



**Palliative Care**  
Australia  
*Matters of life and death*

# Young-Onset Dementia & Palliative Care

Report for the Joint Solutions Young-Onset Dementia Project

APRIL 2025

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# The Joint Solutions Young-onset Dementia project

The Joint Solutions Young-onset Dementia project will map the services required by people living with YOD and their families from diagnosis to end of life care, and identify the programs best placed to provide support. The project will run until April 2025.

The project is being conducted by a consortium of leading dementia organisations. Led by the Young People in Nursing Homes Alliance (YPINHA), the consortium includes the Young-onset Dementia – Special Interest Group (YOD-SIG), Eastern Cognitive Disorders Clinic (ECDC), and Dementia Australia (DA). The consortium is overseeing the project's research with people living with young-onset dementia and their families, clinicians and specialist service providers.

Funded by the Department of Social Services to mid-2025, the project has commissioned a **national cross-sectional survey** by the Young-onset Dementia Special Interest Group and a **literature review on systems of care** internationally for YOD through the University of Canberra. **A series of consultations** with providers (residential providers and service coordinators) and kitchen table conversations with people with lived experience have also been held by the YPINHA and selected partners.

**Palliative Care Australia** joined the project in November 2024, to conduct a roundtable discussion and report on the current state of play in regard to receiving timely and high quality palliative care for people with young-onset dementia and their families, and to provide recommendations for the project to consider in its system of care.

It is intended that the **outputs of the project**, from various partners, will be collated into a long form report to Government in mid-2025. In this context, this report will not cover other project areas, such as dementia and end of life law, genetic counselling, or aspects of care.

## About Palliative Care Australia

Palliative Care Australia (PCA) is the national peak advocacy body for palliative care in Australia. PCA represents all those who work towards high-quality palliative care for all Australians who need it. Working closely with consumers, our Member Organisations and the palliative care workforce, PCA aims to improve access to and promote palliative care.

All people in Australia have a right to the highest possible standard of health<sup>1</sup>, and this includes a right to palliative care<sup>2</sup>.

### Process of consultation for the development of this report

To contribute to the system of care design, Palliative Care Australia developed a Discussion Paper (Appendix i) which was distributed with an invitation to a facilitated an Expert Roundtable.

A select group of 31 professionals from palliative care, dementia care and lived experience representatives were identified to participate in the 3.5 hr Expert Roundtable held online on 18 February 2025. It was designed to interrogate the current state of play for people with young onset dementia and their families in regard to getting the palliative care supports they need.

**On the day, 21 people were able to participate with a mix of fields and experiences represented.** Further, the Summary Discussion (Appendix ii) was distributed to all those participating, and those that had indicated an intension to attend, for additional comment to be captured and incorporated.



### Key Areas of Discussion

- Informing on Diagnosis and Illness Trajectory
- Proactive Planning and Advance Care Planning
- Care Settings and Workforce training
- System interfaces
- Carer and family needs

**A further four interviews** were conducted with a current carer, two bereaved carers, one palliative care nurse/ respite manager. These interviews sought to understand additional experiences of the issues and opportunities raised in the Roundtable.

*Documents associated with this Roundtable are provided as Appendices, including:*

- Discussion Paper*
- Discussion Summary*

**Palliative Care Australia would like to thank all those that provided input to this report.**

# What is palliative care?

PCA and the Australian Government subscribe to the World Health Organisation's definition of palliative care:

**Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.**

Palliative care is therefore both person and family-centred care provided for a person of any age with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.

Palliative care is often misunderstood as being the care provided in the last few weeks of life as a person with a life-limiting illness is rapidly approaching death. The needs of people and their carers is of course higher clinically at this time. This end of life phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the health care team is being delivered. This takes into account the terminal phase or when the patient is recognised as imminently dying, death and extends to bereavement care.

**Palliative care is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness, such as younger-onset dementia.**

Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social.

Because palliative care is based on individual and family needs, the services offered will differ but may include:

- Relief of pain and other symptoms  
e.g. swallowing issues, vomiting, shortness of breath
- Resources such as equipment needed to aid care at home
- Assistance for families to come together to talk about sensitive issues
- Links to other services such as home help and financial support
- Support for people to meet cultural obligations
- Support for emotional, social and spiritual concerns
- Counselling and grief support
- Referrals to respite care services
- Palliative care is a family-centred model of care, meaning that family and carers can receive practical and emotional support.



Palliative care treats  
all symptoms  
physical,  
emotional,  
spiritual & social.

Palliative care can be given alongside services provided by other doctors and specialities. For those living with dementia, a palliative care approach may be beneficial from the time of diagnosis in order to set-out the care planning that will be required as a result of progression of the illness and changes in decision making capacity.

Early access to palliative care can reduce the provision of clinically non-beneficial therapies, improve the quality of life of people with a life-limiting illness and their families, and significantly reduce hospital distress and cost.

## **Existing palliative care frameworks in Australia**

Australia has the agreed [National Palliative Care Strategy 2018](#) that all governments, services and projects are supporting and working toward. The strategy outlines the roles of varying levels of government in palliative care service delivery, and through its respective Implementation Plan (2020-2024), which is consistent with the Australian health system.

Put in its most simplified form, and noting there are levers between these systems, the Federal Government has responsibility for primary care and aged care, and the States and Territory governments has responsibility for the acute sector and community health services. As you will see moving forward through this and related reports, each level of government and care settings, along with private providers, are providing palliative care, and provides services for those living with young-onset dementia(s).

While each State and Territory has a version of its own end-of life and palliative care strategy, plan or framework, which may include dementia, only Western Australia has explicitly developed a framework focussed specifically on this care for people living with dementia(s).

The End-of-Life and Palliative Care for People with Dementia Framework (WA) (Appendix iii) provides a guide to planning, developing, and implementing local processes to support the end-of-life and palliative care needs of people with dementia. This framework provides a sound base for additional considerations for people living with YOD to be overlaid, as an outcome of this project.

# Terminology

## Generalist/ Primary Palliative care

Care provided to people living with a life-limiting condition, their families and carers by healthcare providers who are not specialist palliative care providers.<sup>3</sup> The medical management and coordination of care for people living with a life-limiting illness may be undertaken by a wide range of health professionals including GPs, geriatricians, physicians, oncologists, paediatricians, renal specialists, cardiologists, endocrinologists and other specialists. Other essential team members will include nurses, allied health professionals, Aboriginal and Torres Strait Islander Health Workers and Liaison Officers, and pharmacists. These health professionals are 'generalists' with respect to palliative care, notwithstanding that many of them may be specialists in their own discipline. Primary palliative care may be delivered with consultation from specialist palliative care services.

## Specialist palliative care service

A multidisciplinary health care service whose substantive work involves consultative and ongoing care and support for people with a life-limiting illness, their carers and family. In general, specialist palliative care services would not be directly involved in the care of people who have uncomplicated needs associated with a life-limiting illness. Specialist palliative care professionals would be expected to have recognised qualifications or accreditation in palliative care.<sup>4</sup>

## End-of-life care

End-of-life care includes physical, spiritual, and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the person's body after their death. People are 'approaching the end-of-life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions;
- general frailty and co-existing conditions that mean that they are expected to die within 12 months;
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition; and
- life-threatening acute conditions caused by sudden catastrophic events.<sup>5</sup>

Many Aboriginal tribal groups share the belief that this life is only part of a cyclic approach to life and death. It is important to ask the family or the Aboriginal Elders, Health Workers or Liaison Officers what terms they wish to use for this time and preparation process, e.g., "finishing up", "journey to dreaming", "sad news" or "sorry business".

## Family

As outlined in the National Palliative Care Standards, 'the term family includes people identified by the person as family. This may include people who are biologically related, however it may not. People who joined the family through marriage or other relationships, such as kinship, as well as the chosen family, street family for those experiencing homelessness, and friends (including pets) may be identified by the person as family. A person may also choose to not to have their family or carers involved in their care, or a person may not have any family or carers.'

