



Recommendations for a gold-standard pathway of care for young-onset dementia

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Recommendations for a gold-standard pathway of care for young-onset dementia

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Declaration of conflicting interest

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13 **Key words**

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16 Young-onset dementia, policy, service provision
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For Review Only

Recommendations for a gold-standard pathway of care for young-onset dementia

Young-onset dementia, characterised by symptom onset before the age of 65, affects approximately 28,900 people in Australia (AIHW, 2024), and represents 5-10% of all dementias (Hendriks et al., 2021). Due to its often atypical presentation, limited awareness among the public and health professionals, and symptom overlap with psychiatric conditions, young-onset dementia is frequently misdiagnosed or diagnosed late (Loi et al., 2022; Tsoukra et al. 2022). Even after diagnosis, age-appropriate care options, including respite and accommodation, are lacking.

The Joint Solutions Project was commissioned by the Australian Government Department of Social Services in 2023, to develop a system of care for Australians with young-onset dementia and their families. As part of this work, we undertook the largest existing stakeholder survey and convened a series of focus groups with people with young-onset dementia, caregivers, and health professionals. Our findings (Loi et al., 2025) identify that there have been improvements in some areas of care over time, but highlight significant outstanding gaps. Building on this and other research in the area, we outline here recommendations for a gold-standard pathway of care for young-onset dementia in Australia, from pre-diagnosis to palliative care and reflect on how the young-onset dementia landscape has changed. The final project report, along with an infographic summarising the findings and recommendations, can be accessed via the following link:

<https://www.australiandementianetwork.org.au/special-interest-groups/yod-sig/>.

Recommendation 1: increasing public awareness

Our research identifies a pressing need to raise public awareness about young-onset dementia—its symptoms, progression, and impact. Unlike older-onset dementia, young-onset dementia often presents with atypical symptoms such as personality changes or language difficulties, which can be misattributed to psychiatric conditions or stress. Greater public awareness can help individuals recognise potential symptoms in themselves or loved ones, leading to earlier consultations with healthcare professionals and timely diagnoses. Early detection improves access to appropriate care,

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3 support, and planning, ultimately enhancing quality of life. Moreover, increasing public awareness
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5 can reduce the stigma and social isolation that often accompanies young-onset dementia.
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7 Misunderstandings about the condition can lead to discrimination and exclusion, but greater societal
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9 understanding can foster empathy and inclusion. Public health campaigns, community education, and
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11 media representation can help shift perceptions.
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16 As with most other conditions, general practitioners (GPs) are often the first point of contact for
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18 individuals seeking clarification of symptoms. But awareness of young onset dementia and its varied
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20 symptomatology remains poor amongst these and other health professionals (Tsoukra et al., 2022). It
21
22 is essential that GPs are empowered to recognise the varied symptoms of young-onset dementia,
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24 which may not always include memory complaints as the primary symptom. Education might include
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26 the implementation of appropriate screening measures and “red flags” to aid early detection and
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28 ensure timely referrals to diagnostic services and specialists.
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33 *Recommendation 2: streamlined services and a hub-and-spoke model*

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35 *Recommendation 3: improve access to diagnostic and post-diagnostic services for diverse groups*

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37 Specialist diagnostic services have been shown to facilitate timely diagnoses (Loi et al., 2022). Our
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39 study indicates that for those who were able to see specialists, they were more likely to access
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41 neuroimaging and cognitive testing, important for confirming or refuting the diagnosis. Ideally,
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43 individuals should have access to a range of expertise and investigations, during the diagnostic
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45 process, including, but not limited to, specialists (neurology, psychiatry, geriatrics), cognitive testing,
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47 brain imaging, and genetic testing and counselling. However, these services are not universally
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49 available or accessible, particularly in rural and regional areas, highlighting a key area that requires
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51 attention.
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56 Our research suggests that access to specialist services often depends on where someone lives. To
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58 improve equity, these services must extend beyond metropolitan areas. A hub-and-spoke model,
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60 where central experts provide guidance and support to regional centres, could help distribute specialist

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3 knowledge, and consequently reduce waitlists. Telehealth consultations could also be explored as a
4 viable option to increase availability (Brown et al., 2023). Additionally, the cost of accessing these
5 services must be addressed to prevent financial barriers from delaying or preventing care.
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9 Once a young-onset dementia diagnosis is confirmed, it is essential that it be communicated
10 sensitively and in a way that both the person and their family can understand. Being given a diagnosis
11 of dementia at a young age can be devastating and difficult to receive and process. Two-thirds of the
12 study participants reported not receiving their diagnosis in a sensitive manner or with adequate
13 information about the subtype, progression, and prognosis. Clinicians should tailor the amount of
14 information shared to the individual's preferences and needs, providing sufficient time for questions
15 and emotional processing. For those with English as a second language, using an interpreter is
16 essential to ensure clear and effective communication. Key topics should include the diagnosis,
17 disease progression, psychosocial implications (e.g., loss of employment, financial and legal matters),
18 and post-diagnostic care. Follow-up appointments, either with the diagnosing clinician or another
19 service, are recommended to be standard practice for ongoing monitoring and support.
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35 *Recommendation 4: a dedicated young-onset dementia website*

