

Standards for Providing
Quality Palliative Care
for all Australians



PALLIATIVE
CARE
AUSTRALIA

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Front Cover Design: The conceptual design of the front cover represents the multilayered, unique and interwoven roles primary health care and specialist palliative care services have in providing high quality end of life care to all Australians.

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Foreword

The Council of Palliative Care Australia (PCA) is pleased to provide the health care sector with the fourth edition of *Standards for Providing Quality Palliative Care for all Australians*. The recently completed national review of the existing third edition of *Standards for Palliative Care Provision*¹ was undertaken to ensure the continuing relevance of the Standards to current community needs. The vision for palliative care set out in the Standards includes and is relevant to consumers (patients, families), general practitioners, community nurses, staff of residential aged care facilities, staff of acute care facilities, as well as specialist palliative care staff. As such, they represent a whole-of-sector approach to ensuring high quality, needs-based care at the end of life.

PCA has had an ongoing interest in the development of consistent Standards for the delivery of care since the publication of the first edition in 1994. The revision of the 1999 Standards contributes to the realisation of Objective 2.1 in the *National Palliative Care Strategy (October 2000)*². The development of these Standards followed a widespread consultation with consumers and the health sector. The Australian Government Department of Health and Ageing (DoHA) funded that phase of the project, under the guidance of the PCA Standards & Quality Committee.

In a general sense, standards are key governing documents that influence both primary and specialist service providers in the way that they plan and deliver care. These newly developed Standards, for the first time, set out the relationship between primary care providers and specialist palliative care services. Detailed criteria for each of the Standards clearly articulate the level of expectations for all services involved in the provision of care to people with a life limiting illness.

The fourth edition of the Standards also moves beyond a simplistic diagnosis basis for determining need, and focuses on establishing networks of care that allow patients to access appropriate and timely care consistent with their level of need. The Standards also recognise and reflect the considerable effort and success that some services/sectors have had in developing and implementing coordinated network based approaches to service development and delivery.

The reading of the Standards needs to occur in conjunction with *A Guide to Palliative Care Service Development: A population based approach*³ and the *Service Provision in Australia: A Planning Guide*.⁴ In these three documents, PCA has provided the platform that has shaped the review of the Standards and ensures consistent advice and direction to the entire health care sector. PCA acknowledges the efforts of the many people who have seen this work through to fruition.

We commend this document to you as an integral tool in the continuing evolution of the provision of palliative care by specialist palliative care services and other health care professionals across the country. PCA is keen to build further towards the vision of quality care for all Australians at the end of life, and looks forward to continuing to work with the whole community in achieving the vision.



Professor David Currow
President



Professor Sue Hanson
Chair – Standards & Quality Committee

- 1 Palliative Care Australia (1999). Standards for Palliative Care Provision. 3rd Edition. PCA, Canberra.
- 2 Commonwealth Department of Health and Aged Care (2000). National Palliative Care Strategy: A National Framework for Palliative Care Service Development. Commonwealth Department of Health and Aged Care, Canberra.
- 3 Palliative Care Australia (2005). A Guide to Palliative Care Service Development: A population based approach. PCA, Canberra.
- 4 Palliative Care Australia (2003). Palliative Care Service Provision in Australia: A Planning Guide. 2nd Edition. PCA, Canberra.

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Introduction

The first edition of the Australian Palliative Care Standards was developed by Palliative Care Australia (PCA, then the Australian Association for Hospice & Palliative Care) in 1994 in collaboration with the palliative care community. The original Standards⁵ represented a set of philosophical standards, reflective of the need at the time to clearly articulate and promote a vision for compassionate and appropriate end of life care. Funding and other structural issues required that the Standards also reflected the status of palliative care as an emergent specialist discipline and allowed the development of services to occur within the community's capacity to support them. Since that time there have been significant changes to the structure, organisation and delivery of palliative care services in Australia, including its role within the wider health care system. These changes require the Standards to be revisited to ensure that they have kept pace with the development of palliative care services across the country and with other health service development work that has occurred over the past decade. In particular two recent policy documents developed by Palliative Care Australia, *A Guide to Palliative Care Service Development: A population based approach*⁶ and *Palliative Care Service Provision*

*in Australia: A Planning Guide*⁷ provide a platform that will shape the review of the Standards and ensures consistent advice and direction to the health care sector.

A specifically funded collaborative project between the Australian Government Department of Health and Ageing (DoHA) and PCA was commenced in March 2004 under the guidance of PCA Standards & Quality Committee. A broad consultation based on the 1999 version of the Standards was undertaken with the palliative care sector and consumers, and has resulted in this completely revised edition. The framework and development of these new Standards reflects the feedback obtained in this consultative and creative process. Further and ongoing consultation with the palliative care sector, consumers and stakeholders, will ensure that the new Standards reflect as far as possible the level of care that the Australian community would expect, when faced with a life limiting illness.

These new Standards should be read in conjunction with the PCA policy documents identified above to support the ongoing development and quality of palliative care in Australia.

5 Australian Association for Hospice and Palliative Care (1994). Standards for Palliative Care Provision. AAHPC, Perth.

6 Palliative Care Australia (2005). A Guide to Palliative Care Service Development: A population based approach. PCA, Canberra.

7 Palliative Care Australia (2003). Palliative Care Service Provision in Australia: A Planning Guide. 2nd Edition. PCA, Canberra.

Utilising the Standards

The Standards have been developed for use in a number of ways to support and enhance quality of care for patients with life limiting illness. Services and providers will be encouraged to adopt the Standards on a voluntary basis, and accreditation services will be asked to incorporate these Standards as part of their assessment of palliative care and other services.

The Standards can be used to support quality management and improvement activities or benchmarking at a local, state or national level. They have been designed to be used alongside other standards for health services (for example The Australian Council of Healthcare Standards – Evaluation and Quality Improvement Program [EQuiP], Quality Improvement Council, Royal Australasian College of General Practitioners or the Aged Care Accreditation Standards) and therefore do not specifically address areas covered by those standards.

The Standards can be used in conjunction with, or as part of service accreditation. Accreditation remains the predominant model for improving safety and quality in health organisations. It promotes a range of benefits, including risk minimisation, improved patient

outcomes, increased efficiency and best practice.⁸ Negotiations to align the Standards to the major accreditation processes used by community and health services have been commenced to allow services to incorporate relevant and meaningful quality measures. It is also intended that indicators for the Standards will be developed in conjunction with accreditation and other relevant bodies to enable the collection and utilisation of consistent data on system and service performance.

These Standards have been designed for use by specialist palliative care services (level 1-3 criteria) and by other health care services and providers that care for people who have a life limiting illness (primary care criteria).

⁸ The Australian Council of Healthcare Standards (2004). Improving Safety and Quality of Care with EQuiP: A Clinicians Guide. ACHS, Sydney.

Definition of Palliative Care

Palliative care is care provided for people of all ages who have a life limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life.

The World Health Organisation describes palliative care as:

“...an approach that improves quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention of suffering by of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.

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 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 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.”⁹

9 World Health Organisation Definition of Palliative Care (sourced 27 April 2005). Available at www.who.int/cancer/palliative/definition/en.

