. Conversely, an impersonal, blunt, and abrupt diagnosis and subsequent discharge from a specialist clinic were associated with

feelings of hopelessness, confusion, and emotional distress, leaving people to self-navigate the path forward without support and guidance, and a missed opportunity to instigate proactive action and connection with services and supports. Information received at diagnosis for our sample predominantly focused on medication, and there was little focus on non-drug interventions or post-diagnostic services. This left many unaware of the available services and forced them to investigate options on their own. Whilst some participants were provided with follow-up appointments, in general, participants perceived the support received as inadequate. The importance of diagnosis delivery is well established. A recent Delphi consensus process identified seven best practices: showing compassion and empathy; asking about diagnosis preferences; instilling realistic hope; providing practical strategies; providing education and connections to resources; connecting caregivers to support; and providing written summaries (Armstrong et al., 2024). However, the application of these principles appears inconsistent.

Transition in care 2: From specialist or memory clinic to post-diagnostic support

After receiving the diagnosis, people with dementia were often discharged from specialist services. This was an abrupt and challenging transition in care, as in most instances, little to no post-diagnostic intervention was provided or offered to participants. This finding is consistent with other Australian research into post-diagnostic support from memory clinics (Naismith et al., 2022; Pavkovic et al., 2024a; 2024b). Inadequate funding to provide support beyond assessment and diagnosis have been identified as a key barrier limiting the ability of memory clinics to provide timely, tailored information and support over multiple appointments to better meet needs (Pavkovic et al., 2024b).

SUMMARY: DIAGNOSIS

Key insights:

- Diagnosis is usually a protracted process, and the extent of assessment and investigation undertaken can vary considerably; people are unclear about the diagnosis process and the purpose of some assessments (Action 4 & 7).
- Communication at diagnosis is a critical moment which can significantly impact future engagement with services, with insensitive communication compounding distress (Action 3, 4 & 7).
- Despite established guidelines for communicating a diagnosis, their application remains highly inconsistent (Actions 4 & 7).
- Referrals to post-diagnostic support at diagnosis or information on what is available are rarely offered (Actions 3, 4, 5, 6 & 7).
- People with dementia are discharged at or shortly after diagnosis without clear pathways to ongoing care, with this care transition experienced as highly stressful for people with dementia and care partners (Actions 4, 5 & 6).

Stage 3: Care after diagnosis

Seeking post-diagnosis information and support

Following a dementia diagnosis, our sample typically underwent a period of grief and sense-making before asking the question of "what's next?" Having received little substantive information at the time of diagnosis, most sought this information soon after, usually through online channels. The timing of information seeking was shaped by several factors: whether information on post-diagnostic support was provided at the time of diagnosis or at a follow-up appointment, emotional readiness, symptom progression, and awareness of available services. Awareness of what allied health services could offer was largely limited to standard assessments, such as occupational therapy home safety assessments. Very few participants had accessed rehabilitation or reablement approaches designed to optimise function, independence and quality of life. Some recognised the value of physical activity, diet, mental stimulation, and social connection in managing symptoms; however, few received structured support to optimise these factors.

These findings are consistent with evidence that post-diagnostic support largely fails to meet the needs of many people with dementia and care partners, or is simply unavailable (Low et al., 2023). The period immediately following diagnosis represents a crucial window for intervention, characterised by high emotional distress and practical need (Low et al., 2023), yet this is also when people are least connected to services. Despite endorsement of reablement and psychosocial interventions in Australia's Clinical Practice Guidelines for Dementia (Guideline Adaptation Committee, 2016), and growing local and international evidence into specific interventions, such as Cognitive Stimulation Therapy, physical exercise, peer support, and multicomponent programs supporting the person with dementia and their care partner in tandem (Clemson et al., 2021; D'Cunha et al., 2025; Keyes et al., 2016; Woods et al., 2023). The low awareness and uptake in our sample indicate low availability and significant barriers to access, including low dementia knowledge, stigma, inadequate funding, and unclear referral pathways (Layton et al., 2024). Also, the absence of age-appropriate programs for people with young-onset dementia reported in our sample aligns with documented mismatches between younger people's needs and services designed primarily for older populations (Cations et al., 2017; Mayrhofer et al., 2018; Loi et al., 2025).

- **Critical moment 5: Encountering a key support person**

With uncertainty and a lack of clear guidance around the availability of post-diagnostic supports, positive experiences were often attributed to a key relationship with a formal or informal support person, who provided practical help with system navigation and connections to services, along with emotional or psychological support. This encounter often represented a turning point, shifting the person's trajectory from confusion and isolation to clarity and control. However, in most instances, this support was not part of a formalised post-diagnostic pathway. It instead relied on individuals who had the skill, willingness, and capacity to provide navigation and coordination beyond what is typical; for example, GPs who invested significant additional time in coordinating supports outside a normally time-constrained GP consultation, or a care partner with significant time and resources to advocate on the person's behalf. Those who did not encounter this kind of support often remained in prolonged confusion.

The "key person" encounter, described by participants as transformative, and participants' calls for a single contact person reflect dementia care navigator models that have been implemented

internationally and strongly advocated for in Australia (Dementia Australia, 2023; Layton et al., 2024). Though this approach has been piloted on a small scale through Primary Health Network (PHN) funding in Australia, access to this support is not readily available to all (WentWest, n.d.). Scotland's 5 Pillars Model of Post-Diagnostic Support represents an international example in which everyone diagnosed with dementia is entitled to at least one year of post-diagnostic support, coordinated by an appropriately trained Link Worker (Monaghan, 2013). The five pillars address understanding the illness and managing symptoms, supporting community connections, peer support, planning for future decision-making, and planning for future care.

Applying for Commonwealth-Funded Aged and Disability Services

Accessing Commonwealth-funded Aged (My Aged Care, CHSP & HCP) and Disability (NDIS) services was experienced as a complex, time-consuming, and cognitively demanding process. Over 75% of participants encountered difficulties understanding eligibility requirements, confusion regarding assessment processes, and frustration with documentation. Most initiated applications, or sought a review of their approval, following diagnosis, at a time when cognitive capacity to navigate the system was already compromised or compounded by stress. Lengthy wait times for assessment or reassessment were common, leaving many without urgently needed support. Receiving support and guidance was closely related to Critical Moment 5: Encountering a key support person. When available, this assistance was pivotal in transitioning from overwhelm to effective navigation of the application process, especially true for people with young-onset dementia applying for the NDIS. However, most participants described a convoluted and confusing process that required input from doctors and advice from health professionals, friends, and people with experience with the system.

