REVISED AGED CARE QUALITY STANDARDS CONSULTATION

Submission from Palliative Care Australia

NOVEMBER 2022

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. Background

PCA welcomes the opportunity to make a submission on the *Revised Aged Care Quality Standards consultation.*

Those with palliative care needs have specific additional care needs. It is critical that these needs are considered and supported in the revised Aged Care Quality Standards (Quality Standards).

Most importantly, PCA supports a human rights approach that enables people's preferences for palliative care when and where it is needed.

PCA would be pleased to provide additional input into the development of any supporting documentation or guidelines for the Quality Standards.

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.

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
- 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.[1]

3. Summary of key points

- PCA commends the Government for a comprehensive consultation draft of the Quality Standards. PCA congratulates the Government on the inclusion of specialist palliative care in Standard 5. However, PCA seeks to ensure the palliative care approach becomes core business in aged care. Consistent with the Royal Commission into Aged Care Quality and Safety's (the Royal Commission) recommendations, PCA advocates for the inclusion of palliative care in the Quality Standards. This should be based on the WHO definition of palliative care in the Quality Standards:

  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.

- PCA is keen to ensure that the WHO definition of palliative care (i.e. not just care at end of life) is appropriately reflected in the final Quality Standards as per the *National Palliative Care Strategy 2018*.

- PCA would be pleased to provide additional input into the development of any supporting documentation or guidelines for the Quality Standards.

- PCA recommends that all elements of the Quality Standards are consistent with the provision of quality palliative care provided in the PCA National Palliative Care Standards. PCA commends its National Palliative Care Standards to aged care services as a resource to reflect on and improve the delivery of palliative care. The PCA Standards are highly regarded internationally for articulating best practice palliative care. PCA would be pleased to assist with collaborating on any supporting or guidance documentation on the Quality Standards and/or palliative care to support the delivery of holistic palliative care that promotes quality of life.

- In particular, PCA makes specific recommendations for the inclusion of palliative care considerations in the Quality Standards these relate to: the standard of care a person can expect, palliative care training for aged care staff, and provider systems and processes to support palliative care needs.

- PCA advocates that the Quality Standards incorporate the requirement for flexibility and adjustment to address rapidly changing needs, particularly unpredictable and rapid deterioration.

[1] Definition of Palliative Care in The National Palliative Care Strategy 2018 | Australian Government Department of Health Based on World Health Organization, 2017.

4. The *National Palliative Care Standards*

The PCA *National Palliative Care Standards*[2] and *National Palliative Care Standards for All Health Professionals and Aged Care Services*[3] (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.

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.

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[2] https://palliativecare.org.au/publication/standards.

[3] https://palliativecare.org.au/publication/national-palliative-care-standards-for-all-health-professionals-and-aged-care-services.

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

PCA recommends that services seeking to improve the delivery of palliative care in their service, could use as a resource/reference or guide, PCA's Standards to assist them in their endeavours. all elements of the Quality Standards are consistent with the provision of quality palliative care provided in the PCA Standards.

PCA commends its National Palliative Care Standards to aged care services as a resource to reflect on and improve the delivery of palliative care. The PCA Standards are highly regarded internationally for articulating best practice palliative care. PCA would be pleased to assist with collaborating on any supporting or guidance documentation on the Quality Standards including incorporating reference to the PCA Standards to support the delivery of holistic palliative care that promotes quality of life.

5. Palliative Care in Aged Care

As Australia's population ages, the number of people requiring and using aged care services will further increase, as will the demand for palliative care in all aged care settings. The Royal Commission's final report acknowledges that too few people in aged care receive evidence-based end of life and palliative care. Many people instead experience unnecessary pain, untreated symptoms or indignity in their final days, weeks and months. The Royal Commission recognised the significant role palliative care must have in aged care:

> *'Palliative and end-of-life care, like dementia care, should be considered core business for aged care providers. People at the end of their lives should be treated with care and respect. Their pain must be minimised, their dignity maintained, and their wishes respected. Their families should be supported and informed.'*[4]

The Royal Commission made a number of recommendations to ensure high quality palliative care becomes core business for aged care services. The Government response to the recommendation of the Royal Commission provided support for training in palliative care for aged care workers and advised it would consider appropriate regulatory levers to ensure staff are appropriately trained, as part of the review of the Quality Standards.[5]

There is strong economic evidence to support investing in expanding palliative care in aged care,[6] which can deliver a return on investment[7] in the form of reduced unnecessary and costly end of life emergency department visits and transport, hospital stays and intensive care unit admissions.[8]KPMG

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[4] Royal Commission into Aged Care Quality and Safety (2021), Final Report: Care, *Dignity and Respect, Volume1 Summary and Recommendations*, pg. 94. Retrieved from: https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1_0.pdf

[5] *Australian Government response to the final report of the Royal Commission into Aged Care Quality and Safety,* recommendations 78 and 80, retrieved from: Australian Government response to the final report of the Royal Commission into Aged Care Quality and Safety | Australian Government Department of Health and Aged Care.

