

# Standards Review Consultation Paper

---

## *In Review: The Standards for Providing Quality Palliative Care for all Australians (4<sup>th</sup> Edition)*

The Australian Association for Hospice and Palliative Care (now Palliative Care Australia [PCA]) developed *The Standards for Providing Quality Palliative Care for all Australians* (the Standards) in 1994, in collaboration with the palliative care community. They have been reviewed three times, most recently in 2005.

Palliative Care Australia has commenced a review of the Standards, which is due for completion in 2014.

The following is a consultation paper that illustrates the developments of the review thus far. It is open for comment, and we encourage your contribution.

A series of steps were incorporated throughout the process of reviewing the Standards to get a wide breadth of input and feedback from the sector. These steps were:

- Establishing a Standards Review Project Board
- Undertaking an initial desktop review and preparing the first consultation paper
- A survey of stakeholders
- Analysis of survey results and consultation on these results with the Standards Review Project Board.

The feedback used in the development of the consultation paper was collected from the survey sent out in late 2013. The survey sought advice from those involved in the palliative care sector on the realities of the effectiveness, adaptability and usability of the current Standards in practice. The survey was distributed and promoted:

- Electronically to over 2000 contacts including people who receive the eBulletin, PCA members, committees, NSAP service list
- A story in the PCA eBulletin and eHospice
- An email sent to Member Organisations asking them to promote the survey through their communication platforms
- Through the National Standards Assessment Program (NSAP) committees and newsletter.

Though the main scope of the project has been to refine and update the 13 Standards, a large portion of the feedback received from the survey (and consistent similar feedback through NSAP) has indicated a need to create Standards that are more succinct and clear. In response to this feedback, as well as a consensus from the Standards Review Project Board, 6 Standards have been proposed. The 6 Standards have been developed through combining the Standards that are

complimentary, related or overlapping. This should also ease their use and applicability in a service setting. It is important to emphasise that these 6 Standards are open for consultation and that changes to the content and number of Standards may result from this consultation process.

For simplification purposes, each Standard falls under a category:

1. Equitable Access to Palliative Care
2. The Person with a Terminal Condition
3. The Provision of Care
4. Support for Family & Carer/s
5. Quality Improvement
6. Community Support

Due to the impending ageing population and subsequent increase in demand for palliative care, it is necessary for the Standards to reflect this rapidly changing sector, in both its current and future settings.

We would like to invite your feedback on the proposed Standards, which will be finalised at the conclusion of this consultation.

Enclosed are the draft Standards and instructions about how to provide comments. Submissions are open until **26 September 2014**. Please send all feedback and direct any questions to Heidi Moore, [heidi@palliativecare.org.au](mailto:heidi@palliativecare.org.au) 02 6232 4433.

Thank you in advance for your comments and your commitment to ensuring quality care at the end of life for all Australians.

Prof. Patsy Yates  
President  
Palliative Care Australia

## Instructions

Under each proposed Standard, there are questions which you are invited to answer. Please tick the yes or no boxes, and provide comments where necessary. Do not feel obliged to answer all of the questions.

You can access the current 13 Standards via this link <http://bit.ly/1t0moXP>

At the end of the 6 Standards, there are some additional questions regarding the format of the Standards, for example, your views about reducing the Standards from 13 to 6 and a question about terminology.

Please keep these answers to a 200 word limit. If you would like to make any further comments, please add additional pages at the end of this word document and include the comments there.

You may choose to make a submission as an individual, or on behalf of an organisation.

Submissions are invited until **26 September 2014** and can be emailed to Heidi Moore, [Heidi@palliativecare.org.au](mailto:Heidi@palliativecare.org.au)

After all the submissions are received, Palliative Care Australia and the Standards Review Advisory Committee will work towards finalising the new Standards.

If you have any further questions please contact Heidi via email or phone 02 6232 4433.

Thank you in advance for your input.

