

JANUARY 2023

NATIONAL DEMENTIA ACTION PLAN CONSULTATION

Submission from Palliative Care Australia



PalliativeCare
AUSTRALIA

1. About Palliative Care Australia

Palliative Care Australia (PCA) is the national peak body for palliative care. PCA represents those who work towards high quality palliative care for all Australians who need it.

PCA Purpose

PCA leads a united voice to strengthen our collective impact towards excellence in palliative care.

Vision

We see a world where quality palliative care is available for all, when and where it is needed.

2. Introduction

PCA welcomes the opportunity to make a submission on the *National Dementia Action Plan consultation* and commends the development of the National Dementia Action Plan (the Dementia Action Plan).

PCA advocates for holistic, person-centred palliative care to be made available to all people diagnosed with dementia – from the time of diagnosis. In 2021, dementia, including Alzheimer's disease, was the second leading cause of death in Australia.¹ This highlights the need for people's palliative care needs to be explicitly considered and supported in the Dementia Action Plan.

PCA would be pleased to provide additional input into the Dementia Action Plan and the development of any actions, supporting documentation or guidelines for the Dementia Action Plan.

PCA also supports the sector's call for funding to deliver the Dementia Action Plan, once in place.

3. Background

Definition of Palliative Care

PCA uses the definition of palliative care outlined in the *National Palliative Care Strategy 2018* (signed by the Australian Government and all State and Territory governments). It is based on a definition first outlined by the World Health Organization (WHO).

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

The [*National Palliative Care Strategy 2018*](#) provides that palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death

¹ Australian Bureau of Statistics: [Causes of Death, Australia, 2021 | Australian Bureau of Statistics \(abs.gov.au\)](#), accessed 26 January 2023.

- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.²

4. The *National Palliative Care Standards*

The [*PCA National Palliative Care Standards*](#)³ and [*National Palliative Care Standards for All Health Professionals and Aged Care Services*](#)⁴ (collectively, the *PCA Standards*) have been developed with the aim of supporting better experiences and outcomes for people receiving palliative care.

The PCA Standards are generally normative standards but also incorporate aspirational components to support providers and services seeking to enhance capability and achieve best practice. PCA encourages consideration of the PCA Standards in all aspects of healthcare.

The PCA Standards provide expectations with respect to the following:

Comprehensive assessment of need

Initial and ongoing assessment comprehensively incorporates the person's physical, psychological, cultural, social and spiritual experiences and needs.

Developing a comprehensive care plan

The person, their family and carers and substitute decision-maker(s) work in partnership with multidisciplinary teams to communicate, plan, set goals of care and support informed decisions about the comprehensive care plan.

Caring for carers

The needs and preferences of the person's family, carers and substitute decision-maker(s) are assessed, and directly inform provision of appropriate support and guidance.

Provision of care

The provision of care is based on the assessed needs of the person, informed by evidence, and is consistent with the values, goals and preferences of the person as documented in their care plan.

² Definition of Palliative Care in [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#), based on World Health Organization, 2017.

³ <https://palliativecare.org.au/publication/standards>.

⁴ <https://palliativecare.org.au/publication/national-palliative-care-standards-for-all-health-professionals-and-aged-care-services>.

Transition within and between services

Care is integrated across the person's experience to ensure seamless transitions within and between services.

Grief support

Families and carers have access to grief support services and are provided with information about loss and grief.

Service culture

The service has a philosophy, strategy, value, cultures, structure and environment that supports the delivery of person and family-centred palliative care.

Quality improvement

Services are engaged in quality improvement and research, based on best practice and evidence, to improve service provision and development.

Staff qualifications and training

Staff and volunteers are appropriately qualified, are engaged in continuing professional development and are supported in their roles.

Application of PCA Standards to Quality Standards

As dementia is a leading cause of death in Australia, PCA recommends reference to the PCA Standards in the Dementia Action Plan. The PCA Standards provide valuable guidance on the provision of optimal care and support - which should be available to people and their families from the time of diagnosis.

The PCA Standards are highly regarded internationally for articulating best practice palliative care. PCA commends its Palliative Care Standards as a resource to reflect on and improve the delivery of palliative care, and therefore, dementia care.

PCA would be pleased to assist with collaborating on inclusion of the elements of the PCA Standards in the Dementia Action Plan, or any additional supporting documentation.

5. Palliative Care and Dementia

PCA is supportive of the development of a Dementia Action Plan that puts the person, their family and loved ones at the centre of the approach. This is also consistent with the [National Palliative Care Strategy 2018](#).⁵

A recent study noted that care should be needs-based, and adopt a palliative approach tailored for dementia that encompasses physical, medical and psychosocial needs.⁶ This approach also includes planning and coordination of care that involves family and considers a person's advance care directive or plan, their culture, language, spiritual beliefs and practices.

⁵ Australian Government (2018) [The National Palliative Care Strategy 2018](#), page 6, accessed on 31 January 2023.

