



NATIONAL CONSENSUS STATEMENT

*Essential elements for safe and high-quality
end-of-life care*

Survey response from Palliative Care Australia

JANUARY 2023



PalliativeCare
AUSTRALIA



Please note: This published version is based on Palliative Care Australia's survey response submitted to the Australian Commission on Safety and Quality in Health Care.

Feedback on elements - is the content of each element relevant and applicable?

PCA welcomes the opportunity to comment on the revised *National Consensus Statement* - Essential elements for safe and high-quality end of life care.

PCA's provides comments on the revised National Consensus Statement in the context that the definition of 'Palliative Care' is that used in the Australian Government's *National Palliative Care Strategy 2018* (available at: www.safetyandquality.gov.au) and that palliative care should be available from the time of diagnosis of a life-limiting illness. Overall, PCA supports the provision of the highest quality and most comprehensive palliative care for those with life-limiting illness, where and when it is needed. In this context, PCA recommends that the revised National Consensus Statement refer to the provision and application of palliative care more broadly. PCA would be pleased to work with the Commission to address this issue.

Essential element 1: Recognising end of life

In recognition that palliative care should be available to those with a life-limiting illness, PCA recommends that Essential element 1 also include reference to non-specialist palliative care. That is, amend the following sentence (amendment provided in **bold** text):

Healthcare workers should be aware of the referral criteria, processes, and timelines for accessing specialist and **non-specialist** palliative care services.

Essential element 2: Person-centred communication and shared decision making

PCA welcomes the inclusion of person-centred communication and shared decision-making.

PCA suggests that the opening sentence could be replaced with:

Healthcare workers should **adopt a person-centred approach to communication and decision-making to assist the person to make** decisions about their care needs at the end of life.

PCA supports the element requiring health professionals to support the capacity of people to make decisions about their own lives and end of life. We also suggest that you consider whether there are options for health professionals to support **building capacity** to make decisions. In this respect, PCA suggests there is value in emphasising the importance of multidisciplinary teams including allied health professions to support capacity building and ensuring a multi-faceted approach to both building decision-making capacity and confirming the person has understood the plan of care.

We suggest that there is also value in referencing the need for health professionals across all specialities to be trained in palliative care and end-of-life care.

PCA is of the view that there is value in providing additional information about how a care coordinator or lead health professional will be identified and what their responsibilities will be. This comment is also relevant to Essential element 3.

Essential element 3: Multidisciplinary collaboration and coordination

We note that this Essential element provides that ‘an identified person’ should take overall responsibility for the coordination of care. This could be a family member, general practitioner, nurse navigator or someone else depending on the circumstances. PCA recommends that this list of individuals also include allied health professionals, as follows (suggested addition in **bold text**):

This could be a family member, general practitioner, nurse navigator, **allied health professional**, or someone else, depending on the circumstances.

Further, given the variation in responsibilities depending on the individual taking on this role, PCA recommends that additional information about how this individual should be identified or appointed should be provided. In addition, it is important to outline the responsibilities of the individual. In the absence of this information, there is a risk that this process will not be as easily applied to *all* settings, and may be more applicable to acute or subacute settings. For other settings, guidance on options and how this identification should be made could be very helpful and would support adoption of the National Consensus Statement.

Essential element 4: Comprehensive care

PCA requests the Commission further consider how ‘palliative care’ and a ‘palliative approach’ are referenced in Essential element 4. We note that, for the purposes of clarity, there may be value in distinguishing between broader palliative care and the provision of ‘Specialist Palliative Care’. We also note that palliative care should be available to those with a life-limiting illness at all times.

PCA recommends that the provision of bereavement and grief services should be included as part of comprehensive care. This may be incorporated in Essential element 4.12, as follows (suggested addition in **bold text**):

Liaise with other relevant services, **including grief and bereavement**, and provide referral, as necessary.

PCA also suggests that some specific examples of clinical pathways options of how to coordinate comprehensive care in non-acute services where a multidisciplinary team may not exist would assist with implementation of this element in all settings. Consideration should also be given to include some guidance on referral processes between health and other social support services, how, when, and on what (broad) criteria these transitions should be undertaken.

Should the Commission require additional examples and information on these issues, PCA would be pleased to support this work.

Essential element 6: Leadership, governance, and readiness

The inclusion of cultural diversity into the organisational element of the revised National Consensus Statement is commended by PCA. Ensuring that palliative care and end-of-life care are provided in a culturally safe and inclusive way is fundamental to quality care and a good death in our society.