# Standard 1

---

*(Current Standard 10)*

## Equitable Access to Palliative Care

*Access to palliative care is available for all people based on need and is independent of diagnosis, age, cultural background, socio-economic status, location or the type of terminal condition.*

### Intent

Everyone who has been diagnosed with a terminal condition, their family and carer/s have access to palliative care services.

Palliative care services are actively involved in the development of policies and structures that ensure equity of access to services based on level of need.

Formal networks with external expertise are established in order to provide holistic specialist assessments, information and advice to the person, their family and carer/s irrespective of the geographic location or size of service.

### Criteria

**Primary Care** The person, their family or carer/s is informed of the availability of palliative care services as soon as appropriate after the diagnosis of a terminal condition. Referral to a palliative care service is initiated when the person's needs exceed the resourced capability (including available expertise) of the primary care service.

Access to a range of internal and external professionals is available to ensure that the holistic needs of the person, their family and carer/s can be appropriately addressed (such as access to services that provide psychological, cultural, and spiritual support).

Formal partnership agreements are established with specialist palliative care services to ensure that the person can be referred to, and have access to specialist care when required for consultation, information and/or management.

The person, their family and carer/s has access to specialist telephone assessment and advice. Clear written instructions, negotiated with local specialist service providers, about how to seek help if needed in 'after hours' or unanticipated situations, are provided.

**Specialist Palliative Care – Level 1 & 2** Formal partnerships with primary care services are established to ensure collaborative working relationships between primary and specialist services based on the level of need. The person, their family and carer/s are referred back to their primary care provider for ongoing care when specialist management is no longer required.

Relevant information and recommendations for care needs are provided to the person, their family and carer/s. The palliative care service has formal links with specialists in other fields to ensure access to expert advice and management of the individual's needs.

Processes and strategies exist to provide after-hours support if required by the person and their primary caregiver. The person, their family and carer/s have access to specialist telephone assessment and advice on a 24 hour 7-day basis.

**Specialist Palliative Care – Level 3** As for Level 1 & 2 Plus: Provide support and information to primary care and Level 1 & 2 specialist palliative care services.

## Questions

- 1) Is the intended purpose and scope of the proposed Standard clear?

Yes

No

Comments:

- 2) Do the criteria give a comprehensive indication of the level of action and responsibilities that are expected from palliative care providers?

The APA would welcome the concept that palliative care includes the the maintainance of quality of life as perceived by the person, family or carer/s as part of a more extensive description of what primary care looks like.

- 3) Is there anything that you think is vital to the proposed Standard 1 that has not been included?

The APA suggests greater mention of quality of life, and a description of a multi-disciplinary team in this context; We also suggest considering a term that better reflects a condition's transition into terminal stage, rather than "terminal condition".

- 4) Overall, are you happy with the revised Standard 1?

Yes

No

Comments:

## Standard 2

---

*(Current Standards 1, 2, 3 & 6 Combined)*

### The Person with a Terminal Condition

*All care, decision making, assessment and care planning is based on a holistic, person-centred<sup>1</sup> principle. Throughout the journey, the unique needs and preferences of the person with the terminal condition, their family and carer/s are considered, their comfort maximised and their dignity preserved.*

#### Intent

A holistic, person-centred approach must be taken, and therefore all cultural beliefs and preferences should be respected and integrated into their individualised assessments and care planning processes.<sup>2</sup> This approach is essential throughout the person, their family and carer/s' entire journey.

Comprehensive and holistic assessments of pain and other symptoms are undertaken and documented regularly. These assessments form the basis of care planning. Assessments and care plans accommodate the evolving needs and preferences of the person, their family and carers.

The person, their family and carer/s are provided with up to date and appropriate information to meet their needs and support and encourage their participation in care planning and decision making.

Health care providers are experienced and skilled in recognising and managing the person, their family and carer/s when the terminal phase of the terminal condition has begun.

#### Criteria

**Primary Care** The person, their family and carer/s are encouraged to develop (according to the person's wishes) an Advance Care Plan or an Advance Care Directive. Health care providers are aware of, and comply with, the legal obligations associated with Advance Care Directives, and in their absence with the primary decision maker's instructions. An ongoing holistic, person centred assessment and care planning process is used to document and assist with the needs and wishes of the person, their family and carer/s. Validated assessment tools should be used where possible.