The delays and difficulties currently being experienced within the broader aged care system have been extensively documented in the final report of the recent inquiry into Aged Care Service Delivery (Senate Standing Committee on Community Affairs, 2025). In a system where around 125,000 are awaiting an aged care assessment, and an additional 102,765 are currently waitlisted to access the HCP for which they have already been assessed (Department of Health, Disability and Ageing; 2025), these are widespread challenges for all older people and their families in securing care and support.

The complexities of accessing Commonwealth Aged and Disability funded services pose a particular challenge for people already experiencing cognitive impairment. Care partners took on heavy administrative loads as a result, which were a considerable source of stress, independent of direct caregiving demands. This is consistent with broader evidence on care partner burden in dementia (Brodaty & Donkin, 2009). Furthermore, the need for formal or informal support to navigate the assessment process raises concerns around equitable access to supports. This systemic barrier is highlighted in the Office of the Inspector-General of Aged Care's Report into the review of My Aged Care (2025).

Lengthy wait times for assessment, coupled with a lack of flexibility in funding, have been highlighted as a challenge for people living with dementia (Senate Standing Committee on Community Affairs, 2025). Aged and Disability funding is assessed based on current need, with reviews required for increased care needs, with the exception of anticipatory approval for residential respite or permanent residential care within the aged care system. To better meet the needs of those with a progressive condition, whose support requirements may change rapidly, systemic improvement is required. The current structures risk placing unsustainable pressure on care partners, and for the person with dementia, may contribute to earlier, crisis-driven admission to residential aged care and increased mortality risk (Visvanathan et al., 2019). The

ongoing roll-out of Support at Home presents a timely opportunity to streamline access and simplify assessment pathways, while addressing ongoing workforce capacity issues.

Using Commonwealth-Funded Aged and Disability Services

Challenges were evident across all funding streams. The timeliness and usefulness of these services were often dependent on provider responsiveness, with mixed experiences in both establishing the support and in ongoing provision. Service access was often dependent on long waiting lists. Participants in rural and regional areas reported a lack of services or workforce availability. A lack of continuity of care was also a concern, and many felt that the workforce lacked dementia-specific knowledge or appropriate training. CHSP services could be complex for participants to obtain, particularly when they were not referred directly to a provider and instead received referral codes to self-initiate. HCP and NDIS supports were transformative for some and inadequate for others. HCP case management and NDIS support coordination experiences were mixed, often depending on whether participants encountered a knowledgeable and responsive case manager.

This points to workforce capability gaps identified in aged care and disability services. The Royal Commission into Aged Care Quality and Safety (2021) highlighted substantial deficiencies in dementia care workforce training and capability. The NDIS workforce may have limited dementia expertise, and the progressive nature of dementia may not be well accommodated within NDIS plan review processes designed for stable or improving conditions. The strengths-based philosophy of the NDIS, focused on maximising independence and achieving goals, was valued by participants with young-onset dementia and contrasted favourably with aged care approaches perceived as more deficit-focused.

Transition in care 3: From applying for, to using Commonwealth-funded Aged and Disability services

The process of moving from applying for Commonwealth-funded supports to receiving an assessment, gaining approval, and finally receiving services can take many months, and in some cases, years. Participant commonly experienced multiple, compounding delays at each stage, including being assessed for funding, being allocated a package, and securing service providers. Many were unsure how to initiate services once funding was approved, particularly those without a key person to help navigate the system. When services did commence, even at a minimal level, this often brought a sense of relief and achievement.

SUMMARY: CARE AFTER DIAGNOSIS

Key insights:

- People with dementia and care partners received no substantive information at diagnosis and sought information online (Relevant to: Actions 3, 4 & 6).
- Encountering a key support person who could provide system navigation, advocacy and/or emotional support was often a transformative enabler, however this person is usually encountered by chance (Relevant to: Action 5).
- Awareness of, and access to evidence-based reablement and rehabilitation interventions is limited (Relevant to: Actions 3, 4, 5 & 7).
- There is a lack of age-appropriate post-diagnostic support available for people with young-onset dementia (Relevant to: Actions 2, 3, 4 & 5).
- Applying for Commonwealth-funded Aged and Disability services was overly complex, slow and unresponsive to the needs of those with a progressive condition, requiring formal or informal support to complete (Relevant to: Actions 1 & 5).
- Participants had mixed experiences with using services, with many noting a lack of dementia training, high staff turnover, and service availability and capacity gaps, particularly in rural and regional areas (Relevant to: Actions 1, 2, 4, 5 & 7).

Stage 4: Ongoing Management

Preparation for the Future

Preparation for the future incorporated advanced care planning, financial and legal arrangements, and housing decisions. Downsizing or moving closer to family or services was commonly raised by participants, including several who had already moved or were in the process of leaving their family home. Whilst participants were aware of the need to plan for the future, many received limited guidance on when or how to undertake this process, with several reporting negative consequences. Participants feared future deterioration and were concerned about burdening their loved ones. Numerous participants reflected on voluntary assisted dying and the gap in legislation for providing choice, expressing that they did not want to live in residential aged care if their symptoms progressed.

Advanced care planning uptake in dementia remains lower than optimal despite its recognised benefits, with barriers including uncertainty about prognosis, reluctance to discuss end-of-life issues, and lack of appropriate timing or prompting from health professionals (Bryant et al., 2022). Although many participants in our study were advised to 'get affairs in order' at diagnosis, they were generally not provided with practical steps to do so. Whilst advance care planning is seen as a core part of general practice, time pressures and GPs' lack of confidence in assessing capacity are barriers to its routine practice.

An anticipatory care approach, in which people are proactively guided through predictable transitions and supported in planning ahead, has been advocated as an alternative to reactive, crisis-driven care (Harrison-Dening et al., 2019). This approach is in line with the NDAP's emphasis on supporting people to plan for the future while they have capacity to do so.

Acceptance

Acceptance of living with dementia was not a single moment but an evolving process of adjusting identity, roles, and everyday routines. Many journey mapping participants reported a point in time where they felt at ease about their dementia diagnosis, which contributed to a sense of agency and hope, even as their abilities were impacted or declining.