## Life-Limiting illness trajectories

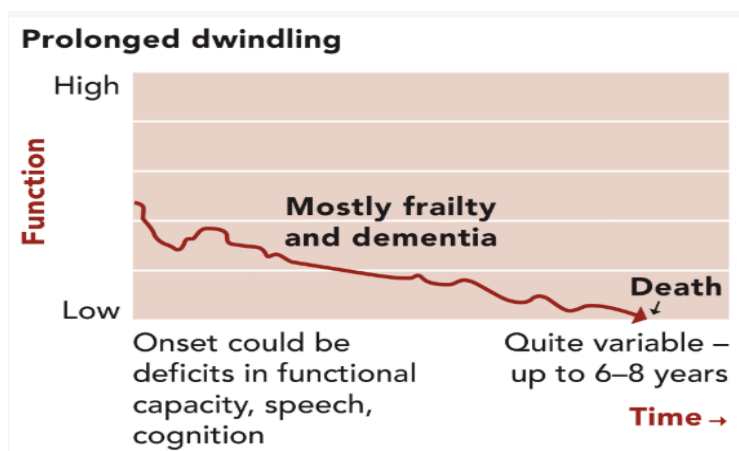
There are three main trajectories of life limiting illnesses discussed in palliative care education<sup>6</sup>. These are:

- Trajectory 1: short period of evident decline, typically cancer
- Trajectory 2: long-term limitations with intermittent serious episodes, mostly heart and lung failure
- Trajectory 3: prolonged dwindling, mostly frailty and dementia

**Dementia falls into Trajectory 3** and the below *Figure 1. Prolonged Dwindling*, represents the peaks and troughs of functional changes over time.

**Importantly, people living with young onset dementia may experience a much longer period of decline, up to 10-20 years**, depending on the specific type of dementia(s) involved and their health at diagnosis.

Figure 1. Prolonged Dwindling.



Source: PCC4U. Module 1: Principles of Palliative Care

Because the trajectory of disease for people with dementia is complex, unpredictable and dependent on individual experience, their palliative care needs may change according to individual preferences and the progression and nature of symptoms. This will likely involve care in different settings and most likely will not always be provided through specialist palliative care services.

## Who provides palliative care?

Palliative care can be provided by a range of health professionals and other support services.

Depending on a person's situation for those with longer illness trajectories in particular, primary palliative care is most often provided by GPs and other treating doctors.

The RACGP notes<sup>7</sup> **Palliative care is a fundamental component of general practice.** Patient care along the illness trajectory can ideally transition smoothly “to a palliative approach, end-of-life care and terminal phase. The GP's role in end-of-life care includes a **terminal care plan**, care after death and bereavement support for patients and their families.

Aged care services provide palliative care support in both residential aged care facilities and in homes. When symptoms become complex or distressing (particularly pain or problems such as swallowing difficulties, vomiting and breathlessness), referral to a specialist palliative care service is advisable.

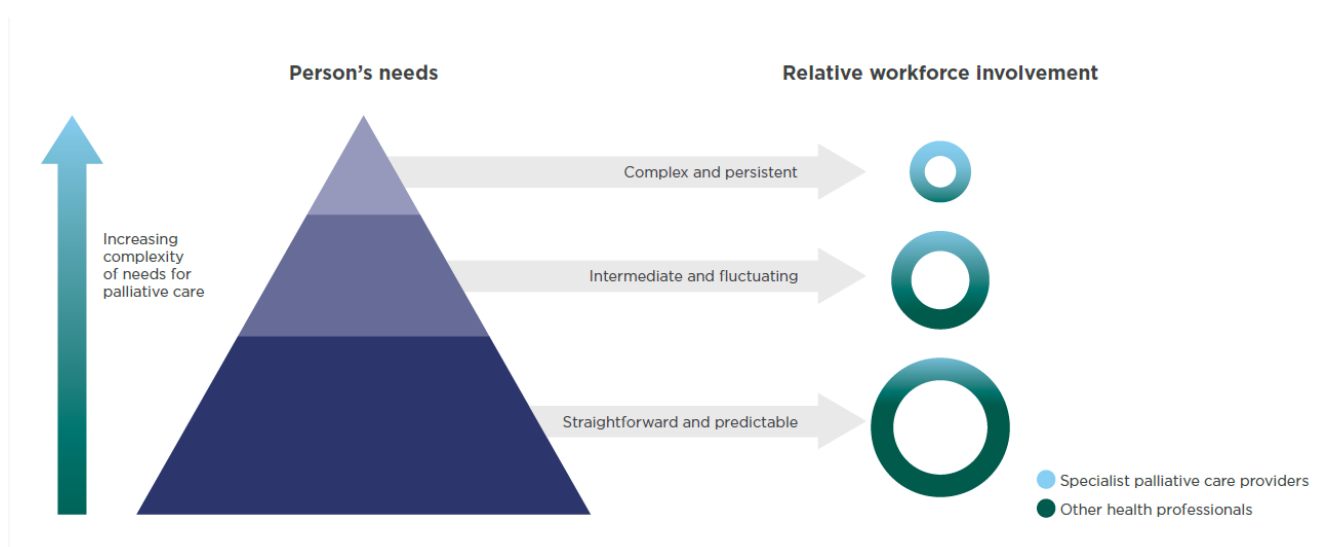
A specialist palliative care service may offer both inpatient and outpatient support, delivered by a palliative care physician or a palliative care nurse practitioner, supported by a palliative care team.

**Palliative care teams may include** people from a range of health and social support professions and backgrounds including:

- Doctors
- Nurses
- Allied health professional
- Social workers
- Pharmacists
- Occupational and speech therapists
- Physiotherapists
- Psychologists
- Dietitians
- Spiritual/pastoral practitioners
- Palliative care trained volunteers

Primary palliative care approaches delivered by those that are not specialist palliative care providers, such as GPs, should establish access to multidisciplinary team members inclusive of these roles, as relevant to the patient's needs and care goals, preferably under a Team Care Arrangement.

Figure 2. Alignment of need for palliative care against workforce capability

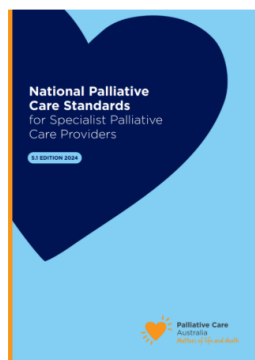


Source: Service Development Guidelines, 2028. Palliative Care Australia

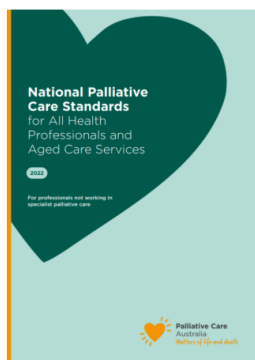
# National Palliative Care Standards

Consistent with the National Palliative Care Strategy<sup>8</sup>, the [National Palliative Care Standards](#) outline the standards and elements of quality care for all Australians. There are two key palliative care standards documents that apply in specialist and non-specialist settings. Standards underpin safety and quality in health care, ensure consistency in service delivery and provide a nationally consistent statement about the level of care consumers can expect from health services.

The workforce involvement diagram (Figure 1.) aligns the palliative care workforce with the care requirement and the colour of the Standards each workforce should look to for a framework of care, service provision and workforce training.