Other definitions

The term **life limiting illness** is used here to describe illnesses where it is expected that death will be a direct consequence of the specified illness. This definition is inclusive of illnesses of both a malignant and non-malignant nature. A life limiting illness might be expected to shorten an individual's life. This differs from chronic illness where, even though there may be significant impact on the patient's abilities and quality of life, there is likely to be a less direct relationship between the illness and the person's death.

The word **patient** is used to describe the primary recipient of palliative care. "People with a life limiting illness" is also used in this document to describe the same group of people where the context and language flow allow for it.

The **caregiver** is generally in the close kin network of the patient and is usually self identified, eg spouse, partner, adult child, parent or friend. This person undertakes to provide for the needs of the patient and may take on additional tasks of a technical nature to provide ongoing care for the patient, eg administration of medications. The **primary caregiver** provides the primary support role for the patient at all levels of need. The term primary caregiver may include

more than one individual, for example the mother and father when the patient is a child.

The **family** is defined as those who are closest to the patient in knowledge, care and affection. The family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (including pets).¹⁰

A **palliative approach** is an approach linked to palliative care that is used by primary care services and practitioners to improve the quality of life for individuals with a life limiting illness, their caregiver/s and family. The palliative approach incorporates a concern for the holistic needs of patients and caregiver/s that is reflected in assessment and in the primary treatment of pain and in the provision physical, psychological, social and spiritual care. Application of the palliative approach to the care of an individual patient is not delayed until the end stages of their illness. Instead, it provides a focus on active comfort-focused care and a positive approach to reducing suffering and promoting understanding of loss and bereavement in the wider community. Underlying the philosophy of a palliative approach is the view that death, dying and bereavement are all an integral part of life.

¹⁰ Adapted from Ferris F D, Balfour H M, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. (2002). A Model to Guide Hospice Palliative Care. Canadian Hospice Palliative Care Association, Ottawa, ON:p 92.

For the purposes of these Standards **primary care providers** is taken to include all those health services and staff that have a primary or 'first contact' relationship with the patient with a life limiting illness. The use of the term 'primary care provider' in this context refers to general practitioners, community nurses, staff of residential aged care facilities and multi-purpose centres. It also includes other specialist services and staff, for example oncologists, renal, cardiac or respiratory physicians, and staff of acute care hospitals and services. These staff, while specialist in their own areas, may undertake an ongoing role in the support of patients with life limiting illness by adopting a palliative approach to the care they provide. In this context they are seen as the primary care service, with specialist palliative care services involved on an 'as required' basis only. In general the substantive work of the primary care provider would not be with people who have a life limiting illness.

Specialist palliative care provider is a medical, nursing or allied health professional, recognised as a specialist by an accrediting body (or who primarily works in palliative care if an accrediting body is not available) who provides consultative or ongoing care for patients with a life limiting illness, and support for their caregiver/s and family. Specialist palliative care builds on the palliative approach adopted by primary care providers, and

reflects a higher level of expertise in complex symptom control, loss, grief and bereavement. Specialist palliative care providers work in two key ways: first, by providing direct care to referred individuals and their families; and second, by providing a consultancy service to primary care providers and therefore supporting their care of the patient and family.

An **interdisciplinary team** is a team of health care providers who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified expectations and needs of the target population. An interdisciplinary team typically includes one or more physicians, nurses, social workers/psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may also be part of the team.¹¹

¹¹ Adapted from the Centre to Advance Palliative Care web site (sourced 27 April 2005). Available at www.capc.org.

Core Values for the Standards

The Standards have been based on a number of core values, assumptions and beliefs. These values, assumptions and beliefs are expressed in action through a number of key tasks and functions that underpin the work of health care services and professionals. These core values were articulated in a consultation with the palliative care community that resulted in the 3rd Edition of the *Standards for the Provision of Palliative Care (PCA, 1999)*.

Quality end of life care is provided by health care workers who:

- endeavour to maintain the **dignity** of the patient, their caregiver/s and family;
- work with the strengths and limitations of the patient and their caregiver/s and family to **empower** them in managing their own situation;
- act with **compassion** towards the patient and their caregiver/s and family;
- consider **equity** in the accessibility of services and in the allocation of resources;
- demonstrate **respect** for the patient, their caregiver/s and family;
- **advocate** on behalf of the expressed wishes of patients, caregiver/s, families, and communities;
- are committed to the pursuit of **excellence** in the provision of care and support; and
- are **accountable** to patients, caregiver/s, families and the community.

In order to ensure high quality, patient-focused and evidence-based services are available to meet patient needs, primary care and specialist providers, as well as, other health care professionals should also:

- follow established practice standards and requirements for quality management such as leadership and governance, human resource management, safe practice, information management, and continuous quality improvement;
- adhere to professional and organisational codes of practice and ethics;
- reflect on and evaluate current practice, and incorporate new evidence into protocols, policies and procedures; and
- participate in continuing professional development in the knowledge, attitudes, and skills required to deliver quality palliative care as this relates to the Standards in this document.

Applying the Standards to special needs populations

Special consideration needs to be given to particular groups in our community when applying the Standards, particularly those people who are disadvantaged or marginalised. The special needs populations include children with a life limiting illness, children and young adults of parents who have a life limiting illness, people with mental health problems or illnesses, temporarily or permanently incompetent adults, people who live in residential aged care facilities, and those who live in other institutions such as prisons. Aboriginal people and people of other ethnic and cultural backgrounds also have special needs related to their cultural beliefs and social situation.

A brief discussion of the special needs and considerations for each of these groups is given below.

Children with a life limiting illness

As with adult palliative care, the unit of care in paediatric palliative care includes the caregiver/s and family. In paediatric palliative care, however the unit of care can also include parents and the other members of the family, for example siblings, who can be overlooked when attempting to meet multiple, sometimes competing or conflicting needs. As parents have legal and moral responsibility for the care of their child they require total inclusion in all aspects of care, while at the same time needing emotional and practical space and support themselves. A higher risk of complicated grief exists in bereaved parents.

This creates a complex dynamic that is best managed by partnership between specialist paediatric and palliative care services.

Paediatric palliative care patients are few in number and their illnesses may last many years. Most often the palliative and end of life phases of care will require a coordinated effort between the family doctor, a specialist paediatric service and a specialist palliative care service providing additional expertise and/or resources. In some cases disability and education services may also be involved. Coordination of the multiple agencies is an important component of quality care to minimise stress on the child and parents/caregiver/s.

Children who need palliative care suffer from a diverse range of conditions, many of which are rare. Fewer than half of the children who need palliative care have a malignant condition. The involvement of paediatric services is critical as they bring specialist knowledge regarding anticipated symptoms, management of symptoms and prognosis especially in the case of obscure or uniquely paediatric conditions. In addition, developmental influences through the neonatal period, childhood and adolescence impact upon the experience of illness; the understanding, reporting and management of symptoms and psychological/emotional distress; the understanding of death and dying; the importance of school and play; decision making; and spirituality. Paediatric services have specialist expertise in providing health care relevant to these needs.

Children are also physiologically different to adults with regard to the use of medications and specialist palliative care services benefit from paediatric service experience and expertise in this area.