PCA notes the reference to the ongoing learning for healthcare workers in Essential element 6. PCA recommends that the reference to training include a cross-reference to the provision of palliative care training for health professionals. In particular, we strongly recommend training that meets the specific needs of First Nations peoples, paediatrics and diverse groups, including LGBTIQ+ and culturally and linguistically diverse communities.

These training requirements could also be cross-referenced to the expanded information on training in Essential element 7.

Essential element 7: Support, education, and training

Consistent with the *National Palliative Care Strategy 2018*, Goal 2 (page 14), PCA recommends that Essential element 7 include specific reference to palliative care education and training.

To support this, there are numerous existing options for providers looking to train staff in palliative care, including online tools and resources. Some examples are:

- [Program of Experience in Palliative Approach](http://www.pepaeducation.com) (PEPA) (www.pepaeducation.com) 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 \(IPEPA\)](http://www.pepaeducation.com/about-ipepa/) (www.pepaeducation.com/about-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 \(ELDAC\)](http://www.eldac.com.au) (www.eldac.com.au) 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.
- CareSearch (www.caresearch.com.au) provides palliative care evidence and tools for health professionals and information about death and dying for the whole community.

PCA also recommends reference to the provision of *palliative care training* for health professionals in meeting the palliative care and end-of-life needs of diverse groups, including First Nations people, people living with disability, and paediatric cohorts. This would support the provision of timely and holistic care as the person approaches end of life.

Essential element 8: Care setting and bereavement support

PCA welcomes the inclusion of care setting and bereavement support, as it is a crucial part of palliative care. PCA also applauds the inclusion of reference to providing private physical spaces for people to engage with their loved ones, as this is an important feature of providing quality palliative care.

PCA recommends that Essential elements 8.5 and 8.6 explicitly reference that the policy and partnerships required for the provision of bereavement care needs may continue for periods long after a person has died.

Essential Element 9: Evaluation, audit and feedback

PCA supports measures to evaluate and improve the provision of palliative care and end-of-life care. We also note that there are a range of valuable resources available relating to the Palliative Care Outcomes Collaboration (PCOC) (www.uow.edu.au/ashri/pcoc/) which may also be useful to reference in this Essential element. PCOC aims to improve palliative care patient and carer outcomes. The PCOC website provides a range of quality improvement and audit tools which also may be of use in the context of this Essential element.

Essential element 10: Systems to support high-quality care

PCA recommends additional consideration of this Essential element to ensure it is applicable to non-acute settings.

PCA would be pleased to assist with additional review of this element to ensure its application to all care settings.

2. Are there any patient populations where end of life care needs will not be met by the requirements set out in this revised version?

PCA is concerned that the Commission has advised that it proposes to discontinue the National Consensus Statement: essential elements for safe and high-quality paediatric end-of-life care (Paediatric Consensus Statement) and integrate it into the revised National Consensus Statement.

While this causes some concern to PCA and its stakeholders, we acknowledge that there is opportunity to amend the revised National Consensus Statement to include more fulsome information with respect to safety and quality in end-of-life care for infants, children, adolescents and young people. The elements need to include or be expanded to provide appropriate guidance for services working with families who have infants, children, adolescents, or young people facing end of life.

We understand from discussion with the Commission that there may have been limited use/access to the Paediatric Consensus Statement, and this supports the inclusion of paediatric content in the revised National Consensus Statement. In this context, PCA notes that the Paediatric Consensus Statement is also available on PCA's Paediatric Palliative Care website:

www.paediatricpalliativecare.org.au/resource/national-consensus-statement/.

During the period April 2022-10 January 2023, this page was accessed by 59 people. Those people access the page 61 times. We hope this may assist with informing whether there is value in retaining the Paediatric Consensus Statement as a separate document.

If the Commission does choose to discontinue the Paediatric National Consensus Statement, and incorporate it into the revised National Consensus Statement, we recommend that this be clearly stated in the Introduction of the revised National Consensus Statement.

The nature of communication with families and carers changes depending on the age of the family member dying. The inclusion of more specific paediatric specific points such as third-party decision making and the concept of the 'best interests' of the paediatric population should be more explicit in the revised National Consensus Statement.

Many paediatric life-threatening diseases/conditions are rare, and this can mean that health professionals are not as familiar with these conditions. Given the broader scope for these elements, some more support references regarding these diseases and conditions could be included. Service coordination in regional and remote areas is also a part of the care delivery for paediatric palliative care, which needs to be articulated more strongly in the document. This might include how this coordination can be supported with existing funding and service delivery available, especially where there are fewer health system resources close by. Many of these concerns also apply to adult needs and services in these areas.