I work in Specialist Palliative Care

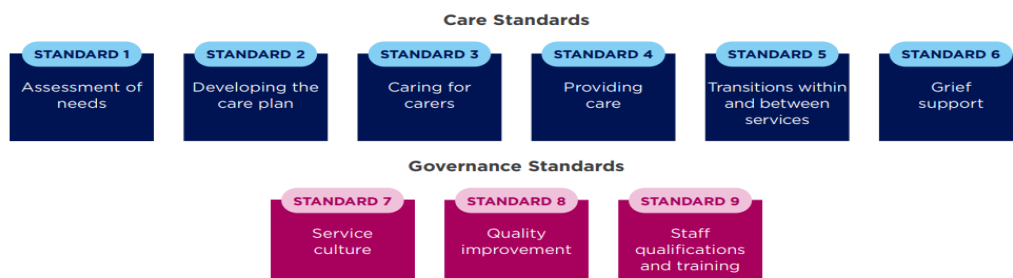


I work in primary, community, aged care and other specialties

Specialist palliative care provision may be available to those living with dementia through their care settings, including through community palliative care teams for those at home or in community residential settings. However, many advanced dementia symptoms are not considered complex in the context of specialist palliative care, and care settings may provide care from *those not working in specialist palliative care*, who should be guided by the National Palliative Care Standards for All Health Professionals and Aged Care Services Ed. 1 (2022), with or without consultancy from specialist palliative care on a case by case basis.

Both versions of the Standards work to nine common Standards, including:

Figure 2: Nine National Palliative Care Standards



# Young-onset Dementia - a terminal diagnosis

**Young-onset Dementia (YOD) is a life-limiting and debilitating condition impacting those diagnosed with a dementia, or mixed dementia, under 65 years of age.**

Dementia itself is not a single specific condition. Rather, it's an umbrella term for a large number of conditions that gradually impair brain function. Impairments or changes caused by dementia can include cognition, language, memory, perception, personality, behaviour, and mobility, and other physical impairments.<sup>9</sup> As these conditions progress, they damage more and more of the brain, eventually affecting the brainstem which forms the connection between the brain and spinal cord and is responsible for controlling vital functions like breathing and swallowing. Dementia eventually leads to death.

For those under 65 years of age, living with young-onset dementia(s) and their families there are a range of factors that those experiencing older onset dementia, and their carers are less likely to need to consider. Factors such as dependent children and familial responsibilities, employment and career, finances, and other caring responsibilities are all impacted. The supports required are not only for the person and their carer, but their broader family and the management of these factors and the associated decisions for care across several service systems.

## Prevalence

Young-onset dementias accounts for about 5% of all dementias, with an estimated prevalence of 119 per 100 000.<sup>10</sup> The number of people currently living with young-onset dementia in Australia, is estimated to be more than 30,000, with this number expected to double by 2050.

In 2021 the Australian Institute of Health and Welfare (AIHW) estimated that over 28,000 people under 65 were receiving anti-Alzheimer's medication.

A number of people are at heightened risk of a young-onset dementia including people living with Down Syndrome where prevalence is almost 50% by age 60<sup>11</sup>, and those living with diseases such as Huntington's or Parkinson's, or infections such as Human Immunodeficiency Virus (HIV)<sup>12</sup>.

## Symptoms and Progression Patterns Specific to Young-Onset Dementias (YOD)

Young-onset dementia(s) (YOD), defined as dementias diagnosed before the age of 65, can exhibit distinct symptoms and progression patterns compared to late-onset dementias. These differences arise due to the types of dementia prevalent in younger populations and their impact on individuals in their prime working and family years.

**Disease Subtype Variability** - As outlined in the Discussion paper (Appendix i), the symptoms often vary depending on the specific type of dementia:

- **Alzheimer's Disease:**
  - Dominant memory loss, followed by disorientation and visuospatial difficulties.

- Gradual decline, with early loss of independence in work or home management tasks.
- **Frontotemporal Dementia (FTD)<sup>13</sup>:**
  - Marked personality and behavioural changes (disinhibition, apathy, compulsive behaviours).
  - Language deficits, such as difficulty producing or understanding speech (progressive aphasia variants).
  - Early preservation of memory but rapid progression in social and cognitive dysfunction.
- **Lewy Body Dementia:**
  - Fluctuating attention and alertness, often mistaken for psychiatric disorders.
  - Hallucinations, particularly visual, early in the disease.
  - Parkinsonian motor symptoms such as tremors and stiffness.
- **Vascular Dementia:**
  - Stepwise progression, with sudden declines following vascular events like strokes.
  - Focal neurological symptoms such as hemiparesis or speech impairments.
- **Rare Subtypes (e.g., Corticobasal Degeneration, Huntington's Disease):**
  - Atypical motor symptoms, such as dystonia or myoclonus.
  - Severe coordination issues and early physical disability.

## Progression Patterns in YOD

YOD tends to **progress faster**<sup>14</sup> than late-onset dementia, possibly due to a higher prevalence of non-Alzheimer's types, like FTD and more aggressive disease traits.

- **Impact on Daily Life:**
  - Rapid loss of independence in work, finances, driver's license, and parenting roles.
  - Earlier need for carer intervention and supportive services.
- **Physical Symptoms in Later Stages:**
  - Dysphagia, immobility, and increased susceptibility to infections in advanced stages.
  - Some subtypes (e.g., Lewy body dementia) may cause severe motor impairments earlier.

## Psychosocial and Emotional Features

- **Psychiatric Symptoms:**
  - High prevalence of depression, anxiety, or obsessive-compulsive behaviours early in the disease.
  - Increased risk of misdiagnosis as a psychiatric disorder due to atypical presentation.
- **Social Isolation and stigma** are key risks, as peer groups and care networks may not be familiar with dementia in younger people and psychiatric symptoms can increase this risk.

## Family-Centred care considerations

Caring can also be physically, mentally, emotionally, and economically demanding. According to the ABS Survey of Disability, Ageing and Carers (SDAC) 2018<sup>15</sup>, among carers of people with dementia (YOD/LOD), the following impact was reported:

- 1 in 2 (47%) provided an **average of 60 or more hours of care per week**
- 3 in 4 (76%) **reported one or more physical or emotional impacts** of the role
- 1 in 4 (23%) reported that they **needed more respite care** to support them
- 1 in 2 (52%) **experienced financial impacts** since taking on the role.

## Diagnosis and Illness Trajectory

The illness trajectory of dementia(s) require extensive care and life planning, and the inclusion of a palliative care approach from the diagnosis stage, noting that there are few, if any, disease modifying treatments available, quality of life should be the priority from the beginning.

Consultations through both the Roundtable and individual interviews with families, indicated that the process for diagnosis was long and delayed. Delays are largely due to there being so many more common issues such as stress and depression that can cause the early signs in this age group. It is also important to note too, that the low prevalence of young-onset dementia means that a general practitioner or other health practitioners, may never have come across a person with early young onset dementia, in their career before, and may never again.

The challenges with diagnosis will be covered by other inputs to the Joint Solutions Project, but what is interesting from a palliative care perspective is the common experience of a lack of information received and the perception that there was a lack of sensitivity in the delivery of diagnosis, which is not what you'd expect for a life altering and life-limiting diagnosis.

The common experience presented was that the diagnosis was delivered within a general consult with limited time for sensitive discussion, a brochure on dementia was generally provided and people were often told they'd need to "get their things in order". This appears to be an all too common experience, and a coordinated follow-up for further discussion was also not commonly scheduled. Dementia Australia has indicated that it is often contacted by people who have received a dementia diagnosis (young onset, or otherwise) and they have not been told and do not understand, that this is an incurable, life-limiting illness.

Additionally, the particular illness trajectory, and likely key decision points for the family to consider were often not covered off by health professionals. Advance care planning also is not consistently raised, even in subsequent appointments.

**Most people want honest information about their situation and care options. This helps them to make decisions and establish realistic goals.**

Roundtable participants noted that the approach at diagnosis of other life limiting illnesses with a shorter life expectancy, such as Motor Neurone Disease (MND), appeared to be more frank and open, and with an urgency to inform the person and their family of the prognosis, trajectory to incapacity and life expectancy. This was a preferred approach by consumers and carers as it provided them immediate opportunities to make memories with, and for, family members, and to put things in place for care management, finances and family needs.

### **Knowledge enables self-determination over elements within one's control.**

Concerns that people want to focus on what they can still do, and not what is coming, was disputed in the Roundtable by a consumer that noted that they must prepare with their family the priority concerns for symptom management prior to an appointment, as appointments are often only long enough to address one or two pressing matters or symptoms. So it isn't that people living with dementia don't want to have an open, honest and sensitive conversations about their mortality, it's more dictated by there not being adequate time in an appointment for such a discussion to be had meaningfully.

