

Palliative Care Australia

**Submission to the Australian Commission
on Safety and Quality in Health Care
National Consensus Statement: Essential
Elements for Safe and High-Quality End-of-Life
Care in Acute Hospitals**

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**Palliative
Care
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Palliative Care Australia (PCA) is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life. Our mission is to influence, foster and promote the delivery of quality care at the end of life through ongoing policy and advocacy, education, and developing collaborative relationships in Australia and internationally.

We believe that palliative care must be available regardless of location, age, income, diagnosis or prognosis, social and cultural background, to support Australians to live well at the end of life.

But we remain a very long way from achieving our goals. In 2011, nearly 147,000 Australians died. Of these, 107,000 would have benefitted from access to palliative care services, yet only one third to one half did.

The Australian Commission on Safety and Quality in Health Care, in giving prominence to the importance of palliative care in health care and factors such as raising awareness of palliative care in the acute health workforce, will play a key role in achieving quality end of life care in acute settings in Australia. As the majority of Australians die in a hospital setting, there is a need to foster systemic support in these settings to move from high intervention to palliative care management plans.

The document is a well-developed draft and captures the issues for palliative care in the acute setting. It represents an important step forward for addressing these issues within the acute sector.

PCA and its state and territory based member organisations supports the purpose and content of the National Consensus Statement, and the overall direction of the document. As is indicated in the Consultation Draft, PCA recognises that the document presents recommended and not mandatory practices. Therefore the mechanisms developed to support the implementation and application of the Consensus Statement elements, will be important to ensure it can be practically applied, and include an evaluative process to determine if the elements are being met and relevant. System support for the document will also enhance the success of this leading to the development of a new standard. Enhancing system support and developing a new end-of-life standard are actions PCA strongly supports.

PCA Priority Areas

A number of the essential elements of the Consensus Statement are reflected in priority areas that have been identified by PCA¹. These include:

Workforce – Care for the dying must be a standard education provision for every health professional across their career. Without supporting the specialist and generalist workforce to provide palliative care across all settings, the needs of dying Australians will continue to be unmet.

¹ Palliative Care Australia 2014-15 Pre-Budget Submission, January 2014

Awareness – There is a need for increased awareness of palliative care and end-of-life care across the community and health professionals. Not discussing or planning for end of life makes it difficult to provide care for a person according to their wishes, particularly where they lose capacity to make decisions, and causes anxiety and stress for families.

Quality – The *Standards for Providing Quality Palliative Care for all Australians*² should inform palliative care practice wherever it is delivered. PCA notes that the Consultation Draft refers to the Standards as being relevant to the implementation of the Consensus Statement, particularly when considering how to develop systems that encourage a collaborative approach between acute and special palliative care services.

PCA supports the statements made in the Consultation Draft regarding the application of the Consensus Statement in that while it is focused on acute hospitals, the principles and elements apply to non-acute settings. Also that the way acute hospitals communicate and work with primary care services and residential aged care facilities, is a factor in planning and implementing systems to address the elements of the Consensus Statement.

The Consensus Statement can work in conjunction with existing standards and guidelines as a means for assisting with the implementation process.

Advance Care Planning – PCA has called for action on implementing nationally consistent advance care planning across the states and territories in Australia, as inconsistent processes and legislation creates confusion for patients and health professionals. PCA supports the Consensus Statement's strong inclusion of advance care planning in the actions of the elements.

Key Consultation Questions

1. Is the intended purpose and scope of the Consensus Statement clear?

The intended purpose and scope of the Consensus Statement is clear. As noted above, PCA supports the direction of the document.

The main point to be made with the scope, which also relates to the essential elements, is that making palliative care available to patients and considering the benefits and burdens of treatment earlier than is indicated in the document, contributes to improved quality of life and more effective use of health resources. This has been demonstrated by international research. In all instances patients and their families would benefit from the option of palliative care earlier than at the terminal phase.

² Palliative Care Australia (2005), *Standards for Providing Quality Palliative Care for all Australians*.

2. Does the Consensus Statement accurately reflect what you think the expected standard of care and practice should be?

The Consensus Statement reflects an appropriate and expected standard of care and practice. It is important that there is recognition of local population, resource and jurisdictional factors.

