Young Onset Dementia Gap Analysis

Young People in Nursing Homes National Alliance

23 May 2025

nous

Nous Group acknowledges Aboriginal and Torres Strait Islander peoples as the First Australians and the Traditional Custodians of country throughout Australia. We pay our respect to Elders past, present and emerging, who maintain their culture, country and spiritual connection to the land, sea and community.

This artwork was developed by Marcus Lee Design to reflect Nous Group's Reconciliation Action Plan and our aspirations for respectful and productive engagement with Aboriginal and Torres Strait Islander peoples and communities.

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1 Executive Summary

People living with young onset dementia face many challenges

Young onset dementia refers to the onset of dementia symptoms in people after age 18 and before age 65. It is differentiated from:

- **childhood dementia**[1] - symptom onset before age 18 (children develop as expected until early childhood when they develop dementia symptoms which often progress quickly to permanent neurocognitive decline, and
- **late onset dementia**[2] - symptoms onset at age 65 or older (individuals first develop dementia symptoms in older age).

Dementia is not a normal part of human development or ageing.[3]

Terms such as 'early onset dementia', 'presenile dementia', 'adult onset dementia' and 'younger onset dementia' – all previously used to describe onset of dementia before old age – are no longer widely used as they tend to create confusion.[2]

Young onset dementia is caused by a range of different brain diseases, all of which have symptoms in common as well as points of difference. All forms of dementia are progressive – that is, the disease gets worse over time.

People living with young onset dementia, their families and carers face significant and distinct challenges in finding and accessing age-appropriate services and supports.

A diagnosis of young onset dementia – often made after several years of symptoms – can put an end to the uncertainty and tension that lingers when the cause of changed behaviour is unknown[4]. However, receiving a diagnosis is almost always confronting and distressing, imposing on the person and their families the realisation that the person has a terminal illness, that the person's functioning will get progressively worse, and that their cognition and other important aspects of their personality will be affected.

A formal diagnosis of young onset dementia will have marked consequences for younger people, their families and carers. This includes forced exit from the workforce and its financial impact, inability to fulfill their parenting role, inability to care for ageing parents, the psychological challenge of coming to grips with progressive cognitive, memory and personality changes, and concerns about the heritability of the underlying disease that has caused the dementia.[4] Needing to navigate an unfamiliar and fragmented service system adds complexity to living with the disease. Families also often experience social isolation

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1 Elvidge KL, Christodoulou J, Farrar MA, Tilden D, Maack M, Valeri M, Ellis M, Smith NJC; Childhood Dementia Working Group. The collective burden of childhood dementia: a scoping review. Brain. 2023 Nov 2;146(11):4446-4455. Accessed on 21 April 2025 at https://pmc.ncbi.nlm.nih.gov/articles/PMC10629766/

2 van de Veen D, Bakker C, Peetoom K, Pijnenburg Y, Papma J; PRECODE study group; de Vugt M, Koopmans R. Provisional consensus on the nomenclature and operational definition of dementia at a young age, a Delphi study. Int J Geriatr Psychiatry. 2022 Mar;37(3):10.1002/gps.5691. Accessed on 21 April 2025 at https://pmc.ncbi.nlm.nih.gov/articles/PMC9305901/

3 Irwin K, Sexton C, Daniel T, Lawlor B, Naci L. Healthy Aging and Dementia: Two Roads Diverging in Midlife? Front Aging Neurosci. 2018 Sep 19;10:275. Accessed on 12 May 2025 at https://www.frontiersin.org/journals/aging-neuroscience/articles/10.3389/fnagi.2018.00275/full

4 Draper B, Withall A. Young onset dementia. Intern Med J. 2016 Jul;46(7):779-86. Accessed on 12 May 2025 at https://onlinelibrary.wiley.com/doi/10.1111/imj.13099

because of the stigma associated with dementia[5], which can compound feelings of disempowerment, anxiety and depression among people living with young onset dementia.[6]

With the prevalence of young onset dementia increasing, current projections suggest the demand for specialised young onset dementia services will continue to grow

Although the true prevalence remains unclear, the estimated 29,000 Australians currently living with young onset dementia is expected to rise to 39,000 by 2050 in line with population growth.[7] Because these numbers are considered to be underestimates, the actual demand for services is likely to be significantly higher. In Australia, First Nations people, socioeconomically disadvantaged people and people with intellectual disability have a higher risk of developing young onset dementia.[8,9]

Dementia is most common among people older than 65 years. People with young onset dementia account for ~7 per cent of the total number of people living with dementia in Australia. The services and supports they require at this young age are markedly different from those needed by individuals with late onset dementia, as people with young onset dementia are often still in the workforce, raising families, or managing other significant life responsibilities. Most dementia services are designed specifically for older people and are unable to meet the needs of people living with young onset dementia[10], including residential aged care, group and community programs, information and telephone support services, individual representation and advocacy, and policy development.

As the population of individuals living with young onset dementia increases, it will be crucial to expand and adapt tailored services and supports throughout the progression of the disease to mitigate these challenges so people can receive the right care at the right time. Without targeted investment, the disparity of availability of specialist services for young onset dementia and those for late onset dementia will continue to grow.

Nous was engaged by the Young People in Nursing Homes National Alliance (YPINHNA) to conduct a service gap analysis

The Department of Social Services (DSS) funded the *Joint Solutions – Young Onset Dementia Project* to address the barriers faced by people living with young onset dementia and their families and carers. YPINHNA convenes a consortium of leading dementia organisations commissioned to deliver the project[11].

The Joint Solutions Project will identify services available to people with young onset dementia, develop a system of care, and identify opportunities for service development to establish an integrated system of young onset dementia care from diagnosis through to palliative care. Nous was engaged to conduct a gap analysis of existing services available for people with young onset dementaia to inform this ongoing work.

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[5] Greenwood N, Smith R. The experiences of people with young-onset dementia: A meta-ethnographic review of the qualitative literature. Maturitas. 2016 Oct;92:102-109. Accessed on 12 May 2025 at https://www.maturitas.org/article/S0378-5122(16)30181-5/fulltext

[6] Lyons A. Removing barriers to care for young onset dementia. NewsGP. (2019). Accessed 12 May 2025 at https://www1.racgp.org.au/newsgp/professional/removing-barriers-to-care-for-young-onset-dementia

[7] Australian Institute of Health and Welfare (2022). Younger onset dementia: new insights using linked data. Accessed on 21 April 2025 at https://www.aihw.gov.au/reports/dementia/younger-onset-dementia-new-insights/summary

[8] Loi S, Cations M, Beard C, Tjokrowijoto P, Stange D, Withall A, Moylan N, Cartwright J, d'Cunha,N. (2024). The Joint Solutions Young-Onset Dementia Report. Royal Melbourne Hospital, University of Melbourne, Department of Psychiatry. Accessed on 21 April 2025 at https://www.australiandementianetwork.org.au/wp-content/uploads/2023/05/FINAL-V2-Joint-Solutions-YOD-SIG-Research-Report.pdf

[9] Loi SM, Cations M, Velakoulis D. Young-onset dementia diagnosis, management and care: a narrative review. Med J Aust. 2023 Mar 6;218(4):182-189. Accessed on 21 April 2025 at https://onlinelibrary.wiley.com/doi/10.5694/mja2.51849

[10] Commonwealth Department of Health and Aged Care (2024). National Dementia Action Plan: 2023-2034. Accessed on 12 May 2025 at https://www.health.gov.au/sites/default/files/2025-02/national-dementia-action-plan-2024-2034.pdf

[11] Yong Onset Dementia, Joint Solutions – Young onset dementia project, November 2024, https://ypinh.org.au/our-work/current-work/young-onset-dementia/

There were four key activities in the gap analysis.

- **Desktop review** - to develop a list of services and supports to improve health outcomes and quality of life of people living with young onset dementia and their families and carers.
- **Develop an inclusion criterion for service selection –** that is, setting threshold criteria to act as the parameters of the service scan and conduct a service scan to identify current young onset dementia specific services and supports that meet the criteria.
- **Conduct a gap analysis** - to map the current services and supports available for people living with young onset dementia at a national, state/territory and philanthropic level against the list of services and supports identified during the desktop review.
- **Test and refine results of gap analysis** - and list the potential implications for people with young onset dementia, their families and carers with YPINH, care partners and service providers.

