National Palliative Care Standards

5TH EDITION – 2018

PalliativeCare
AUSTRALIA

Acknowledgements

Contents

Chair's Foreword

Palliative Care Australia (PCA) is delighted to provide the community with the 5th edition of the National Palliative Care Standards. The enthusiasm with which the review and consultation process was received indicates the importance of articulating the components of quality palliative care which are reflected in the 5th edition of the Standards.

Much has changed within the speciality of palliative care since the first National Standards were written in 1994, with the current edition having a strong focus on the provision of care that is person-centred and age-appropriate. The person, their family and carers are a unit that experience palliative care, but each of these have individual needs that should also be recognised.

Furthermore, providing quality palliative care relies upon a committed team of professionals and volunteers who assist the person, their family and carers. The aim of the 5th edition of the Standards is to articulate a vision for the provision of holistic, individualised, sensitive and best practice palliative care as we approach new and demanding challenges in the health sector.

PCA is extremely grateful for the collaboration and work of a large group of people in bringing these Standards to fruition. PCA commends these Standards to you as a tool to assist in the delivery of quality care for all Australians at the end of life.

Andrew Allsop
Chair, Standards Review Group

President's Foreword

On behalf of Palliative Care Australia (PCA) would like to thank Andrew Allsop and the members of the Standards Review Group for their commitment to ensuring this 5th Edition of the National Palliative Care Standards are contemporary and encompass all aspects of high-quality palliative care.

PCA looks forward to continuing to support services to deliver best-practice palliative care that is person and family centred. On behalf of the Board of PCA, I commend these Standards to you and encourage you to adopt them in your practice. Together, we will work towards achieving our vision of quality palliative care for all.

Dr Jane Fischer
President Palliative Care Australia

Introduction

These Standards (5th edn) have been updated following consultation with the palliative care community and other stakeholders. Much has changed within palliative care over the past decade, including expansion of the evidence base for clinical care, re-design of service delivery models of care to meet changing community expectations and needs, and changes to the language used to describe those we care for. **Most importantly there is increasing recognition that caring for people who are approaching and reaching the end of life is everybody's business – everybody in health, aged and community care has a role to play.**

Palliative Care Australia (PCA) defines palliative care in the contemporary Australian context as:

Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.

PCA considers that the following elements are integral to understanding this definition of palliative care:

» Palliative care should be strongly responsive to the needs, preferences and values of people, their families and carers. A person and family-centred approach to palliative care is based on effective communication, shared decision-making and personal autonomy.

» Palliative care should be available to all people living with an active, progressive, advanced disease, regardless of the diagnosis.

» Palliative care affirms life while recognising that dying is an inevitable part of life. This means that palliative care is provided during the time that the person is living with a life-limiting illness, but it is not directed at either bringing forward or delaying death.

These Standards clearly articulate and promote a vision for compassionate and appropriate specialist palliative care. The Standards recognise the importance of care that is person-centred and age-appropriate. In particular they point to the requirement for specific attention to the needs of people who may be especially vulnerable or at risk.

The Standards need to be relevant to those specialist palliative care services with a sole practitioner, as well as larger services that are more resourced with comprehensive research and teaching roles – and to everything in between. They are generally normative standards but also incorporate aspirational components to support those services with growing capacity and capability.

This 5th edition of the Standards has been developed to reflect the significant changes that have occurred since 2005 and to continue to support specialist palliative care services as they work to ensure that the people they service have access to the highest quality of care as they approach and reach the end of life.

Development of the National Palliative Care Standards 5th Edition

PCA began the Standards revision process in 2013. At this time the palliative care community felt strongly that any revision to the Standards should be done carefully, with deep consideration and input from the sector, and in reference to current evidence to ensure the 5th edition of the Standards adequately reflect the evolution of palliative care. As such, PCA took the decision to recommence the review process when adequate resources could be allocated towards this important piece of work.

The revision of the Standards was recommenced in 2015 with the establishment of the Standards Review Group, who have presided over the ongoing revision and consultation process. This panel of palliative care clinicians, researchers and executives closely examined the 4th edition of the Standards to identify their strengths, limitations, gaps and areas of duplication. This group developed the first draft for review.