---

<sup>1</sup> Person centred care: Recognises and maintains person hood; Recognises uniqueness and individuality, and acknowledges this in care plans and care pathways; Is professional care that respects autonomy, dignity, privacy and the rights of the person; Identifies strengths and positive aspects, rather than weaknesses and problems; Acknowledges the person's lived world. (*Caresearch* accessed from <http://www.caresearch.com.au/caresearch/tabid/2515/Default.aspx>)

<sup>2</sup> For example, for many Aboriginal and Torres Strait Islander peoples, being able to die or be buried 'on country' is extremely important. Therefore, regular evaluation of the person's progress should be undertaken to ensure they are able to travel to their own country in sufficient time to achieve their goals.

The social, cultural, psychosocial and spiritual needs and preferences of the person, their family and carer/s are determined, respected and provide guidance for care throughout the journey.

Appropriate cultural resources, including interpreter services, are utilised.

Regular and ongoing assessment of the person with the terminal condition identifies transition into the terminal phase. The person, their family and carer/s are assisted to prepare and plan for death by honestly discussing anticipations and expectations, as appropriate, in order to reduce fear and increase involvement. Services encourage the person, their family and carer/s, if able, to express their feelings and last wishes and to say their goodbyes.

Immediately following the death of the person and during the early bereavement phase, their family and carer/s are given time, information and continuing care to provide comfort, and assist with adjustment to the death of the person.

**Specialist Palliative Care Level 1** Assessment tools that have demonstrated validity and sensitivity with specific populations are used when appropriate.

If required, specialist palliative care services assist primary care services by providing consultation-based assessments, support and recommendations for ongoing management of identified problems.

**Specialist Palliative Care 2 & 3** As for level 1 plus: The service undertakes a leadership role in research and/or research implementation related to person centred assessment and care of people living with terminal conditions. This includes further understanding of the palliative care needs of cultural and special needs groups.

## Questions

- 1) Is the intended purpose and scope of the proposed Standard clear?

Yes

No

Comments:

- 2) Are you content with using the term 'Journey' to identify the time and experiences from diagnosis to death?

Yes

No

Comments:

The experience of APA members is that 'journey' may have mixed acceptance and suggest "transition through" for consideration.

*Standards Review Consultation Paper*

- 3) Do the criteria give a comprehensive indication of the level of action and responsibilities that are expected from palliative care providers?

yes

- 5) Is there anything that you think is vital to the proposed Standard 2 that has not been included?

- 4) Overall, are you happy with the revised Standard 2?

Yes

No

Comments:



## Standard 3

---

*(Current Standards 4, 7 & 13 Combined)*

### The Provision of Care

*The person, their family and carer/s receive coordinated palliative care from services that effectively utilise resources and have the appropriate formal qualifications, philosophy, values, structure and environment to enable optimal person-centred care.*

### Intent

Palliative care is most effectively delivered by an interdisciplinary team of health care providers who are trained, knowledgeable and skilled in all aspects of their discipline of practice. Formal networks between internal and external health care professionals are sustained, information exchanged and connections maintained and utilised. Effective communication, group function, and the ability to promote and manage change are important elements in interdisciplinary teamwork.

Palliative care can be provided as either the sole form of care or used in conjunction with disease-modifying therapy.

### Criteria

**Primary Care** All staff and health care providers are trained, knowledgeable and skilled in all aspects of their discipline and practice. The service has appropriate values, philosophies and an environment which reflects and nurtures excellence in care.

One health care provider is identified as the coordinator of care (lead agency) and this is communicated and accepted by other care providers involved. Formal networks are established between services to provide holistic care and minimise unnecessary duplication of services. All staff are aware of the limits of the services that they provide (the scope of both the individual and the organisation), and understand the process of internal and/or external referral to specialists to ensure appropriate and seamless care. Training for referral criteria and processes is provided by the service.