Specialist palliative care services will most often be involved in the end of life phase of the child's illness, particularly if a home death is planned. An inclusive team-based approach will ensure that services can participate if and when they are required, without overwhelming the family.

Children and young adults with a parent who has a life limiting illness

The children (minors and young adults) of people with life limiting illness can be overlooked when attempting to meet multiple family, caregiver/s and patient needs. These young individuals may be excluded from participating in an active way in the care of their parents, and may feel isolated and fearful for their future. In some cases they may be required, particularly if they are a little older, to participate as caregivers for their parents. In these cases they have needs as caregivers and individuals in their own right that will need to be balanced by services. Children particularly have specific needs associated with their developmental stage and these may require additional or specific responses by their carers.

People with mental health problems or illness

Providing services to people with a co-morbid mental illness can create access and management challenges for palliative care services and patients, primarily because of environmental, procedural or systemic issues. It is important to recognise that mental health problems and illnesses may be present across all identified patient populations and in this way people with a mental health problem or illness do not represent a distinct and separate group in the community. Acute and chronic depression, anxiety or other chronic mental health problems can complicate care for patients at the end of life. Not all mental illness is severe, but nonetheless raises important care issues for the patient, caregiver/s, family and the health professionals. It is known that many people with mental illness have difficulty gaining appropriate identification, assessment and care of their physical illnesses and often do not receive diagnosis until late in an illness trajectory.¹² Furthermore, people with mental health problems or illness may have poorly met social, housing, income and support needs. Many palliative care units do not have the facilities to ensure patient safety or to manage difficult and challenging behaviours where these occur. Partnerships between mental health and palliative care services are necessary in most cases to achieve optimal

¹² Australian Health Ministers (2003). National Mental Health Plan 2003-2008. Australian Government, Canberra.

patient outcomes. Partnership between palliative care services and the wider social service sector are also necessary to meet the needs of patients with mental health problems or illness.

Adults who do not have the capacity to make informed choices

In order for a patient to be autonomous, or to make competent decisions in their own interest, they must be fully informed of the facts and probabilities, able to understand, able to make a voluntary and reasoned choice, and be able to communicate that choice. When a patient's autonomy is compromised, decision-making is supported using other agents, such as enduring guardian/ power of attorney, health care proxy or a guardianship order.

Managing the needs of patients with a life limiting illness, who are not able to make informed decisions on their own behalf, for example patients with dementia, requires careful attention to the decision-making and care delivery process. This will ensure that the needs of the patient remains the primary focus. In addition to the legal and moral requirement to obtain proxy consent and direction, patients should be afforded every possible opportunity to contribute as far as they are able to the care planning and decision-making process.

People who live in residential aged care

For some people a residential aged care facility will be their last home. It is important that residents of aged care facilities have access to the same range of community and inpatient based services available to people residing in their own homes. This will include access to appropriate and adequate levels of support from primary care services, general practitioners and aged care nurses, and access to consultative support and/or direct care from specialist palliative care services on an inpatient or community basis, depending upon their level of need.

People who live in other institutions or who are homeless

Each year a small number of people die in institutions other than hospitals or aged care facilities such as prisons, shared or group homes or hostels. Some homeless people may also require access to competent end of life care. It is important that services be flexible enough to meet the needs of these potentially highly vulnerable patients. Partnership models between health and community services, for example housing and justice health, should be in place to ensure that the needs of these patients can be appropriately met.

People of Aboriginal or Torres Strait Island descent

The historical journey of the Aboriginal people in Australia, particularly the period that extends from European colonisation, has major implications for their care at the end of life. Traditional beliefs surrounding the sacredness of the land and their relationship to it through the dreamtime are also central to end of life needs and practices. The health care providers relationship with the patient and their family should be based on trust and collaboration. The past experience of the Aboriginal peoples, particularly the experience of the *Stolen Generations*¹³ has led many to distrust government services including health care services. A care plan developed for an Aboriginal or Torres Strait Islander

person is best developed in partnership with Aboriginal controlled health organisations where they exist. Despite advances in government policy and Aboriginal rights, social indicators, including health indicators for Aboriginal people, remain the lowest of all Australian people. Understanding the impacts of past injustices and striving to eliminate discriminatory practices are important factors in improving social outcomes for Aboriginal Australians.¹⁴

Further research into the needs of Aboriginal people living with a life limiting illness, and at the time of death, is required to enable the development of comprehensive policies and procedures in palliative care.

¹³ Stolen Generations is a term that relates to groups of indigenous Australians who were forcefully removed as children from their parents under the Australian Government's protection and assimilation policies. These policies were not fully abolished until 1972 as a result of growing Aboriginal activism.

¹⁴ NSW Department of Health (2004). *Communicating positively: A guide to appropriate Aboriginal terminology*. NSW Health, Sydney.

Capabilities and Resources

The provision of quality care for people with life limiting illnesses, their caregiver/s and family is a commitment made to all Australians. The level and complexity of their need, as well as strengths and limitations of the patient, their caregiver/s and family will determine the appropriate level of service response for individual patients and families. The PCA policy document, *A Guide to Palliative Care Service Development: A population based approach (PCA, 2005)* describes a framework for accessing palliative care based on level of need. It articulates and describes the unique and interwoven roles of primary health care and specialist palliative care services

in collaborative efforts to provide high quality end of life care to the Australian people. The capability and resource framework described briefly here is based on that policy document.¹⁵ Specialist palliative care services are further defined by the level of resources available to them and by their expected capabilities. Criteria for the Standards have been developed according to the four levels contained within the Capability and Resource Matrix, that is Primary Care and Specialist levels 1, 2 and 3 Palliative Care.

The Matrix is shown in Table 1.

¹⁵ Palliative Care Australia (2005). *A Guide to Palliative Care Service Development: A population based approach*. PCA, Canberra.

Table 1: Capability and Resource Matrix

| Level | Capability | Typical resource profile |
|------------------------------------|--|---|
| Primary care | <p>Clinical management and care coordination including assessment, triage, and referral using a palliative approach for patients with uncomplicated needs associated with a life limiting illness and/or end of life care.</p> <p>Has formal links with a specialist palliative care provider for purposes of referral, consultation and access to specialist care as necessary.</p> | <p>General medical practitioner, nurse practitioner, registered nurse, generalist community nurse, aboriginal health worker, allied health staff. Specialist health care providers in other disciplines would be included at this level.</p> |
| Specialist palliative care level 1 | <p>Provides specialist palliative care for patients, caregiver/s and families whose needs exceed the capability of primary care providers. Provides assessment and care consistent with needs and provides consultative support, information and advice to primary care providers.</p> <p>Has formal links to primary care providers and level 2 and/or 3 specialist palliative care providers to meet the needs of patients and family/carers with complex problems. Has quality and audit program.</p> | <p>Multi – disciplinary team including medical practitioner with skills and experience in palliative care, clinical nurse specialist/consultant, allied health staff, pastoral care and volunteers. A designated staff member if available coordinates a volunteer service.</p> |
| Specialist palliative care level 2 | <p>As for level 1, able to support higher resource level due to population base (eg regional area). Provides formal education programs to primary care and level 1 providers and the community.</p> <p>Has formal links with primary care providers and level 3 specialist palliative care services for patients, caregiver/s and families with complex needs.</p> | <p>Interdisciplinary team including medical practitioner and clinical nurse specialist/consultant with specialist qualifications. Includes designated allied health and pastoral care staff.</p> |
| Specialist palliative care level 3 | <p>Provides comprehensive care for the needs of patients, caregiver/s and families with complex needs. Provides local support to primary care providers, regional level 1 and/or 2 services including education and formation of standards. Has comprehensive research and teaching role.</p> <p>Has formal links with local primary care providers and with specialist palliative care providers level 1 and 2, and relevant academic units including professorial chairs where available.</p> | <p>Interdisciplinary team including a medical director and clinical nurse consultant/ nurse practitioner and allied health staff with specialist qualifications in palliative care.</p> |

Adopting and implementing the Standards

It is important that the Standards are implemented in ways that support innovation and continual quality improvement. Using the Standards provides a meaningful framework for expressing quality in palliative care that enables services to ensure they meet industry endorsed benchmarks.