36 Post-diagnosis care for young-onset dementia includes psychoeducation and a broad range of
37 practical, emotional and community support for people affected and their families. Good post-
38 diagnostic care is crucial for maintaining quality of life, given that disease-modifying treatments are
39 only accessible for some people with Alzheimer's disease. Our findings show that these resources are
40 scattered and piecemeal and often dependent on the clinicians' knowledge and networks. It is difficult
41 for individuals, families, and other clinicians to find age-appropriate information that is relevant for
42 young-onset dementia. Being unable to access support (including to the National Disability Insurance
43 Scheme; NDIS), compounds adverse mental health and social isolation that people with YOD and
44 their families experience. A centralised website for young-onset dementia would enhance access to
45 reliable information and support. This website should provide clear, evidence-based information on
46 dementia subtypes, prognosis, and management, along with plain-language resources for individuals
47 and caregivers. It should also offer a directory of age-appropriate services, including respite and peer-
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3 support programs, as well as links to research and clinical trial opportunities. Practical guidance on
4 financial assistance, legal planning, and navigating healthcare and disability systems would further
5 support informed decision-making and access to care.
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11 Similarly, the online resource could include a directory of clinicians and services available for people
12 with young-onset dementia (e.g., allied health, peer support groups, cognitive stimulation), along with
13 referral pathways for advance care planning and behaviour change. This would also assist GPs who
14 are uncertain about whom to refer people with young-onset dementia to and how to navigate post-
15 diagnostic support. Current websites such as *Forward with Dementia* and *Dementia Australia* could
16 be further expanded to provide young-onset dementia specific information. Alternatively, a stand-
17 alone, specific young-onset dementia website could be developed.
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28 *Recommendation 5: improve communication and collaboration between families and professionals*
29 *through a confidential portal*
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32 Our research shows that people with young-onset dementia and their families are frustrated by the
33 need to repeatedly provide the same information, reports, and forms, to different clinicians, healthcare
34 providers, and support services. Poor communication can delay access to supports, often leaving
35 families—who are caring for their loved one and may be experiencing their own psychological
36 distress—to navigate the system alone. Collaboration between different clinicians and community
37 service providers could be facilitated through a secure, confidential communication portal that
38 provides access to care notes and letters. Enhancements to MyHealthRecord could fulfill this purpose.
39 This portal would also mean that GPs and monitoring clinicians stay informed and involved in care
40 delivery to ensure coordinated, ongoing support. Supporting an individual living with young onset
41 dementia is a comparatively new experience for disability service providers, many of whom have only
42 a cursory understanding of the disease and how to best meet their needs. Greater collaboration
43 between health practitioners and disability services would help providers respond more effectively to
44 the rapidly evolving care needs that characterise young-onset dementia.
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3 *Recommendation 6: provision of individualised support*
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5 Currently, most dementia programs are designed for older adults, leaving a gap in services tailored
6 specifically for young-onset dementia, a key finding of our work. Post-diagnostic services should be
7 age-appropriate, flexible and individualised. A critical area of need is psychological support for both
8 the person living with young-onset dementia and their family, including children. Additionally,
9 individuals with young-onset dementia usually require assistance in accessing the NDIS and other
10 supports to meet their physical, psychological, and social needs, based on their specific circumstances.
11 Our research highlighted the difficulty for people with young-onset dementia in obtaining increasing
12 supports from the NDIS, as their cognition, function and behaviours decline, and the requirement of
13 repeated paperwork and reports to “prove” worsening function.
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26 Advance care planning should be discussed early while the person still has capacity to make informed
27 decisions, to ensure that their preferences are understood and respected. Decision-making capacity
28 assessments should be completed in a timely manner when needed. Other key considerations include
29 driving, with notifications to governing bodies made in accordance with state regulations, and
30 optimising alternative transport options to maintain community participation and prevent social
31 isolation.
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41 *Recommendation 7: improve access to day programs, respite care, and age-appropriate*
42 *accommodations*
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44 People with young-onset dementia require opportunities for social engagement and cognitive
45 stimulation. Day programs and respite care are important in providing these, especially so that
46 families can continue to work or have a break from caregiving. As the dementia progresses and
47 remaining at home becomes no longer feasible, suitable accommodation options should be readily
48 available, with trained staff who understand the specific challenges of younger individuals. Our
49 findings showed a significant gap in this area of need in young-onset dementia.
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3 The recommendations above aim to guide care and drive ongoing improvements in the care system
4 and pathway. However, the absence of a well-defined, streamlined care pathway towards and beyond
5 diagnosis, remains a significant unmet need, leading to the final and critical recommendation.
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11 *Recommendation 8: a key person to support, inform, and help navigate services*

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13 Individuals diagnosed with young-onset dementia and their families often need to access services
14 across multiple systems, including health, disability, housing, and, in the absence of more appropriate
15 options, sometimes aged care. A dedicated individual, similar to the former YOD Key Worker
16 program, which was discontinued in 2019, is recommended to guide people through the care and
17 support process from the point of diagnosis. Without a skilled key worker providing this vital
18 guidance, access to needed services may not occur. Our research shows the important role that this
19 person could play, in clarifying needs and connecting individuals and their families to appropriate
20 services at each stage of the journey. Taking advantage of technology, community resources and other
21 international models of care, could provide a revised iteration of this. Given budgetary constraints,
22 this role may need to be reimaged in a cost-effective and equitable manner, potentially leveraging
23 technology or community-based resources to provide ongoing support without compromising
24 accessibility or quality.
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41 **Concluding remarks**

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43 Together, these recommendations form the foundation for a gold-standard pathway of care for people
44 with young-onset dementia and their families. This pathway is not only a guide to appropriate
45 supports at each stage—from pre-diagnosis through to palliative care—but also a roadmap of shared
46 responsibilities across health, disability, aged care, and other service sectors. It outlines what
47 individuals and families should be able to expect, regardless of where they live or which service they
48 engage with. By centring the voices of those with lived experience and addressing the gaps identified
49 through our research, this roadmap aims to promote earlier diagnosis, improve service access and
50 navigation, and ensure that care is equitable, age-appropriate, and future-focused.
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