Health care providers performing assessments are flexible in timing and methods so that the assessment is as unobtrusive as possible.

Discharge plans are prepared and include readmission protocols and ongoing support strategies. Plans are in place for the certification of death should this occur out of hours, and also for informing relevant authorities of any notifiable deaths.

**Specialist Palliative Care – level 1** Health care providers have formal qualifications and experience. The written philosophy and objectives of the service are informed by these Standards and definitions, and are used to guide the work of the team.

Effective referral policies and procedures and ongoing communication strategies are established with non-specialist services to ensure continuity of care for the person, their family and carer/s. Strategies are in place for transitions from paediatric to adult palliative care. Ongoing assessment is undertaken to ensure the most appropriate point for care coordination.

Resources are allocated to respond to urgent needs. Protocols document procedures for responding to palliative care emergencies.

**Specialist Palliative Care – level 2 & 3** As for level 1 plus: Consultative advice and support is provided to specialist and non-specialist services to facilitate system-wide service enhancement and development. Staff contribute to, and participate in, the provision of undergraduate and postgraduate education in palliative care.

## Questions

- 1) Is the intended purpose and scope of the proposed Standard clear?

Yes

No

Comments:

APA believes that primary care services would continue until death ( if in community) but the discharge would be from specialist services.

- 2) Do the criteria give a comprehensive indication of the level of action and responsibilities that are expected from palliative care providers?

Yes

No

Comments:

- 3) Is there anything that you think is vital to Standard 3 that has not been included?

- 4) Overall, are you happy with the revised Standard 3?

Yes

No

Comments:

All healthcare providers provide some level of bereavement support. All levels of service need education or training and support to increase awareness of contribution each can make - this may be during clinical placement or formal education programmes



## Standard 4

---

*(Current Standards 5 & 8 Combined)*

### Support for the Family and Carer/s

*The primary carer/s is adequately provided with information, support and guidance about their role according to their needs and wishes. Formal mechanisms are in place to ensure that the person, their family and carer/s have access to bereavement care, information and support services.*

#### Intent

The primary carer plays a pivotal care-coordinating role in the care of the person, particularly in community contexts where the person is being cared for at home. The role of the primary carer, although often rewarding, can also be stressful. A particular focus on the primary carer's wellbeing (physical, psychosocial, emotional and financial) allows them to better fulfil their role and reduce associated stress. Primary carers need to be regularly assessed, the results documented, and their requirements responded to. Networks and support services are established to meet the carer's needs.

Psychosocial, emotional and spiritual support should also be offered to the secondary carer/s and family of the person from the time a terminal condition is diagnosed. Ongoing support, advice and resources based on self-identified need are offered to the family and carer/s.

Bereavement care is offered to the family and carer/s before and after death, and is provided by staff with the necessary qualifications (psychologists, psychiatrists, general practitioners, nurses, pastoral care workers, social workers and counsellors). This is an interdisciplinary process that requires excellent coordination and communication skills amongst health providers, as varying information may be disclosed to different people.

A referral to specialist support services must be made if an assessment determines the person/their family or carer/s to be at risk of experiencing complicated bereavement.

#### Criteria

**Primary Care** The primary carer is identified by the person and their family and carer/s at the initial assessment. This is re-confirmed on an ongoing basis. The carer's wellbeing and understanding and acceptance of their roles are assessed regularly and independently, and are documented in the care plan. Adequate information is provided and shared decision making is facilitated.

The family and carer/s are given information about beneficial organisations and government services. Networks are established to provide respite and supportive care for the family and carer/s (for example, social workers, respite services, carer support groups and mental health services). Information (both verbal and written) on loss and grief and the availability of bereavement support services is routinely provided to family members and carer/s prior to and after the death of the person. The carer/s is also encouraged to practice self-care activities.

The service providing palliative care has policies and procedures that guide its bereavement support program. Staff and volunteers who are routinely involved in bereavement support are trained and provided with regular supervision and support.