The time it took people to reach the acceptance phase varied, with some approaching their diagnosis with ambivalence and a resolve to live in the moment and do everything they could to live well and make the most of their time. For others, there was significant emotional distress and fear, and for some, suicidal ideation. There was inconsistent emotional support provided to these people, with some experiencing a key interaction or turning point towards acceptance of their diagnosis. In contrast, for others, it was a long, ongoing process. In that time, without a significant change in symptoms, eventual resilience and self-determination to live well in the moment developed. Once they felt a sense of acceptance, most participants were more comfortable engaging in meaningful activities, receiving or providing peer support, and spending time with their families.

Psychological adjustment to illness following a dementia diagnosis has been explored in qualitative research, with acceptance identified as an important adaptive coping strategy associated with increased quality of life and mood (Gilhooly et al., 2016). Research also indicates elevated rates of depression and suicidal thoughts following dementia diagnosis (Draper et al., 2010). This suggests a need for routine screening for psychological distress and better access to mental health support as part of post-diagnostic care pathways. Adapting and coping following a diagnosis of dementia is supported through timely, person-centred post-diagnostic support which addresses emotional well-being, including access to counselling and opportunities for peer support to assist with adjustment and maintain identity and agency (Bamford et al., 2021).

SUMMARY: ONGOING MANAGEMENT

Key insights:

- Planning for the future by making medical, financial, legal and housing arrangements provided many participants with a sense of agency and comfort, though some struggled to navigate this process (Relevant to: Action 1 & 4).
- Access to Voluntary Assisted Dying was seen as a gap by some participants who called for system reform (Relevant to: Action 1).
- Acceptance of dementia was a key psychological adjustment that was aided by engagement in meaningful activities, accessing emotional and practical support, and engaging in compensatory strategies (Relevant to: Actions 2, 3, 5 & 6).
- Ongoing management requires anticipatory, coordinated care to guide people with dementia and care partners as symptoms progress (Relevant to: Actions 4, 5, 6 & 7).

Barriers and enablers

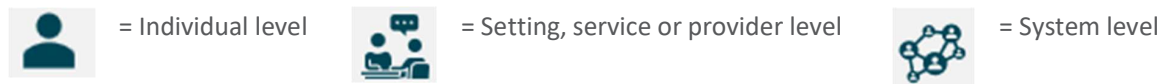
Key barriers and enablers were identified during the analysis, with significant impacts cutting across journey stages and key touchpoints with health, aged care and disability services (Table 2).

Barriers and enablers were identified at various levels:

- **Individual:** These were factors related to the person themselves, such as their knowledge, confidence, financial situation, or personal circumstances, that make it easier or harder for them to navigate the journey;
- **Setting, service or provider level:** These were factors related to the places where people receive care, such as clinics or community services, including how they were run, the skills of their staff, and the way care was delivered; and
- **System:** These were factors related to how the broader health, aged and disability services were designed and funded, including government policies, funding structures, and how different services were connected to each other.

Table 2. Key barriers and enablers

Table Key: 1. Awareness; 2. Diagnosis; 3. Post-diagnostic support; 4. Ongoing management



BARRIERS		ENABLERS	
Workforce knowledge or capacity Workforce knowledge and capacity gaps significantly impacted individual journeys. Beginning with initial help seeking, this led to dismissal and invalidation of symptoms, missed or delayed diagnosis, and poor experiences of care across the journey. Often, overcoming these barriers required a change in provider or care setting.	 Journey stage  Barrier level	Resourcefulness and self-advocacy Those with the knowledge, capability, and resolve to continue pushing for answers, challenge the status quo, or seek alternatives were often able to overcome roadblocks or accelerate access to services and supports.	 Journey stage  Enabler level
Lack of knowledge or awareness Limited knowledge or awareness of dementia, including the perception that it is a normal part of ageing, delayed initial help seeking and contributed to fear and anxiety following diagnosis.	 Journey stage  Enabler level	Individualised or tailored Information, education and support Timely, needs-based and individualised information and services empowered people with dementia and care partners to make informed decisions about the best way to live well and maintain independence, enabling them to take control of their situation and seek support earlier and more effectively.	 Journey stage  Enabler level

System complexity

Complex and bureaucratic processes, regulatory requirements, and multiple interacting systems were significant hurdles for participants. In some cases, the opportunity cost of attempting to navigate the system's complexity led participants to abandon this process.



Journey stage



Barrier level

Peer support

Connecting with others in similar circumstances helped people with dementia and their care partners to build confidence, feel less isolated, and learn about programs, services, and practical strategies. This was crucial for coping and adjustment for many. Peer support was not available to all, but some encountered this through certain service providers or their personal networks.



Journey stage



Enabler level

Care fragmentation

Fragmentation of care across the health and aged care system, along with poor communication, led to unnecessary duplication (e.g., multiple assessments), increased confusion for people with dementia and care partners, and impacted the coordination of care.



Journey stage



Barrier level

Care coordination or navigation support

Support to navigate the health system, access services and coordinate supports was a significant enabler, which improved the experience of people with dementia; however, many did not have access to this support. Care coordination support was not systemically available to all, but some encountered this through certain service providers or their personal networks.



Journey stage



Enabler level

System-centred approach to care

Many participants spoke of a lack of individualised support and the need to shift to a “one size fits all” system. This led to dissatisfaction with health services and the inability to access supports that would reduce excess disability.



Journey stage



Barrier level

Care partner support

Having a care partner was a significant support, which often enabled the person with dementia to more effectively overcome system complexity barriers.



Journey stage



Enabler level

Geographical access Service availability was a particular challenge for those in regional, rural and remote areas, affecting access to specialists, testing and post-diagnostic care and support. Increased wait times are also a challenge for people outside of major urban centres.	234 Journey stage  Barrier level	Continuity of care Continuity of healthcare providers, support services and workers, notably to support transitions of care, significantly improved the experience of individuals and was associated with better outcomes such as earlier access to support services.	1234 Journey stage  Enabler level
Funding or cost constraints Funding and cost-related barriers impact access to diagnostic testing and/or investigations, as well as post-diagnostic services and supports. Insufficient funding for services limited access to supports such as allied health and care services. Inflexibility of funding guidelines also impacted access to assistive technology, and reablement and independence supports.	1234 Journey stage  Barrier level	Person-centred care Considering the holistic needs of people with dementia and care partners, a collaborative approach to care planning, and focusing on the person's preserved capabilities led to better experiences of diagnosis and post-diagnostic support.	1234 Journey stage  Enabler level
Waitlists and capacity constraints Waitlists and service capacity constraints affected all stages of the journey, with most participants waiting multiple times for healthcare or services.	1234 Journey stage  Barrier level	Telehealth and flexible care models The use of telehealth and flexible service provision models enabled better access to services and supports, particularly for those in regional, rural and remote areas.	1234 Journey stage  Enabler level

Ability to pay

Those with financial resources at their disposal were able to bypass waitlists and funding limitations by paying privately for earlier diagnostic assessment, more comprehensive testing, and additional treatments or support services.



