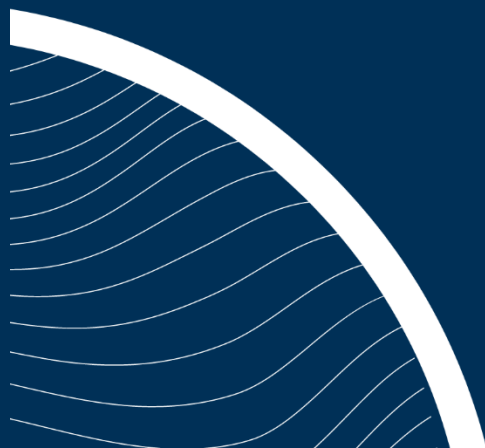


INDEPENDENT HEALTH AND AGED CARE PRICING AUTHORITY - TOWARDS AN AGED CARE PRICING FRAMEWORK

Submission

OCTOBER 2022



PalliativeCare
AUSTRALIA

Summary

- 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 welcomes the opportunity to make a submission on *the Towards an Aged Care Pricing Framework* Consultation, and supports IHACPA's commitment to annual public consultation and regular engagement with stakeholders. PCA would be pleased to support any future consultation processes.
- PCA is of the view that all aspects of the provision of aged care, including the pricing framework for residential aged care and residential respite care, must have the flexibility to support quality, timely and person-centred palliative care.
- The PCA [National Palliative Care Standards](#)¹ and [National Palliative Care Standards for All Health Professionals and Aged Care Services](#)² (collectively, the *PCA Standards*) have been developed with the aim of supporting better experiences and outcomes for people receiving palliative care. We encourage IHACPA to consider the PCA Standards for both specialists and all health professionals to inform the level of care and funding required to provide quality palliative care in residential aged care.
- PCA advocates that the national price and associated weights must be sufficient to deliver best practice palliative care in all reasonably foreseeable scenarios, including people whose health deteriorates rapidly and those whose diagnoses are terminal but whose functioning declines over a long period. This would align with the principles of the PCA Standards, the Aged Care Quality Standards and the human right to health.
- Noting the scope of the consultation is about the pricing framework, we remain concerned about the definition in AN-ACC that someone assessed as palliative must have a terminal diagnosis of less than three months. This definition is not consistent with clinical best practice regarding the provision of palliative care.
- With respect to the classification system, PCA is concerned about the flexibility of the funding provided for each class and the ability to respond quickly to an individual's rapidly changing care needs.
- PCA recommends a number of additional medical adjustments be included in the model and notes the pricing model should include funding for specialist palliative care, allied health care, rehabilitation, mental health support and /or grief and bereavement support for carers.
- With respect to respite care, PCA notes that the pricing model needs to accommodate the continuity of support for people receiving palliative care, so that carers can be confident to take up the option of respite.

¹ <https://palliativecare.org.au/publication/standards>.

² <https://palliativecare.org.au/publication/national-palliative-care-standards-for-all-health-professionals-and-aged-care-services>.

2. 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.

3. Background

PCA welcomes the opportunity to make a submission on the *Towards an Aged Care Pricing Framework Consultation*.

Those with palliative care needs have specific additional care needs. It is critical that these needs are reflected in the pricing framework for residential aged care.

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* 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.³

³ Definition of Palliative Care in [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#) Based on World Health Organization, 2017.

From this perspective, it is important to factor in the full costs of all aspects of palliative care in the pricing framework.

4. Palliative care in residential aged care

Over one third of all deaths in Australia occur in residential aged care facilities.⁴ However, only one in 50 residents of an aged care facility received palliative care under the former Aged Care Funding instrument.⁵

As Australia's population ages, the number of people using aged care services will further increase, as will the demand for palliative care in both community and residential aged care. The Royal Commission into Aged Care Quality and Safety's (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.'*⁶

The Royal Commission made a number of recommendations to ensure high quality palliative care becomes core business for aged care services.

There is economic evidence to support investing in expanding palliative care in aged care,⁷ which can even deliver returns on investment⁸ – in the form of reduced unnecessary and costly end-of-life emergency department visits and transport, hospital stays and intensive care unit admissions.⁹

Unfortunately, given many people in residential aged care do not receive quality palliative care, costings formulated on the basis of current residential aged care service models may deviate substantially from what is required to deliver best-practice palliative care.

