

Living with dementia in Australia:

A national journey mapping study of experiences from symptom onset to ongoing management

Isobel Sanger ^a, Diane Gibson ^a, Stephen Isbel ^a, Kasia Bail ^a, Sarang Kim ^b, Bronte O'Donnell ^b, Nathan M D'Cunha ^a

^a Centre for Ageing Research and Translation, University of Canberra, Bruce, ACT 2617, Australia

^b Australian Institute of Health and Welfare, Bruce, ACT 2617, Australia

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.

Person with dementia

We weren't given any information. We weren't given anything about people to contact or groups or anything like that.

Person with dementia

For the time that I was waiting for the aged care process to commence, I had to stop my own personal things so that I could look after him [...] Until we've now got the [services] up and running effectively. We've got some sort of semblance of life now.

Care partner

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.

Person with dementia

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Contact isobel.sanger@canberra.edu.au with questions or to receive the final publication when available.

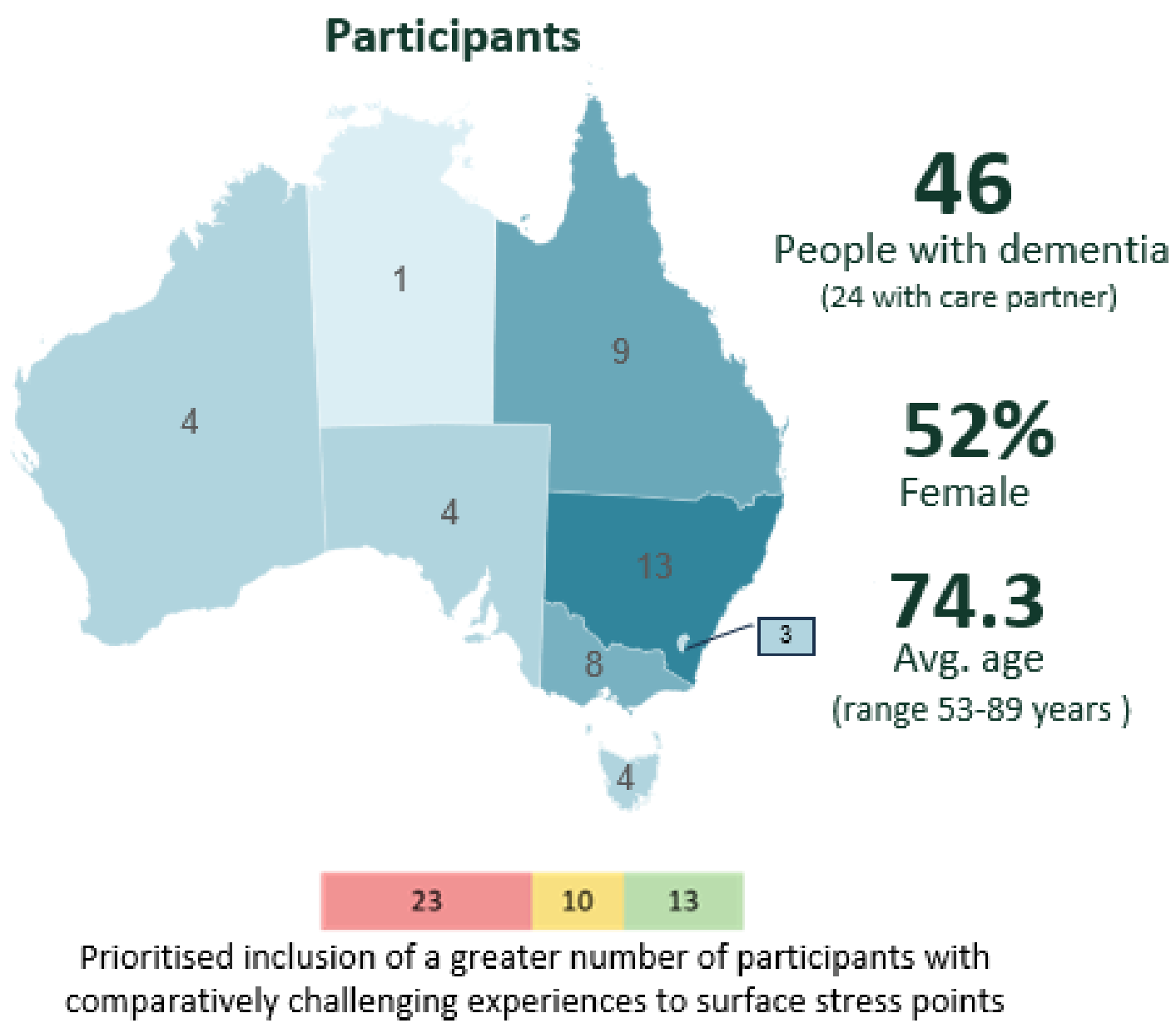
1 •Background

In Australia, 459,048 people are estimated to be living with dementia, and this number is expected to more than double by 2056 as the population ages. In recent years, dementia has become Australia's leading cause of death, and second leading cause of disease burden. To respond to this growing health priority, the Australian Government has released the National Dementia Action Plan (2024 - 2034). This ten-year initiative sets out a policy vision for all levels of government, aimed at improving health and wellbeing for people with dementia, their families and care partners.

Qualitative insights on the experiences and needs of people living with dementia and their care partners, including their experiences with services and supports, is crucial to successfully achieving the goals of NDAP. However, how people experience services across the dementia pathway in Australia is poorly understood. This sub-study of the Living with Dementia Survey aimed to map the lived experience of people with dementia and care partners across the dementia continuum of care in Australia with particular attention to identifying barriers, challenges and stress points.