Primary care services

The criteria for primary care services apply to all Residential Aged Care Facilities, medical, oncology and other wards/units/services in the acute care sector, general practice and generalist community services - in fact to all services that may provide care for people who have a life limiting illness. Criteria for primary care providers should be adopted by these services as part of their quality projects and processes, including accreditation. Currently work is underway to link the Standards to formal accreditation programs, and to support their use as part of an organisation's quality assurance program.

All non-specialist health services that provide care to people with life limiting illness are required to meet the primary level criteria for Standards 1 to 13.

Role Delineation and the Standards for specialist services

All specialist palliative care services are required to meet level 1 criteria for all Standards (ie Standards 1–13). Some services will have additional delegated roles conferred through the clinical services planning process

at a regional or jurisdictional level. These roles will generally be related to the provision of additional consultancy, leadership and research functions that provide system wide benefit and that extend beyond the general expectations of contribution for health services and professionals. It would be expected that these additional functions would be supported with appropriate financial and human resources, and that formal relationships and agreements would be in place to enable the expectations to be achieved.

How do services determine which level of criteria apply?

Levels 1, 2 and 3 criteria describe the normative expectations for services, based on where they are positioned within the resource and capability framework (See Table 1). It sets out three broad service categories for specialist palliative care services, and describes these as levels 1 to 3. These categories represent the minimal (level 1), moderate (level 2) and maximal (level 3) points along a hypothetical continuum of resource availability and expected capability. While this is acknowledged as a relatively crude categorisation model, it is sufficiently flexible to allow services to customise utilisation of level 2 and 3 criteria based on evaluation of local conditions and expressed expectations, provided that the minimal standards expressed in level 1 are met by all services.

In the future?

Each of the states and territories are either in the process of developing or will develop a role delineation or resource and capability framework for palliative care services.

Assignment to a defined level of a local role delineation framework is based on agreement between service funding bodies, planners and providers. This agreement will cover the provision of resources and will also establish the expectations of service in terms of capacity, role and function.

The local role delineation frameworks should articulate with the generic framework for role delineation in palliative care as presented in the Standards. These local frameworks will provide specialist palliative care services with a more detailed description of the characteristics of services within each level. They will enable services to identify precisely the level of the criteria for each of the Standards that are appropriate for their service.

In the meantime?

Not all states and territories have finalised their role delineation framework for palliative care services. A review of work being undertaken around Australia conducted during the development of the NSW Resource and Capability Framework, indicated that there was considerable alignment between the role delineation frameworks being developed locally in each state and territory and the National Resource and Capability Matrix.¹⁶ A planned project to map the respective state and territory based role delineation frameworks to the National Resource and Capability Matrix will enable the comparison of performance and the aggregation of data at the national level.

Until such work is completed, all specialist palliative care services should, as a minimum, be required to meet the level 1 criteria for Standards 1 – 13 (ie all Standards). Services can align themselves on a voluntary basis against the additional criteria in level 2 and level 3 according to their usual roles and responsibilities.

¹⁶ Palliative Care Australia (2005). A Guide to Palliative Care Service Development: A population based approach. PCA, Canberra. p 39.

Understanding and navigating the Standards

The format for presenting the Standards is set out below to assist readers. Table 2 (below) describes the purpose of each of the components of the Standard.

Table 2: Structure for the Standards with explanation of terms.

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| Standard | Contains the specific Standard. There are 13 Standards. |
| Intent | A series of statements that provide further details as to the intent of the Standard to assist with interpretation. |
| Criteria | <p>Key elements of the Standard that are measurable or in evidence. It is understood that many areas of palliative care practice at primary and specialist levels are currently unable to be quantitatively 'measured' using validated tools or methods. In these cases qualitative or other forms of evidence should be explored to ascertain compliance with the Standards.</p> <p>The criteria are organised by role delineation levels as depicted in the Resource and Capability Framework (see Figure 1) to ensure that expectations are aligned with provided resources and are consistent with service capabilities. Specialist Criteria at each level also apply to higher levels unless otherwise specified.</p> |
| Primary care | <p>Criteria for primary care express the key elements of practice related to the Standard that represent quality equivalent to the resourced capability of a primary care service.</p> <p>Primary care criteria are applicable to all non-specialist health care services and providers that provide services to patients with life limiting illness. Primary care providers include aged care facilities, acute care services, generalist community services, general practitioners and other specialist areas, for example oncology, cardiology.</p> |
| Specialist palliative care level 1 | All palliative care service providers should be required to meet level 1 criteria as a minimum, unless otherwise stated. Criteria identified for level 1 represent the minimal acceptable standard for all specialist palliative care services. |
| Specialist palliative care level 2 | Level 2 criteria are applied where services have an additional role and/or function to provide consultation, education, research and leadership. |
| Specialist palliative care level 3 | Criteria that apply at level 3 reflect a capability to meet the most complex needs and provide a leadership role within the sector. |

Standards for Providing Quality Palliative Care for all Australians

Standard 1

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| <p>Standard 1</p> | <p>Care, decision-making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patients, their caregiver/s and families needs and wishes are acknowledged and guide decision-making and care planning.</p> |
| <p>Intent</p> | <p>The uniqueness of each patient, their caregiver/s and family members is respected, as is the importance of the community to which they belong. “Every person is in certain respects (a) like all others, (b) like some others, (c) like no other.”¹⁷</p> <p>The patient, their caregiver/s and family are considered the unit of care. The needs of individual members of the unit of care therefore need to be identified and addressed individually and balanced with service provider’s legal and professional responsibilities.</p> <p>Cultural brokers or others able to assist in crossing cultural boundaries for the purposes of providing care should be utilised to assist families to articulate and express their needs in culturally appropriate ways.</p> <p>Open and respectful communication with the patient, their caregiver/s and family will facilitate the sharing of relevant information regarding cultural beliefs and/or practices that may be beneficial to holistic well being.</p> <p>Information regarding the patient, their caregiver/s and family needs is most appropriately gathered over time, recognising the complexity of issues, the readiness of the patient, their caregiver/s and family, and the burden the assessment process itself can place on them.</p> <p>The culture¹⁸ and personal meanings disclosed or made evident during interaction with a service provider are integrated into the overall assessment and care planning of the patient, their caregiver/s and family</p> <p>For many Aboriginal people being able to die or be buried ‘on country’ is extremely important. Culturally sensitive care will seek wherever possible to assist Aboriginal people to return to their country at this time. Regular evaluation of the patient’s progress should be undertaken to ensure they are able to travel to their own country in sufficient time to achieve their goals.</p> |