Some of the elements could be enhanced to include reference to infants, children and young people. For example:

- Essential element 1.3 references advanced age-related issues, but does not include issues faced by younger people
- Essential element 4 references dementia and could be enhanced by identifying that there are relevant paediatric conditions and therefore, specific care needs to be met.

PCA recommends that, given the significant difference in paediatric palliative care and end-of-life care needs, that the Guiding Principles should include a reference to meeting the specific needs of

paediatric cohorts. PCA would be very pleased to assist with the development of a Guiding Principle relating to the provision of paediatric end-of-life care.

3. Can the revised version be applied to all settings where end-of-life care is delivered?

PCA notes the expansion of scope of the National Consensus Statement to include all settings where healthcare is provided to people who are dying. PCA understands that this scope includes primary care, aged care services and other community-based services. This increase in scope is an important development and, if appropriately supported, has the capacity to increase access to palliative care for many Australians. It also has the capacity to improve efficient use of the health system for palliative care.

Please also refer to other comments for recommendations and suggestions for improvement of the revised National Consensus Statement.

PCA would be pleased to assist the Commission to ensure the revised National Consensus Statement is fit for purpose.

4. Is the language and structure of this revised version clear and relevant

The revised National Consensus Statement is generally clear, however, in some instances, the delivery could be enhanced for readability and clarity. In addition, there may be instances where further details or examples (for instance, circumstances relating to different age groups) could enhance or support readability and therefore implementation of the National Consensus Statement.

PCA would be pleased to provide more detailed feedback in future if this would assist.

5. Will the revised National Consensus Statement be useful for improving end-of-life care?

PCA is of the view that the National Consensus Statement is of value, particularly if health professionals are appropriately trained in the provision of palliative care and end-of-life care - combined, this will support the provision of quality end-of-life care.

In our view, there is significant value in providing an education campaign to launch the National Consensus Statement, most importantly, alongside expanded information and materials (particularly for diverse groups and cohorts, such as paediatrics), to support application and implementation of the National Consensus Statement.

PCA would be very pleased to assist the Commission to develop any supporting documentation.

6. Please provide any other feedback

There appears to be a strong focus on the last year of life in the draft *Consensus Statement* which may reduce the capacity to improve quality of life and health outcomes for patients who have been recently diagnosed with a life-limiting condition, but whose life expectancy is longer than 12 months. PCA is concerned that this focus could reduce the efficiencies that early provision of palliative care can provide. These efficiencies for many people, could be provided for longer than the last year of care. This is critical for paediatric palliative care patients, and for patients diagnosed with certain cancer types or a range of degenerative diseases such as dementia and motor neurone disease.

PCA notes that the World Health Organization (WHO) acknowledges palliative care relieves suffering and improves quality of life for both patients and families throughout someone's illness, not just at the end of life. WHO also advocates for the implementation of palliative care services at all levels throughout society and has always advocated a public health approach to its adoption.¹

In the spirit of providing comprehensive, holistic and person-centred care, PCA recommends that the National Consensus Statement include reference to allied health professionals as members of the healthcare team. This reference could be included in the 'Application' section on page 6 of the Consensus Statement, where there is reference to (amendment added in **bold text**): 'general practitioners, residential aged care facilities and providers, acute services, specialist aged care services **and allied health professionals...**'

PCA also recommends that reference to the *PCA National Palliative Care Standards* and *National Palliative Care Standards for All Health Professionals and Aged Care Services* (palliativecare.org.au) be included specifically in the National Consensus Statement, as these assist with establishing best practice in palliative care.

PCA notes that the revised National Consensus Statement does not include reference to emergency situations and natural disasters, such as pandemics. We suggest that additional information could be incorporated to guide how such situations are handled, including whether advice is to be sought from National or State/Territory bodies on how to respond to such situations and how the National Consensus Statement operates in this context.

Other matters

PCA is uniquely placed with State and Territory membership and established clinical and consumer panels. PCA would be pleased to assist the Commission with the ongoing revision of the National Consensus Statement.

Should the Commission also decide to develop supporting documentation for specific groups or cohorts, such as paediatrics, we would be most pleased to contribute to these discussions and engage with our members, panels and networks to provide additional comprehensive input for the Commission's consideration.

¹ WHO 2021, Quality health Services and Palliative Care: Practical approaches and resources to support policy, strategy and practice.