Journey stage



Enabler level

Strengths and limitations

The journey mapping project has several notable strengths. We recruited a first-of-its-kind Australia-wide sample of 46 people with dementia for in-depth, semi-structured interviews. Just over half were supported by their care partners during interviews. Data were collected by an experienced team, familiar with dementia and the health, disability, and aged care systems, who used targeted follow-up questions to elicit a richer understanding of people with dementia's experiences. The use of framework analysis supported a systematic and rigorous analytical process. An advisory group consisting of members with living experience and professional expertise participated in feedback workshops to strengthen the trustworthiness and credibility of the findings. Collectively, over 52 hours of interview data were collected, representing a substantial qualitative data set.

The sample was drawn from people with dementia who completed the LwDS. The proposed sample was 1,500 people; however, only 152 had completed the survey by the time journey mapping recruitment commenced. This smaller-than-expected pool necessitated inviting a broader range of people to participate in journey mapping, rather than adopting a more targeted approach. Despite this constraint, the final sample included participants from across Australian states and territories, and the majority of quotas were met. The sample comprises people with relatively high levels of education; 56% of the people with dementia in our sample held educational qualifications equivalent to a Bachelor's degree or above, as compared to around 34% of the general Australian population aged between 15 and 74 years (Australian Bureau of Statistics, 2025). This may also be viewed as a strength, as challenges reported by our sample suggest that less advantaged populations may be experiencing similar or more pronounced difficulties in navigating the dementia pathway.

The collected data consisted of retrospective accounts, reflecting participants' subjective recollections and interpretations of their experiences. The capacity to recall specific details may have been influenced by the time elapsed since key events. This was mitigated by the inclusion of care partners in just over half of the interviews, whose accounts complemented and enriched the data provided by people with dementia. The interviews were supported by visual tools, which provided cues to facilitate recall and supported participants in their responses across each relevant stage of their journey.

Several logistical considerations warrant acknowledgement. In-person interviews were conducted at Dementia Australia offices and other locations, which posed scheduling and travel challenges. This issue was exemplified in Perth, Western Australia, where two last-minute cancellations prevented us from securing additional face-to-face interviews. If the project were to be conducted again, ethics approval to conduct home visits would be recommended. The project was also conducted within a defined timeframe, which precluded the use of prospective journey mapping or participatory workshops with people with dementia. Such approaches may offer complementary insights and should be considered in future research.

Policy Implications

In this section, the policy implications of these findings are set out, focusing on the first [Collective Priority Framework 2025–2027](#), which prioritises Actions 3, 4, and 8, while highlighting connections to other NDAP actions where relevant. Table 2 provides a concise summary of policy implications for all NDAP priority areas.

Action 3

ACTION 3: EMPOWER INDIVIDUALS AND COMMUNITIES TO MINIMISE RISK WHERE THEY CAN, AND DELAY ONSET AND PROGRESSION	
1.	Improve Australians’ awareness of risk factors and preventive actions that can be taken to reduce the risk of developing, delay the onset or slow the progression of dementia. This includes health promotion and prevention programs which support overall health.
2.	Promote the brain health benefits of people regularly and safely participating in sports, exercise and movement.
3.	Increase awareness of strategies to improve brain health and establish whole of population brain health approaches for earlier dementia detection and intervention.
4.	Develop targeted strategies and messages for people from diverse communities or at higher risk of developing dementia in partnership with relevant communities.
5.	Implement evidence-based interventions to reduce the risk of dementia, including for higher risk populations and people with mild cognitive impairment (MCI).

Action 3 aims to empower people to take preventive actions to reduce dementia risk and to delay progression of dementia for those who have a diagnosis. Journey mapping interviews revealed low awareness of dementia symptoms and risk factors contributed to delays in help-seeking. Many participants described a period of subjective cognitive change during which they were aware that something was not right but did not associate this with possible dementia risk. Stigma was an additional barrier to acting early. Delaying the progression of dementia is also a key aim of this action, yet participants were rarely offered evidence-based interventions to reduce risk or maintain their cognitive function. Few were made aware of the benefits of cognitive interventions, physical activity, or rehabilitation and reablement approaches. Where people accessed such programs, it was through their own initiative rather than referral. These findings directly support the need for greater investment in risk reduction and early intervention, including whole-of-population approaches and specific strategies for primary care settings (Actions 3.1, 3.3), where there were missed opportunities to provide health education in our sample.

‘There’s quite a few good [...] American publications, from doctors and so on over there, who quite clearly outlined that diet was really important in terms of if you want to try and avoid [dementia], or if you’ve got Alzheimer’s, you can slow it down [...] So now I think my diet’s pretty good [...] I stopped drinking too [...] there’s a lot of common sense things, but they all related to giving you a better outcome [...] So, I think that’s where it really, it came to me that [...] there are things you can do for yourself. which are going to be good for you anyway.’
(Participant #8, male, 74 years)

Action 4

NDAP ACTION 4: IMPROVE DEMENTIA DIAGNOSIS AND POST-DIAGNOSTIC CARE AND SUPPORT

1. Review and update clinical practice guidelines and principles of care for people living with dementia every 3 to 5 years.
2. Review how the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) support effective dementia diagnosis and ongoing management every 3 to 5 years.
3. Clarify pathways for dementia screening, assessment and diagnosis across the country, including identification of best practice.
4. Increase the capacity and reach of memory clinics and review the funding model.
5. Embed memory clinics in targeted Aboriginal Community Controlled Health Organisations (ACCHOs) and Aboriginal Community Controlled Organisations (ACCOs) to support improved access, diagnosis and care for First Nations people.
6. Develop and promote culturally appropriate cognitive assessment tools in partnership with diverse communities and experts, and support training for clinicians to use these tools.
7. Improve support, care coordination and planning for people living with dementia and their care partners following a dementia diagnosis, including models for First Nations, CALD and other diverse communities.
8. Improve diagnostic and post-diagnostic services and supports for groups facing additional barriers to care, such as people living with younger onset dementia and children living with dementia and their families.
9. Improve and embed supports for people living with dementia in disability support services.