There were two consultation rounds for the draft 5th edition of the Standards. Firstly feedback was sought from PCAs National Policy Advisory Committee (NPAC), Member Organisations and Affiliate Members from May to August 2017.

The second round of consultation involved an online survey in September 2017, culminating in receipt of 55 responses from palliative care services who previously engaged with the National Standards Assessment Program (NSAP), people or organisations with a vested interest in the Standards, and affiliated government bodies. Where necessary, additional specialist feedback was sought from experts in a particular area.

In summary, a rigorous and extensive consultation process has supported the development of the 5th edition of the Standards. PCA is grateful for the wide interest and input it has received in the revision process and hopes that you find value in the 5th edition of these Standards.

Mapping of the Standards

There is a growing number of standards that relate to the care of people approaching and reaching the end of life. Some are relevant to all services while others are specifically targeted at components of the health, aged and community care systems, for example aged care or acute care hospitals. These Standards are designed to complement other standards programmes. To assist services to identify these intersections and avoid duplication of effort, PCA have undertaken internal mapping of these Standards against standards of the agencies listed below:

» The Australian Commission on Safety and Quality in Health Care (ACSQHC) National Safety and Quality Health Service (NSQHS) Standards (Version 2)[1]

» The ACSQHC National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care[2]

» The ACSQHC National Consensus Statement: Essential Elements for Safe and High-Quality Paediatric End-of-Life Care[3]

» The Accreditation Standards, as identified in the Quality of Care Principles 2014 and administered by the Australian Aged Care Quality Agency (AACQA)[4]

» The previous version of Palliative Care Australia's Standards for Providing Quality Palliative Care for all Australians (2005)[5]

PCA will continue to work with key stakeholders as newer versions of any relevant standards are released.

Core Values of the National Palliative Care Standards

Quality palliative care is provided by professionals who:

» Endeavour to maintain the dignity of the person, their family and carers,

» Work with the strengths and limitations of the person, their family and carers to empower them in managing their own situation;

» Act with compassion towards the person, their family and carers,

» Consider equity in the accessibility of services and in the allocation of resources;

» Demonstrate respect for the person, their family and carers;

» Advocate on behalf of the expressed wishes of the person, their family, carers and communities;

» Are committed to the pursuit of excellence in the provision of care and support;

» Are accountable to the person, their family, carers and the community.

In order to ensure high quality, person-focused and evidence-based services are available to meet peoples' needs, primary care and specialist providers, as well as, other 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;

» Participate in continuing professional development in the knowledge, attitudes, and skills required to deliver quality palliative care.

The National Palliative Care Standards – Overview

Standard 1	Initial and ongoing assessment incorporates the person's physical, psychological, cultural, social and spiritual experiences and needs.
Standard 2	The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan.
Standard 3	The person's family and carers needs are assessed and directly inform provision of appropriate support and guidance about their role.
Standard 4	The provision of care is based on the assessed needs of the person, informed by evidence and is consistent with the values, goals and preferences of the person as documented in their care plan.
Standard 5	Care is integrated across the person's experience to ensure seamless transitions within and between services.
Standard 6	Families and carers have access to bereavement support services and are provided with information about loss and grief.
Standard 7	The service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative care and end-of-life care.
Standard 8	Services are engaged in quality improvement and research to improve service provision and development.
Standard 9	Staff and volunteers are appropriately qualified, are engaged in continuing professional development and are supported in their roles.

How to Use the Standards

The Standards have been developed to be used by specialist palliative care services to support the delivery of high quality palliative care for the person receiving care (the person), their family and carers. Implementation of the Standards should occur in accordance with the *Privacy Act 1988*, associated Australian Privacy Principles and other relevant local and national health policies.

The Standards are divided into two categories (as shown in Figure 1):

» Care Standards (Standard 1 to 6) which describe the systems and enablers necessary to deliver high quality clinical care, and

» Governance Standards (Standard 7 to 9), which describe expectation in regards to quality management, quality improvement and benchmarking.