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

[7] KPMG (2020), *Investing to Save,* page 4.

[8] KPMG (2020), *Investing to Save,* page 4.

estimates that a $1.00 investment in home and community based palliative care can return between $0.53 and $1.56.[9] Investing in palliative care makes good economic sense.

The Australian Institute of Health & Welfare (AIHW) recently reported that in the five years to 2020, palliative care-related hospitalisations increased by 18%, a steeper rate than that for hospitalisations for all reasons (6%) over the same period.[10]

All aspects of the provision of aged care programs, including respite care, in-home care and residential aged 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 as recognised by the United Nations.[11] This includes the availability of palliative care after hours where people commonly need support for symptom control.

6. Revised Aged Care Quality Standards

PCA welcomes the revised person-centred, rights-based and trauma–informed Quality Standards.

PCA is very pleased to note the inclusion of specialist palliative care in the Quality Standards. We note, however, that this only goes part-way to addressing the recommendations of the Royal Commission. Below, we discuss the need to include additional references to palliative care in the revised Quality Standards to support the recommendations made by the Royal Commission relating to embedding palliative care in aged care.

Significantly, PCA is of the view that palliative care is far broader than providing clinical care at the end of life. This is consistent with the WHO definition and the *National Palliative Care Strategy 2018,* which has been agreed by Commonwealth, State and Territory governments.

Quality palliative care adopts a holistic approach that includes contributions from allied health professionals, general practice and specialist doctors, nurses and personal care workers. PCA welcomes the person-centred approach and advocates for palliative care to be integrated into all aspects of the Quality Standards, so that holistic, person-centred care is consistently provide to all people. PCA promotes palliative care that includes individualised care and responsive medical care, but also includes bereavement care for family and carers, spiritual care, psychological care, and acknowledges the impact of other social elements that impact on the quality of life of the individual.

Palliative care must be available to all who need it, in all settings. Palliative Care is about supporting quality of life – all people are entitled to the best quality of life possible at any age.

Suggested amendments to the revised Quality Standards

The following suggestions are premised on embedding palliative care in aged care and are consistent with the recommendations of the Royal Commission.

Standard 1 - The Person

PCA welcomes the person-centred focus of the revised Quality Standards. In the context that palliative care should be embedded in aged care, PCA recommends that the Quality Standards

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[9] KPMG (2020), Investing to save, page 36.

[10] AIHW: Palliative care services in Australia, About - Australian Institute of Health and Welfare (aihw.gov.au)

[11] 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.

include acknowledgement that, along with recognising diversity in background, older people may be living with life-limiting illnesses and have palliative care needs.

On this basis, PCA recommends that the *Intent of Standard 1,* paragraph three is amended to include reference to ***'people with palliative care needs.'***

PCA also recommends that the Notes for Standard 1, Outcome 1.1, dot point five, which references specific needs and those with diverse backgrounds, also include reference to people with palliative care needs or living with life-limiting conditions.

Standard 2 – The Organisation
Outcome 2.2 - Quality and safety culture
Consistent with the above recommendations, PCA recommends that Outcome 2.2, under Actions, be amended to include care for people with palliative care needs. We suggest the addition ***in bold italics***, below:

> 2.2.2.(b) – ensures that care and services are accessible to, and appropriate for, people with specific needs and diverse backgrounds, Aboriginal and Torres Strait Islander people, people living with dementia ***and people with palliative care needs.***

This addition should also be reflected in the corresponding *Notes* for *Outcome 2.2*.

Outcome 2.9: Human Resource Management
Consistent with the recommendations of the Royal Commission, PCA recommends that all aged care workers should be regularly trained in palliative care.

PCA suggests that this can be achieved by varying 2.9.6 to include either:

> ***(c) caring for people living with dementia and/or palliative care needs***
>
> *OR*
>
> *add a new sub-paragraph:*
>
> ***(d) providing palliative care.***

There are numerous existing options for providers looking to train staff in palliative care, including online tools and resources. These include:

- Program of Experience in Palliative Approach (PEPA) aims to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements in specialist palliative care services or interactive workshops.
- Indigenous Program of Experience in Palliative Approach (IPEPA). This is a grassroots approach to breaking down the barriers to palliative care for Aboriginal and Torres Strait Islander peoples across Australia.
- End of Life Directions for Aged Care (ELDAC) provides information, guidance, and resources to health professionals and aged care workers to support palliative care and advance care planning to improve the care of older Australians.