Action 4 aims to ensure people can recognise the signs of dementia, access health professionals who are willing and qualified to assess their symptoms, and receive a diagnosis, along with information and support, as soon as possible. The journey mapping findings suggest this action area requires urgent and sustained attention. Participants described a lengthy, fragmented, and often distressing pathway from awareness to diagnosis to post-diagnostic care. Once concerns were raised with a GP or other health professional, almost half the sample encountered delays because their symptoms were dismissed, misattributed to other conditions, or because screening conducted in primary care settings was inadequate to detect early changes. Many changed GPs or self-advocated for a specialist referral before being diagnosed. These findings support clearer pathways for dementia screening, assessment, and diagnosis and a review of how the MBS supports effective assessment (Action 4.2, 4.3).

Following referral, participants experienced highly variable assessment pathways. Wait times ranged from one week to twelve months, with rural and regional participants facing limited access to specialists or having to travel long distances. Assessment procedures were inconsistent, and clear communication about the purpose of assessments and explanations of results were often lacking. These findings inform Action 4's emphasis on increasing the capacity and reach of memory clinics, including reviewing the sufficiency of funding (Action 4.4), and on improving access in rural and regional areas (Actions 4.6 & 4.8). Communication of the diagnosis was a pivotal moment. Participants expressed a need for clear guidance, written information, or referrals to services. Feelings of abandonment and overwhelm were common, yet few were offered a timely follow-up appointment. Despite the existence of best practice guidelines for communicating a diagnosis, their application appears inconsistent in our sample, indicating a missed opportunity to connect people with support when it is most needed. Action 4's focus on improving support, care coordination, and planning for people with dementia and care partners following a diagnosis (Action 4.7).

Most people were not referred to post-diagnostic services or provided with substantive information about support available. People sought information independently, typically online. Crucially, there was little awareness of the benefits of allied health, and very few were offered rehabilitation or reablement, despite well-established evidence supporting independence and maximising quality of life. People with young-onset dementia faced additional frustrations due to a lack of age-appropriate programs and supports. These findings highlight the need for structured post-diagnostic support, guided by a trained care navigator.

'I didn't even know what I was looking for. And that's the problem. You don't know what you don't know. So, if your health care provider doesn't say you now need rehab, OT, speech therapy, blah, blah, blah [...] If nobody's giving me the right advice, or in fact, any advice, how's anyone supposed to know what to do?' (Participant #40, female, 67 years)

Action 8

NDAP ACTION 8: IMPROVE DEMENTIA DATA, MAXIMISE THE IMPACT OF DEMENTIA RESEARCH AND PROMOTE INNOVATION

1. Review and update clinical practice guidelines and principles of care for people living with dementia
2. Encourage investment in research, innovation and research translation on prevention, risk reduction, diagnosis, treatments (including a cure), holistic care and management for all types of dementia.
3. Improve alignment of Australian dementia research priorities and funding sources and include people living with dementia and their care partners in setting future research priorities.
4. Improve understanding of outcomes for people living with dementia from First Nations, CALD and other diverse communities.
5. Promote whole-of-system approaches to improve dementia data, (e.g. through clinical quality registries).
6. Improve health, social and aged care data collection, accessibility and integration to support research, inform policy and service planning, monitor improvements and reporting on outcomes for all types of dementia every 3 to 5 years.

'I just hope there's enough research, maybe like yours, that can influence the government to make it easier for people to access the benefits that they deserve, they should get, instead of going through all this rigmarole.' (Participant #3, male, 75 years)

Action 8 aims to improve national dementia data, maximise research impact, and promote innovation. The journey mapping study uniquely captures in-depth, qualitative accounts from people with dementia across Australia, revealing how people experience different stages along the dementia pathway. This study demonstrates the value of including the voices of people with dementia in national data collection (Action 8.1). The findings highlight gaps identified in the AIHW National Dementia Data Improvement Plan 2023-2034, particularly regarding time to diagnosis, post-diagnostic support, and the experiences of specific groups, such as those living with young-onset dementia. The

NDAP also encourages investment into research, innovation, and translation (Action 8.1). Despite well-established international evidence for the benefits of interventions such as cognitive stimulation therapy and cognitive rehabilitation, more Australian evidence is needed. Critically, this should focus on local implementation and evaluation research to support widespread use, as few were offered these interventions. Overall, the journey mapping findings support the development of new interventions and scaling of existing evidence-based interventions, as well as systematic evaluation of how well existing services meet the needs of people with dementia and care partners.

Summary of key policy-relevant findings

The journey mapping study reinforces the dementia journey as non-linear and highly variable in people's experiences depending on where they live, the health professionals they encounter, their ability to self-advocate, and the availability of support. However, several consistent patterns were identified across NDAP action areas which offer opportunities for improvement:

- Preventable delays in receiving a diagnosis at multiple points;
- Absence of structured, coordinated post-diagnostic support;
- Limited access to evidence-based rehabilitation and reablement interventions;
- Burdensome processes for accessing Commonwealth-funded support;
- The transformative impact of a key support person; and
- The value of peer support in reducing isolation and facilitating coping and acceptance.

The journey mapping sample was generally well educated and of relatively high socioeconomic status. Therefore, it can be expected that people with dementia with more limited social and financial resources are experiencing similar or worse outcomes in navigating the health, aged care, and disability systems after a diagnosis of dementia.

Table 3 presents key findings from this study that hold relevance for the NDAP's ten-year vision, alongside the related NDAP actions. Drawing on the experiences of participants, we offer questions intended to inform ongoing policy and practice development which could improve the experiences of people with dementia and care partners across the dementia continuum. These questions are offered as a starting point for continued dialogue with people with dementia and care partners about their experiences, and with the health and care workforce about policy in action. The insights of both will be central to NDAP's success.

Table 3 – Summary of journey mapping findings and further questions for NDAP policy implementation

NDAP ACTION	JOURNEY MAPPING FINDINGS	QUESTIONS FOR FUTURE POLICY AND PRACTICE
Action 1: Promote equity and human rights	• People in rural and regional areas faced significant barriers to accessing assessment and post-diagnostic support. • More positive journeys were attributed to self-advocacy or having a knowledgeable support person, which are not available to all.	• To what extent should dementia pathways be redesigned to improve equity of access regardless of geographical location, capacity for self-advocacy, availability of knowledgeable informal support or a key person in the health system?
Action 2: Tackle stigma, improve awareness and promote inclusivity	• Stigma, including both actual experiences of stigma and the fear of being stigmatised had a pervasive negative impact on social relationships and healthcare experiences • Stigma was reported among health professionals and service providers • Misconceptions around dementia led to some participants not being taken seriously	• Among the general public, health professionals and service providers, to what extent do current awareness initiatives address the stigma and misconceptions about dementia reported by journey mapping participants? ○ What opportunities exist to strengthen awareness initiatives targeting health professionals and service providers, to reduce stigma, discrimination and abuse? ○ What opportunities exist to address these broader impacts to support the dementia inclusive society envisaged under Action 2?