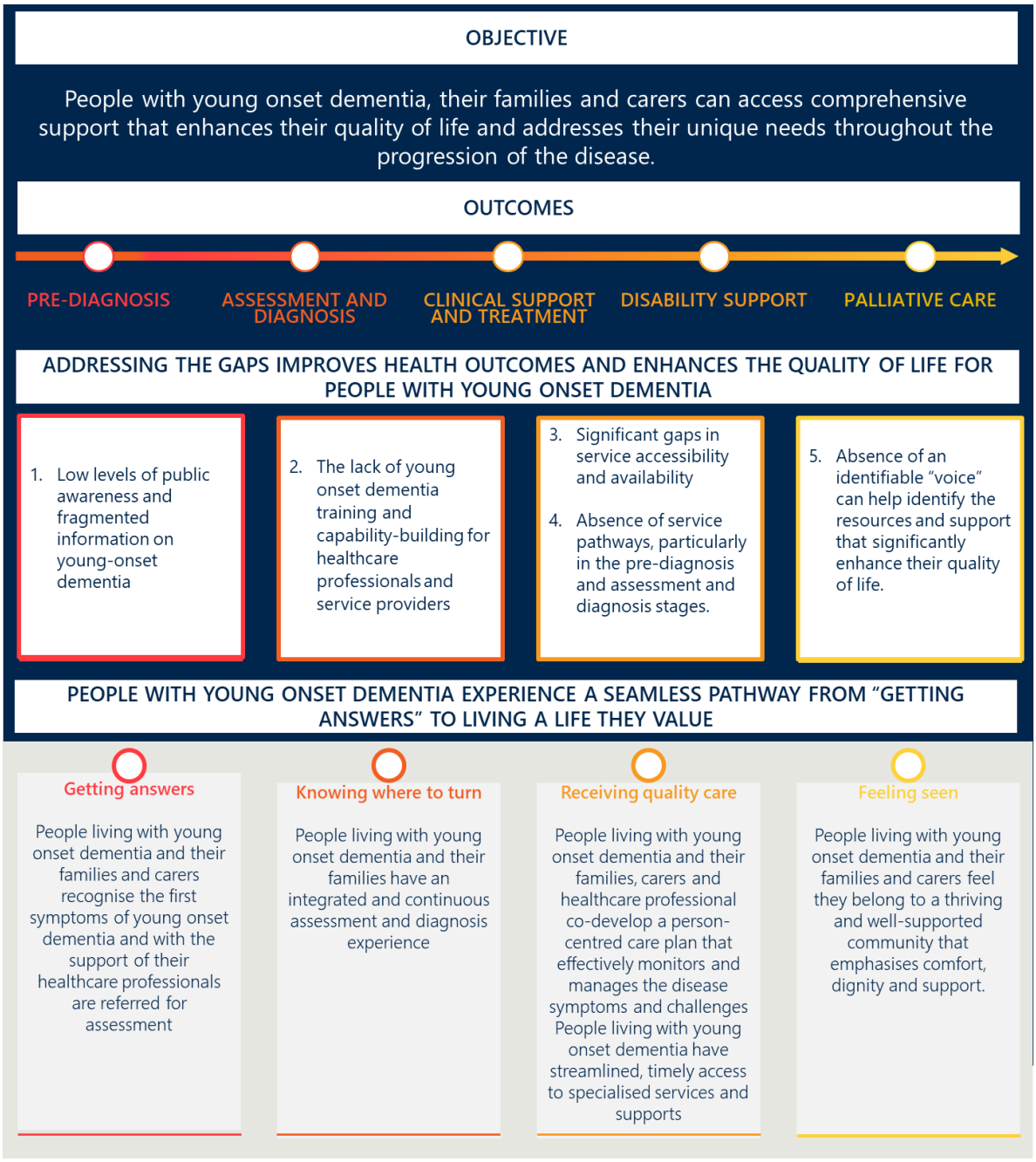
The analysis revealed significant gaps in young onset dementia service and support provision across Australia

The gap analysis found five areas for urgent consideration (see Figure 1. overleaf). Addressing these five areas is essential to support people with young onset dementia, their families and carers to access comprehensive support that enhances their quality of life and addresses their unique needs throughout the progression of their disease.

These five areas are:

1. **Low levels of public awareness and fragmented information on young onset dementia**
2. **Lack of training and capability building for healthcare professionals and service providers**
3. **Significant gaps in services accessibility and availability**
4. **Absence of service pathways, particularly in the pre-diagnosis, assessment and diagnosis phases**
5. **Absence of an identifiable 'voice' for the young onset dementia community, especially in the areas of service design, service development and advocacy.**

Figure 1 | Addressing support gaps improves the quality of life for people with young onset dementia



2 Background and context

This chapter outlines the current challenges people living with young onset dementia, their families and carers face, the services and supports required to improve their health outcomes and quality of life and the implications of not receiving the right services at the right time.

Services and supports for people living with young onset dementia are fragmented, inconsistent and disjointed

A recent report by the *Younger Onset Dementia - Special Interest Group* (YODSIG)[8] noted that some specialist services are working well in some areas, and meeting the needs of people living with young onset dementia, their families and carers, including:

- specialist clinicians assessing and diagnosing the disease
- information sharing on the diagnosis and support services
- timely and appropriate young onset dementia support and services with NDIS funding, and
- flexible approaches to service access and availability in rural and remote locations.

However, the report also identified significant gaps in service and support delivery including:

- low public awareness
- delayed referral to diagnostic investigation
- lack of service and support navigation and coordination
- delayed access to NDIS access and plan review processes
- limited specialised services
- lack of young onset dementia-specific education and training for healthcare professionals and service providers, and
- lack of access to funding, legal and employment support.

This report highlighted the limited number of young onset dementia-specific services. Even when funding for services and supports was available, people living with young onset dementia experience difficulties navigating the 'grey area' between state and the National Disability Insurance Agency (NDIA) funded initiatives, misdiagnoses resulting in delays accessing to the National Disability Insurance Scheme (NDIS) funding[8], the NDIS application and review processes not keeping pace with progression of the disease[8] and the lack of a young onset dementia diagnostic pathway.[12]

People living with young onset dementia are disadvantaged by the lack of specialist services

There are multiple potential consequences that arise when people living with young onset dementia cannot locate and access appropriate specialist services and must wait for necessary supports, including:

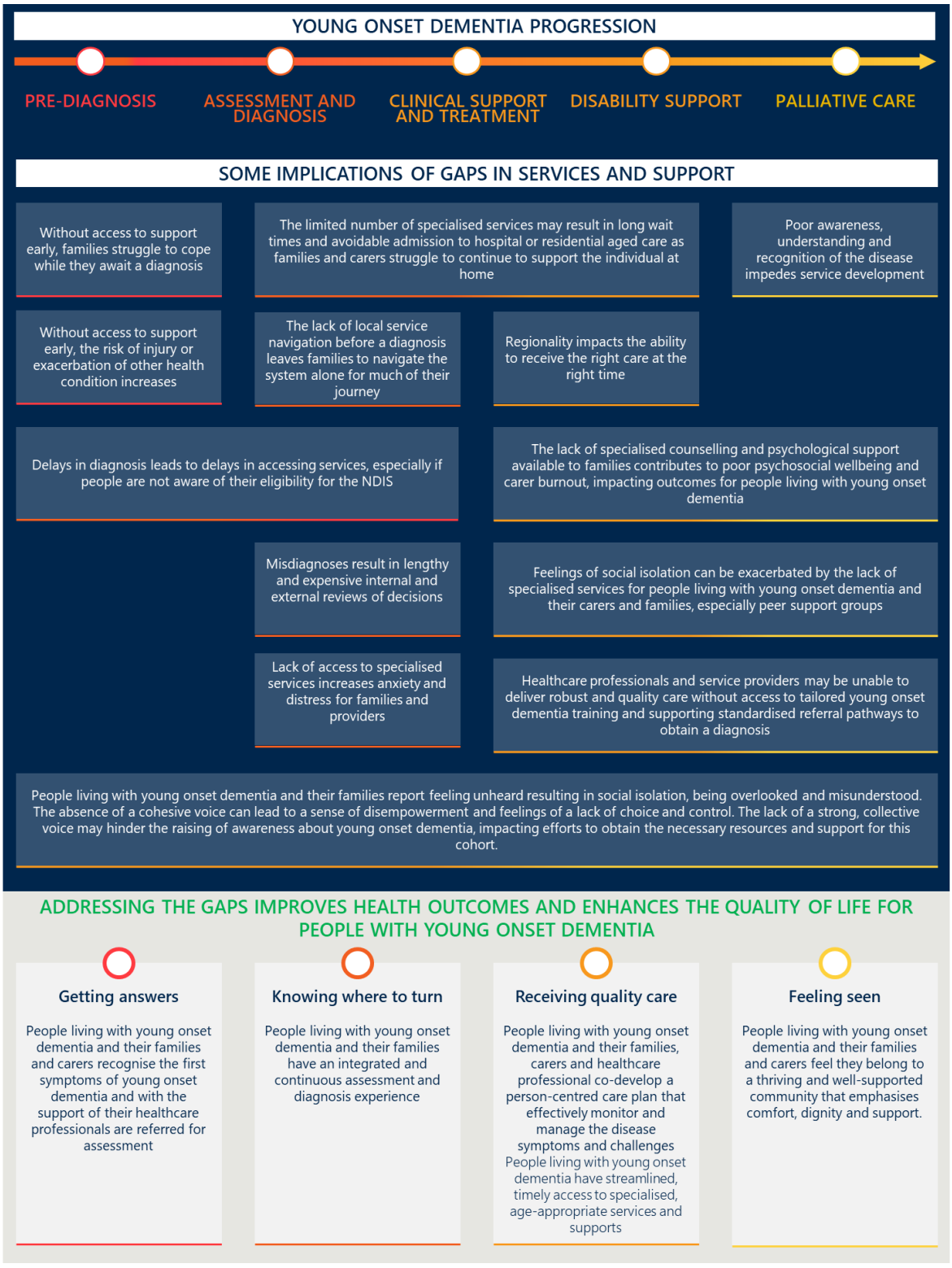
[12] Cations M, Loi SM, Draper B, Swaffer K, Velakoulis D, Goh AM for the Australian Young Onset Dementia Special Interest Group. A call to action for the improved identification, diagnosis, treatment and care of people with young onset dementia. Aust N Z J Psychiatry. 2021 Sep;55(9):837-840. Accessed on 12 May 2025 at https://journals.sagepub.com/doi/10.1177/00048674211037542