This consumer representation provides a lesson to our health system more broadly. There is scope within our system to arrange periodic longer consultations to have meaningful discussions. There is also consideration that palliative care social workers and/or trained occupational therapists can play a significant role in this work following diagnosis, and this can provide an early warm introduction to the palliative care team.

There was a sense that those involved in diagnosis and treatment should be encouraged to undertake training on how to respectfully and sensitively communicate that **dementia is a terminal illness**, and secondly, to create a planned follow up with time for sensitive and open discussion about the critical information that the family needs

in respect of: prognosis, expected life course, key decision points and planning for whole of life, care needs, and end of life care needs.

### Key opportunities identified:

**Medicare Items:** Within general practice specifically, there are a range of long consult Medicare Items that could be used to enable adequate time to undertake sensitive discussion, and give people time to ask questions, or include a broader team for introductions ahead of care planning. These include Items D (at least 40 minutes) and, from November 2024, Item E. (greater than 60 minutes). Chronic Disease Management Planning and Team Care Arrangement Items are also available for follow up planning consultations, preferably once a family understands the diagnosis and trajectory.

**Multidisciplinary Teams:** Supporting illness trajectory understanding and care planning is within the scope of Nurse Practitioners, Practice Nurses and allied health professionals, such as Social Workers or Occupational Therapists. These roles may be attached to general practice or other specialist clinics, or by referral with the specialist or community palliative care team.

**Existing Education on Communicating a Palliative Diagnosis:** For those not working in specialist palliative care, there are a range of free Commonwealth funded educational programs, that offer Continuous Professional Development (CPD) points to support communication and management of palliative care approaches to care. The [Program of Experience in a Palliative Approach \(PEPA\)](#) is run in every state and territory in Australia and is one national example. (*refer to Resources*)

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## Principles of a ‘good death’

In delivering providing palliative care for a person and family, it’s important to understand what ‘quality of life’ means for them personally, and what makes a ‘good death’.

Principles of a ‘good death’ have been summarised from surveys of people approaching death and their families. Priorities for end-of-life care include<sup>1617</sup>:

- **knowing** when death is coming and what to expect – reasonable control of what happens – ensure wishes are respected – choice to leave when it is time – avoid prolonging dying.
- **choice and control** over where death occurs – who is present and who shares the end – time to say goodbye – arrange important affairs.
- **access** to – ‘hospice-style’ **quality care in any location** – necessary information and expertise – control of pain and other symptoms – dignity and privacy – spiritual or emotional support.
- strengthening of relationships, and **relieving burdens** placed on the family.

# Advance Care Planning

Palliative care planning, especially through Advance Care Planning, is crucial for ensuring individuals receive care aligned with their wishes and values, improving quality of life and reducing stress for both the person living with dementia and their families.

Advance care planning is the process of planning for your current and future health care. It involves talking about your values, beliefs and preferences with your loved ones and doctors. This helps them make decisions about your care when you can't.

Ideally these conversations start when a person is well, or at diagnosis of young onset dementia, and then continue throughout the illness trajectory as options of care are learned, and there is decision making capacity. A person with dementia's capacity for decision making will decline at different stages depending on the type of dementia and its impacts on the person, so focussing on the persons values is important as a base to guide substitute decision makers, families and health professionals as to what is likely to be acceptable to the person.

Advance care planning documents, including Advance Care Plans or Personal Care Plans and Advance Care Directives (legal document), vary across the country, so [Advance Care Planning Australia](#) provides key information to support families and health professionals to work within their local requirements.

Key issues raised through the Roundtable and interviews included the need to **ensure that Advance Care Planning and legal Advance Care Directives, including determination of Substitute Decision Makers, are put in place as early in a person's trajectory as possible.** It was noted that this should be encouraged at the time of, and in the context of, the illness trajectory conversation.

Participants noted that there are a range of resources available for Advance Care Planning, including localised education for community in a number of states e.g. Western Australia and Tasmania and online offerings through these and other services such as PalliLearn. There were still concerns, however that many are reporting that it can be difficult to find and understand information on how to undertake the advance care planning process.

Clinically, advance care planning, and palliative care records, should include a person's preference of location of care and end-of-life care (these may differ). There is also a preference of persons and carers to include provisions that outline preferences and timing for either Voluntary Stopping Eating and Drinking (VSED) if that is the persons preference, or even their desired preference and timing for Voluntary Assisted Dying (VAD) should legislation change within the period of their illness to allow this treatment choice for those living with dementia.

**Considerations and decisions for families living with young-onset dementia** include preparing for changing needs over time, such as parenting and potentially caring for elderly parents simultaneously ('sandwich generation'); employment and career for both the person with the dementia and for their partner-carer; accommodation considerations, including are their local services? and if not, how far away may future accommodation options be? These issues impact the financial stability and position of the families as a whole over a long term, and as care needs increase, the financial strain increases as living arrangements, care and equipment needs increase.

Additionally, not all people living in Australia with young onset dementia will be eligible for the National Disability Insurance Scheme (NDIS) or have Income Protection (IP) insurance, or Total & Permanent Disability (TPD) insurance to access. Additionally, not all carers are eligible for carer support payments, and this is designed to supplement, rather than substitute, a person's wage regardless.

## Key opportunities identified:

**'Whole of life' Planning** - The Roundtable highlighted the importance of a 'whole of life' plan for people living with young-onset dementia, inclusive of advance care planning for the health and end of life components. Such

planning would focus the person on planning for the management of life whilst living with young onset dementia and is a more palatable early discussion for people to work through following diagnosis as it promotes self-determination.

There is work being done in this area, and a template and assistance model could be developed out of this research, to support people beyond health care planning, to include financial and career planning, relocation as necessary, disability management and parenting and caring responsibilities as needs change along the trajectory of the illness. Advance care planning would then form part of a much broader and contextualised planning discussion for the family, outlining the supported decision making processes for that family, and the likely decisions of substitute decision makers later in the trajectory.

**Use of MBS items for planning** - Additional promotion to general practices on the use of existing longer consultation items (Level C, D and E) with guidance about their relevance to palliative care and the ability for these to create the necessary space for sensitive discussions around prognosis, decision making and life planning, or commencing ACP.

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## Legal and Ethical Issues

A person living with dementia will get to a point where they do not have the capacity to make decisions about their health care and medical treatment, including whether or not to withdraw or withhold treatment, and therefore cannot provide consent. In those circumstances, both guardianship legislation and the common law in each Australian State and Territory provide ways in which medical treatment can lawfully proceed or, in some cases, be withheld or withdrawn.

In most cases, consent to withholding or withdrawing life-sustaining treatment may also be provided by a person in their Advance Care Directive, if legally accepted.

### Voluntary Assisted Dying (VAD)

In Australia in 2025, all jurisdictions with voluntary assisted dying (VAD) legislation enacted, require the person to have decision-making capacity throughout the process. It is therefore not possible at this time to request voluntary assisted dying through an Advance Care Directive or to have a Substitute Decision-Maker request it on your behalf.

This creates a significant barrier for those with dementia who are unable to plan ahead to access this care or its timing, for example once they are unable to feed or toilet themselves. Consultation with carers indicated that there is hope that this legislation will change over time, and as such, people are documenting their preferences for substitute decision makers to enact if this treatment option becomes available when they are no longer able to advocate for themselves.

### Voluntarily Stopping Eating and Drinking (VSED)

In the absence of the VAD option, another option raised in the Roundtable as being researched by people living with dementia, while they have decision-making capability, is voluntarily stopping eating and drinking (VSED). This process aims to reduce the length of time a person is living with terminal disease, such as young-onset dementia, will suffer the condition, and follows the body's natural dying processes. For a terminally ill person the process may take several days to several weeks after intake of food and water stops. Some people experience unconsciousness in as little as two to three days.