Action 3: Empower individuals and communities to minimise risk where they can, and delay onset and progression	• Low awareness of risk factors of modifiable risk factors and potential benefits of acting early • Stigma was a barrier to acting early on early symptoms • Evidence-based interventions for delaying symptom progression were not known or offered to most participants	• What approaches could build the capacity of both the general public and primary care professionals to recognise dementia symptoms earlier? ○ What is needed to ensure evidence-based interventions for delaying symptom progression are consistently available and promoted?
Action 4: Improve dementia diagnosis and post-diagnostic care and support	• Variable experiences with specialist assessments, including long wait times and inconsistent procedures • Experiences of receiving the diagnosis were variable, however the majority of participants perceived that the information and support they were provided at diagnosis was inadequate. A substantial number of participants reported the delivery of their diagnosis was performed in an insensitive manner, and this was a highly distressing experience • A structured post-diagnostic pathway was absent	• What is needed to reduce variability in specialist assessment and diagnostic experiences, including provision of information and support, to move services closer to the benchmarks outlined in the Australia Dementia Network Memory and Cognition Clinic Guidelines? ○ What opportunities exist to better support health professionals in compassionate and sensitive delivery of diagnosis so that more people report positive experiences of diagnostic care? • What features are required in post-diagnostic care models to ensure that structured and coordinated support is timely and consistently provided following diagnosis and how can this be measured?
Action 5: Improve treatment, coordination and support	• Accessing Commonwealth-funded supports (MAC, CHSP, HCP, NDIS) was complex, lengthy, and cognitively demanding, with the administrative burden falling predominantly on care partners	• What opportunities exist to simplify access to aged care and disability supports to better support people with dementia and their care partners?

	• It was difficult to locate reliable information about available supports and services and subsequently access these, with many participants relying on outside assistance to navigate services • The aged care system faces significant capacity constraints, including lengthy wait times and limited service availability, undermining the effectiveness of services that are providing benefits • Reablement approaches were seldom offered to participants	• Given the difficulty participants faced in locating reliable information about available dementia supports, what opportunities exist to improve access to comprehensive, up-to-date information for people with dementia, care partners, and health professionals? • Given participant experiences of lengthy wait times and limited availability of appropriate services, to what extent can care coordination improvements be realised?
Action 6: Support carers	• Care partners were integral to navigating the system, absorbing the practical and emotional challenges of paperwork, service coordination, and advocacy • The demands of managing government-funded supports were a significant and largely under-recognised source of care partner stress	• To what extent do current policies consider and support care partners with the practical and administrative demands associated with their caring role? ○ What opportunities exist to streamline paperwork, coordination, and information sharing across services? ○ To what extent do current care partner supports provide assistance with system and funding navigation?
Action 7: Build capability of the workforce	• Workforce knowledge and capacity gaps were a barrier at every stage of the journey, and across the health, aged care, and disability systems • Participants frequently encountered workers with limited dementia-specific knowledge or awareness • High staff turnover negatively impacted continuity of care	• What investment in dementia-specific workforce training across primary care, aged care, and disability workforces is warranted to reduce barriers to cross-system knowledge and understanding? • What opportunities are there to address workforce turnover through improvements in

		workforce conditions, job satisfaction, remuneration, and career pathways?
Action 8: Improve dementia data, maximise the impact of dementia research and promote innovation	• Qualitative data, such as the findings presented in the journey mapping study, provide a voice to people living with dementia navigating the Australian health and aged care system • Variable participant experiences were often contingent on whether they encountered a knowledgeable support person, which cannot be captured in quantitative data	• To what extent do the current indicators in the National Dementia Data Improvement Plan adequately capture and consider qualitative outcomes in identifying gaps in the health and aged care system in this population? • What opportunities exist to improve translation of existing evidence into practice (e.g. improvement in offering reablement and rehabilitation approaches) and how can this be measured? • How can successful services and initiatives be supported to be embedded in routine care and sustainable?

GLOSSARY

Aged Care Assessment Service (ACAS): A team of health and allied health professionals who assess whether an older person is eligible for government-funded aged care services, and what level of support they may need.

Advance care planning: The process by which a person thinks about, discusses, and documents their preferences for future healthcare and medical treatment, particularly for situations where they may no longer be able to speak for themselves. This often involves completing legal documents such as an Advance Care Directive.

Allied health: A group of health professionals who are not doctors or nurses, but who provide specialised care and rehabilitation. Examples include occupational therapists, physiotherapists, speech pathologists, social workers, and dietitians. Allied health professionals play an important role in supporting people living with dementia.

Alzheimer's disease: The most common form of dementia, accounting for approximately 60–70% of cases. It is caused by the gradual buildup of abnormal proteins (amyloid plaques and tau tangles) in the brain, which damage nerve cells and disrupt their communication. Symptoms typically begin with memory loss and worsen over time.

Culturally and Linguistically Diverse (CALD): A term used to describe people from backgrounds where English is not their first language, or whose cultural practices, values, and beliefs differ from those of the mainstream Australian population. People from CALD backgrounds may face additional barriers to accessing dementia diagnosis and support services.

Carer or care partner: A family member, friend, or other person who provides unpaid support and assistance to someone living with dementia. The term 'care partner' is often preferred over 'carer' or 'caregiver' as it emphasises the reciprocal and collaborative nature of the relationship. Care partners may provide emotional, physical, and practical support.

Commonwealth Home Support Programme (CHSP): An Australian government programme that provides entry-level support services to older people (generally 65 years and over, or 50 and over for Aboriginal and Torres Strait Islander people) to help them live independently at home. Services may include allied health, domestic assistance, personal care, transport, and social support.

Clustering: A research analysis technique that groups participants with similar characteristics, experiences, or responses into distinct categories (clusters) so that differences and similarities between subgroups can be examined more closely.

Coding (qualitative): A process in qualitative research where the researcher reviews interview transcripts or other data and assigns labels (codes) to specific passages of text that relate to a particular theme or concept. Codes are then grouped together to identify broader patterns and themes.

Cognitive decline: A gradual worsening of a person's ability to think, remember, concentrate, reason, or make decisions. Cognitive decline may be a normal part of ageing, or it may indicate the early stages of dementia or another neurological condition.