- remaining at risk of injury (e.g. falls, accidents, aggression from strangers) or exacerbation of other health conditions (e.g. pressure wounds)
- experiencing increased anxiety and distress, as do their families and providers
- pursuing lengthy and expensive internal and external reviews of decisions
- inability to remain at work or continue their studies
- families being required to give up or reduce work, study or other commitments to care for them
- being at risk of avoidable admission to hospital or residential aged care as they do not have funding to remain living safely at home, and
- bearing the financial cost of paying for services themselves.

Even when additional supports are approved, the person's condition may have progressed further, and their support needs increased, which can result in approved funding levels not fully aligned with their current requirements.

Error! Reference source not found.. below provides an overview of some of the implications of these gaps in tailored services and supports for people living with young onset dementia and describes the impact that addressing these gaps will have on enhancing their quality of life and addressing their specific needs more effectively.

Figure 2 | Implications of gap analysis findings

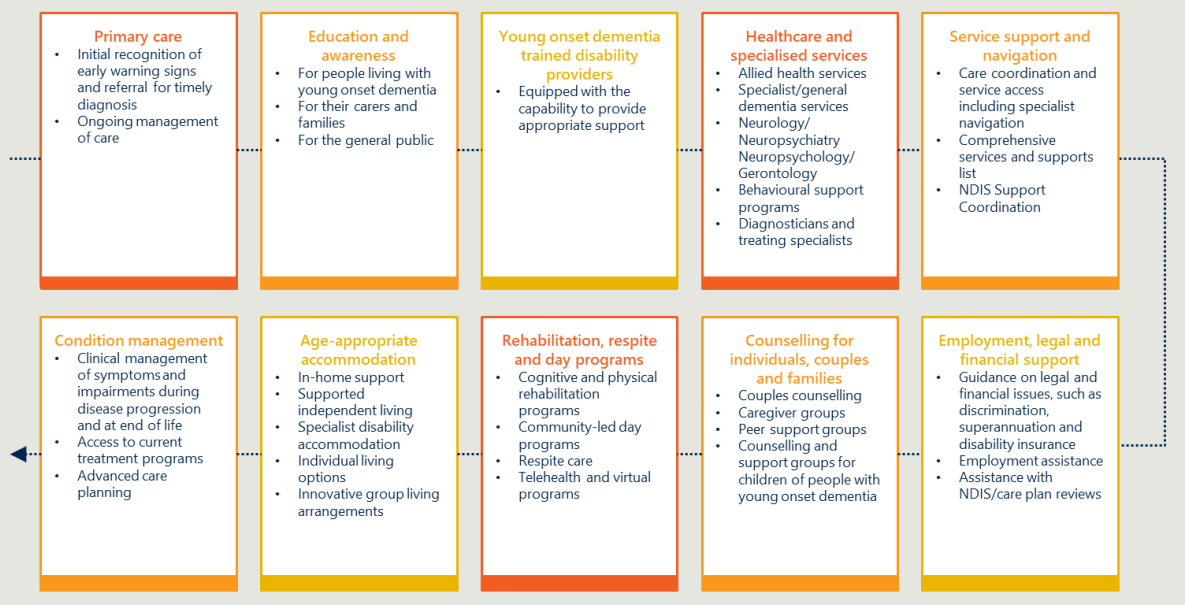


People living with young onset dementia require specialised services and support

People with young onset dementia have specialised and complex support needs that span health, disability, housing, aged care and social services from assessment and diagnosis, clinical support and treatment, disability support through to palliation and end-of-life.[12]

Figure 3. depicts the outcome of the desktop review. It identifies a list of services and supports that should be in place to improve the health outcomes and quality of life for people living with young onset dementia.

Figure 3 | Ideal list of services and supports required to support people with young onset dementia, their families and carers



3 Methodology

This chapter describes the methodology for the gap analysis, including: the approach and key activities, the scope of the Review and limitations.

This project aims to conduct a gap analysis of young onset dementia-specific services and support

There were four streams of activity to complete the gap analysis:

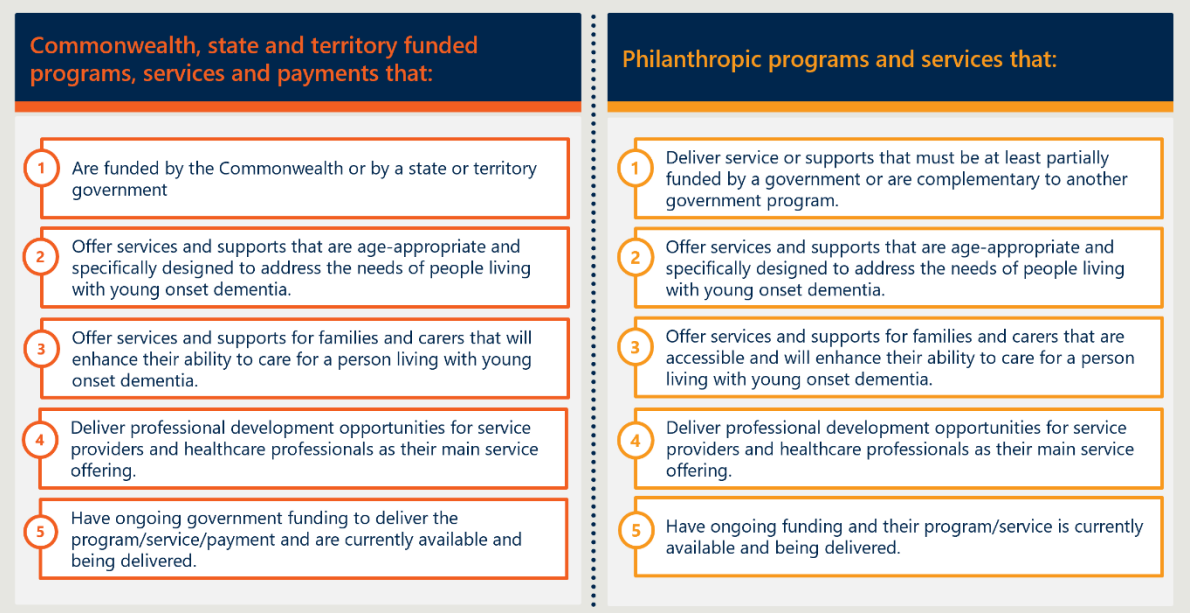
1. Completion of a targeted **desktop review** of data and information from:
    a. qualitative and quantitative research completed in the Joint Solutions – Young Onset Dementia Project to-date
    b. Commonwealth, state/territory and philanthropic policies and programs
    c. Australian Institute of Health and Welfare (AIHW) and other relevant sources on the number and circumstances of people living with young onset dementia
    d. Consultations with key stakeholders on their perspectives on the services and supports needed for people with young onset dementia, their families and carers, to enable good health outcomes, and
    e. a service scan to identify current services and supports for this cohort.
2. **Development of a list of services** and supports and an inclusion criteria:

    The desktop review generated a list of young onset dementia services and supports as noted in Figure 3. Example services and supports include in-home support, community-led day programs, counselling and peer support and education and awareness. An inclusion criterion (illustrated in Figure 4.) with an established set of parameters (e.g., services and supports are part of an established program delivering specialist care), was used to ensure current services and supports identified as part of the service scan had a direct application in supporting people living with young onset dementia in Australia.
3. Conduct the **gap analysis**:

    This included mapping the current services and supports available for people living with young onset dementia at a national, state/territory and philanthropic level against the list of services and supports identified during the desktop review to facilitate the gap analysis. The findings of the gap analysis were tested with members of the consortium and key stakeholders including state and territory representatives (10 consultations).
4. **Test and refine** gap analysis:

    This stream included conducting working sessions with YPINHA and other key stakeholders to test and refine the results of the gap analysis and explore the implications. The stakeholders consulted included:
    a. care partners for people living with young onset dementia
    b. service providers including Caladenia Dementia Care, St Louis Homes, Fresh Approach Support Coordination, The Care Connect Co., and
    c. Specialist Memory Services and other clinical services.