The Standards are self-assessed by tools and resources available under PCA's Palliative Care Self-Assessment (PaCSA), formerly the National Standards Assessment Programme (NSAP).

Figure 1: The National Palliative Care Standards

Assessment of needs	Developing the care plan	Caring for carers	Providing care	Transitions within and between services	Grief support
Standard 1	Standard 2	Standard 3	Standard 4	Standard 5	Standard 6

Service culture	Quality improvement	Staff qualifications and training
Standard 7	Standard 8	Standard 9
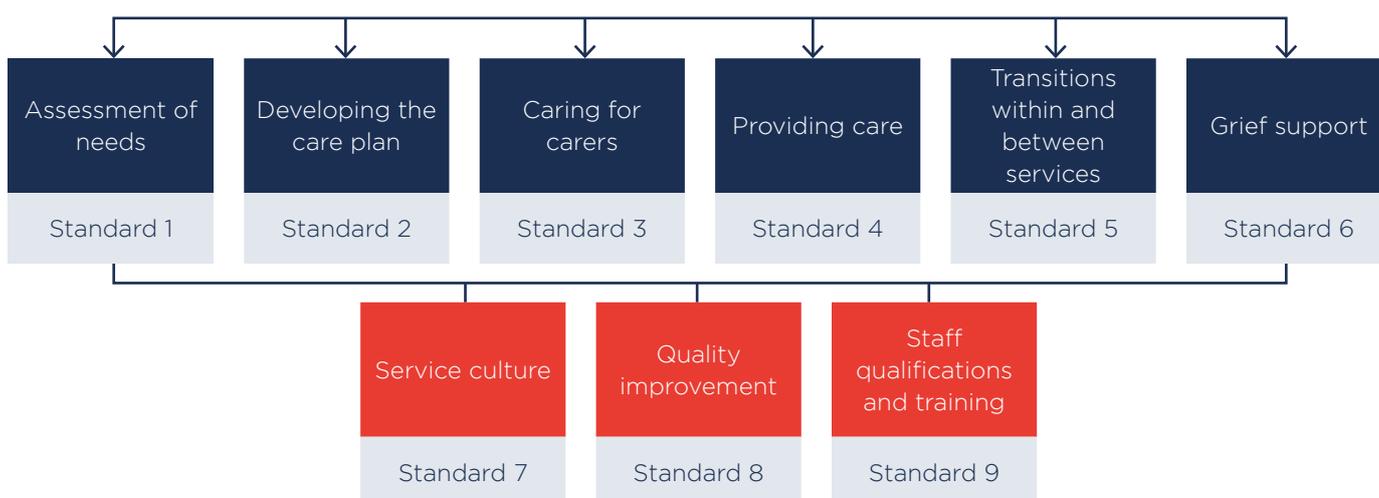
The table following describes the purpose of each of the components of the Standards.

Standard	Contains the specific Standard. There are 9 standards.
Intent of the Standard	A series of statements that provide further detail and explanation to assist with interpretation.
Standard elements	The quality components of the Standard to which services are encouraged to aspire.

Applying the Standards to Underserved Population Groups

The provision of effective palliative care should directly benefit the individual, but also support the family as a preventive health initiative, which can have long term implications for family functioning, mental health, education and employment.

Providing palliative care is complex and can include a number of people who are invested in the caring process. For health professionals, the complexities include a collaborative decision-making approach that encompasses the wishes of the individual, family and the clinicians involved. At a systems level, palliative care should be available to all individuals and their families who are living with life-limiting illnesses or conditions on a needs basis. This requires a collaborative approach between clinicians from a range of disciplines, specialties in the paediatric and adult sector and colleagues in the palliative care sector. In addition, it also requires support from Commonwealth and State and Territory Governments with their responsibility for the planning and provision of the workforce and the services.[6,7]