Cognitive impairment: A condition in which a person has noticeable difficulty with thinking, memory, language, attention, or problem-solving. Cognitive impairment ranges in severity from mild (where daily activities are largely unaffected) to severe (where significant assistance is needed). It is a key feature of dementia.

Comorbidities: The presence of two or more health conditions in the same person at the same time. For example, a person living with dementia may also have heart disease, diabetes, or depression. Comorbidities can complicate diagnosis and care.

Co-production: A way of working in which researchers, service providers, and people with lived experience work together as equal partners throughout the design, delivery, and evaluation of research or services. In the context of this report, co-production involved people living with dementia and care partners contributing to the development of the research.

Convergent validity: A measure of research quality that examines whether different methods of measuring the same concept produce similar results. If two different approaches yield consistent findings, this increases confidence in the accuracy of the results.

Credibility: In qualitative research, credibility refers to how trustworthy and believable the findings are, that is, whether they accurately reflect the experiences and perspectives of the participants. Credibility is strengthened through methods such as triangulation and member checking.

Computer Tomography scan (CT Scan): A medical imaging test which produces detailed cross-sectional images of the brain or body. CT scans are commonly used in the dementia diagnosis process to rule out other causes of cognitive symptoms, such as a brain tumour or stroke. CT scans are not able to definitively rule out or exclude a diagnosis of dementia.

Dementia Behaviour Management Advisory Service (DBMAS): An Australian government-funded service that provides guidance, support, and education to people living with dementia, their care partners, and aged care workers on how to understand and manage behavioural and psychological symptoms of dementia.

Dementia: An umbrella term for a group of conditions that affect the brain, causing a progressive decline in memory, thinking, language, behaviour, and the ability to carry out everyday activities. Dementia is not a normal part of ageing. It is caused by damage to brain cells from various diseases (such as Alzheimer's disease or vascular disease), and is ultimately life-limiting.

Dependability: A criterion for assessing the quality of qualitative research. A study is considered dependable when its processes are well-documented, consistent, and transparent, so that another researcher could follow the same steps and reach similar conclusions.

Framework Analysis: A structured and systematic method of qualitative data analysis. It involves five key stages: familiarisation with the data, identifying a thematic framework, indexing (applying the framework

to the data), charting (organising data into a framework matrix), and interpreting patterns and connections. It allows researchers to analyse both predetermined themes and new themes that emerge from the data.

Frontotemporal lobe dementia (FTD): A group of brain disorders caused by progressive damage to the frontal and/or temporal lobes of the brain. Unlike Alzheimer's disease, FTD typically affects personality, behaviour, and language abilities before it affects memory. It is one of the most common forms of dementia in people under 65.

Geriatrician: A medical specialist who focuses on the health, care, and wellbeing of older adults. Geriatricians are trained to diagnose and manage complex health conditions common in older age, including dementia, frailty, and multiple chronic conditions.

Home Care Package (HCP): An Australian government-funded programme that provides a coordinated package of care and services tailored to older people with more complex care needs, to help them live independently at home. There are four levels of Home Care Packages, ranging from basic (Level 1) to high-level care (Level 4).

Health literacy: A person's ability to find, understand, and use health information to make informed decisions about their own care and wellbeing. Low health literacy can be a barrier to seeking dementia diagnosis and navigating complex health and aged care systems.

Indexing: A step in Framework Analysis where the researcher applies a thematic coding framework to the full dataset, labelling sections of data with relevant codes or themes. This makes it easier to locate and compare data across participants.

Inductive analysis: A research approach in which themes, patterns, and conclusions emerge from the data itself, rather than being decided in advance. The researcher reads the data with an open mind and allows key ideas to surface naturally from what participants say.

Informed consent: A process in which a potential research participant is given clear, accessible information about a study including its purpose, what participation involves, and their rights, and then voluntarily agrees to take part. Participants must be able to withdraw at any time without penalty.

Journey mapping: A qualitative research method that traces a person's experiences over time across multiple stages of a process, in this case, the dementia care pathway. Journey mapping identifies key steps, decision points, emotional experiences, challenges, and positive moments, providing a holistic picture of the person's experience from their own perspective.

Lewy body disease / Lewy body dementia: A form of dementia caused by abnormal protein deposits called 'Lewy bodies' that form inside nerve cells in the brain. Symptoms often include visual hallucinations, fluctuating alertness and concentration, movement difficulties similar to Parkinson's disease, and disrupted sleep. It is the third most common form of dementia.

Lived experience: Personal, first-hand experience of a health condition, service, or situation. In this report, 'lived experience' refers to the perspectives of people living with dementia and their care partners, which are considered valuable sources of knowledge alongside clinical and research expertise.

Lumbar puncture: A medical procedure (also known as a spinal tap) in which a fine needle is inserted into the lower back to collect a small sample of cerebrospinal fluid. This fluid can be tested for proteins associated with Alzheimer's disease and other dementias, helping to support or confirm a diagnosis.

LwDS (Living with Dementia Survey): National survey of people living with dementia and care partners in Australia, conducted to gather information about their everyday experiences, needs, and challenges. Participants in the Living with Dementia Survey were recruited to take part in this Journey Mapping research study.

My Aged Care (MAC): The Australian Government's central entry point to the aged care system. My Aged Care provides information about aged care services, assists with arranging assessments, and connects older Australians and their families to appropriate support services. It can be accessed by phone or online.

Memory clinic or Cognitive Dementia and Memory Service (CDAMS): A specialist outpatient clinic, typically located within a hospital or health service, where a multidisciplinary team of health professionals assess and diagnose memory problems and dementia. Memory clinics may also provide post-diagnostic support, care planning, and referrals to other services.

Mild Cognitive Impairment: A condition characterised by a slight but noticeable decline in memory or other cognitive abilities which is measurable on a standardised assessment. The change is serious enough to be noticed by the person or their family, but does not significantly interfere with the ability to carry out daily activities.

Mixed methods: A research approach that combines both qualitative methods (such as interviews, which produce descriptive data about experiences and perspectives) and quantitative methods (such as surveys, which produce numerical data) within the same study. This provides a richer and more complete understanding of a topic.

MRI (Magnetic Resonance Imaging): A medical imaging technique that uses strong magnetic fields and radio waves to create detailed images of the brain and other organs. In dementia diagnosis, MRI scans can reveal brain shrinkage, strokes, or other changes that may indicate the type of dementia a person has.