17 Kluckholm C. and Murray H. (1948). Personality in Nature, Society and Culture. Alfred Knopf, New York.

18 Definition of culture: “a patterned behaviour response that develops over time through social and religious customs, intellectual and artistic activities. It is shaped by shared values, beliefs, norms and practices that are shared by members of the same culture”. Potter and Perry (2001). Fundamentals of Nursing. Harcourt. Australia. p 116.

| Criteria | |
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| Primary care | <p>The assessment and care-planning process specifically assesses and documents the needs and wishes of the patient, their caregiver/s and family. On-going assessment ensures that the changing of needs and wishes are identified and incorporated into the care plan.</p> <p>Communication with the patient, their caregiver/s and family is respectful of their preferences regarding disclosure, information giving, and decision-making. The patient’s wishes regarding the degree to which information may be shared with family members must be determined and should guide all communication with them. Ultimately the patient has a legal right to privacy that must be respected.</p> <p>The cultural needs, important relationships and responsibilities of the patient, their caregiver/s and family members are established. Ongoing communication with the unit of care respects these relationships and roles.</p> <p>Appropriate cultural resources, including interpreter services, are utilised during assessment, care planning and ongoing care delivery to assist patients, their caregiver/s and family members express their needs in culturally safe and individually relevant ways.</p> |
| Specialist palliative care level 1 | <p>The specific needs of Aboriginal people wishing to return to ‘country’ to die or be buried are respected and accommodated wherever possible, in consultation with their family and community. Regular evaluation of the patient’s progress should be undertaken to ensure they are able to travel to their own country in sufficient time to achieve their goals.</p> <p>Education and community development programs sensitive to the needs of the local community that promote and build awareness are developed and implemented. These programs are developed and delivered in partnership with local members of the community and cultural group/s.</p> |
| Specialist palliative care level 2 & 3 | <p>As for level 1 plus:</p> <p>Research initiatives and/or participation in research projects assist services to further the understanding of the palliative care needs of cultural and special needs groups.¹⁹</p> <p>Formal education and development programs that build awareness and a sensitivity to diverse cultural traditions are developed and delivered in collaboration with educational institutions, Aboriginal Health Organisations and other cultural representatives.</p> |

¹⁹ As discussed under section heading “Applying the Standards to special needs populations”.

Standard 2

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| Standard 2 | The holistic ²⁰ needs of the patient, their caregiver/s and family, are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes |
| Intent | <p>Health care providers use sensitive communication skills and allow sufficient time to enable patients to express their holistic needs and/or offer referral to appropriate support and/or counselling services.</p> <p>Members of the interdisciplinary team offer a diverse range of skills in the provision of emotional, religious or spiritual support, and it is recognised that all team members play a vital role.</p> <p>Health care providers make available information resources and other options so that the patient their caregiver/s and family can make informed choices.</p> <p>It is recognised that patients, their caregiver/s and families also have strengths and expertise in managing their own care.</p> |
| Criteria | |
| Primary care | <p>The holistic needs of the patient, their caregiver/s and family are acknowledged in the assessment and care planning process.</p> <p>Formalised networks with specialist palliative care services are established to ensure that patients whose needs exceed primary palliative care service capability are referred to appropriate specialist services.</p> <p>The patient's primary caregiver is identified and supported in their role with education, information, support, explanation and encouragement.</p> |
| Specialist palliative Care level 1 | <p>Care planning incorporates an interdisciplinary specialist assessment and care planning process in partnership with primary care services to address the holistic needs of patients, their caregiver/s and family.</p> <p>Access to a range of specialist professionals is available to ensure that the holistic needs of patients, their caregiver/s and family can be appropriately addressed. Where specialist positions cannot be supported locally, formal arrangements are in place to enable access to specialist care for patients when required.</p> <p>The palliative care service, on behalf of patients, their caregiver/s and families, facilitates appropriate contacts with community based religious or spiritual leaders, or support groups.</p> <p>Education and support for all staff and volunteers is provided to enable them to give supportive care which meets patient, their caregiver/s and family needs.</p> |

²⁰ Holistic is a whole made up of interdependent parts. You are most likely to hear these parts referred to as the mind/ body connection; mind/ body/ spirit, or physical/ mental/ emotional/ spiritual aspects. When this meaning is applied to illness, it is called holistic medicine and includes a number of factors, such as dealing with the root cause of an illness; increasing patient involvement; and considering both conventional and complementary therapies.

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| <p>Specialist palliative care level 2</p> | <p>As for level 1 plus:</p> <p>Counsellors, spiritual and/or pastoral care workers are available as a core part of the interdisciplinary service to provide comprehensive care to patients, their caregiver/s and family who have complex care needs and to provide guidance to staff and volunteers.</p> <p>Formal education programs that promote the use of holistic assessment and care delivery skills are developed and implemented.</p> <p>In consultation with local religious leaders/services the palliative care service has appropriate resources to inform staff about customs, rituals and icons important for individual religious expression.</p> |
| <p>Specialist palliative care level 3</p> | <p>As for level 2 plus:</p> <p>Specialist allied health, counselling, pastoral care and clinical support roles are available to ensure that the needs of patients, their caregiver/s and family can be addressed.</p> <p>Consultation-based support is provided for level 1/2 and primary care services to enable them to address complex needs of patient's being cared for.</p> <p>Formal education programs that develop understanding and capability related to the holistic needs of patients, caregiver/s, families and communities are developed and implemented.</p> <p>The service undertakes a leadership role in research and/or implementation of research findings related to holistic care of patients with life limiting illness.</p> |

Standard 3

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| Standard 3 | Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family. |
| Intent | <p>The needs, strengths, understandings and expectations of the patient, their caregiver/s and family are documented and reflected upon in the assessment. The patient, their caregiver/s and family are encouraged to express their care needs during the assessment and care planning process.</p> <p>Health care providers performing this function are flexible in timing and methods so that the assessment is as unobtrusive as possible.</p> <p>The ongoing gathering and recording of information is considered to be an integral part of assessment and care planning.</p> <p>Where discharge from the service is anticipated a comprehensive discharge plan is initiated on admission. Discussion and documentation of the patient, their caregiver/s and family wishes about end of life care is also begun as is appropriate for the expectations of the patient, their caregiver/s and family.</p> |
| Criteria | |
| Primary care | <p>A comprehensive, holistic initial and ongoing assessment is undertaken and documented for all patients with a life limiting illness.</p> <p>Treatment and care decisions are based on established or agreed protocols developed in conjunction with specialist palliative care services and based on best available evidence.</p> <p>Treatment options and choices are clearly explained to enable the patient and their caregiver/s and family to make informed decisions.</p> <p>Care plans are responsive to the changing needs of the patient and their caregiver/s and family and the changing phase of the patient's illness.</p> <p>Effective referral policies and procedures are established to ensure appropriate and seamless care is available for patients, their caregiver/s and families.</p> <p>Discharge plans are prepared that include readmission protocols and ongoing support strategies for the patient, their caregiver/s and family.</p> |
| Specialist palliative care level 1 | <p>The assessment process and documentation reflects an interdisciplinary approach and is coordinated to reduce repetition of history taking or clinical assessment.</p> <p>Assessment tools that have demonstrated validity and sensitivity with specific populations are used when appropriate.</p> <p>Specialist, consultation-based assessment of patients referred by primary care services is provided with recommendations for ongoing management of identified problems.</p> |
| Specialist palliative care level 2 & 3 | <p>As for level 1 plus:</p> <p>Consultation-based assessment for patients whose needs exceed the resource capability of Primary Care or level 1 services is provided with recommendations for ongoing management of identified problems.</p> <p>Research to understand the needs of patients, their caregiver/s and families is initiated and findings are integrated into policy and practice.</p> <p>Education and training programs to develop assessment and care planning skills specific to palliative care are implemented.</p> |