Children with a life-limiting conditions

Caring for infants (including the perinatal period), children and adolescents (referred to as child or children) with a life-limiting condition can have unique characteristics that differentiate it from the provision of care for adults. The needs of the child, and their family, vary considerably based on their developmental stage and the range of conditions seen can lead to a variety of illness trajectories that can make predicting a prognosis difficult.[8] The way in which children process information, the methods for assessing and managing their pain and other symptoms and their ability and willingness to participate in decision making all needs to be considered. Children may remain under the care of their primary treating team, receiving care aimed at a cure in parallel with support from specialist paediatric palliative care through a consultative model. Paediatric palliative care embraces the physical, emotional, social and spiritual elements from the point of diagnosis or recognition through to death and beyond. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.[9]

Aboriginal and Torres Strait Islander people

For Aboriginal and Torres Strait Islander people, the time before, during and after passing often have a number of customary practices. These practices may be sacred and may not be widely discussed outside of the community.[10] The time surrounding the end of someone's life is precious and needs to be respected and approached in a safe and responsive manner.

Directly referring to 'death' and 'dying' may make people uncomfortable and instead alternative terms can be considered such as finishing up, passed on and not going to get better. It is important to talk to the key family members and/or decision makers about what they would like to know. In doing so, relevant information on the symptoms experienced by the person with a life-limiting illness, including pain, and the options to manage these symptoms, can be provided. The family may express specific preferences, such as use of traditional medicine, space to accommodate more than one person to stay overnight and room for multiple visitors at once.[11] Supporting people to observe their traditions at the end of someone's life can assist the person with a life-limiting illness as well as help their family and community with their grief and bereavement.[12]

People living with a mental illness

For people living with a mental illness there is a known association with experiencing comorbidities and poor physical health outcomes. This combination of pathologies can result in people being underserved by the relevant specialties. People living with a mental illness may not want to engage with medical staff and so often do not receive diagnosis until late in an illness trajectory, this may be further complicated by the person's legal decision making capacity.[13] They may also have poorly met social, housing, income and support needs. Consideration should be given to partnership models between palliative care and mental health services.[14]

People living with dementia

A person living with dementia can require different care to people with other life-limiting illnesses; in part because of the long, unpredictable course of the disease, issues regarding decision-making capacity, challenges with communication and a lack of community understanding of the condition. People living with dementia may struggle to access palliative care, especially if they are culturally and/or linguistically diverse or may have challenging behavioural symptoms.[15] Managing the needs of people with a life-limiting illness, who may not be able to make decisions on their own behalf requires careful attention to the decision-making and care delivery process to ensure that the needs of the person remains the primary focus. Services may need to work collaboratively to deliver appropriate care to the person living with dementia in a range of care settings, including in the home and in residential aged care.[16]

People living in residential aged care

It is important that older people are supported to receive high quality palliative care in the setting of their choice, whether that be in their own home, in residential aged care, in hospital or in a dedicated hospice service.[17] For many people a residential aged care facility is their home and it is important they have access to the same range of community and inpatient based services available to people residing in their own homes. This includes access to appropriate and adequate levels of support from general practitioners and access to consultative support and/or direct care from specialist palliative care services on a needs basis.

People who live in prison custody

Each year a small number of people die anticipated deaths whilst in prison custody. In 2014-15 of the deaths of people in prison custody, natural causes accounted for 71% of the known causes of death[18] (i.e. 41 people of a total of 58 people), with one third being related to heart disease.[19] However, there is only limited information available on the end-of-life related care and decision making preferences of this population.[20] The need for delivery of palliative care in prison custody is likely to increase given the increasing number of people in prison custody who are 65 years and older, noting that many people in prison custody are considered older from 50 years (and 45 years for Aboriginal and Torres Strait Islander people) given their experience of accelerated ageing due to, for example, poor health.[21]

People who live in supported accommodation

Provision of palliative care for people who live in supported accommodation (e.g. disability residential services) is likely to require coordination of care between different services and different sectors including disability and health. The staff engaged to support people living with a disability in residential services generally will not have additional health care training, unless they are supporting a person with a specific need, but they may be able to support palliative care through the provision of information about the person.[22] For some people living with a disability, additional support may be required to assist them in understanding a diagnosis and prognosis, which can also complicate symptom management. Staff may also need to be aware of non-verbal or alternative communication strategies to assist them in the provision of care.[23]