Multidisciplinary team: A group of health and care professionals from different specialties, such as doctors, nurses, psychologists, social workers, and allied health professionals, who work together to assess, plan, and deliver comprehensive care for a person. Multidisciplinary teams are commonly involved in dementia diagnosis and post-diagnostic support.

NDIS (National Disability Insurance Scheme): An Australian government scheme that provides funding and support to people who have a permanent and significant disability that substantially affects their ability to participate in everyday activities. Some people with younger-onset dementia (diagnosed before age 65) may be eligible for the NDIS.

Neurologist: A medical specialist who diagnoses and treats conditions affecting the brain, spinal cord, and nervous system. Neurologists may be involved in the diagnosis of dementia, particularly in more complex or atypical cases.

Neuropsychological assessment / neuropsychological testing: A series of structured, standardised tests administered by a neuropsychologist to evaluate a person's memory, attention, language, reasoning, and

other cognitive abilities. The results help to identify patterns of cognitive impairment and can confirm or clarify a dementia diagnosis.

Neuropsychologist: A psychologist who specialises in understanding the relationship between the brain and behaviour. Neuropsychologists conduct cognitive assessments to help diagnose dementia and other brain-related conditions, and can also provide therapeutic support.

NVivo: A computer software programme widely used in qualitative research to help organise, manage, code, and analyse large volumes of text data, such as interview transcripts or survey responses.

Palliative care: Specialised care focused on improving quality of life for people with serious, life-limiting illness. Palliative care aims to relieve pain and other distressing symptoms, and to provide emotional, psychological, and practical support for both the person with dementia and their family at any stage of the illness, not just at end of life.

Parkinson's dementia (Parkinson's disease dementia): Dementia that can develop in some people who have Parkinson's disease, a condition primarily known for causing movement difficulties (such as tremors and rigidity). Parkinson's dementia shares features with Lewy body dementia and typically develops after the movement symptoms of Parkinson's disease have been present for some time.

PET scan (Positron Emission Tomography scan): A specialised medical imaging scan that detects changes in how the brain uses energy and can identify specific proteins such as amyloid plaques associated with Alzheimer's disease. Amyloid PET scans are sometimes used to confirm a dementia diagnosis when other tests are inconclusive.

PHN (Primary Health Network): Regional organisations funded by the Australian Government to improve access to primary healthcare services within their local area, and to better coordinate care for people with complex health needs, including those living with dementia.

Post-diagnostic support: The services, information, education, and care provided to a person with dementia and their family following a formal diagnosis. Post-diagnostic support may include counselling, care planning, connection to community services, and education about the condition.

Posterior cortical atrophy (PCA): A rare form of dementia that primarily affects the back (posterior) part of the brain, which is responsible for processing visual and spatial information. As a result, early symptoms typically involve difficulties with vision, reading, recognising objects or faces, and spatial navigation, rather than memory loss. It is most often caused by Alzheimer's disease affecting this region of the brain.

Power of Attorney: A legal document that authorises a nominated person (the 'attorney') to make financial, legal, or healthcare decisions on behalf of someone else, if that person loses the capacity to do so themselves. For people living with dementia, establishing a Power of Attorney while they still have capacity is an important part of advance care planning.

Primary Progressive Aphasia (PPA): A rare neurological condition and form of dementia in which language abilities, including speaking, understanding, reading, and writing, gradually deteriorate over time. It is caused by degeneration of the brain regions that control language and is most often associated with frontotemporal lobe dementia.

Prospective journey mapping: A research approach in which participants are followed and interviewed over time as their experiences unfold, rather than asking them to recall past events retrospectively. This method reduces memory-related biases and captures experiences as they happen.

Psychosocial support: Support that addresses both the psychological (emotional and mental health) and social (relationships, community connection, practical) aspects of a person's wellbeing. For people living with dementia, psychosocial support might include counselling, peer support groups, respite care, and help with maintaining social engagement.

Qualitative research: A type of research that focuses on understanding people's experiences, perspectives, feelings, and behaviours, typically through methods such as in-depth interviews or focus groups. Qualitative research produces descriptive data (words and narratives) rather than numbers, and is particularly suited to exploring complex human experiences such as living with dementia.

Recall bias: A type of error that can occur in research when participants are asked to remember past events or experiences. People may not accurately or completely recall what happened, particularly events that are distant in time, emotionally difficult, or less memorable, which can affect the reliability of the data collected.

Recency bias: The tendency for people to more easily and vividly recall recent events compared to older ones. In research, this can mean participants give disproportionate weight to their most recent experiences when describing their overall journey, potentially misrepresenting earlier stages.

Respite care: Temporary care arranged for a person with dementia so that their regular care partner can take a break, attend to their own needs, or manage other responsibilities. Respite care can be provided in the person's home, in day programmes, or through short-term residential stays.

Scoping review: A type of literature review that maps out the available research evidence on a broad topic, identifying what is known, what types of studies have been conducted, and where gaps in knowledge exist. A scoping review does not typically grade or synthesise evidence in the same depth as a systematic review.

Self-management: The ability of a person with a health condition (and their family) to manage the day-to-day aspects of living with that condition. In the context of dementia, self-management may include monitoring symptoms, managing medications, maintaining routines and social connections, and planning ahead for future care needs.

Thematic analysis: A method of analysing qualitative data (such as interview transcripts) that involves identifying, organising, and interpreting recurring patterns or themes across the dataset. It is one of the most commonly used approaches in qualitative health research.

Transferability: In qualitative research, it refers to the extent to which a study's findings are relevant or applicable to other settings, contexts, or populations. Researchers support transferability by providing rich, detailed descriptions of their study context and participants.

Triangulation: A technique used to increase the credibility and rigour of qualitative research by using multiple data sources, methods, researchers, or theoretical perspectives to examine the same question. If different approaches point to similar findings, this strengthens confidence in the results.

Typology: A classification system used in research to group people, experiences, or phenomena into distinct categories based on shared characteristics. Typologies help researchers identify meaningful patterns and differences across a diverse group of participants.

Vascular dementia: The second most common form of dementia, caused by reduced or blocked blood flow to the brain, which deprives brain cells of oxygen and causes them to die. Vascular dementia often occurs after a stroke or a series of small strokes, sometimes called 'mini-strokes' or transient ischemic attacks.

Young-onset dementia / younger-onset dementia: Dementia that is diagnosed in people under the age of 65. People with younger-onset dementia often face unique challenges, including managing work, parenting, and financial responsibilities, and may have different service needs compared to older people with dementia.

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