Figure 4 | Service and support inclusion criteria



Limitations

Nous encountered several limitations when collating the insights of this report that should be considered.

- **Sample size:**

  The sample size of consultations to test and refine service and support gaps may not represent the collective experience of stakeholders working across the sector. As well as desktop research, this report relied on individually reported service data, which may be subject to bias. The engagement approach sought perspectives from ten system stakeholders including some members of *the Joint Solutions Project* consortium to test and refine the variety of initiatives offered. Refer to **Appendix A** for a complete list of consultation participants.

- **Visibility**

  The gap analysis may not capture young onset dementia-specific services and supports operating offline or with limited online visibility. While this report synthesises previous research, (including a scan of specialised young onset dementia services available across Australia and the experiences of stakeholders) it is not intended to be an exhaustive list of all services and supports available to people living with young onset dementia and their families and carers. Challenges were encountered during the development of the gap analysis in identifying relevant services and supports available nationally and across states/territories through:

  - smaller philanthropic organisations / local entities
  - those unknown to consulted stakeholders
  - late onset dementia services that may be accessed by people living with young onset dementia, or
  - those services that are *ad hoc* and/or short term in nature for the young onset dementia cohort.

- **Social determinants**

  The gap analysis sought to identify gaps in the availability of specialised young onset dementia services and support, however, the gap analysis did not investigate the impact of social determinants on access to services and supports by people living with young onset dementia and their families and

carers, including cultural or linguistic service needs, sexuality, access to transport/ability to travel, experiences of homelessness or regionality.

- **Quality**

  This gap analysis focused on the availability and accessibility of services and supports available to people with young onset dementia, however, it did not investigate the quality of the service delivered. That is, the existence of an initiative does not guarantee the quality of service delivered.

- **Exclusions**

  This report identifies gaps in services for both people living with young onset dementia as well as their families and carers in recognition of the impact of a young onset dementia diagnosis on the entire family unit.[9] **Legal and palliative care services were excluded** from this review to avoid duplication with ongoing research being conducted by the *Joint Solutions Project*.

- **Cost**

  The gap analysis did not incorporate an evaluation of the costs associated with accessing specialised services for young onset dementia. Financial barriers could significantly influence the accessibility of support services, particularly for individuals and families with limited resources. Without assessing the cost implications, the analysis may not fully represent the affordability of these services or reflect potential disparities in service uptake among different socioeconomic groups.

- **Point in time analysis**

  This report identifies gaps in services for both people living with young onset dementia as well as their families and carers, their healthcare professionals and service providers. The gap analysis was conducted from December 2024 to January 2025. It provides a snapshot of young onset dementia-specific services and supports uncovered during that specific period.

4 Summary of findings

This section includes an overview of the young onset dementia-specific services and support, and findings of the gap analysis.

4.1 Approach to identifying young onset dementia-specific services and support

The list of identified services and supports aligned to the five stages of progression of young onset dementia

Supporting people with young onset dementia requires a tailored approach that considers the unique circumstances and needs of the individuals and their family and carers, and the progressive nature of the underlying disease.

Best practice services and supports should be holistic. That is, these services should integrate primary care (for example, GPs, allied health and mental health practitioners), specialised health services (for example, neuropsychiatry, neurology, geriatrics and neuropsychology), community and social programs, and practical assistance.

Because young onset dementia is a progressive disease, it is essential to recognise that the needs of people living with young onset dementia, their families and carers will evolve over time, sometimes quickly and unexpectedly. The timing and specific services and supports needed by people living with young onset dementia vary depending on the progression of the disease and their circumstances.

For this gap analysis, the progression of young onset dementia was broadly categorised into five stages:

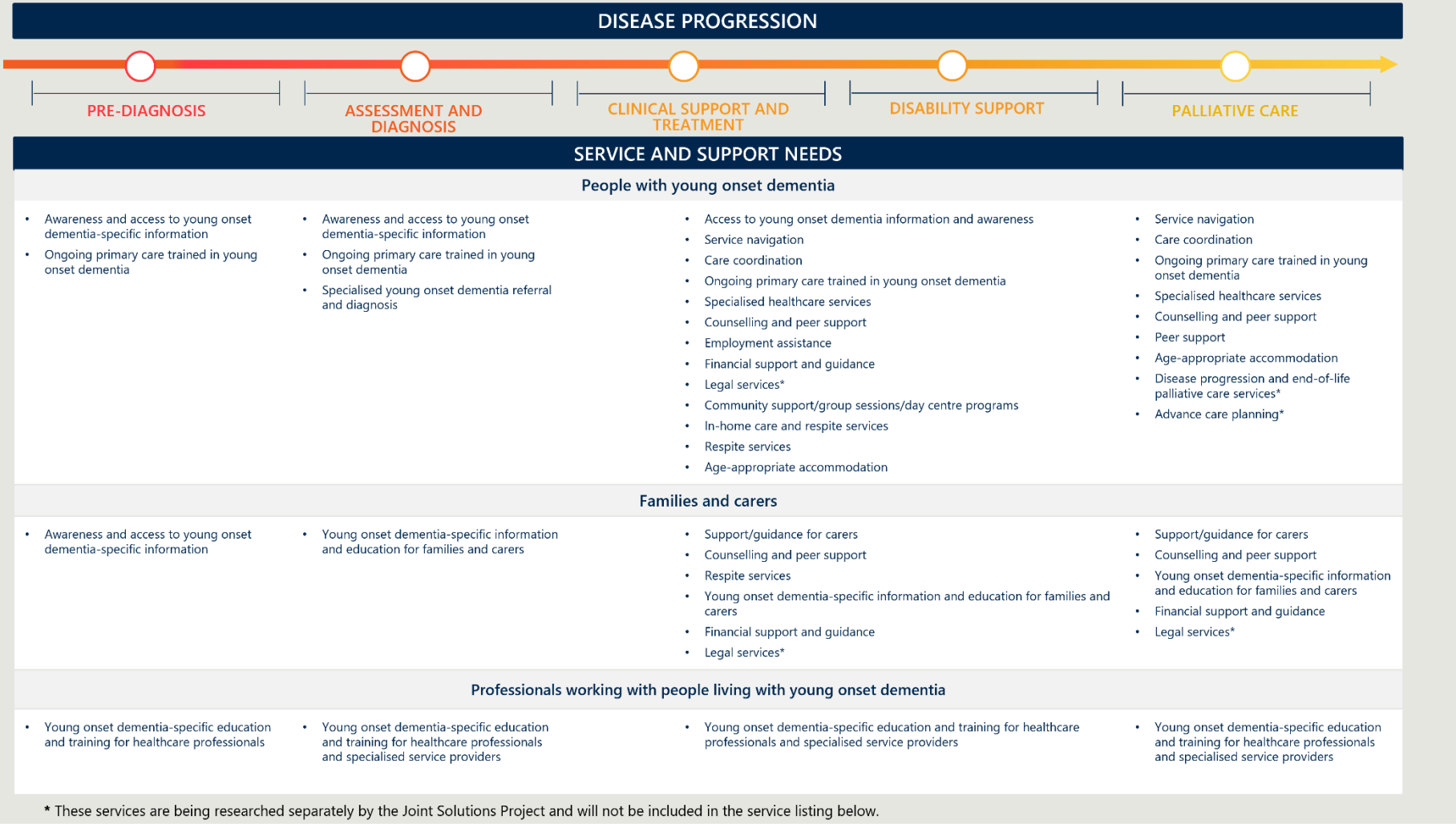
- pre-diagnosis
- assessment and diagnosis
- clinical support and treatment
- disability support, and
- palliative care.

Consultation with caregivers and service providers, literature on young onset dementia care provision in Australia[9] and the *Joint Solutions Project* research[8,13], informed the allocation of services and supports to each stage of progression. By mapping services and supports to these five stages of progression, the care provided can be more appropriately tailored to meet the evolving needs of individuals living with young onset dementia and their families.

Appendix B contains a list of the services and supports needed to meet the needs of people living with young onset dementia, their families and care professionals. This serves as a roadmap of potential future state services and supports for delivering comprehensive, high-quality care and support to people living with young onset dementia, ensuring their unique needs are met at every stage of the condition.