3. Are the guiding principles clearly outlined? How do you think they could be applied in practice?

As discussed previously, PCA supports the guiding principles and they are clearly outlined.

The principles could be improved by covering additional areas in particular cultural responsiveness, including Aboriginal and Torres Strait Islander people, Culturally and Linguistically Diverse (CALD) groups, lesbian, gay, bisexual, transgender and intersex (LGBTI) communities, and people living with a disability.

This cultural responsiveness needs to be reflected in the essential elements in relation to effective communications with diverse communities, such as using accredited interpreters for people who speak a language other than English and communicating with people who are hearing impaired. Cultural responsiveness should also be a part of education in cultural competencies for health staff, including Aboriginal and Torres Strait Islander people, CALD groups and LGBTI communities.

As noted earlier, there is a need to raise awareness of palliative care in the acute health workforce and to foster systemic support in acute settings to move from high intervention to palliative care management plans. Cultural change will be required in some instances for the guiding principles to be adopted, implemented and practically applied. Education about the Consensus Statement will be needed for the acute hospital workforce, along with consumers and families.

4. Are the essential elements clearly outlined? How do you think they could be applied in practice?

The essential elements are clearly outlined.

A number of the elements address education and training and support for staff to develop capacity in end of life care. Education and modelling good palliative care practice is likely to be needed across the workforce. That is not only for junior team members but more experienced team members, as improved communication about end of life care is needed across all levels.

As addressed in question 3, issues around cultural responsiveness and reflecting this in patient-centred and family-centred communications needs to be included throughout the essential elements.

In relation to essential element A) 2. *Team work and coordination of care*, the key point relating to care coordination and continuity should also recognise the importance of timely discharge planning, to enable appropriate needs assessment

and community services to be put in place. This ensures that services are in place when discharge occurs prior to weekends or out of hours, lessens the stress on patients, families and health professionals, and minimises the need for emergency care or re-admission to hospital.

It is also important that essential element A) 2 *in discussing interdisciplinary teams*, recognises the importance of encouraging referrals to specialist palliative care where there are complex needs, such as physical, psychosocial, emotional and spiritual, that are not being addressed through the interventions in place or require specialised expertise. The specialised expertise of palliative care should also be given more prominence throughout the essential elements and recognised as an integral part of a quality approach to end of life care.

5. Is there terminology that needs further exploration or clarification?

The terminology used is appropriate.

However, there needs to be a distinction made within ‘palliative care’ by defining a palliative approach or generalist palliative care and specialist palliative care. The point of giving greater prominence to specialist palliative care was made previously in question 4 and drawing out the definitions would assist with this.

It would also be useful to add an explanation of ‘Clinical Care Plans’ as distinct from resuscitation orders/plans or patient-directed Advance Care Plans.

In ‘Limitations of medical treatment’, where the other common terms in use are listed, it would be useful to include comments on the concepts of ‘withdrawing care’ or ‘limiting care’ when what should be limited are inappropriate medical interventions.

6. What enablers exist to help with implementing the elements of the Consensus Statement? How can these be leveraged to promote best practice?

Identifying and empowering health professionals working in the acute sector as champions, including medical, surgical, and allied health, who have expertise and experience in the palliative approach or specialist palliative care. This will encourage and assist with application of the elements of the Consensus Statement within their workplace. Targeted funding could be one way to implement this approach.

Fostering a systematic approach to end of life care through hospital-wide and state/territory-wide processes to underpin the use of tools for palliative care assessment, care coordination and clinical care and support should be encouraged and supported.

The Commonwealth funds three related programs to support high quality palliative care and end of life care in Australia:

1. The National Standards Assessment Program (NSAP) is a national voluntary program that provides a range of tools and opportunities, such as self-assessment, collaborative projects, and education, to measure how well the health service is meeting the National Palliative Care Standards. NSAP enables health services to track improvements in their performance and to benchmark this alongside other services over time.

2. Palliative Care Outcomes Collaborative (PCOC) is a national voluntary program utilising standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care. Participation in PCOC enables palliative care service providers to improve practice and meet the national palliative care standards.
3. CareSearch Palliative Care Knowledge Network provides the health community and the general public with up-to-date information and links to quality resources in palliative care including materials produced specifically for patients, carers and GPs. These resources reflect the significant role that primary care and family caregivers have in caring for people at the end of life.