People experiencing homelessness

Some people who are at risk of, or experiencing homelessness may require access to palliative care. It is important that services are flexible enough to meet the needs of these highly underserved populations, especially given people may move around and not have a fixed location or address. If the person loses capacity to make decisions, the staff at, for example, a hostile or a health professional may be placed in a position of having to make decisions for the person. Partnership models between health and community services should be in place to ensure that the needs of people can be appropriately met.[24]

Culturally and linguistically diverse communities

Differences in beliefs, values, and traditional health care practices may be of particular relevance for people at the end of their life. Quality, appropriate and comprehensive care is culturally sensitive and requires health professionals to understand each person's view of the situation and their expectations regarding decision making and type of care. Some people may be unfamiliar with the concept of palliative care and the services available to them, including access to interpreters and the funding/ payment method of these services. Flexible models of care may assist in considering how to best support local communities, as well as to support people to access care that not only considers their culture and language but also recognises their individualised needs as well.[25]

Lesbian, gay, bisexual, transgender and intersex people

Although there have been increasing levels of social acceptance and legislative improvements, LGBTI people continue to experience prejudice and discrimination in healthcare settings and often feel compelled to hide their sexuality, gender identity or intersex status for fear of negative responses. Many LGBTI people have experienced discrimination, stigma, rejection, criminalisation, exclusion, medical abuses, persecution and isolation. Palliative care services must provide a safe environment where LGBTI people with life-limiting illnesses can live and die with equity, respect and dignity, and without fear of prejudice and discrimination. Their self-designated family and chosen carer(s) should be treated with the same level of dignity and respect, as they can often fall secondary to biological relatives through assumed rights.[26]

Standard 1: Assessment of needs

Initial and ongoing assessment incorporates the person's physical, psychological, cultural, social and spiritual experiences and needs.

Intent of the standard

The person, their family and carers are actively involved in the initial and ongoing person-centred assessment, which focuses on their physical, psychological, cultural, social and spiritual needs.

A comprehensive and holistic assessment of the person's needs and preferences is established on presentation and in early consultations, with assessment guided by the person. As more than one clinician may be involved, care is taken to ensure that assessment is coordinated and the information gathered is communicated effectively among the treating team. Reassessment should occur regularly, particularly at changes in the phase of care. This includes identifying when the person is imminently dying and incorporating assessment of the specific needs associated with this phase.

The life experiences of the person, their family and carers will influence their preferences as they approach and reach the end of their life. Their life may be influenced by age, culture, religion, ethnicity or experience. Some people will have very deep attachments to such aspects– others less so. Consideration of the physical, psychological, cultural, social and spiritual experiences and needs of the person is an integral part of the initial and ongoing assessment.

The person's care plan, and any changes that may occur to it, are directly informed by comprehensive and holistic assessments.

To meet this Standard, the health service is expected to ensure:

1.1. The initial and ongoing assessments are carried out by qualified interdisciplinary personnel.

1.2. The assessment is coordinated to reduce the burden of duplication on the person, family and carers.

1.3. Clinical assessment tools are informed by the best available evidence and identify those approaching the end of life as well as those that are imminently dying.

1.4. The person's needs are reassessed on a regular basis.

1.5. Initial and ongoing assessments are documented in the person's clinical record.

1.6. Ongoing assessments are used to inform the care plan and any subsequent changes to it.

Standard 2: Developing the care plan

The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan.

Intent of the Standard

The person should be an active partner in their care planning as they approach and reach the end of life.

Where the person is not able to participate in care planning or decision-making it is important that a substitute decision-maker or legal guardian is identified in accordance with the person's goals and preferences and relevant legislation and/or policies.

Comprehensive assessment provides the foundation for care planning. Each re-assessment should inform a re-evaluation of the care plan. In addition, the person should be supported to consider and document their future care goals and preferences (for example in an Advance Care Plan, Goals of Care or Advance Care Directive). The person's future care goals and care plan are documented in their clinical record, and communicated to all involved in the delivery of care.

Recognising that every person is unique, that their experiences as they approach the end-of-life will be different and that the agreed goals of care may change over time is crucial to the delivery of care that is respectful, compassionate and maintains dignity.