Standard 3 - The Care and Services

PCA welcomes Standard 3 describing the way providers must deliver individually tailored care and services. In the context of palliative care being person-centred and supporting quality of life, we recommend that the Standard 3 expectation statement: ***The care and services I receive,*** includes the following dot point:

- **Is responsive to changes in my needs or preferences.**

This inclusion is important as people's needs may change or deteriorate rapidly. Responsiveness to changing needs would support not only best practice palliative care but a range of other aspects of care that may need to change.

PCA would be pleased to assist the Department with input into any supporting documentation or guidelines on this Standard.

Outcome 3.2 Delivery of care and services

PCA recommends that this Outcome include reference to palliative care, by incorporating an additional Action:

3.2.8 The provider implements a system for caring for people with palliative care needs.

PCA advocates that the Quality Standards incorporate the requirement for flexibility and adjustment to address rapidly changing needs, particularly unpredictable and rapid deterioration.

Providers will need to have processes in place to ensure more frequent assessment where necessary, to track and manage both rapid and gradual deterioration. This may include working with families and other informal carers, as they are often well-placed to identify changes in someone's condition.

Standard 5 – Clinical Care

PCA welcomes the inclusion of specialist palliative care in the Quality Standards and is of the view that the actions provided in Outcome 5.5 should address the needs of a person at or near end of life.

However, we note that quality palliative care is not confined to clinical care or restricted to end of life care. We recommend that the definition of palliative care adopted in the *National Palliative Care Strategy 2018* be adopted in the Quality Standards.

To this end, PCA recommends that Outcome 5.5 be amended to: **'Clinical palliative and end of life care'.**

PCA suggests the following additional requirements be included in any supporting or guidance documentation to support holistic care:

- The person, family and carers must be informed of the diagnosis and prognosis to help them prepare for the fact they are about to enter the end of life phase
- The person, family and carers should be informed of symptoms they/their loved one might experience and reassured that symptoms will be treated with medication or other appropriate intervention to keep the person comfortable
- Symptom management should also be about anticipating symptoms that might arise and having measures in place to ensure such symptoms are managed when they arise. For

example: having a supply of medications to treat the commonly experienced symptoms at or near end of life

- Frequent assessment to ensure changes in symptoms are identified and addressed to, if appropriate
- Assessment methods must provide relevant information about the person's level of comfort, regardless of their level of consciousness or ability to communicate.

Time period for the provision of palliative care

PCA notes that the AN-ACC funding model provides for a person to be assessed as palliative if they have a terminal diagnosis of less than three months. This definition is not consistent with clinical best practice regarding the provision of palliative care, which should begin upon diagnosis of a life-limiting condition.

PCA would be very concerned if the Quality Standards only supported a three-month period for the provision of palliative care. We also note that this would be inconsistent with the WHO definition of palliative care, the *National Palliative Care Strategy 2018* and consensus across the palliative care sector.

We also note data from the Australian Institute of Health & Welfare (AIHW) that highlights the substantial number of people with palliative care needs that last well beyond three months. In 2020–21, among people entering permanent residential aged care who were assessed as requiring palliative care under the former Aged Care Funding Instrument, approximately one-third lived in a residential aged care facility for a year or more, and approximately one-fifth for more than 2 years.[12]

Based on this data, it is clear that there are significant variations in how long aged care residents require palliative care. PCA therefore reiterates its recommendation that the WHO definition of palliative care is applied in the Quality Standards to ensure palliative care is available for all who need it.

PCA would be pleased to assist with additional information on how this definition can be accommodated in the Quality Standards, or any supporting documentation or guidelines.

Standard 7 – The Residential Community

PCA welcomes and supports the inclusion of the essential element requirement of 'continuity of care' for those who move into residential care. In particular, for those with a life-limiting illness, continuity of care is vital to support the person's quality of life.

Workforce and models

The Quality Standards need to include flexibility for providers of aged care services to adjust for workforce issues, within reason and with all care needs met, and not be punitive. In particular, PCA notes the issues and challenges relating to obtaining specialist medical support in regional and remote areas.

[12] AIHW data: Palliative care services Glossary - Australian Institute of Health and Welfare (aihw.gov.au): 1 in 2 exited permanent residential aged care within 8 weeks of admission; 32% within 4 weeks; 50% within 8 weeks; 69% within one year, and 21% after 2 years. For those appraised as requiring other care, 2 in 3 exited after 1 year – 32% within 1–3 years and 34% after 3 years, while less than 9% exited within 8 weeks.