Standard 4

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| Standard 4 | Care is coordinated to minimise the burden on patient, their caregiver/s and family. |
| Intent | <p>Recent studies and other feedback indicates that lack of coordination of care and services increases the stress experienced by the patient, their caregiver/s and family and that alleviation of this would add significantly to their quality of life.^{21,22,23,24}</p> <p>Scheduling of care, interventions and/or visits provides opportunities for rest and privacy according to the wishes of the patient, their caregiver/s and family.</p> <p>Communication between service providers facilitates the smooth and timely delivery of services.</p> <p>The patient, their caregiver/s and family provide informed consent to communication and sharing of information between service providers.</p> |
| Criteria | |
| Primary care | <p>Formal networks are established between services to provide holistic care and minimise unnecessary duplication of services.</p> <p>One health care provider is identified as the coordinator of care (lead agency) and this is communicated to and accepted by other care providers involved.</p> <p>The patient, their caregiver/s and family have clear written instructions, negotiated with local specialist service providers, about how to seek help if needed in 'after hours' or unanticipated situations.</p> <p>A plan is in place for certification of death should this occur out of hours.</p> <p>A plan is in place for informing relevant authorities of any notifiable deaths.</p> <p>Networks are established to provide respite and supportive care for caregiver/s and family members as appropriate (for example, social work, respite service, carer support groups).</p> |
| Specialist palliative care level 1 | <p>Effective referral policies and procedures and ongoing communication strategies are established between specialist and non-specialist services to ensure continuity of care for patients, their caregiver/s and family. Duplication of effort is minimised.</p> <p>Primary care providers remain involved in the care of patients, their caregiver/s and family. Ongoing assessment is undertaken to ensure most appropriate point for care coordination.</p> |
| Specialist palliative care level 2 & 3 | <p>As for level 1 plus:</p> <p>Research or service development initiatives that improve understanding of service level needs and outcomes for palliative care patients their caregiver/s and families are initiated and/or implemented.</p> <p>Contributions are made to the development of formal training and education programs/initiatives to support service development.</p> <p>Consultative advice and support is provided to specialist and non-specialist services to facilitate system-wide service enhancement and development.</p> |

21 Palliative Care Australia (2004). The Hardest Thing We Have Ever Done – The Social Impact of Caring for Terminally Ill People in Australia. PCA, Canberra.

22 Australian Government Department of Health and Ageing (2004). National Indigenous Palliative Care Needs Study. Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing, Canberra.

23 Australian Government Department of Health and Ageing (2003). Paediatric Palliative Care Service Model Review Final Report, Rural Health and Palliative Care Branch. Australian Government Department of Health and Ageing, Canberra.

24 Presentation by Millward Brown Firefly to PCA (2004). Consumer and Sector Consultation on the National Palliative Care Standards.

Standard 5

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| Standard 5 | The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes. |
| Intent | <p>The primary caregiver plays a pivotal care-coordinating role in the care of the patient, particularly in community contexts where the patient is being cared for at home. Primary caregiver/s may also have an important role during periods of inpatient care or hospitalisation to continue to provide support and care.</p> <p>The role of primary caregiver, although often rewarding, can also be stressful. A particular focus on the specific and personal needs of caregiver/s would allow them to better fulfil their role and reduce the associated stress.²⁵ This may include support that facilitates effective negotiation where patient, caregiver/s and/or family experience conflicting needs.</p> |
| Criteria | |
| Primary care | <p>The primary caregiver/s is identified by the patient and their caregiver/s and family at initial assessment. This is re-confirmed on an on-going basis.</p> <p>The needs of the primary caregiver/s are assessed independently and are documented along with supportive strategies in the plan of care. The need for information, emotional support, education and respite relevant to their role is assessed and included in the care plan.</p> <p>Networks are established to provide respite and supportive care for caregiver/s and family members as appropriate (for example, social work, respite services, carer support groups).</p> <p>The primary caregiver/s is provided with information about relevant organisations and government services that may be beneficial.</p> <p>Caregiver/s are encouraged to practice self-care activities that may minimise stress and promote their wellbeing and safety.</p> |
| Specialist palliative care level 1 | <p>Specialised information, resources and materials relating to care needs are available for patients, their caregiver/s and family.</p> <p>Support and assistance to primary care services to meet the needs of caregiver/s is provided.</p> |
| Specialist palliative care level 2 & 3 | <p>As for level 1 plus:</p> <p>Education and information resources are developed and/or available to provide support to primary care services and meet the needs of caregiver/s.</p> <p>Networks and formal agreements are in place to ensure that the identified needs of caregiver/s can be met.</p> |

²⁵ Palliative Care Australia (2004). The Hardest Thing We Have Ever Done – The Social Impact of Caring for Terminally Ill People in Australia. PCA, Canberra.

Standard 6

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| Standard 6 | The unique needs of dying patients are considered, their comfort maximized and their dignity preserved. |
| Intent | <p>Health care providers need to be experienced and skilled in recognising when the terminal phase of the life limiting illness has begun. This is important in order to facilitate appropriate care for the patient, their caregiver/s and family.</p> <p>The patients, their caregiver/s and families psychosocial, emotional, cultural and spiritual needs, belief systems and values regarding death and dying are addressed and respected.</p> <p>Patients, their caregiver/s and families are assisted to prepare and plan for death by discussing expectations to reduce fear and increase involvement, by discussing death certification processes, and by encouraging them, if able, to express their feelings and last wishes and to say their goodbyes.</p> |
| Criteria | |
| Primary care | <p>Regular and ongoing assessment of the patient identifies transition into the terminal phase.</p> <p>End of life issues and anticipation of death are honestly discussed with the patient, their caregiver/s and family in a socially and culturally appropriate manner.</p> <p>Symptoms at the end of life are assessed and documented with appropriate frequency and treatment and care is based on patient, their caregiver/s and family needs and wishes.</p> <p>The caregiver/s and family members are given information regarding the signs and symptoms of approaching death in a manner appropriate to their individual needs and circumstances.</p> <p>Provision is made to enable the patient and family to participate in customary or religious end of life rituals that have meaning for them.</p> <p>Immediately following the death of the patient and during the early bereavement phase, caregiver/s and families are given time and continuing care to provide comfort, and assist with adjustment to the death of the patient.</p> <p>Plans are in place for the certification of death should this occur out of hours.</p> <p>All providers of care (in particular the patient's general practitioner) receive information about the end phase of illness and/or death as soon as possible.</p> <p>Personal communication via telephone precedes official written communication.</p> |
| Specialist palliative care level 1 | Guidance and support is given to primary care providers regarding decision making and end of life care. |
| Specialist palliative care level 2 & 3 | <p>As for level 1 plus:</p> <p>Protocols to guide care at the end of life are developed and disseminated.</p> <p>Processes are established to respond to the need for urgent assessment and guidance.</p> <p>Guidance and support is available to health care providers seeking advice about ethical dilemmas related to end of life care and decision-making.</p> |