Healthcare providers are legally protected when respecting an adult with decision-making capacity exerting their right to refuse food and drink, and they are not obligated to provide sustenance if the person refuses it, however, there is uncertainty amongst health professionals about this in the context of an advance care directive.

There is some uncertainty in Australia <sup>18</sup>about whether an adult with decision-making capability can make an advance care directive to action VSED, and whether such a directive, once made, would be binding, and legally actionable by the Substitute Decision Maker. There is concern that a lack of clarity on this issue, will see substitute decision makers negatively impacted where health professionals or disability workers refuse to enact this treatment as instructed by their person. Such situations heighten the risk of carers and guardians experiencing complicated bereavement.

**Recommendation:** Legal clarity on a substitute decision makers, health professionals and disability workers right to action this treatment under an advance care directive is considered to be an important step in the end-of-life care options people living with degenerative and progressive disease, such as young-onset dementia.

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# Care Settings

In Australia, people under 65 years of age living with dementia may require specialised residential care services. Dementia Australia highlights a significant lack of appropriate facilities and setups for younger individuals requiring residential care<sup>19</sup>. The options are further limited by geography, in terms of being available where a family lives, and the person's ability to access the NDIS.

Many families choose to care for their person at home for as long as is manageable and safe for the person living with YOD and their family, including wellbeing considerations for children and young people. For those eligible, NDIS functional and daily living supports may be accessible to assist people to continue to live in the family home.

*Later in this report the needs of carers and families and the challenges with the NDIS and palliative care systems interface will be discussed.*

Residential options may include one or a number of the following permanent, or temporary, settings:

## 1. Specialist Young-onset Dementia (YOD) Residential Care

- Whilst specialised services are scarce in Australia, facilities have and can be designed specifically for younger people living with dementia. These services provide age-appropriate care, activities, and social engagement and are often located in dementia-specific care homes or units.
- HammondCare opened the first specialised YOD Residential Care service in Australia in 2010. [Streeton Cottage](#), Horsley NSW, is a 15 residential unit.

## 2. National Disability Insurance Scheme (NDIS) Supported Accommodation

- The NDIS provides funding for housing and support services (if eligible and available), which should be tailored to the needs of younger people living with dementia.
- Options include:
  - Specialist Disability Accommodation (SDA) – purpose-built housing with high-level support.
  - Supported Independent Living (SIL) – shared or individual accommodation with 24/7 support.
    - An example of a tailored SIL service is operated by Brightwater. [Polaris House](#), Kingsley WA is a five bed residence offering tailored support for people with YOD, focusing on promoting independence and community engagement.
  - Individual Living Options (ILO) – flexible housing arrangements tailored to the individual's needs.

## 3. Aged Care Facilities with Young-onset Dementia Support

- Some aged care homes accept younger people with dementia, though they may not be age appropriate.
- Facilities with specialised dementia care units may provide better support.
- Additionally, the Australian Government's [Specialist Dementia Care Program](#) (SDCP) funds units within residential aged care homes to provide specialised care for individuals with severe behavioural and psychological symptoms of dementia. These units enable a 'step up- step down' model of care, aiming to stabilise symptoms for transition into, or back to, less intensive care settings, e.g. SDA or SIL. These units are not exclusively designed for younger individuals.

## 4. Group Homes for Younger People with Dementia

- Small-scale, home-like environments with professional carers aim to encourage independence and social interaction.

## 5. Hospital-Based Care for Complex Cases

- For individuals with severe behavioural or medical needs requiring intensive management.

These services are often provided in psychogeriatric or neuropsychiatric units.

## 6. Transitional or Respite Care

- When people living with dementia are still living at home, short-term residential care options provide temporary relief for carers.
- Services may offer overnight, weekend, or longer stays in specialised dementia facilities.
- Palliative Care ACT provides, Leo's Place, a short term respite service for all those living with terminal conditions. It is not specifically equipped or staffed for dementia care; however, it has been able to support low-need young onset dementia families with day, overnight and weekend respite services by arrangement.

### **The National Palliative Care Strategy priorities include:**

- **People can receive timely palliative care in the place of their choice.**

The above residential care locations are most likely to be used by people with moderate to advanced dementia and in order for people to receive “at home” palliative care, they need to be able to access palliative care in their place of residence. Unfamiliar environments, including hospitals, are particularly challenging and distressing places for people living with dementia, and as a result, their families so the options for ‘at home’ palliative care need to be expanded to include these housing options wherever a person with dementia is living.

Roundtable discussions did point to views that residential aged care facilities, while improving in their capability for providing access to palliative care, delivered by either visiting GPs or specialist palliative care in-reach units, are not universally providing palliative care for residents with advanced dementia. Where this is being provided, residential aged care services are not always an appropriate care setting for those with younger-onset dementia.

In terms of palliative care access, a significant gap appears to be in the disability housing SDA/SIL options. It was noted that that the disability workers and clinical staff are not necessarily receiving the available training to identify deterioration, pain and distress, and end of life symptoms such as swallowing issues. Accessing this free training is reliant on proactive engagement by individual staff and is often not provided as mandatory training for the care setting, backfilled and often not supported by the employers.

Families have expressed frustration in their attempts to advocate for their persons needs as substitute decision makers in disability settings. The disability sector works on a supported decision making model, and there appears to be a lack of understanding in relation to the difference between supported decision making of the person living with disability and the rights of the substitute decision maker in enacting wishes of the person once decision making capacity is lost.

Whilst identified in the Palliative Care Service Development Guidelines (2018) as a place where palliative care services are provided, many palliative care teams are not routinely conducting in-home visits or services through these houses.

The incentives for general practice to establish relationships to visit SDA/SIL home is also not in place, as it is for in-reach to aged care services. After hours visits are also not well support by the MBS. This is an increasing gap, noting that more people with young-onset dementia are now entering SDA/SIL housing, many at an earlier stage in the illness trajectory due to family needs and cost of living pressures requiring carers to maintain their employment, etc. This is a growing barrier to palliative care for people living with young-onset dementia is disability housing.

## Key opportunities identified:

### Mandatory training for SDA/SIL staff

Free Commonwealth funded training programs exist for the disability workforce, in recognising decline and end of life symptoms, and foundational palliative care. PCA recommends that a base level of training should be mandatory for anyone working in care settings with people living with advanced dementia or other life-limiting illnesses. In [its 2025 Federal Budget submission](#), PCA called for back-filling of roles for nurses and care workers in aged care in order for them to be able to participate in the free palliative care training funded by the Commonwealth. This too could be requested and implemented for SDA/SIL staff to engage in available training, or it could be integrated into induction training for all staff working in service settings where people living with young-onset dementia are residing (refer to *Resources*).

### Supported decision making versus Substitute Decision Makers

Disability workforce training in dementia care and foundational palliative care must incorporate education on the difference between supported decision making and the role of substitute decision makers. This understanding will enable disability workers to appreciate a family's need to enacting advance care planning, advance care directives, and end of life wishes, and work in partnership with the family to reduce distress.

### In-home care

Incentives similar to the primary care into aged care arrangements, and improvements in after-hours care access, would support community palliative care for those living in SDA/SIL housing and other residential care settings, particularly once a person is no longer able to attend a clinic.

Palliative Care Australia understands that a genuine palliative care approach, offering home regular home visits toward end of life, delivered by general practitioners is currently considered uneconomical by many practice owners. Key components such as travelling to in-home services (often after hours), and shared palliative care consultancy time without the patient present are not remunerated.

Noting that currently 38% of people that would benefit from palliative care, are seen by specialist palliative care services, the primary care and community care teams need to have the confidence and means to provide palliative care to that other 62% of people, including those living with younger-onset dementia. In its [2025 Federal Election campaign](#), PCA calls all governments to ensure better access to palliative care in primary care, through:

- **A new practice-level payment for palliative care and end-of-life care**, covering activities undertaken by primary care multidisciplinary teams that currently cannot be billed to Medicare.
- **Additional guidance in the use of existing longer consultation items** (Level C, D and E) to be more explicit about their relevance to palliative care.
- **Additional funding** for home visits, after-hours care (in-person and via telehealth), shared care arrangements with specialist palliative care teams, and medical certification of death.