[13] Young People in Nursing Homes National Alliance (YPINHNA). Joint Solutions – Young Onset Dementia Project - *Kitchen Table Conversations*. Melbourne. May 2024.

Figure 5 | The ideal services and supports for the young onset dementia community at each stage of the disease



The inclusion criteria determined the services and supports currently available to support people with young onset dementia

Although people living with young onset dementia, their families and carers may potentially access and benefit from a range of general services and supports (for example, Medicare, Disability Support Pension, Carer Pension/Payment, Carer Directed Supports from Carer Gateway), the gap analysis focused on young onset dementia-specific services and supports available to this cohort. Inclusion criteria (Figure 4.) were used to ensure identified services and supports have a direct application in supporting people living with young onset dementia in Australia. The resulting output provides a high-level view of the gaps in services and supports at the national and state/territory level.

Appendix C provides an overview of the services and supports identified in this study.

The following sections describe the key findings of the gap analysis.

4.2 Gap analysis qualifications

Several qualifications should be considered when analysing the findings below.

This section provides a state/territory breakdown of gap analysis outputs. Several assumptions and caveats acknowledged through the analysis need to be considered when interpreting findings:

✓ **SERVICE ACCESSIBILITY**

The existence of a service does not guarantee a person's eligibility to access that service. There may be other eligibility requirements for specific services and supports that have not been specified. Further, a person's eligibility for the NDIS does not directly equate to them being eligible for specialist disability accommodation (SDA) funding (as an example), suggesting that an individual's circumstance must be considered to determine their eligibilities for specific initiatives.

✓ **GEOGRAPHY**

The location of services and supports has only been captured at a Commonwealth, state/territory, metropolitan and regional level. While this is useful to indicate gaps in service provision, it does not account for the availability and accessibility of services at the local level and the experiences of people accessing the services.

This means that even when a service or support is shown as available in a jurisdiction, it may be inaccessible for a particular individual, as the individual cannot easily get to where the service or support is being delivered. For example, whilst there are a small number of specialist memory clinics in Victoria, they are almost exclusively located in metropolitan areas.

This report acknowledges that the need to travel to access young onset dementia-specific services and supports for people living in regional, rural and remote areas often represents significant logistical, time and financial burden for families.

✓ **QUALITY**

This gap analysis focused on the availability and accessibility of services and supports available to people with young onset dementia. It did not investigate the quality of the

service delivered. That is, the existence of an initiative does not guarantee the quality of service delivered.

✓ **OTHER SOCIODEMOGRAPHIC BARRIERS**

The gap analysis also does not investigate the impact of other social determinants on access to services and supports by people living with young onset dementia and their families and carers. These could include cultural or linguistic service needs, sexual preference, insecure housing or regionality.

4.3 Many people living with young onset dementia cannot access required services

The gap analysis indicated that there are very few specialised services and supports available for people living with young onset dementia before a diagnosis.

An overview of the services identified in the gap analysis at the national and state/territory levels is provided below. The gap analysis found no evidence of specialised services and supports in Tasmania or the Northern Territory for people living with young onset dementia.

4.3.1 Gap Analysis - National Services

There are national services and supports available irrespective of location that can support people with dementia including, but not limited to, those funded or provided by:

- NDIS
- Dementia Australia, and
- Care of People with Dementia in their Environments (COPE) Australia.

NDIS

The NDIS is the national scheme that provides funding to eligible Australian residents with permanent disability to support their participation in everyday activities. Individuals must be under 65 years at time of entry. Access is dependent on permanent functional impairment, resulting in a disability.[14] It is the key funding body for people with young onset dementia.

Services that may be funded by the NDIS for people with young onset dementia include assistance with daily life, home modifications, assistive technology, disability-related health supports and specialised accommodation.

However, as the NDIS primarily functions as a funding mechanism, the responsibility for developing specialist disability services has been devolved to the marketplace. The emergence of new services depends largely on entrepreneurship and access to capital, rather than on strategic system planning or targeted market stewardship. Given that participants with young onset dementia represent only a small proportion of the total NDIS population (~0.9 per cent[15]) there may be limited incentives or strategic drivers for service providers to invest in or develop specialised services for this group.

The current NDIS planning and funding approach does not account for the progressive trajectory of conditions like young onset dementia. Specifically, NDIS plans for participants with progressive neurodegenerative conditions do not anticipate or fund the inevitable increase in support needs over the

[14] National Disability Insurance Agency. (2022). Eligibility and medical conditions FAQ, Accessed on 12 May 2025 at https://www.ndis.gov.au/applying-access-ndis/how-apply/information-gps-and-health-professionals/eligibility-and-medical-conditions-faq

[15] The number of participants with young onset dementia, as provided to YPINHA by the Scheme's Actuary in 2024.

course of a plan. Instead, the NDIS is structured to assess and fund current support needs at a given point in time. This approach can pose significant challenges for individuals living with progressive diseases, as it may lead to service and support gaps. As needs evolve, participants may experience delays or shortfalls in accessing appropriate supports, which can negatively impact their quality of life and ability to manage their condition effectively.

Dementia Australia

Dementia Australia is a national peak body that supports people living with dementia, their families and carers. Dementia Australia provides advice and information primarily focussed on older people with dementia and their families.

It also provides some targeted advice and information to people living with young onset dementia and their families that recognises the unique challenges and needs that arise when dementia impacts individuals earlier in life. This includes, but is not limited, to a national helpline, 'live chat', young onset dementia-specific information, videos and books.

COPE Australia

COPE Australia provides the COPE Program, which facilitates access to up to 10 sessions with an occupational therapist (OT) or nurse who has undertaken mandatory COPE Program training to assist people with dementia to continue living in the community. Services are funded by customers who may be able to access rebates or funding from government or other programs, such as My Aged Care, Commonwealth Home Support Programme (CHSP) or NDIS.

4.3.2 Gap Analysis - State/Territory services

Prevalence estimates (that is, the number of people in the population who have been diagnosed with young onset dementia) for each jurisdiction referred to below are drawn from the estimates published by Dementia Australia[16].

Gap Analysis - Northern Territory (NT)

Estimated prevalence 2025: 240.

Estimated prevalence 2054: 360.

Projected change 2025-54: +50 per cent.

There was no evidence of specialised service provision in the pre-diagnosis, assessment or diagnosis stages in the NT.

Gap Analysis - Tasmania

Estimated prevalence 2025: 700.

Estimated prevalence 2054: 700.

Projected change 2025-54: NIL.

There was no evidence of specialised service provision in the pre-diagnosis, assessment or diagnosis stages in Tasmania.

Gap Analysis - Australian Capital Territory (ACT)

Estimated prevalence 2025: 430.

[16] Dementia facts and figures, February 2025, Dementia Australia, https://www.dementia.org.au/about-dementia/dementia-facts-and-figures

Estimated prevalence 2054: 650.

Projected change 2025-54: +51 per cent.

There was no evidence of specialised service provision in the pre-diagnosis, assessment or diagnosis stages in the ACT. This study identified one service provider offering specialised accommodation and respite services to people living with young onset dementia in the post-diagnosis and treatment stages.

Gap Analysis - New South Wales (NSW)

Estimated prevalence 2025: 9,200.

Estimated prevalence 2054: 12,800.

Projected change 2025-54: +38 per cent.

The tailored services and supports available to people with young onset dementia living in NSW are limited.

The study identified the following tailored services and supports in the post-diagnostic and treatment phase:

- Age-appropriate permanent accommodation: Short-term accommodation and Supported Independent Living (SIL) targeted at young onset dementia
- Respite services - day and in-home
- In-home care
- Peer support

There is no evidence of specialised pre-diagnostic, assessment or diagnosis services for people with young onset dementia living in NSW identified by this study.

Gap Analysis - Queensland

Estimated prevalence 2025: 5,900.

Estimated prevalence 2050: 8300.

Projected change 2025-54: +41 per cent.

Similar to other jurisdictions, this study found no evidence of tailored services or supports during the pre-diagnosis, assessment or diagnosis stages in Queensland.

The study found evidence of four specialised services available during the post-diagnosis and treatment phase. These included peer support, counselling, psychological therapy and respite services.

Gap Analysis - South Australia

Estimated prevalence 2025: 2100.

Estimated prevalence 2050: 2300.

Projected change 2025-54: +10 per cent.

This study identified three tailored services and supports in South Australia.

The specialised service providers were identified in Adelaide metropolitan areas and only provided services in the post-diagnostic and treatment phase. Services provided included:

- Day respite: community support, group sessions and day centre programs
- In-home care and respite services, and

- Age-appropriate accommodation - short-term accommodation and SIL.