Verbal permission is sought from the person, their family and carer/s prior to assessments, referrals and bereavement interventions. This consent is documented.

**Specialist Palliative Care – Level 1** Specialised information, resources and materials relating to palliative care needs are available for the person, their family and carer/s. Support and assistance to primary care services are provided. The palliative care service has policies and procedures for its bereavement support program.

Staff and volunteers who are routinely involved in bereavement support are trained and provided with regular supervision and support. A directory of professional counselling resources is available and referrals offered where appropriate. Services have access to specialist palliative care social workers, religious advisors and qualified psychologists and psychiatrists for referrals. Emotional and bereavement support is provided to the person's family and carer/s before and after death.

A system is in place to inform the carer's general practitioner of the death within 24 hours.

**Specialist Palliative Care – Level 2 & 3** As for Level 1 plus: A designated qualified person coordinates the bereavement support program. Education about loss, grief and bereavement is provided for the family and carer/s, the staff, volunteers and the community including those working in primary care and level 1 services. Networks and formal agreements are in place to ensure that the identified needs of carer/s can be met. Research is undertaken by the service to benefit all the family, carers and extended support networks of people with terminal conditions.

## Questions

5) Is the intended purpose and scope of the proposed Standard clear?

Yes

No

Comments:

6) Do the criteria give a comprehensive indication of the level of action and responsibilities that are expected from palliative care providers?

Yes

No

Comments:



*Standards Review Consultation Paper*

7) Is there anything that you think is vital to Standard 4 that has not been included?

8) Overall, are you happy with the revised Standard 4?

Yes

No

Comments:

## Standard 5

---

*(Current Standard 11 & 12 Combined)*

### Quality Improvement

*The service is committed to continuous quality improvement, evidence-based practice and maintaining the wellbeing and ongoing professional development of staff and volunteers.*

### Intent

Professional development and clinical up-skilling are continuously undertaken by all members of the team to ensure quality care is provided. Staff and volunteers have the support from their service to critically reflect on practice and initiate and maintain effective self-care.

Services are committed to providing the best possible quality of care for people living with terminal conditions and regularly participate in quality programs, external accreditation programs and research projects (including independently), and seek feedback from consumers to meet these goals. These quality management programs are based on evaluation and continuous improvement principles.

Service development and evaluation is planned and formalised. All evaluation and research should comply with the National Health and Medical Research Council Guidelines for Ethical Practice.

### Criteria

**Primary Care** Primary care providers have access to ongoing education about the holistic principles, objectives and practices of palliative care as they relate to these Standards and local palliative care provision. Quality improvement, professional development and research activities are regularly undertaken by the service, and include research relevant to roles. Primary care services participate with specialist palliative care services in these activities. Education resource materials are available to staff to support the development of specialist knowledge and skills.

**Specialist Palliative Care – level 1** Strategies are in place to provide support for staff and volunteers. Specific policies and a culture of shared responsibility guide the support and care of staff and volunteers, including critical incident debriefing and response.

Education is available to enable staff and volunteers to develop effective preventative self-care and coping strategies to minimise the personal impact of working in the palliative care service. Staff and volunteers have access to confidential employee assistance programs and/or counselling services.

An ongoing education program for staff and volunteers is in place. An outreach program is provided to educate other health professionals in order to facilitate a palliative approach across the wider health care community.

There are existing policies and procedures to guide a program of quality improvement and research within the palliative care service. The service undertakes its own independent research projects relevant to its community's needs. There is evidence that research has been incorporated into practice. Clinical and performance criteria are consistent with professional standards.

Comparing quality benchmarks with other service providers is undertaken as a means of implementing better practice. Internal benchmarking is also practiced to support sustainable quality improvement within the service. Protocols, standards and projects to support ongoing service evaluation and development are constructed and circulated.

**Specialist Palliative Care – level 2** As for level 1 plus: Research or service development initiatives that improve understanding of service level needs and outcomes for palliative care consumers are initiated and/or implemented. Contributions are made to the development of formal training and education programs/initiatives to support service development.