⁶ Browne B, Kupeli N, Moore KJ, Sampson EL, Davies N. Defining end of life in dementia: A systematic review. *Palliative Medicine*. 2021;35(10):1733-1746. doi:10.1177/02692163211025457, accessed on 26 January 2023.

Consistent with the WHO definition of ‘palliative care’, PCA notes that there are also international examples of dementia plans and strategies that reference the value of palliative care from the time of a dementia diagnosis.

Relevantly, the White Paper expert consensus of the European Association of Palliative Care, recommends that optimal palliative care should be provided across all stages of dementia and that timely recognition of end of life remains a research priority to enable appropriate palliative care.⁷

By way of example, Canada’s *Dementia Strategy* provides that palliative care can begin at the time of a dementia diagnosis and aims to reduce suffering and improve quality of life through pain and symptom management, psychological, social, emotional, spiritual and practical support, as well as support for caregivers throughout the trajectory of the condition, including after death. It focuses on comfort, respect, and dignity and complements other therapies intended to prolong life.⁸

PCA recommends that the Dementia Action Plan explicitly provides for palliative care to be available from the time of diagnosis of dementia. This includes providing holistic and person-centered care and support for the person, their family and loved ones.

We also note that the Dementia Action Plan is intended to be consistent with the World Health Organization’s (WHO) Global Action Plan on the public health response to dementia 2017-2025.⁹ It is crucial to note that the WHO Global Action Plan provides:

*Palliative care is a core component of the continuum of care for people living with dementia from the point of diagnosis through to the end of life and into the bereavement stages for families and carers. It provides physical, psychosocial and spiritual support for people with dementia and their carers including support with advance care planning.*¹⁰

The lack of a palliative approach for people living with dementia can result in poor management of symptoms toward the end of life, especially pain, which has been linked to reduced quality of life, depression, increased agitation and other behavioural and psychological symptoms.¹¹ This is particularly important as those living with dementia may have decreasing ability to articulate or identify their symptoms, including pain. Consequently, assessment of symptoms must be undertaken frequently, and by employing a range of clinical assessment methods.

Dementia prevalence is expected to continue to rise as a result of Australia’s ageing population over the next 40 years. It is expected to become the leading cause of death in coming years.¹² This highlights the need for quality palliative care to be available to those living with dementia.

In addition to the medical and personal reasons for integrating palliative care into all aspects of dementia care, there is also strong economic evidence to support investing in palliative care. Investing in palliative care can deliver a return on investment in the form of reduced unnecessary and costly end of life emergency department visits and transport, hospital stays and intensive care

⁷ van der Steen JT, Radbruch L, Hertogh CPM, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care, *Palliative Medicine* 2014; 28(3): 197–209, accessed on 26 January 2023.

⁸ [A Dementia Strategy for Canada: Together We Aspire](#), 2019, page 36, accessed on 25 January 2023.

⁹ Department of Health & Aged Care, National Dementia Action Plan Consultation Paper, 2022, page 6.

¹⁰ World Health Organization, [Global action plan on the public health response to dementia 2017 - 2025 \(globaldementia.org\)](#), page 22, accessed on 25 January 2023.

¹¹ [A Dementia Strategy for Canada: Together We Aspire](#), 2019, page 36, accessed on 25 January 2023.

¹² The Commonwealth of Australia (2021), [2021 Intergenerational Report \(treasury.gov.au\)](#), accessed 26 January 2022.

unit admissions.¹³ KPMG estimates that a \$1.00 investment in home and community based palliative care can return between \$0.53 and \$1.56.¹⁴ Investing in palliative care makes good economic sense.

All aspects of the provision of dementia care, including primary care, respite care, in-home care and residential care must have the flexibility to support quality, timely and person-centred palliative care, irrespective of the location or level of need. Further, access to palliative care is a human right and is recognised by the United Nations.¹⁵

PCA recommends that the importance of quality palliative care from the time of diagnosis of dementia is recognised and reflected in the Dementia Action Plan.

Vision

PCA supports a vision for the Dementia Action Plan that supports people living with dementia, their carers, families and loved ones having the best quality of life possible. This is consistent with the principles of delivering quality palliative care in the PCA Standards and the [National Palliative Care Strategy 2018](#).

Principles

PCA supports a Dementia Action Plan that is person-centred and focused on quality of life for people living with dementia, their carers and families.

PCA supports an inclusive and accessible Dementia Action Plan that can be applied to support all people, including priority population groups and people from diverse backgrounds. PCA recommends that this also includes the need to support those living in rural and remote areas where services may be limited and/or more difficult to access.

PCA recommends that the second-last dot point of the principles (page 13) could provide (additional text provided in **bold font**):

- evidence based, **needs directed** and outcomes focused.