As noted earlier, PCA supports the development of a new National Safety and Quality Health Care Standard on End of Life Care to complement the National Consensus Statement. Standard 9 on Recognising and Responding to Clinical Deterioration in Acute Health Care has relevance, but does not adequately cover end of life care.

7. What barriers to implementing the elements of the Consensus Statement exist? How do you think these can be addressed?

Barriers to implementation relate to health governance structures not prioritising the provision of end of life and palliative care as an activity of acute care, and a lack of understanding of the importance of good end of life care for the health and mental health of all involved.

Barriers can be addressed through identifying champions to promote the Consensus Statement, engagement of hospital governance processes, and as noted previously, education. The introduction of a future standard should be considered to ensure the elements of end of life care are implemented in the acute setting.

8. In what ways can consumers engage with acute hospitals to help implement the elements of the Consensus Statement?

This question has been addressed in other parts of this submission, in particular how consumer involvement can be better facilitated. This includes involving consumers and their families in discussions around palliative care earlier than at the terminal phase; educating consumers and their families about the Consensus Statement; and adopting patient-centred and family-centred communications throughout the essential elements.

Consumers have an important role to play by participating in satisfaction surveys, as capturing the experiences of consumers and families is important to progressing quality improvement processes.

9. What principles and elements do you think need to be addressed most urgently in acute hospitals?

1. Systematic recognition of the triggers to consider referral to specialist palliative care and the commencement of end of life care.
2. Giving quality end of life care the priority it needs within the current health system.

3. Establishing interdisciplinary teams and increasing skills and confidence of all team members in a palliative approach to care and end of life care.
4. Ensuring 24 hour access to specialist palliative care advice, and encouraging flexible responses from these services.
5. Acceptance that a ‘good death’ is a legitimate goal of care when death is unavoidable, and that death is a natural part of life.

10. What resources or tools do you need to help implement the elements of the Consensus Statement?

Tools to assist with the implementation of the Consensus Statement elements include:

- Consistent Advance Care Planning legislation in each state and territory, which PCA has called for.
- Endorsement of an advanced care plan to replace resuscitation status only statements.
- Nationally consistent guardianship legislation to reduce confusion with the operation of legislation at the end of life, particularly around whether substitute decision-makers have the power to authorise the refusal or withdrawal of treatment.

Referring to evidence based and research directed practice in hospitals currently involved in palliative care research, would be useful to demonstrate to other acute hospitals what practises are already working and successful, and encourage up-take of the Consensus Statement. This point is also relevant to question 11.

11. What resources or tools already exist that could be used to implement the elements of the Consensus Statement?

The End of Life Care 7 Step Pathway³ is an existing resource/program in use in South Australia. This is a program being trialled which provides support for clinicians to have a discussion with patients and their families in order to involve them in end of life care decision making. The program uses triggers for end of life planning, incorporates discussions of existing Advance Care Directives, clarifies resuscitation status, and leads to a Clinical Care plan for ongoing and palliative care.

Resources or references which may be useful in implementing the Consensus Statement are:

Identifying Patients in Need of a Palliative Care Assessment in the Hospital Setting, A Consensus Report from the Center to Advance Palliative Care.
David E. Weissman, M.D. and Diane E. Meier, M.D., Journal of Palliative Care Medicine, Volume 14, Number 1, 2011.

Family meetings in palliative care: Multidisciplinary clinical practice guidelines.
Peter Hudson, Karen Quinn, Brendan O'Hanlon and Sanchia Aranda, BMC Palliative Care, 2008.

³ Improving end of life care through the 7 Step Pathway, Change@South Australia, Office for Public Sector Renewal, Government of South Australia,
<http://change.sa.gov.au/projects/improving-end-of-life-care-through-the-7-step-pathway/>, Accessed 13 March 2014

The Melbourne Family Support Program: evidence based strategies that prepare family carers for supporting palliative care patients, Peter Hudson and Sanchia Aranda, BMJ Supportive & Palliative Care.