PCA is of the view that all aspects of the provision of aged care, including the pricing framework for residential aged care and residential respite care, must have the flexibility to support quality, timely and person-centred palliative care.

⁴Australian Institute of Health and Welfare (June 2021) [Interfaces between the aged care and health systems in Australia—where do older Australians die?](https://www.aihw.gov.au/reports/aged-care/interfaces-between-the-aged-care-and-health-systems-in-australia-where-do-older-australians-die/), www.aihw.gov.au.

⁵ KPMG (2020), *Investing to Save – The economics of increased investment in palliative care in Australia*, page 4, commissioned by PCA, www.palliativecare.org.au

⁶ Royal Commission into Aged Care Quality and Safety (2021), *Final Report: Care, Dignity and Respect, Volume 1 Summary and Recommendations*, pg. 94. Retrieved from:

https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-1_0.pdf

⁷ KPMG (2020), *Investing to Save*, page 6.

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

⁹ KPMG (2020), *Investing to Save*, page 4.

5. The National Palliative Care Standards

The [PCA National Palliative Care Standards](https://palliativecare.org.au/publication/standards)¹⁰ and [National Palliative Care Standards for All Health Professionals and Aged Care Services](https://palliativecare.org.au/publication/national-palliative-care-standards-for-all-health-professionals-and-aged-care-services)¹¹ (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. 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.

Staff qualifications and training

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

¹⁰ <https://palliativecare.org.au/publication/standards>.

¹¹ <https://palliativecare.org.au/publication/national-palliative-care-standards-for-all-health-professionals-and-aged-care-services>.

We encourage IHACPA to consider the PCA Standards for both specialists and all health professionals to inform the level of care and funding required to provide quality palliative care in residential aged care. Proper adherence to the PCA *National Palliative Care Standards for All Health Professionals and Aged Care Services* would require levels of care and coordination, including with respect to external services, that may not be sufficiently captured in current pricing models or the new pricing framework. We encourage IHACPA to collect data at sufficient granularity to better understand the full range of cost drivers for palliative care in residential aged care, including essential services that are met by external health and non-health providers.

6. Principles for activity-based funding in residential aged care

Broad comments

PCA welcomes IHACPA's principles-based approach to funding residential aged care.

We suggest, however, that the Overarching Principle relating to **Access to care** be adjusted to include reference to 'timely access to care', rather than care that is 'not unduly delayed'. Our concern is that care that is 'not unduly delayed' is not a sufficient measure for access to care. At a minimum, care must be responsive and timely to ensure individuals are not in pain, discomfort or distress. This must be a priority for all healthcare.

The Australian Government has recognised that every person is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity.¹² This right must be considered in the context of any health reform, including aged care services.¹³ The principles must provide an explicit person-centred approach to ensure all levels of care are appropriate. In our view, 'not unduly delayed' is not consistent with this human right.

Further, as the Government will be adopting a human rights-based approach to the new *Aged Care Act*, we recommend that this approach is also adopted across all aged care reform to ensure harmonisation and adherence to appropriate levels of care.

With respect to the Overarching Principle relating to **Quality of Care**, we suggest that this principle include reference to taking a 'person-centred approach'. Adopting a person-centred approach is crucial in all health care settings and makes care safer and of a higher quality.¹⁴ Including reference to a person-centred approach in the Quality of Care principle will ensure that the funding principles are clearly linked to the new Aged Care Quality Standards (currently under consultation), but also stand alone.

Cost-based and best-practice approaches to pricing

PCA is reassured by IHACPA's acknowledgement of the risks associated with a purely 'cost-based' pricing model. However, consistent with our previous comments about the connection the PCA Standards, the Aged Care Quality Standards and the human right to health, PCA advocates that the national price and associated weights are sufficient to deliver best practice in all reasonably foreseeable scenarios.

¹² [Right to health | Attorney-General's Department \(ag.gov.au\)](#).

¹³ [Right to health | Attorney-General's Department \(ag.gov.au\)](#).

¹⁴ Australian Commission on Safety and Quality in Healthcare (2011), *patient-centered care: Improving quality and safety through partnerships with patients and consumers*, www.safetyandquality.gov.au.