To meet this Standard, the health service is expected to ensure:

2.1. Care planning is informed by the assessment process and reflects a person-centred, holistic approach that incorporates cultural, spiritual, physical, psychological and social needs.

2.2. The person, their family and carers are provided with up to date information appropriate to meet their needs and support informed participation in care planning and decision-making.

2.3. Systems are in place to identify a substitute decision maker if a person does not have the capacity to make decisions for themselves.

2.4. The person is supported to consider, document and update their future care goals, including in an advance care plan.

2.5. A system is in place for receiving, storing, accessing and sharing existing advance care plans.

2.6. Specific attention is paid to the needs of people who may be vulnerable or at risk, to support communication, goal setting and care planning. This includes, but is not limited to Aboriginal and Torres Strait Islanders, asylum seekers, people who have experienced torture and trauma, people who are experiencing homelessness; people living with mental ilness, intellectual disabilities or dementia; paediatric populations or people from ethnically and culturally diverse backgrounds.

2.7. Initial and ongoing discussions informing the care plan are documented and readily available to guide care delivery.

2.8. The expectations and preferences of the person, their family and carers for the type and place of care are discussed, negotiated and an agreed plan is documented.

2.9. The care plan is reviewed and updated regularly, on the basis of re-assessments of the person's condition, needs, and preferences, and in consultation with the person, their family and carers. Changes to the care plan are documented.

2.10. Care plans incorporate management for emergency and out-of-hours support, including certification of death and plans for the care and collection of the body where this is required after hours.

Standard 3: Caring for carers

The needs and preferences of the person's family and carers are assessed, and directly inform provision of appropriate support and guidance about their role.

Intent of the Standard

The person's family and carers play an important role in providing physical, emotional, social and spiritual support and care. It is very important that services value this role, appreciate its importance, and support the person's family and carers by working with them to understand the level of care that they are willing and able to provide.

The needs and preferences of the family and carers, including their need for information, should be assessed independently from that of the person and aim to assist them to better fulfil their caring role and reduce associated stress. Support may include facilitating access to equipment, nursing support, respite, counselling, information about financial support and any other services that may be required.

It is important that the family and carers are provided with a clear plan for the management of out-of-hours concerns or unexpected events in relation to the care of the person.

It is important to recognise that carers are often but not always family members and that a person may have more than one carer, each one requiring assessment, information and support.

Moreover a person may want specific family members or friends who are not their identified carers to be involved in and informed about their care. Clear identification of these individuals is necessary to enable effective communication and avoid distress caused by inadequate communication.

To meet this Standard, the health service is expected to ensure:

3.1. At least one carer is identified for each person as far as possible and their specific needs, including their need for information, are assessed and documented.

3.2. The service works with the family and carers to understand their needs and desired level of involvement in care. The potential benefits and risks around assisting with care are discussed with the person, their family and carers and there is ongoing assessment of their willingness and ability to participate in the provision of care.

3.3. There are systems in place to ensure that the person's nominated family and carers are supported to participate in the provision of health care in accordance with the preferences of the person, their family and carers (taking into account privacy requirements).

3.4. The family and carers are provided with up to date information and resources that are adapted to meet their needs and that inform their participation in care planning and delivery. This may include information about accessing respite services, equipment, financial support and other services, as well as encouraging the involvement of personal support networks and self-care.

3.5. The family and carers are provided with a clear plan for emergency and out-of-hours events.

3.6. Depending on the location of care and the person's needs and preferences, the family and carers are educated on how to safely assist with care, including managing risk, manual handling and activities of daily living.

3.7. The family and carers are provided with information about the signs and symptoms of approaching death and the steps to take following death, in a way that is appropriate for their age, culture and social situation.

Standard 4: Providing care

The provision of care is based on the assessed needs of the person, informed by evidence, and is consistent with the values, goals and preferences of the person as documented in their care plan.

Intent of the Standard

Care is based on current and comprehensive clinical assessment, delivered in accordance with the person's expressed values, goals of care and preferences as evidenced in their care plan, and informed by the best available evidence. Effective care enables the person to live as well as possible, to the end of their life.