Standard 7

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| Standard 7 | The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care. |
| Intent | <p>Palliative care aims to relieve suffering and improve the quality of living and dying.</p> <p>Palliative care strives to help patients, their caregiver/s and family to:</p> <ul style="list-style-type: none"> • address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes, and fears; • prepare for and manage end of life and the dying process; and • cope with loss and grief during the illness and bereavement. <p>Palliative care may complement and enhance disease-modifying therapy or it may be the total focus of care.²⁶</p> <p>Palliative care is most effectively delivered by an interdisciplinary team²⁷ of health care providers who are both knowledgeable and skilled in all aspects of their discipline of practice as it relates to end of life care.²⁸ Effective communication, group function and the ability to promote and manage change are important elements in interdisciplinary teamwork.²⁹</p> <p>When patients do not require specialist palliative care a palliative approach should be adopted by primary care providers and other specialists. This approach incorporates a concern for the holistic needs of the patient, includes the caregiver/s and families needs, and is based on an open and receptive attitude towards death and dying.</p> <p>Appropriate expertise is available to meet the needs of the patient, their caregiver/s and family. This expertise is not always available in a single service and requires appropriate links to be established between services to ensure the patient, their caregiver/s and family have access to expertise irrespective of the geographic location or size of service.</p> |
| Criteria | |
| Primary care | Primary care providers have access to education about the principles, objectives and practices of palliative care as they relate to these Standards and local palliative care provision. |

²⁶ Adapted from Ferris F D, Balfour H M, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. (2002). A Model to Guide Hospice Palliative Care: Canadian Hospice Palliative Care Association. Ottawa, ON p 17.

²⁷ Is defined as a team of caregiver/s who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified expectations and needs. An interdisciplinary team typically includes one or more physicians, nurses, social workers/psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may be part of the team if resources permit. Adapted from the Centre to Advance Palliative Care. Available at www.capc.org.

²⁸ Adapted from Ferris F D, Balfour H M, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. (2002). A Model to Guide Hospice Palliative Care. Canadian Hospice Palliative Care Association. Ottawa, ON, p 18.

²⁹ Ibid, p 21.

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| Specialist Palliative Care | <p>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.</p> <p>Staff receive education about these Standards and structure their practice to reflect expectations within their resource level. The team has an expressed philosophy and values that inform its programs and activities and ensure that these Standards are achieved.</p> <p>The composition of the team includes specialist palliative care practitioners drawn from a wide range of disciplines that will support and enable the service to meet the cultural, physical, psychological, social and spiritual needs of the patient, their caregiver/s and family.</p> |
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Standard 8

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| Standard 8 | Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information and support services. |
| Intent | <p>Emotional and spiritual support focussed on loss and grief includes the patient, their caregiver/s and family and begins when a life limiting illness is diagnosed. Ongoing support based on self-identified need is offered to the caregiver/s and family.</p> <p>Bereavement support before and after death of the patient may assist reducing the morbidity associated with loss and grief for the patient, their caregiver/s and family.</p> <p>The majority of people will integrate their loss into their life with the support of their own community.</p> <p>Evidence suggests that personal and social circumstances may place some caregiver/s at increased risk of experiencing bereavement problems.³⁰</p> |
| Criteria | |
| Primary care | <p>Information (both verbal and written) on loss and grief and the availability of bereavement support services is routinely provided to family members prior to and after the death of the patient.</p> <p>Bereavement risk for caregiver/s and family members is assessed during the patient's illness and support is offered based on need.</p> |
| Specialist palliative care level 1 | <p>The palliative care service has policies and procedures for its bereavement support program.</p> <p>Staff and volunteers who are routinely involved in bereavement support are trained and provided with regular supervision and support.</p> <p>A directory of professional counselling resources is available and referral is offered as appropriate.</p> |
| Specialist palliative care level 2 | <p>As for level 1 plus:</p> <p>A designated appropriately qualified person coordinates the bereavement support program.</p> <p>Education about loss, grief and bereavement is provided for staff, volunteers and the community including those working in primary care and level 1 services.</p> |
| Specialist palliative care level 3 | <p>As for level 2 plus:</p> <p>Experts in psychology and psychiatry related to grief, loss and bereavement are available for referral in situations involving complex needs.</p> <p>Emotional and bereavement support is provided to the patient's family and caregiver/s before and after the death. The needs of dying children, their siblings and parents are assessed and ongoing and seamless support is provided as required.</p> |

³⁰Aranda S and Milne D. (2000). Guidelines for the assessment of complicated bereavement risk in family members of people receiving palliative care. Centre for Palliative Care, Melbourne.

Standard 9

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| Standard 9 | <p>Community capacity to respond to the needs of people who have a life limiting illness, their caregiver/s and family is built through effective collaboration and partnerships.</p> |
| Intent | <p>Good palliative care builds community capacity and reclaims the notion that death is a part of life. Promoting community awareness towards the normalcy of death, dying and bereavement can have a significant impact on the level of distress experienced within the community.</p> <p>Members of the community are given an opportunity to contribute to the development of systems and services that meet the requirements of people who have palliative care and bereavement needs.</p> <p>Palliative care services through their knowledge and experience of death, dying and bereavement are an invaluable resource to the community. Facilitating a positive and open discussion will increase general knowledge and understanding of these aspects of life.</p> <p>Community understanding is best served by an awareness that a palliative care approach or service can be provided for people living with a life limiting illness at appropriate times to maximise quality of life and alleviate suffering.</p> <p>Information is available to the community, patients, their caregiver/s and family in various formats, languages and styles.</p> |
| Criteria | |
| Primary care | <p>Opportunities to increase community awareness and capacity are identified and acted upon.</p> <p>Primary care providers respond to consultations and provide information that contributes to social and health policy development.</p> |
| Specialist palliative care level 1 | <p>Palliative care services take the opportunity to raise awareness of palliative care and services available to individuals and groups within the community including through the establishment of effective media liaison mechanisms.</p> <p>Palliative care services, through their staff and volunteers, represent palliative care and participate in the promotion and support of local and national palliative care awareness initiatives.</p> <p>Palliative care services collect and report data on social and community need as required.</p> <p>Palliative care services access and utilise information that assists them in developing service systems which address the needs of the community they serve (eg demographic profiles including common cause of death, and special needs groups).</p> <p>Links are established with other service providers and relevant community, local and state government organisations as a means of facilitating policy directions.</p> |