There was no evidence of specialised service provision in the pre-diagnosis, assessment or diagnosis stages in South Australia.

Gap analysis - Victoria

Estimated prevalence 2025: 7,360.

Estimated prevalence 2050: 11,550.

Projected change 2025-54: +57 per cent.

While the tailored services and supports available to people with young onset dementia living in Victoria are limited, those with young onset dementia can access the Cognitive Dementia and Memory Service (CDAMS) "specialist multidisciplinary diagnostic, referral and educational service for people experiencing memory loss or changes to their thinking (cognition), and for those who care about them". CDAMS are located in metropolitan areas.[17]

The study identified the following services and supports specific for young onset dementia in Victoria:

- There were no pre-diagnosis services and supports for people with young onset dementia identified by this study.
- Two metropolitan, multi-disciplinary specialist diagnosis and management services were identified that provide services and supports during the assessment and diagnosis phase, accessible on referral from a medical practitioner.
- The study identified three other metropolitan services available to people with young onset dementia during the post-diagnosis and treatment phases including one specialised residential accommodation service, and two respite and day centre programs.

Gap Analysis - Western Australia

Estimated prevalence 2025: 3000.

Estimated prevalence 2050: 4250.

Projected change 2025-54: +42 per cent.

Although Western Australia has the greatest number of tailored services and supports available to people with young onset dementia, gaps in services remain. Addressing these gaps becomes more urgent as the prevalence of young onset dementia increases.

The study identified the following tailored services and supports in Western Australia:

- tailored information and education resources for people living with young onset dementia undergoing assessment and diagnosis were available online and included educational resources and an informal peer support group. These online resources are available to people with young onset dementia across all of Western Australia, and

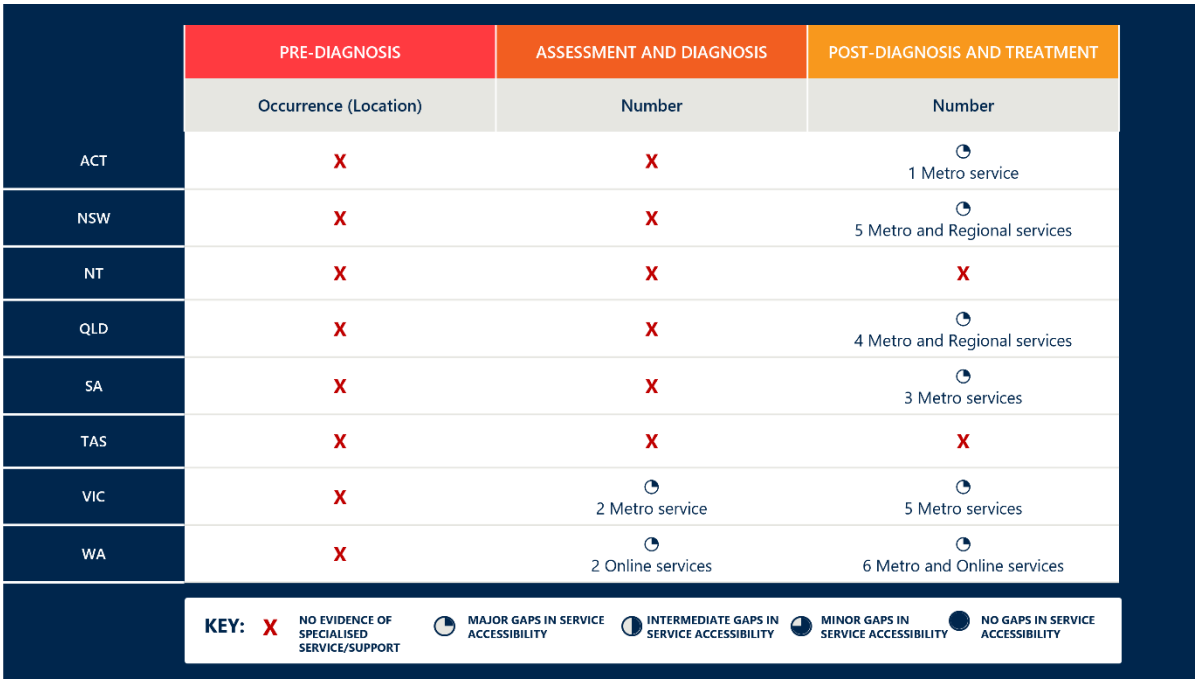
the study found evidence of six post-diagnostic services and supports delivered in Perth metropolitan areas or available online. These included tailored independent living options which included short-term accommodation, in-home care and respite, and informal peer support.

Figure 6. below shows the mapping of specialised young onset dementia services and supports across jurisdictions. Gaps have been graded by the number of services in the state or territory (Number) and the

[17] Better Health Channel Victoria. Cognitive, Dementia and Memory Services. Accessed on 21 April 2025 at https://www.betterhealth.vic.gov.au/health/serviceprofiles/cognitive-dementia-and-memory-service

geographic dispersion of access (Regionality). The study found major gaps in service provision across all states and territories and a significant lack of representation outside of metropolitan areas.

Figure 6 | State/territory services and supports for young onset dementia



4.4 Key findings: Families and carers

There are significant gaps in specialised services and supports available to families and carers

There was limited evidence of specialised services and supports for families and carers of people with young onset dementia.

Most national services available to families and carers of people living with young onset dementia are focused on late onset dementia and are delivered either online or by phone.

The evidence for state/territory or local services is difficult to identify but indicates significant gaps in relation to in-person initiatives. Although peer support networks may be available to carers and family members of people living with young onset dementia before an official diagnosis, these services have been categorised as accessible in the post-diagnosis and treatment stage (that is, when families are more likely to seek out such supports).

Refer to **Appendix C** for a full list of the services identified for families and carers.

Only four jurisdictions offered tailored services and supports for the families and carers of people with young onset dementia. These services and supports are only available in the post-diagnostic and treatment stage and are outlined below.

Gap Analysis - New South Wales

The study identified two peer support programs and one service offering young onset dementia-specific information and education available to families and carers of people with young onset dementia and delivered in metro and regional locations.

Gap Analysis - Queensland

Two regional-based service providers delivered education and psychosocial supports to the families and carers of people living with young onset dementia.

Gap Analysis - Victoria

The study identified five programs that provided post-diagnostic services and supports for the families and carers of people with young onset dementia. These programs are located in metropolitan and regional areas. The programs offer young onset dementia-specific information and education for families and carers, counselling/psychological support for people living with young onset dementia and families, and social programs (carer and peer support groups).

Gap Analysis - Western Australia

The study found five services and supports for caregivers and family members of people living with young onset dementia. Two supports were available online to caregivers across Western Australia providing young onset dementia-specific information and education for families and carers and peer support. Two programs delivered partner and carer respite services, one program offered counselling and psychological therapy supports and one program offered young onset dementia-specific information.

Figure 7. shows the mapping of specialised families and carers services and support. The study found no evidence of specialised services for caregivers and family members tailored for the pre-diagnosis, assessment or diagnosis stages.

The study identified gaps in post-diagnostic service accessibility where service accessibility represents the ease and ability of people with young onset dementia, their carers families, carers, healthcare professionals and service providers to access services across different regions.

Figure 7 | State/territory services and supports for families and carers

	PRE-DIAGNOSIS	ASSESSMENT AND DIAGNOSIS	POST-DIAGNOSIS AND TREATMENT
	Occurrence (Location)	Number	Number
ACT	X	X	X
NSW	X	X	◔ 3 Metro and Regional services
NT	X	X	X
QLD	X	X	◔ 2 Regional service
SA	X	X	X
TAS	X	X	X
VIC	X	X	◔ 5 Metro and Regional services
WA	X	X	◔ 5 Metro and Online services

KEY: X NO EVIDENCE OF SPECIALISED SERVICE/SUPPORT ◔ MAJOR GAPS IN SERVICE ACCESSIBILITY ◑ INTERMEDIATE GAPS IN SERVICE ACCESSIBILITY ◕ MINOR GAPS IN SERVICE ACCESSIBILITY ● NO GAPS IN SERVICE ACCESSIBILITY

4.5 Key findings: Professionals

There is a lack of specialised training for care professionals on young onset dementia

Training for care professionals has been identified as a critical element in achieving better outcomes for people with young onset dementia.

Our study found evidence of only two services to build the capacity of healthcare professionals and service providers of people living with young onset dementia (refer to **Appendix C** for details). Our study also found evidence of one digital resource for healthcare professionals and service providers available through the Dementia Australia library service. This program provided tailored education and training.

Although programs exist to build dementia capability of healthcare professionals and disability support workers, they do not provide young onset dementia-specific capability building and were not, therefore, included in the mapping.