### Importance of suitable and rolling assessments in palliative care for dementia

Regardless of the care setting, there are regular assessments that should be undertaken for those living with young-onset dementia(s) and are recommended at least annually and more frequently as the persons status changes. In practice, this should include:

- Regular discussion and agreement about current/future goals and goals of care with the person with dementia and carer and family. *At least annually, more frequently as status changes.*

- Regular needs assessments conducted by a member of the palliative care or multidisciplinary team, considering physical, psychological, social, and spiritual needs. A formal tool to assess palliative care symptoms specifically in a person with dementia should be considered, such as IPOS dem (integrated palliative care outcome scale for dementia- community version available through the ELDAC website)
- Use of appropriate tools to assess individual symptoms, particularly as dementia progresses, and including the carer/family's insights in these assessments e.g. for pain and depression. Dementia appropriate tools resource should be available nationally.
- Aiming for integration of a range of pharmacological and non-pharmacological treatments to address symptoms will depend on local services, e.g. reiki or massage for agitation, singing and music therapy for improved mood, communication and memory recall.
- Critical access to appropriate counselling for grief and loss, and peer support programs for the person and their family/carers, and bereavement support services.

# System Navigation and Support Models

Roundtable discussions highlighted the benefits of a systems navigation services for the families of those living with young-onset dementia, and for those coordinating care through multidisciplinary teams via a one stop model. This concept is expected to be covered in greater detail through other inputs to the project.

Navigating services is extremely challenging for families due to disconnected systems and may go some way to achieving greater coordination between health and disability sectors to prevent gaps in care, especially for smooth transitions between systems and providers of care.

A YOD-specific care navigator role was considered by both the YOD-SIG and the Roundtable participants. Such a role would provide consistent support from the point of diagnosis, through the illness trajectory and transitions of care, and into bereavement for the family. The Irish Dementia Model was considered to offer a potential example, models that integrate navigators from the time of diagnosis. This model also included components of peer support for families.

Importantly, while call centre-based navigation services can be supportive for families and carers, for people with young-onset dementia(s) struggling with memory, they are considered ineffective as the key identification requirements to start a conversation, such as dates of birth, or prompting questions, allude them.

Call centre services would ideally utilise a combination of national databases, such as HealthDirect and Carer Gateway, as a basis for such a navigation service, as it needs to be comprehensive and accurate. These services are notoriously expensive and difficult to maintain data quality, and therefore a dedicated investment, leveraging existing systems should be considered.

In Australia, there are limited examples of palliative care support models relevant to young-onset dementia however those that are available are considered exemplars, including:

**The Nightingale Program** is a specialist nurse-led support and palliative care service promoting choice, wellbeing and forward planning for people living with advanced dementia, their families, and care providers. This service is available free of charge throughout South Australia.

**Metropolitan Palliative Care Consultancy Service (MPaCCS)** operates in metro Perth as a mobile specialist palliative care team. It works collaboratively with general practitioners and other health professionals to build the palliative care workforce through training, education, assistance, and mentoring where there are currently no specialist palliative care consultation services available. MPaCCS assists care settings including residential aged care, residential disability, mental health and psycho-geriatric, and correctional facilities.

**Palliative Care Connect** provides state-wide Palliative Care Navigators in South Australia, available through an information line. They provide information, service linkages, and empower individuals to make choices aligned with their culture and preferences. These navigators also support general practitioners and other healthcare professions, including those who work in palliative care units, acute care and aged care services to organise and link people to appropriate palliative care, supports or services. Aboriginal and regional specific palliative care navigation services, and bereavement navigation services are also available

This model is being piloted over a four year period as a joint State and Commonwealth health initiative and there is hope that its evaluation will prove that similar models could be implemented nationally.

**The Neuro Wellness Hub** is a recently established place to offer support, services, and community for Queenslanders living with neurological conditions including young -onset dementia, multiple sclerosis (MS), Parkinson's, epilepsy, motor neuron disease (MND), stroke, and many others. Services include physical therapies, support coordination, webinars and an assistance info line. This first hub has been provided by MS Queensland and is being considered for broader roll out.

**Residential Care Line Outreach Service** is offered to better support those living in residential aged care by providing clinical teams with better support. It provides clinical consultancy, including palliative care consultancy, for staff in Residential Aged Care Facilities (RACF) and care coordination assistance to RACF staff and Hospital staff for timely, safe and effective discharge for patients returning to RACF.

# NDIS and palliative care interface barriers

Many people with young-onset dementia and disabilities, or functional disabilities associated with their dementia, continue to face barriers to realising their right to disability support and health, which includes the right to palliative care. These barriers include non-inclusive mainstream service models, restrictive eligibility criteria for functional supports at end of life, and geographic variability in the availability of services.

Crucially, people with functional support needs due to their life-limiting illness, and palliative needs rely on services provided by various systems – health, disability and social services among them. Too often, the funding and policy boundaries between these systems create artificial barriers to the person-centred care and services that people need, from the time of their diagnosis with a life-limiting condition. In this context, provision of information, advice and navigation supports is essential.

**“People are really spending the ends of their lives... fighting systems and trying to get support. We really need to fill this gap.”** – *Palliative Care Professional*

The NDIS, including its interface for palliative care, was a significant part of the discussion at the Roundtable and through interviews with families. As outlined in the Discussion Paper (Appendix i) the 2024 Independent NDIS Review acknowledged that the “interface between palliative care and disability supports can be difficult to navigate, and result in very poor outcomes for people”. The Review also acknowledged that “there is complexity as to whether support needs are best met by the NDIS or the palliative care and health system”.

The NDIS Transitional Rules introduced in October 2024 aimed to clarify what is, and what is not, a NDIS funded support, setting out that:

- State/territory health services provide “sub-acute palliative care including inpatient and outpatient services... in the person’s home or clinical setting:
- NDIS provides functional disability supports, which may continue while a person receives sub-acute palliative care.

The NDIS Transitional Rule does not specify what services sub-acute palliative care includes. Complexity arises as some functional supports could be considered both, or either disability or health supports – for example, assistive technology, domestic/ household assistance and personal care services. Unclear and disputed responsibility for these supports has led to very poor outcomes for people with disabilities who also require palliative care.

Furthermore, PCA estimates that at least 5,000 people under 65 currently have no access to basic day-to-day functional supports for a disability stemming from a terminal diagnosis, though how many of these would have young onset dementia is unclear. This group is caught in the funding gaps between the NDIS, state/territory health and community care systems, and/or the aged care system.

Further detailed information on these issues is available in PCA’s 2024-25 Federal Budget Submission. (*Appendix v*).

## Key Opportunities identified:

### Joint-systems pilot for YOD client group

Roundtable participants posed the question as to whether the young -onset dementia cohort may be a good client group for a joint-system pilot of a new “*person-centred approach, where systems reach into one another to provide more effective and coordinated support,*” building on the recommendations of the Independent NDIS Review, including that palliative care be a “*critical priority when reviewing arrangements for interactions between the NDIS and other service systems*”. This pilot could establish the much needed clearer definitions of respective service system responsibilities and specific guidance on working arrangements.

## For those without the NDIS

The Roundtable also raised the issue that not all people living with young-onset dementia are able to access the NDIS at all. An urgent priority of the PCA 2024-25 Federal Budget Submission was for the Australian Government to establish a new program of home-based non-clinical support for people under 65 with a disability associated with a life-limiting illness who need functional support to remain at home with family, and who cannot access this support through the NDIS or State or Territory-funded services. The program was proposed to be established on an interim basis for 2 years, or until a lasting solution had been found.