Distress caused by symptoms (physical, psychosocial or spiritual) is actively pre-empted, and when it occurs, the response is timely and effective. This includes prompt response to needs, regularly reviewing the effectiveness of treatment, and ensuring the person, their family and carers have timely access to specialist palliative care at all times. The dignity of the person is prioritised at all times through a person-centred approach to their overall care.

It may not always be possible to provide care that matches a person's preferences. Where the person's preferences cannot be met, the service is expected to explain the reasons for this to them, their family and carers, and to discuss acceptable alternatives.

To meet this Standard, the health service is expected to ensure:

4.1. Care is delivered promptly, in accordance with the changing needs of the person, their family and carers, their documented care plan and their goals and preferences.

4.2. The service takes practical steps to keep abreast with new and emerging evidence, and uses the best available evidence to inform clinical practice.

4.3. Where care cannot be delivered in accordance with the goals and preferences of the person, this is discussed with the person, their family, and carers, and an agreed alternative plan is documented and communicated.

4.4. There are protocols and procedures in place for the escalation of care where required, based on assessed needs.

4.5. The service aims to actively pre-empt distress to the best of their ability but when it occurs, the response to it is timely, appropriate and effective, and actions are documented.

4.6. The effectiveness of care is measured according to established indicators and outcomes.

Standard 5: Transitions within and between services

Care is integrated across the person's experience to ensure seamless transitions within and between services.

Intent of the Standard

People may receive care from multiple services throughout the course of thei illness, and particularly as they approach and reach the end of life. Understanding the values, goals and preferences of the person, their family and carers and communicating these effectively during movements within and between care settings will support delivery of effective, person-centred coordinated care.

Oral communication between care providers should be supported by sufficient written information on the person's condition, their care plan and goals of care to ensure seamless care and to avoid the provision of ineffective care or care that does not align with the person's preferences.

Specialist palliative care services have a role to play throughout a person's palliative care experience, working directly with the person, their family and carers and in partnership with other care providers where appropriate, to coordinate and deliver care. When working in partnership with other services, clear strategies for referral, communication and designated areas of responsibility are essential.

All services providing palliative care should make information available to local and wider health communities about the populations they serve, and how their service can be accessed. This information should promote equitable access to the service. Specialist palliative care services should have clear admission criteria that are transparent and non-discriminatory in nature.

To meet this Standard, the health service is expected to ensure:

5.1. There are policies and procedures in place that support and promote continuity of care across settings and throughout the course of the person's illness.

5.2. The service has in place effective communication systems to support integrated care, including processes for communicating information about the care plan, goals of care, prognosis and death of the person within and between services.

5.3. Care plans demonstrate appropriate actions to support seamless transition between care settings.

5.4. Specialist palliative care services' admission criteria are clear, applied consistently, and communicated to the local health and wider community, and result in equitable access to services based on clinical need.

5.5. Referrals from the specialist palliative care service are made to appropriate specialists or services that are able to meet the identified physical, social and spiritual needs of the person, their family and carers (for example acute pain services, mental health services, bereavement counsellors).

5.6. Discharging a person from a specialist palliative care service should allow adequate time for services to be put in place prior to discharge, and include a formal handover to ensure continuity of care and minimise risk. Plans should be discussed with the person, their family and carers to ensure that their needs and preferences are accommodated, and that they understand that the person may enter the service again if and when their needs change.

5.7. Services assist local community-based service providers to build their capability to help people to be cared for in their home, where this aligns with the person's preferences.

5.8. Policies for prioritising and responding to referrals in a timely manner are documented and audited regularly to identify improvement opportunities.

5.9. The organisation has mechanisms in place to assess unmet needs, and uses this information to develop plans for future improvement of the service.

Standard 6: Grief support

Families and carers have access to bereavement support services and are provided with information about loss and grief.