The training identified care professionals in the gap analysis often lagged behind agreed best practice and new research in a dynamic area of medical science.[18]

Figure 8. below shows the mapping of specialised services and supports available to healthcare professionals and service providers. No resources were identified in the pre-diagnosis, post-diagnosis or treatment stages. Apart from the Neurohub Wellness Program[19] identified in Queensland, this study found no other evidence of statewide funded professional development opportunities for health professionals and service providers that work with people with young onset dementia.

Figure 8 | State/territory services and supports for professionals

	PRE-DIAGNOSIS	ASSESSMENT AND DIAGNOSIS	POST-DIAGNOSIS AND TREATMENT
	Occurrence (Location)	Number	Number
ACT	X	X	X
NSW	X	X	X
NT	X	X	X
QLD	X	X	1 Online service
SA	X	X	X
TAS	X	X	X
VIC	X	X	X
WA	X	X	X

KEY: X NO EVIDENCE OF SPECIALISED SERVICE/SUPPORT | MAJOR GAPS IN SERVICE ACCESSIBILITY | INTERMEDIATE GAPS IN SERVICE ACCESSIBILITY | MINOR GAPS IN SERVICE ACCESSIBILITY | NO GAPS IN SERVICE ACCESSIBILITY

Although only services and supports for professionals involved in care provision for people living with young onset dementia were assessed, the study recognises that there is a lack of awareness of the disease more broadly among clinicians and care professionals. This has impacts on early diagnosis and referral,

[18] Couzner L, Day S, Draper B, Withall A, Laver KE, Eccleston C, Elliott KE, McInerney F, Cations M. What do health professionals need to know about young onset dementia? An international Delphi consensus study. BMC Health Serv Res. 2022 Jan 2;22(1):14. Accessed on 21 April 2025 at https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-021-07411-2

[19] MS Queensland. Welcome to the Neuro Wellness Hub. MS Queensland. Accessed on 12 May 2025 athttps://msqld.org.au/neuro-wellness-hub/

social inclusion, service development and innovation, service delivery and at a system level, policy development.[12]

4.6 Gap analysis- summary of findings

This gap analysis highlights the current state of specialist services for people living with young onset dementia and those that care for them.

The gap analysis found:

- fragmented information on young onset dementia, and low levels of public awareness and understanding of the disease
- lack of training and capability building for healthcare professionals and service providers
- significant gaps in service accessibility and availability, particularly in the pre-diagnosis, assessment and diagnosis phases
- absence of clearly defined service pathways, and
- an absence of an identifiable 'voice' for the young onset dementia community, especially in the areas of policy, service design and development, and advocacy.

Addressing these gaps will improve health outcomes and enhance the quality of life for people with young onset dementia.

5 Conclusion

This section highlights the six concluding statements.

Summary of findings

The gap analysis reveals substantial deficiencies in specialist services for people living with young onset dementia and those who care for them. It highlights fragmented information, low public awareness, insufficient training for healthcare professionals, and significant service accessibility gaps, especially in the pre-diagnosis and diagnosis phases. There is also a lack of structured service pathways and an absence of a unified advocacy voice to influence policy and service development.

Addressing these issues is crucial for improving health outcomes and quality of life, particularly considering the projected ~50 per cent increase in individuals with young onset dementia by 2050.

5.1 Concluding statements

5.1.1 There is an urgent need to address the gaps identified in pre-diagnosis specialist services and supports

Apart from two online services (a young onset dementia-specific information and education for families and carers and an online young onset dementia library) and a dementia hotline, the gap analysis found no evidence of supports for people with young onset dementia and their families and carers before they receive a confirmed diagnosis.

Diagnosis often depends on individuals being informed and advocating for assessment and/or referral. A timely diagnosis is key to providing individuals with access to appropriate treatments that might slow the disease's progression and improve the quality of life.[20] Early diagnosis allows for better future planning, financial decisions, and the setting up of necessary support systems.[21]

5.1.2 Young onset dementia-specific training and capability-building for healthcare professionals and service providers is inadequate

Training healthcare professionals and service providers who care for people with young onset dementia ensures that individuals receive accurate diagnoses, tailored care, and appropriate support services. It also helps reduce stigma and enhances advocacy. Trained professionals are better advocates for the needs of individuals in their care which leads to better health outcomes for people with young onset dementia.

This study found evidence of only two services to build the capacity of healthcare professionals and service providers of people living with young onset dementia (doctors, allied health practitioners, and disability and other service providers).

Where healthcare professionals and service providers cannot access up-to-date training and resources relating to young onset dementia, they operate at a disadvantage, including being at higher risk of:

[20] Gauthier S, Rosa-Neto P, Morais JA, Webster C. World Alzheimer Report 2021. Alzheimer's Disease International. Accessed on 12 May 2025 at https://www.alzint.org/resource/world-alzheimer-report-2021/

[21] National Institute on Aging. Cognitive Assessment Considerations: Understanding the Evidence. National Institute on Aging. (2023). Accessed on 12 May 2025 at https://www.nia.nih.gov/health/cognitive-assessment-considerations-understanding-evidence

- **Delayed diagnosis**: Healthcare professionals may miss or misdiagnose early signs, leading to delayed diagnosis and treatment, which can hinder the management of symptoms and progression of the disease
- **Limited resources**: Service providers may be ill-equipped to develop or offer appropriate programs and support services, leaving individuals without necessary assistance
- **Inadequate care**: Professionals might apply general dementia approaches that do not address the unique needs of individuals with young onset dementia, resulting in suboptimal care and support. Inadequate care due to a lack of specialised training can lead to:
    - delayed referrals for active rehabilitation
    - delayed referral for legal assistance and assessment of driving capacity
    - difficulties in supporting patients to navigate the NDIS and disability supports
    - delayed access to peer support services and supports for families, and
    - delayed referral to palliative care.

5.1.3 The lack of awareness and young onset dementia-specific information increases social isolation and stigma

There is limited awareness of young onset dementia in the general community. There are also few easily accessible information sources available to those who want to find out more. Stigma, low awareness, poor understanding or misunderstanding, and fear, of young onset dementia can result in families experiencing discrimination[22] and isolation[23] both before and after a diagnosis. Interviewees told us that these are times when those experiencing cognitive and behavioural changes, and their families, have an acute need for understanding and support.

Beyond service and support provision, the lack of young onset dementia-specific awareness and information suggests there is a need to increase public recognition of the disease and its unique challenges and to address stigma.

5.1.4 The voice of people with young onset dementia, their families and carers can help to accurately understand their needs and preferences

Stakeholders engaged during our study noted the absence of an identifiable 'voice' for the young onset dementia community, especially in the areas of service design and development, policy and advocacy. It is important for people living with young onset dementia to have a voice for several reasons:

- **Tailored services**: A vocal presence ensures that the specific needs and experiences of people living with young onset dementia are considered in the design and provision of services, leading to more effective and appropriate support.
- **Policy influence**: Having a unified voice allows people living with young onset dementia to influence healthcare policies and practices, ensuring they reflect the unique challenges faced by this group.

[22] Australian Institute of Health and Welfare (2024). Dementia Awareness Survey. Accessed on 21 April 2025 at https://www.aihw.gov.au/reports/dementia/dementia-awareness-survey/contents/attitudes-towards-dementia

[23] Dementia Australia & Carers Australia (2020). Carers of people living with dementia and discrimination: Joint position statement between Dementia Australia and Carers Australia. Accessed on 21 April 2025 at https://www.carersaustralia.com.au/wp-content/uploads/2020/10/DA-CA-Joint-Policy-Statement_FINAL.pdf

- **Awareness and understanding**: Advocacy and visibility help raise awareness and promote understanding of people living with young onset dementia among the public and healthcare professionals, reducing stigma and misinformation.

Having a voice helps ensure that people living with young onset dementia receive the appropriate recognition, resources, and support necessary to improve their quality of life. The overarching goal should be the amplification of the voice of people with young onset dementia and the development and promotion of tailored services.

Overall, addressing these gaps will lead to a more comprehensive and responsive support system, significantly benefiting those living with young onset dementia and their families and the healthcare professionals and service providers who care for them.

Appendix A - List of stakeholders engaged

Table 1 | List of stakeholders engaged

Date	Stakeholder cohort	Role
7 January 2025	Lived experience	Care partner
7 January 2025	Service provider	CEO – Caladenia Dementia Care
8 January 2025	Service provider	Manager – St Louis Homes Accommodation
8 January 2025	Service provider	Support Coordinator – Fresh Approach Support Coordination
19 January 2025	Lived experience	Care partner and network facilitator
20 January 2025	Service provider	Cognitive Occupational Therapist – Specialist Memory Services
21 January 2025	Service provider	Support Coordinator – The Care Connect Co.