Assessments and Classifications

We note that the pricing framework consultation document builds on a large body of work, including multiple studies to inform the development of the AN-ACC. While this consultation is not directly about the AN-ACC, but instead the pricing framework, we remain concerned about the definition in AN-ACC that someone assessed as palliative must have a terminal diagnosis of less than three months. This definition is not consistent with clinical best practice regarding the provision of palliative care, particularly for people with conditions such as dementia, where functional decline may extend over many years, whose ultimate prognosis is terminal, and who is likely to benefit from the provision of palliative care well before the notional three-month cut-off. This is an issue PCA is keen to explore further with IHACPA and other policy-makers.

Beyond this critical issue, PCA's primary concerns relate to the flexibility of the funding for the classes and the ability to respond quickly to an individual's rapidly changing care needs.

One particular concern we have is ensuring adequate funding is available for residents whose condition deteriorates very quickly, including those who may not survive until they are able to be assessed as requiring palliative care. It is not clear that in this circumstance the pricing framework would attract appropriate or sufficient funding to support providers to deliver responsive and patient-centred palliative care.

Feedback from a large residential care provider (which, notably, has invested significantly to improve access to quality palliative care) identified concerns regarding situations where a permanent resident (classed as 11, 12,13) becomes palliative and may pass away, before a reclassification is made by the external assessor, with funding not back-dated. This provider suggests that a possible solution would be implementing a process similar to a person entering care, where an independent doctor/nurse signs off on a resident being re-classified as requiring palliative care. Whether or not this particular solution is favoured, it is important the funding model is sufficiently flexible to support rapid re-assessment and the delivery of the full suite of palliative care services required in different circumstances.

Adjustments and additional factors

We recommend IHACPA consider the following additional factors for the provision of quality palliative care:

- Complex medication regimens including the need to manage syringe drivers
- Complex psychosocial needs, including, but not limited to family conflict, anticipatory grief and mood disorders associated with palliative diagnosis
- Complex clinical needs, such as Percutaneous Endoscopic Gastrostomy (PEG) tubes, fungating wounds, respiratory support (i.e., Continuous Positive Airway Pressure (CPAP) for motor neurone disease patients)
- Complex symptoms, such as neuropathic pain, breathlessness and confusion
- Rapid deterioration and changing needs.

The pricing model should align with the PCA Standards for the provision of quality palliative care, and include funding for specialist palliative care, allied health care, rehabilitation, mental health support and /or grief and bereavement support for carers.

With respect to respite care, we note that the pricing model needs to accommodate the provision of palliative care needs. Families and carers seeking respite for a person receiving palliative care need to know that their loved one's full palliative care needs will be met. Knowing that respite care will

fully accommodate all the individual's needs, such as disability and diverse needs or other complex needs, will enable the carer and volunteer community to continue their support – without placing additional unnecessary pressure on the residential aged care and hospital systems.

What does a good model of care look like?

Quality palliative care must be holistic and is comprised of a range of multidisciplinary services. For those in residential aged care it is important that they have access to the same range of community and inpatient-based services available to people residing in their own homes. In accordance with the PCA Standards, this includes access to appropriate and adequate levels of support from general practitioners, specialist palliative care, allied health care, rehabilitation, mental health support and grief and bereavement support on a needs-basis. The pricing model should incorporate the costs of these much-needed services.

We suggest consideration of the value of 'needs rounds' for residents with complex needs, in which a palliative care specialist meets with residential aged care providers to discuss residents who are at risk of dying and to put care plans in place.¹⁵ This in turn supports clinical decision making, education and training. We note that implementing specialist palliative care services and 'needs rounds' could provide a return on investment of \$1.68 to \$4.14,¹⁶ and could be considered as part of the pricing framework.

We note the value of data systems incorporating a broad range of palliative care quality measures and outcomes, not just access to or instances of palliative care treatment. We would be pleased to assist with future discussions on the collection of data over time to identify quality indicators and actions to overcome barriers to the provision of quality palliative care in residential aged care.

¹⁵ KPMG (2020), *Investing to Save*, Acknowledgements – Clare Holland House ACT 'Needs Rounds'.

¹⁶ KPMG (2020), *Investing to Save*, page 62.