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| Specialist palliative care level 2 | <p>As for level 1 plus:</p> <p>Education programs/activities are developed in collaboration with community groups and where possible professionals qualified in health promotion.</p> <p>Palliative care services together with community members contribute to the development of policies and structures that address the palliative care needs of their community.</p> |
| Specialist palliative care level 3 | <p>As for level 2 plus:</p> <p>Research that contributes to the understanding of the needs of populations is conducted and disseminated to decision makers and the community.</p> <p>Leadership is provided to advocate for the appropriate development of palliative care services.</p> |

Standard 10

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| Standard 10 | Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography. |
| Intent | <p>Palliative care services are actively involved in the development of policies and structures that increase equity of access to services based on level of need.</p> <p>Palliative care services at all levels have formal links that facilitate patient and family access to more or less complex care based on level of need.</p> <p>Direct care from a specialist palliative care service may be episodic rather than ongoing, and based on specific complex needs.</p> <p>Specialist palliative care services support the work of primary care services through the availability of direct consultation and training.</p> |
| Criteria | |
| Primary care | <p>Patients are informed of the availability of palliative care services as soon as appropriate after the diagnosis or recognition of a life limiting illness. Choices and options available to the family are discussed with them at this time to ensure their needs and wishes can be accommodated in the care plan.</p> <p>Formal partnership agreements are established with specialist palliative care services to ensure that patients can be referred to specialist care when required for consultation and/or management.</p> <p>Referral to a palliative care service is initiated when the patient's needs exceed the resourced capability (including available expertise) of the primary care service.</p> |
| Specialist Palliative Care | <p>Formal partnerships with primary care services are established to ensure that patients can move smoothly between primary and specialist services based on their level of need.</p> <p>Patients, caregiver/s and families have access to specialist telephone assessment and advice on a 24-hour 7-day basis.³¹</p> <p>Primary care services have access to 24-hour 7-day telephone assessment and advice to support them in their care of patients with life limiting illnesses.</p> <p>The patient, their caregiver/s and family 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.</p> <p>Resources are allocated to respond to urgent needs.</p> <p>Protocols document processes for responding to palliative care emergencies.</p> <p>Processes and strategies exist to provide direct after hours support if required by patients and primary caregiver.</p> <p>The palliative care service has formal links with specialists³² in other fields to ensure access to expert advice and management of patients with specific needs in these areas.</p> |

³¹ Nursing expertise with additional medical support is required, but can be arranged at a regional level.

³² For example, surgeons, physicians, radiotherapists, oncologists, psychologists, allied health and so on.

Standard 11

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| Standard 11 | The service is committed to quality improvement and research in clinical and management practices. |
| Intent | <p>Services are committed to providing the best possible quality of care for people living with life limiting illness and participate in quality programs and research projects to meet these goals. These quality management programs are based on evaluation and continuous improvement principles.</p> <p>Ensuring the safety and quality of palliative care is the responsibility of all care providers. In practice, many sources of knowledge inform care decisions. Research evidence is one source of knowledge that can be used to improve care outcomes, when it is considered and applied in the context of a patient's individual preferences and clinical circumstances. Evidence based practice requires the integration of clinical expertise with the best available evidence and patient values.³³</p> <p>Participation in research will vary based on the capacity of the service and will range from contributing to or facilitating data collection for research, to initiating research projects based on collaboration with others.</p> <p>Participation in external accreditation programs assists in development of structured quality improvement programs including evaluation of patient care and service outcomes.</p> <p>The service is evaluated from the perspectives of the patient and their caregiver/s and family, health professionals and the community.</p> <p>All evaluation and research should comply with the <i>National Health & Medical Research Council Guidelines for Ethical Practice</i>.³⁴</p> |
| Criteria | |
| Primary care | <p>Primary care providers undertake quality improvement and research activities, including processes appropriate to their role as primary care providers for patients with life limiting illness.</p> <p>Primary care services participate with specialist palliative care services in palliative care research and quality activities.</p> |
| Specialist palliative care level 1 | <p>Policies and procedures to guide a program of quality improvement and research exist within the palliative care service.</p> <p>There is evidence of the dissemination and incorporation of research and quality improvement findings into practice.</p> <p>Clinical and performance criteria are consistent with professional standards.</p> |

³³ Sackett, D L & Straus, S (1998). Finding and applying evidence during clinical rounds. The Evidence Cart. The Journal of the American Medical Association, 280, p 1336-8.

³⁴ National Health and Medical Research Council/ Australian Vice Chancellors' Committee (1997). Joint NHMRC/AVCC Statement and Guidelines on Research Practice NHMRC/ AVCC. Australian (Currently under revision). Also available at www.nhmrc.gov.au/issues.

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| <p>Specialist palliative care level 2</p> | <p>As for level 1 plus:</p> <p>Quality improvement and research programs are collaborative, interdisciplinary and focussed on the identified needs of patients, caregiver/s, families and the community.</p> <p>Benchmarking with other service providers is undertaken as a means of developing quality and implementing better practice.</p> <p>Mechanisms are established for involving community members in service development and evaluation.</p> <p>Strategies for facilitating the uptake of new knowledge and evidence about palliative care are implemented.</p> |
| <p>Specialist palliative care level 3</p> | <p>As for level 2 plus:</p> <p>Protocols, standards and projects to support ongoing service evaluation and development are constructed and disseminated. Research is conducted in collaboration with other palliative care and primary care service providers and academic units.</p> |

Standard 12

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| Standard 12 | Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development. |
| Intent | All health professionals should demonstrate capabilities in providing a palliative approach to care of patients, caregiver/s and families as required. Health professionals and volunteers involved in the provision of palliative care at any of the resource levels undertake appropriate continuing professional development to ensure that quality care is provided. |
| Criteria | |
| Primary care | Continuing professional development in the principles and practices of palliative care is available, including referral criteria and processes. |
| Specialist palliative care level 1 | A continuing education program for staff and volunteers is in place. The service provides outreach education for other health professionals to facilitate the development of a palliative approach in the wider health care community. Education resource materials are available for staff to support the development of specialist knowledge and skills. |
| Specialist palliative care level 2 & 3 | As for level 1 plus: The service provides education for primary care and level 1 specialist palliative care services and evaluates its programs. Staff contribute to, and participate in, the provision of undergraduate and postgraduate education in palliative care. Staff provide leadership and education within the service have relevant qualifications and experience. |

Standard 13

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| Standard 13 | Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies. |
| Intent | <p>The provision of care for people who are dying and their caregiver/s and family can have an emotional and spiritual effect on staff (and volunteers). Education about potential effects and possible management strategies need to be provided to maintain sustainable practice and services.</p> <p>Opportunities to reflect upon and express feelings related to interaction with patients, their caregiver/s and family needs to be part of the palliative care service culture and structure.</p> |
| Criteria | |
| Primary care | Mechanisms for support are identified and utilised as required. |
| Specialist Palliative Care | <p>The team identifies and maintains formal and informal mechanisms necessary to provide support for individuals. Primary care providers are included in this according to their needs and wishes.</p> <p>Strategies are in place to provide situational support for staff and volunteers.</p> <p>Specific policies guide the support and care of staff, including critical incident debriefing and response.</p> <p>Education is available to enable staff and volunteers to develop effective coping strategies to minimise the personal impact of working in the palliative care service.</p> <p>Staff have access to confidential employee assistance programs and/or appropriate counselling services.</p> |

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