Appendix B - Ideal list of services and supports mapping category definitions

Table 2 | Services and supports mapping category definitions

Category	Definition
Stage of service or support need	**Distinct periods of the young onset dementia journey and associated service and support needs.**
Pre-diagnosis	The pre-diagnosis stage, individuals, their families and carers notice early signs of cognitive and behavioral changes, but the cause is unclear. These changes are not always recognised as indicative of a neurodegenerative condition.
Assessment and diagnosis	The process to receive a diagnosis. The process of assessment and diagnosis is a critical stage in the journey of young onset dementia, as it provides clarity and allows for evaluation, neuropsychological testing, imaging and diagnosis and the eventual development of a treatment plan.
Post-diagnosis and treatment	The period following a diagnosis when future planning and post-diagnostic support provision occurs. People living with young onset dementia, their families and carers implement care plans, manage symptoms, and lifestyle adjustments.
End of life	The final stage of a terminal illness. This stage shifts focus from symptom management to advanced care planning, and end-of-life palliative care for both people living with young onset dementia and their families and carers.
Service categories	**A set of standardised categories of services and supports available to people living with young onset dementia and their families and carers.**
Advance care planning	These services allow an individual to plan for their future health and personal care, particularly in the event a person with young onset dementia loses the capacity to make decisions for themselves. This process involves discussing and recording one's wishes, values, and preferences for future care and treatment.
Care coordination	These services organise information sharing and care activities among participants involved in caring for an individual living with young onset dementia. Care coordination aims to meet an individual's needs and preferences and facilitate access to support.
Career transition support	These services assist an individual living with young onset dementia to navigate the decision to leave employment as their condition progresses.
Community support/group sessions/day centre programs	These services assist an individual to participate in community life and meet and engage with others. These services also provide carers with a break from caregiving.

Category	Definition
Counselling/psychological therapy	These services provide professional psychosocial support to help an individual to manage psychological distress, clarify issues and develop new habits and coping strategies.
Diagnosis and assessment	These services assist an individual to obtain a diagnosis of young onset dementia through specialist referral and diagnostic testing.
Employment assistance	These services help an individual living with young onset dementia to remain in employment through arranging accommodations, establishing support systems and assisting with communication and disclosure at work.
Financial support guidance	These services assist an individual to access financial support.
In-home care and respite	These services provide an individual with short-term care at home, ranging from domestic chores to assisting with activities of daily living, and are intended to alleviate the burden of care for families.
Ongoing primary care trained in young onset dementia	These services provide people living with young onset dementia with access to continuous provision of health services and supports to manage long-term health conditions including allied health.
Peer support	These services connect people living with young onset dementia, their carers and their families to each other within a system of mutual support and exchange, providing social connection, shared experiential knowledge and emotional support. This can include online and in-person settings.
Respite services	These services provide short- or medium-term accommodation for a person living with young onset dementia or their carers and are intended to provide carers with a break.
Service navigation	These services provide the linkage to assist an individual to access and coordinate the various services, resources, and information required. These services maximise an individual's likelihood of being connected to the right services and building their ongoing capacity to do so.
Specialised young onset dementia care	These services provide an individual with the specialised care of trained health professionals, such as (but not limited to) neurologists and neuropsychiatrists.
Age-appropriate accommodation	These services provide an individual with a place to live and can include SIL or SDA.
Young onset dementia-specific education and training for healthcare professionals	These services include informative resources and training designed to equip medical professionals with an essential understanding of the unique challenges, diagnostic processes, and care requirements for individuals living with young onset dementia.
Young onset dementia-specific information and	These services provide information on young onset dementia and the caregiver role through informative resources or training.

Category	Definition
education for families and carers	
Awareness and access to young onset dementia-specific information	These services provide information on young onset dementia to people living with the disease, possibly encompassing aetiologies, symptoms, seeking a diagnosis and planning for the future.
Young onset dementia-specific education and training for service providers	These services include informative resources and training designed to equip service provider workforces such as disability support workers with an essential understanding of the unique challenges and care requirements for individuals living with young onset dementia.
Young onset dementia-specific education and training for specialists	These services include informative resources and training designed to equip professionals who deliver specialist services to people living with young onset dementia with an essential understanding of the unique challenges and care requirements for individuals living with young onset dementia. This may include neuropsychologists/neuropsychiatrists, cognitive occupational therapists, positive behaviour support practitioners and Level 3 Support Coordinators.

Appendix C - List of identified services

Table 3 | List of services identified in the mapping

Service or support	Category
Commonwealth	
Resources directory page	Awareness and access to young onset dementia-specific information Young onset dementia-specific information and education for families and carers Service navigation
COPE Program	Support/guidance for families and carers
National Dementia Helpline	Counselling/psychological therapy Awareness and access to young onset dementia-specific information
Family engagement counselling for younger onset dementia	Counselling/psychological therapy Education and training for families and carers
Dementia Australia Library Service – Young Onset Dementia	Education and training for families Education and training for healthcare professionals Education and training for service providers
Carer conversations	Peer support
Younger onset dementia web page	Awareness and access to young onset dementia-specific information Young onset dementia-specific information and education for families and carers
YPIRAC Planners	Financial support and guidance
YPIRAC Accommodation team	Service navigation
NDIS-funded support coordinators	Service navigation Care coordination
Disability Support Pension	Financial support and guidance
Carer Payment Carer Allowance Carer Supplement	Financial support and guidance
ACT	

Service or support	Category
Specialist residential homes	Respite services Accommodation
NSW	
Specialist residential homes	Respite services Age-appropriate accommodation
Short-term accommodation Young Onset Dementia Supported Independent Living	Respite services Accommodation
Dementia care in the home	In-home care and respite services
Younger Onset Dementia Occupational Therapy	Ongoing primary care trained in young onset dementia
Young Onset Dementia Carers Group	Peer support
Younger Onset Dementia Carer Support Group	Peer support Young onset dementia-specific information and education for families and carers
QLD	
Occupational therapy services	Ongoing primary health trained in young onset dementia
Dementia supports	Respite services Counselling/psychological therapy Ongoing primary care trained in young onset dementia
Looking forward program	Counselling/psychological therapy Ongoing primary care trained in young onset dementia
Family support	Counselling/psychological therapy (carers)
Younger onset dementia – Diagnosis guide	Young onset dementia-specific information and education for healthcare professionals
SA	
Day respite	Community support/groups sessions/day centre programs
Short-term accommodation and supported independent living	Respite services Age-appropriate accommodation
Dementia care in the home	In-home care and respite services

Service or support	Category
VIC	
Day centre	Community support/group sessions/day centre programs
Social and respite programs	Community support/group sessions/day centre programs Peer support Service navigation Young onset dementia-specific information and education for families and carers
Multidisciplinary specialist diagnosis and management	Awareness and access to young onset dementia-specific information Ongoing primary care trained in young onset dementia Counselling/psychological support for people living with young onset dementia and families
Specialist residential homes	Age-appropriate accommodation
WA	
Supported Independent Living for Young Onset Dementia	Age-appropriate accommodation
Partners respite	Respite services
Keeping Us in Mind Project	Young onset dementia-specific information and education for families and carers
Young Onset Dementia Assistance	Ongoing primary care trained in young onset dementia
COPE Program	Young onset dementia-specific information and education for families and carers
Living with dementia program	In-home care and respite Respite services Counselling/psychological therapy
Carers retreat	Respite services
Short-term accommodation Supported Independent Living	Respite services Age-appropriate accommodation
Peer support	Peer support

Appendix D - National Dementia Action Plan 2023-34

The following are actions under the National Dementia Action Plan 2023-34 (NDAP) that refer specifically to young onset dementia:

2.4 Improve the uptake of dementia enabling design and practices in aged care and disability support services, hospitals, public spaces, businesses and local services. This will maximise opportunities for participation by people living with dementia.

4.8 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.

The following NDAP actions include the word 'disability' and may, therefore, be relevant to young onset dementia:

4.9 Improve and embed supports for people living with dementia in disability support services.

5.3 Enable best dementia care practice in aged care and disability support services, focused on enhancing the quality of life, wellbeing and safety of people living with dementia and that meets their social and cultural preferences.

5.4 Support aged, disability and health care providers in residential care and community settings as well as informal carers to better understand and respond appropriately to the needs of people living with dementia. This includes changes in behaviours and environments, without inappropriate use of restrictive practices.

5.6 Improve interfaces and information sharing between primary care, disability support, aged care and hospital settings at a system-level to improve integration and continuity of care.

6.1 Strengthen dementia training, including embedding a dementia focus within core competencies, improve training pathways and provide mentoring and supervision opportunities for health, aged care, disability support and other workforces, including carers and volunteers. This will support best practice dementia care and support, capacity building and retention.

6.6 Encourage organisational cultures of quality, safe, person-centred and culturally safe dementia care in health, disability and aged care services.

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