2 •Methodology

- Design:** Qualitative journey mapping; iterative Framework Analysis.
- Sample:** Purposive multistage sampling; selecting for variable experiences of diagnosis, post-diagnostic treatment, stigma, and care coordination.
- Data collection:** semi-structured interviews using visual journey tools; 35 in-person, 11 online; mean length 68 minutes.
- Analysis:** Iterative, inductive coding in NVivo15; framework refined across waves of data. Mapped chronologically to four pre-determined stages.



3 •Results

The findings revealed common experiences across periods of awareness, diagnosis, care after diagnosis and ongoing management. Within this, along with transitions in care, and critical moments shaped the dementia journey from symptom recognition through to ongoing management. These were points at which timely information, support, or care coordination could most meaningfully alter a person's experience and trajectory.

Stages: pre-determined chronological phases

Sub-stages: specific periods or processes within each stage, which people may move through more than once or skip entirely

Transitions in care: movement between providers, settings, or levels of care

Critical moments: pivotal points where the quality of response within a care setting shaped the outcome.

Awareness

Early dementia symptoms were often noticed by the person or those around them, sometimes triggered by an event like a driving incident, however these changes were rarely linked to dementia and were commonly explained away, delaying help-seeking. Three moments shaped people's experiences of early help-seeking: deciding to seek help for symptoms, having concerns validated or dismissed by a GP, and securing a timely specialist referral. Stigma, low public awareness, primary care constraints, and geographic inequity all contributed to delays in diagnosis.