Regardless of which level(s) of government fund(s) these supports, there will continue to be a need for a system of supports for people with disabilities linked to a terminal condition who cannot access the NDIS, or (as with people with Young Onset Dementia in the early stages) whose condition is not yet sufficiently severe to qualify for the NDIS.

## Clearly defined Roles of Governments and Portfolios

Through their responsible agencies of DOHAC, DSS and S&T Health, all Governments should provide a clear resolution of the respective roles of different tiers of government and different portfolios regarding responsibility for the delivery of non-clinical support services for people under 65 with life-limiting conditions. The PCA 2024-25 Federal Budget Submission called for this to occur both through the National Health Reform Agreement, and, as recommended by the Independent Review of the NDIS, a new system of *'foundational disability support'*, including *'state and territory home and community support programs to provide additional support to people with disability outside the NDIS'*.

PCA is confident that both Commonwealth and State/Territory Governments are well aware of these interface issues and the impact they continue to have on this group of vulnerable Australians. However at the time of writing no decisions have been made that would deliver a lasting solution.

## New NDIA Rapid Access Pathway

One area where there has been tangible progress is the NDIA's Rapid Access Pathway for people with terminal illness, which started operation in mid-2024. The Pathway has reportedly greatly reduced turnaround times for NDIS access requests and (for people who are successful in their NDIS access request) getting an NDIS plan. It is unclear whether the Pathway's client group includes people with young-onset dementia – something that could be clarified with the NDIA.

# Families, Partner Carers and Carers

A key differentiation of palliative care from other health care specialties is the explicit focus on family-centred care. This care includes considerations for the wellbeing of the carers and their grief and loss both before and after the death of their loved one.

The National Palliative Care Strategy priorities include:

- Carers get the support they need, including in-home support, respite care and bereavement support.

The National Palliative Care Standards require specialist palliative care services, and those delivering primary palliative care, to address the needs of the carers through: Standard 3 – Care for Carers and Standard 6 – Grief Support.

## Palliative Care Social Workers

An important part of the palliative care team is the social worker role. These specialised professionals work in specialist palliative care services, hospices and other settings such as hospitals, community and primary health, aged care facilities, and group homes, and other government and non-government agencies.

When social workers are involved with people early in their illness trajectory, they have a positive impact on the person, and their carers and family outcomes<sup>20</sup>. Social workers provide a range of symptom management and psychosocial interventions; however, they also engage with communities and navigate systems to address gaps and fragmentation across health care and social services.

## Peer Support

The Roundtable participants noted the value of both formal and informal peer support initiatives.

The model developed by families for families in Western Australia, includes families coming together and providing holistic support for each other throughout their dementia journey, as well as later options to join into a social group for those widowed.

Two key things that resonated from interviews with families in relation to formal support structures.

- **Time limits:** Despite the illness trajectory for young-onset dementia spanning many years, and up to two decades, there was a two year time limit on involvement in the support group. This meant that families didn't get the benefits of the group throughout the trajectory of the illness, or for all their times of stress, such as for decisions to transition care.
- **Bereavement supports:** Carers that are bereaved are invited to come and say farewell to the group, but their young-onset dementia support group does not cater to those bereaved. There was a strong feeling that there should be a period of transition offered to all family members, so as to not isolate them from those that had understood their journey and their needs. There was also concern that if they were offered another dementia bereavement support group, that these may not be age-appropriate for the carers of younger people living with dementia.

Children of people living with dementia, may also be carers. For Young Carers there should be age appropriate support groups that can be accessed and that palliative care social workers can refer young carers to.

## Existing Models of Dementia Palliative Care

There are a number of models for dementia palliative care around the world. The primary considerations for young-onset dementia, are less about the clinical end of life care, and more about those factors covered in this report, such as the need for life planning, accessibility of palliative care services in the care settings in which people reside, their ability to access the NDIS and the knowledge of these conditions in disability services.

In 2020, Dr Elissa Campbell undertook a Churchill Fellowship to explore a range of international models for palliative care for those living with dementia and their families\* and carers. It is noted that this list of recommendations is suited to palliative care models for anyone living with dementia, regardless of age, life stage or type of dementia.

Importantly, the researcher visited experts and exemplar models of palliative care for people with dementia at clinical, research and community settings in 12 cities in the USA, Netherlands, Belgium, UK, Ireland and Singapore. The Fellowship findings<sup>21</sup> confirmed that “*although there were differences in health and care systems across countries, these were outweighed by the similarities in challenges faced in each setting.*”

### **Dr Campbell identified 12 Core elements for a successful model of palliative care for people with dementia**

- Care must be co-designed
- Care must be person-centred
- Carers are essential
- Diagnosis and post-diagnostic support are important
- Care navigation is essential, ideally with a single point of contact
- Care must be needs-based, not prognosis-based
- Care must be multidisciplinary and interdisciplinary, yet also be integrated
- Palliative care must be proactive, not reliant on referrals
- Outcomes of palliative care should be measured
- Advance care planning is important, especially for transitions of care
- Public health interventions are key to sustainability
- Big Data and design methodology can help develop better models of care

The **Ireland Principles of a Dementia Palliative care model** was specifically noted in the Roundtable as offering navigation services and peer support services. Its key principles include:

- 1 Comprehensive Care that covers all dementia needs from diagnosis onwards
- 2 Person Centred Practice and Care (PCC) that tailors the person’s care to their interests, abilities, history, personality
- 3 Integrated Care that links people with services that work seamlessly together
- 4 Accessible Care that ensures a basic level of support to everyone regardless of location, time, illness, ability
- 5 Care for Carer/Supporter ensures that family members are enabled to support the person with dementia and that their own needs are met
- 6 End-of-Life Care ensures a dignified death in the person’s preferred place with limited suffering

As noted earlier in this report (page 6) the only state in Australia to currently have a dementia palliative care specific framework being implemented by services is Western Australia. This framework (Appendix iii) provides a comprehensive base for any Australian framework, including the team engagement, and patient centred clinical and psychosocial needs across the five Care Points: stable, unstable, deteriorating, terminal and bereavement.

# Model of Palliative Care for Young-Onset Dementia (YOD)

This model of care integrates the critical elements discussed in the Roundtable and through interviews, focusing on the unique needs of people living with young-onset dementia and their families. It emphasises continuity of care, system navigation, person-centred and trauma-informed care, and the inclusion of peer support, family advocacy, and clear communication across systems.

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## 1. Person-Centred Care Framework

- Core Principles:
  - o Empowerment, choice, and collaboration with patients and families.
  - o Respect for the individual's insight, agency, and evolving needs over time.
  - o Care approaches must be adaptable to different stages and subtypes of YOD.
  - o Acknowledge the impact on family members, including children and caregivers.
- Key Components:
  - o *Individualised Care Plans:* Each patient's care plan is developed collaboratively with input from patients, families, and healthcare providers, reflecting personal preferences and future care needs.
  - o *Care Coordination:* Designated care coordinators or navigators (e.g., social workers, care coordinators) who provide ongoing support, acting as the primary point of contact for families.

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## 2. Integrated and Holistic Approach

- Multi-Disciplinary Team: Care involves a team of healthcare professionals, including GPs, palliative care specialists and community care, allied health professionals (e.g., physiotherapists, psychologists, social workers), and disability service providers.
- Continuity of Care: Seamless transitions between services, ensuring no gaps in care when moving from diagnosis to palliative care stages. This includes transitioning from curative treatment to palliative care when appropriate.
- Shared Care Plans: Systems for sharing care plans across healthcare and community services to ensure consistency. This could involve a shared electronic health record accessible to all involved parties (GPs, specialists, NDIS providers, residential care, etc.).

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## 3. System Navigation and Support

- Care Navigators: A key feature of the model, providing families with a consistent point of contact to navigate complex healthcare systems (including NDIS, palliative care, aged care, etc.).
  - o *Responsibilities:* Ensure appropriate referrals, provide emotional and logistical support, assist with accessing services (e.g., NDIS, allied health, peer support groups).
  - o *Proactive System Coordination:* Develop partnerships between health services (palliative, disability, and aged care) to improve awareness and access to appropriate services for people with YOD.