PCA notes that all actions should be capable of being responsive to changes in care needs, particularly rapid and unexpected deterioration. We recommend that **responsiveness** is integrated into the Principles in the following way (additional text provided in **bold font**):

- Coordinated, integrated, planned and **responsive to needs**

With respect to the image provided on page 14, while PCA welcomes the inclusion of palliative care in focus area 4.3, we suggest that palliative care is provided as either a separate point to end-of-life care, or is provided as follows:

4.3 Palliative care – including end-of-life care.

¹³ KPMG (2020), Investing to Save – The economics of increased investment in palliative care in Australia, page6, commissioned by PCA, www.palliativecare.org, page 4.

¹⁴ KPMG (2020), Investing to save, page 36.

¹⁵ United Nations Committee on Economic, Social and Cultural Rights. *General Comment No. 14: The right to the highest attainable standard of health*. Office of the High Commissioner of Human Rights. Contained in Document E/C.12/200/4/11. 2000. Retrieved from: <http://www.refworld.org/pdfid/4538838d0.pdf>, accessed 26 January 2023.

Objectives

PCA recommends that all objectives of the Dementia Action Plan include reference to the availability of palliative care at all times, and specify what palliative care can do to support people, their families and loved ones. This applies to all Objectives in the Dementia Action Plan.

Objective 3 - Improving dementia diagnosis and post-diagnostic care

PCA suggests that this Objective include reference to support for families and loved ones on page 29. Consistent with the [National Palliative Care Strategy 2018](#), supporting the family and loved ones has an overall beneficial impact for the community as well as supporting the person living with dementia.

Objective 3 references getting effective, immediate post-diagnostic support (page 34). Consistent with the definition of palliative care, palliative care can support the person and their family/loved ones from the time of diagnosis and can continue after death. People can request palliative care, at any time, from diagnosis.¹⁶ PCA suggests that this support, from the time of diagnosis, is included in the Dementia Action Plan.

With respect to Objective 3.3: Post diagnostic care and support (page 37), this proposes a roll out of dementia care coordinators. PCA recommends that the coordinators are well-connected with palliative care services. This would provide access to the most comprehensive multi-disciplinary care for the person.

PCA would be very happy to harness its networks and members to assist with the development of these connections.

Objective 4 – Improving treatment, coordination and support along the dementia journey

As previously noted, palliative care is available from diagnosis and is not limited to end-of-life care. PCA recommends that the final dot point on page 38 references the availability of palliative care from the time of diagnosis to support the best quality of life, as well as enabling the person to die in comfort and with dignity. These comments also apply to the figure on page 39 and the section on *End of life and palliative care* for people living with dementia on page 41.

PCA welcomes the inclusion of the PCA website and the resources available to support people's journeys and decision-making.

PCA supports the inclusion of service provision for young people and children living with dementia. PCA's [paediatric palliative care website](#) has been co-designed with health care professionals, support organisations, and families to provide quality information, and resources about paediatric palliative care, as well as access to PCA's National Service Directory.

PCA recommends this website is referenced in the Dementia Action Plan as a valuable resource to support children and young people living with dementia.

Regarding 4.3: End of life and palliative care (page 47), PCA reiterates its view that palliative care should be available from the time of diagnosis. PCA would be pleased to assist with further developing this part of the Dementia Action Plan.

¹⁶ See: [How to get palliative care | Australian Government Department of Health and Aged Care](#), accessed on 26 January 2023.

PCA would be pleased to help explore options for dementia-specific palliative care services. PCA is uniquely placed, with its [National Services Directory](#), extensive national networks and clinical and consumer panels to contribute to this valuable work.

PCA also supports the longer-term plan to increase community-based palliative care options and would be pleased to assist with informing this work.

Objective 5: Supporting people caring for those living with dementia

PCA welcomes the proposed focus area: *5.1 Recognising carers and assisting carers in their roles* and the associated proposed actions. PCA recommends the inclusion of palliative care services, including access to allied health services and support, to support family members and loved ones. This is consistent with the PCA Standards.

Objective 6: Building dementia capability in the workforce

PCA welcomes the focus on building capability in the workforce and acknowledges the importance of various measures and training in supporting the workforce.

PCA notes that End of Life Directions for Aged Care (ELDAC) has a range of resources to assist with developing dementia capability: see [Clinical Care - Dementia \(eldac.com.au\)](#). The ELDAC homecare App may also be of useful for the home care workforce: [Home Care App Project - Technology and Innovation \(eldac.com.au\)](#). We suggest there may be value in including these sites in the Dementia Action Plan.

PCA also supports compulsory training in palliative care for all undergraduate health and medical courses.

Objective 7 – Improving dementia data and maximizing the impact of dementia research and innovation

PCA supports the development of data collections to provide an evidence-basis for decision-making and investment in services. PCA also notes that the collection of data relating to palliative care services and referrals (for all health professionals as well as specialist palliative care) may also enhance the broader picture of dementia care.

We also note that current palliative care-related data holdings and reports are held by the [Australian Institute of Health & Welfare](#) and the [Palliative Care Outcomes Collaboration](#) and there may be value in exploring these further to inform this work.

Please contact policy@palliativecare.org.au if you wish to discuss this submission or PCA's contribution to this important work.