Diagnosis

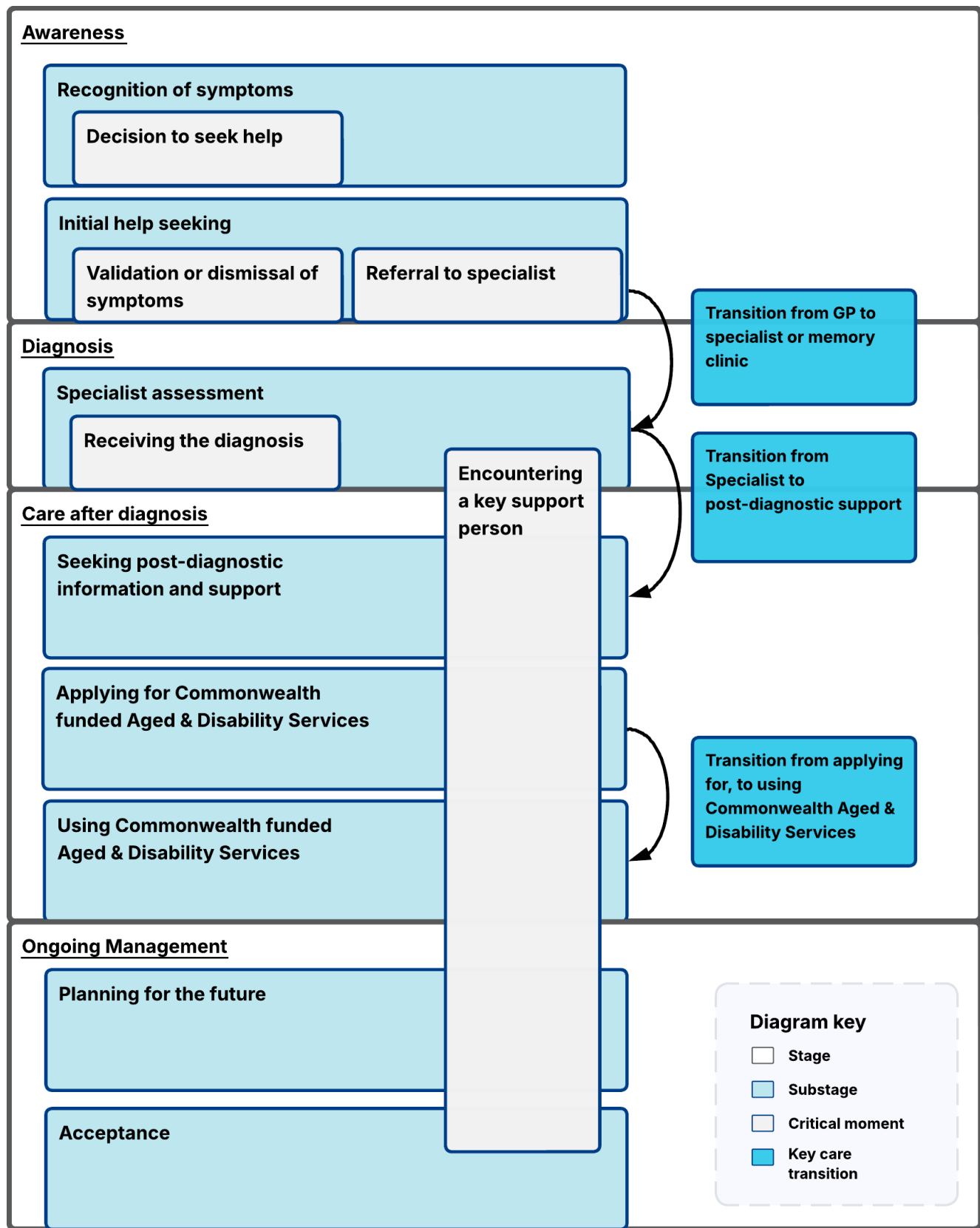
People accessed varied public and private specialist pathways for diagnosis; this was usually a protracted process. Referrals to post-diagnostic support, or information about what was available, were rarely offered, and people were discharged at or shortly after diagnosis without clear pathways to ongoing care, a transition experienced as highly stressful for people with dementia and their care partners. How the diagnosis was communicated could significantly shape future engagement with services, yet despite established guidelines, insensitive and inconsistent delivery often compounded distress.

Care after diagnosis

Following diagnosis, most participants described a period of grief and adjustment before seeking information about subsequent care. Individuals who were not directly referred to post-diagnostic services typically sourced them independently online. Accessing and using Government-funded aged care and disability services was characterised as complex, protracted, and inconsistently delivered. More positive experiences of care after diagnosis were reported when people had encountered a key support person who aided with system navigation and advocacy, though such encounters occurred largely by chance rather than through any formalised pathway.

4 •Conclusion

Across the dementia care pathway from awareness to ongoing management, Australians with dementia and care partners consistently encounter preventable delays in diagnosis, fragmented and under-resourced post-diagnostic support, and challenges accessing evidence-based care and support, underscoring the urgent need for improvements aligned with the National Dementia Action Plan 2024–2034.



Ongoing management

Preparing for the future encompassed advance care planning alongside financial, legal, and housing decisions. While participants recognised the need to plan, many received little practical guidance on how or when to do so. Some participants reported reaching a point of acceptance of their diagnosis. This was an evolving process of adjusting identity and routines, reached at varying pace and, for some, required overcoming significant distress. Acceptance was supported through engagement in meaningful activity, and connection with family and peers, and helped to sustain a sense of agency.