- **Database of Services:** A central, accessible database listing available local services required by those living with younger-onset dementia and their families, including specialised dementia services, family member support groups, respite care, specialised allied health services, etc. This could leverage existing systems to ensure quality and up to date data.
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#### 4. Education and Training

- **Health Professional Education:** Develop specific training for healthcare professionals (e.g., GPs, palliative care staff, allied health, disability care workers) about the unique needs of YOD patients. This includes understanding the illness trajectory, advanced care planning, and how to recognise end-of-life symptoms such as repeated infections, swallowing issues, behavioural changes, etc.
  - **Disability Care Worker Education (SDA/SIL):** This includes understanding the illness trajectory, understanding supported decision making versus substitute decision makers, and advanced care planning, including decisions to cease feeding. Risk-feeding and how to recognise and escalate end-of-life symptoms such as behavioural changes, swallowing issues, repeat infections etc.
  - **Family and Caregiver Education:** Offer regular, accessible educational resources to families and caregivers on managing the progression of dementia, end-of-life planning, symptom management, and how to communicate effectively with care teams.
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#### 5. Peer Support and Family Advocacy

- **Peer Support Programs:** Establish peer support networks for individuals living with YOD and their families. Programs like Dementia Australia's "Connecting Peers" program and local community-led initiatives can provide emotional support, shared experiences, and practical advice.
  - **Targeted Peer Support:** Include programs for younger individuals with dementia, children, and young carers, ensuring age-appropriate support and information sharing.
  - **Family Advocacy and Peer Leaders:** Empower family members to act as advocates for their loved ones. Peer leaders, trained through programs like the "Connecting Peers" initiative, can offer support and help families navigate complex decisions and healthcare systems.
  - **Children and Young People's Support:** Specific programs designed to support children and young people whose parents or guardians have YOD, similar to models like CanTeen for Offspring members or young carer programs.
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#### 6. Advance Care Planning (ACP)

- **Early and Ongoing ACP Discussions:** Ensure ACP begins immediately after diagnosis and is revisited periodically. This includes discussions about future care needs, end-of-life planning, and any decisions regarding quality of life. It should not be just a one-time brochure handed to the family but a dynamic, ongoing process.
  - **Supported Decision-Making:** Work with families and patients to support decision-making, acknowledging the patient's ability to make decisions at various points in the illness trajectory. Consider the broader family context, including children and caregivers.
  - **Clear Documentation:** Establish clear, accessible ACP documents that include directives around treatment preferences, decision-making authority, and end-of-life care choices. These should be shared across all care providers.
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## 7. End-of-Life and Bereavement Support

- End-of-Life Care: Ensure that healthcare staff are trained to recognise signs of nearing end-of-life stages (e.g., difficulty swallowing, recurrent infections, and general physical decline).
- Family Bereavement Support: Offer ongoing support after the death of a loved one, including grief counselling and access to peer support groups. Acknowledge anticipatory grief that families experience throughout the illness trajectory.
- Post-Diagnosis Grief and Loss Programs: Implement post-diagnosis grief and loss support for families, especially for those who may experience complex grief due to the long, often unpredictable illness trajectory.

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## 8. Collaboration and Integration Across Systems

- Cross-System Collaboration: Explicitly align NDIS, palliative care, and other relevant services (such as social services) to ensure that families and patients receive holistic support. This includes:
  - o *Joint Statement by Governments*: Advocate for a coordinated approach between state, territory, and federal governments to integrate NDIS and palliative care services.
  - o *Coordination with Aged and Disability Care*: Ensure that palliative care teams are integrated into residential aged care facilities (RACFs) and supported independent living (SIL) settings.
- Integrated Models of Care: Use existing models like the Nightingale program as a blueprint for integrating palliative care into dementia care, with a focus on community-based models, and supporting patients outside the hospital environment.

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## Recommendations for Implementation

1. Pilot Integrated Care Programs: Launch pilot programs that bring together NDIS, palliative care, and other health services to provide a cohesive care plan for YOD patients and their families. The YOD community can serve as a test case for these integrated care models.
2. Create Centralised Care Navigation Tools: Develop a national or state-level care navigation platform, which includes a centralised database of services and a single point of contact for families to navigate all aspects of YOD care.
3. Expand Peer Support Services: Scale up peer support programs and ensure they are specifically tailored to different age groups and caregiving roles, with emphasis on young carers and children.
4. Strengthen Education for Health Professionals and Disability Support Workers: Regularly update and expand training programs for health and care professionals to ensure they understand the unique needs of younger dementia patients and their families.
5. Advocate for Systemic Policy Change: Push for policy changes that mandate collaboration between NDIS and palliative care services to ensure that those with YOD receive seamless support across both domains.

# References

- <sup>1</sup> United Nations [International Covenant on Economic, Social and Cultural Rights](#), Article 12; United Nations Convention on the [Rights of Persons with Disabilities](#), Article 25
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# Appendices

|              |   |
|--------------|---|
| Appendix i   | Roundtable Discussion Paper                                 |
| Appendix ii  | Roundtable Discussion Summary                               |
| Appendix iii | End-of-Life and Palliative Care for Dementia Framework (WA) |
| Appendix iv  | Palliative Care Australia 2025 Federal Election Platform    |
| Appendix v   | Palliative Care Australia 2024-25 Federal Budget Submission |

## Resources

### Palliative Care Resources for Carers

**CarerHELP** is a website dedicated to supporting those caring for someone with a life-limiting illness. It covers a range of topics about caring, staying well and connected and grief and loss in 10 languages. [www.carerhelp.com.au](http://www.carerhelp.com.au)

**The HELP App** is a free tool recommended by the palliative care sector as a dedicated app for building, organising and activating your social networks to support the care of someone with a life-limiting illness. It assists with the daily living activities that palliative care teams can't do - like walking the dog, dropping kids to sport, getting to appointments and mowing the lawn. It gives family and friends practical ways to lend a hand and helps to keep families connected to their various social networks throughout the illness trajectory and into bereavement. [www.healthyendoflifeprogram.org](http://www.healthyendoflifeprogram.org)

### Palliative Care Education for Care Workers

**PCC4U Resources for the Vocational Education Training** sector are mapped to units of competency for various health training packages. The Care Worker Toolkit includes the core topics of: Principles of palliative care; Communicating with people affected by life-limiting illness; Assessing and managing symptoms; and Optimising function in palliative care. [www.pcc4u.org.au/learning](http://www.pcc4u.org.au/learning)

**PEPA Aged Care** brings specialist palliative care in aged care educators into an aged care service to provide free customised learning programs over two to four days, onsite at the workplace. [pepaeducation.com/pepa-aged-care/](http://pepaeducation.com/pepa-aged-care/)

**ELDAC Dementia Toolkit** provides information and guidance to support palliative care and advance care planning for people living with dementia and their families. [www.eldac.com.au/Our-Toolkits/Dementia](http://www.eldac.com.au/Our-Toolkits/Dementia)

### Palliative Care Education for Primary Care Providers

**PEPA/IPEPA** provides opportunities for all health professionals to develop capabilities in providing a palliative approach to care through participation in placements, workshops and a range of learning resources. PEPA also supports integration of learning into your work setting and promotes networks of support between specialist palliative care providers and non-specialist settings. [pepaeducation.com/pepa/](http://pepaeducation.com/pepa/)

**Palliative Care ECHO** is a series of interactive case based virtual mentoring sessions that address a range of palliative care topics. Discussion of deidentified patient cases and 10 minute lectures aim to increase palliative care knowledge, skills and confidence in primary care health professionals. [uqecho.org/pallcare-echo/](http://uqecho.org/pallcare-echo/)

**CareSEARCH** Health Professionals Centre provides palliative care evidence and tools for health professionals and information about death and dying. [www.caresearch.com.au/Health-Professionals](http://www.caresearch.com.au/Health-Professionals)



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