Quality improvement and research programs are collaborative, interdisciplinary and focussed on the identified needs of the community.

**Specialist Palliative Care – Level 3** As for Level 1 & 2 plus: Research is conducted in collaboration with other palliative care and primary care service providers, peer mentors and academic units.

## Questions

- 1) Is the intended purpose and scope of the proposed Standard clear?

Yes

No

Comments:

- 2) Do the criteria give a comprehensive indication of the level of action and responsibilities that are expected from palliative care providers?

Yes

No

Comments:

- 3) Is there anything that you think is vital to Standard 5 that is not included?

APA members believe that the text might usefully indicate that training can be conducted in a number of ways, not necessarily face-to-face.

- 4) Overall, are you happy with the revised Standard 5?





Yes

No

Comments:

## Standard 6

---

(Current Standard 9)

### Community Support

*Community awareness, support and engagement in response to the needs of people who have a terminal condition, their family and carer/s, is built through effective collaborations and partnerships.*

#### Intent

Palliative care services, through their knowledge and experience of death, dying and bereavement are a valuable resource to the community. These services participate in the development and delivery of community awareness and engagement initiatives.

Facilitating community engagement through positive and open discussions about death and dying will increase general knowledge, understanding and the normalcy of these aspects of life. The promotion of social support networks through individuals and community groups can increase the quality of life for both individuals and the collective.

Members of the community are given opportunities to contribute to achieving palliative care goals. They are encouraged to raise awareness and partake in systems and services that meet the requirements of people who have palliative care and bereavement needs. Educating and involving the community in palliative care matters and the palliative approach raises awareness and builds support networks. Palliative care services involve the community in education programs and quality improvement projects using various formats, languages and styles.

Community and government groups play a significant role in progressing and building a sense of community. Relationships with these groups need to be fostered as they are an important component in raising awareness and community receptiveness towards death and dying.

#### Criteria

**Primary care** Opportunities to increase community awareness, support and engagement are identified and acted upon. Primary care providers respond to consultations and provide information that contributes to social and health policy development.

**Specialist palliative care - level 1** Palliative care services take the opportunity to raise awareness of palliative care services available to individuals and groups within the community. Palliative care staff and volunteers represent palliative care and participate in the promotion and support of local and national palliative care awareness initiatives. Palliative care services collect and report data on social and community needs as required, and utilise information that assists them in addressing the palliative care needs of their community. Links are established with other service providers, relevant individuals, community groups and local and state government organisations as a means of facilitating policy directions and the best quality palliative care.

**Specialist palliative care - level 2** As for level 1 plus: Education programs/activities are developed in collaboration with community groups and, where possible, professionals qualified in health promotion. Palliative care services together with community members, contribute to the development of policies and structures that address the palliative care needs of their community.

**Specialist palliative care - level 3** As for level 2 plus: Research that contributes to the understanding of the needs of populations is conducted and disseminated to decision makers and the community. Leadership is provided to advocate for the appropriate development of palliative care services.

## Questions

- 1) Is the intended purpose and scope of the proposed Standard clear?

Yes

No

Comments:

- 2) Do the criteria give a comprehensive indication of the level of action and responsibilities that are expected from palliative care providers?

Yes

No

Comments:

- 3) Is there anything that you think is vital to Standard 6 that is not included?

- 4) Overall, are you happy with the revised Standard 6?

Yes

No

Comments:

## Additional Questions

---

1) Please select one of the following terminologies which you would like to see used in the Standards

- The patient
- The person with a terminal condition
- The person with a life limiting condition
- The person with a terminal illness
- The person with a life limiting illness
- The dying person

2) Do you believe the proposed 6 Standards would increase the usability of the Standards in Practice?

- Yes
- No

Comments:

3) Do you believe that there should be any additional Standards to the proposed 6?

- Yes
- No

If yes, what are they? Why?

Any further comments:

If you have any further comments that cannot be accommodated through these questions, please insert additional Word pages, and write your comments there.

Thank you