Intent of the Standard

Grief is a normal emotional reaction to loss, but the course and consequences of bereavement will vary for each individual. Personal and social circumstances may place some family members and/or carers at increased risk of experiencing problems in the lead up to and aftermath of a person's death. These may be emotional or psychosocial problems, or more practical issues such as financial insecurity or risk of homelessness. The loss of a child or a violent death can create particular vulnerability and expected need for more support for families and carers. Early identification and referral can improve experience and outcomes for at risk people.

Support for family members and carers in preparing for the death and in understanding the process of dying, as well as bereavement support at designated timeframes after a death may assist in reducing physical and psychosocial morbidity associated with loss and grief. There should be multiple opportunities for bereaved persons to self-identify their requirement for bereavement support.

While the majority of people will integrate loss into their life with the support of family, friends and community, some people will experience more intense and persistent symptoms of distress or adverse psychological outcomes such as Prolonged Grief Disorder, Post Traumatic Stress Disorder and increased risk of self-harm.[27,28,29] Although systematic, predictive screening of all recently bereaved people is not recommended, the use of standardised, validated tools to diagnose prolonged grief in those who have persistent signs and symptoms can assist in appropriate referral for treatment. Structured screening and assessment is both indicated and effective in these situations.

Services should develop partnerships with a range of community organisations able to support people who are anticipating or living with loss. Specialist palliative care services should employ staff with appropriate training and skills to support families and carers in their experience of loss and grief. Services must also have mechanisms in place to identify people who are at risk of, or who are experiencing a complex response to bereavement, and facilitate access to experts in grief, loss and bereavement management where possible. The timeliness of tailored support and consistency of relationship between the service and the bereaved are vital to building rapport and trust with the service's ability to help after death.

To meet this Standard, the health service is expected to ensure:

6.1. Culturally appropriate information and resources about loss and grief and bereavement support services is routinely provided to families and carers before and after the death.

6.2. The service provides education about loss, grief and bereavement to staff, volunteers and other community providers.

6.3. The service employs a structured assessment of bereavement that addresses emotional, behavioural, social, spiritual and physical domains.

6.4. The risk assessment process begins on intake to the palliative care service and continues throughout the service's involvement with the person and beyond.

6.5. The service uses validated tools to assess for signs and symptoms of persistent and intense distress in bereaved persons.

6.6. The service develops strategies and referral pathways, in partnerships with other providers in the community, to assist families and carers in feeling more prepared for the death and to accommodate grief into their lives after bereavement.

6.7. Referrals to bereavement, specialist mental health and/or counselling professionals are made when clinically indicated.

6.8. The organisation has mechanisms in place for the specialist palliative care team to access education, training and supervision to meet the loss, grief and bereavement needs of the family and carers.

Standard 7: Service culture

The service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative care.

Intent of the Standard

Specialist palliative care services are leaders in the delivery of high quality palliative care for people with complex needs, or for people whose needs exceed the expertise of local care providers. It is important that specialist palliative care services have a clearly stated philosophy, set of values and culture that guide the delivery of high quality palliative care.

Services should seek opportunities to influence the delivery of palliative care in other settings, through collaboration and partnerships. In particular, partnership should be sought with services that provide support to Aboriginal and Torres Strait Islander and other cultural populations.

To meet this Standard, the health service is expected to ensure:

7.1.   The values and culture of the service explicitly support the provision of person-centred palliative care.

7.2.   The philosophy and objectives of the service are documented and incorporated into clinical practice guidelines, policies and procedures.

7.3.   The care setting provides an appropriate environment to support people reaching the end of their lives, their family and carers.

7.4.   Services understand the community they serve, and use this information to both provide optimal specialist palliative care services and influence wider health, aged and social care systems that meet the needs of that community.

Standard 8: Quality improvement

Services are engaged in quality improvement and research to improve service provision and development.

Intent of the Standard

In order to maintain and continuously improve the high standard of palliative care delivery in Australia, it is important for services to engage in quality improvement and lead or participate in research. The specialist palliative care service should engage in research and quality improvement activities aimed at developing new evidence to inform practice. Where relevant, these activities should contribute to the quality improvement approach of the broader health service in which the specialist palliative care service is located.

All services are expected to embed quality improvement activities into their daily practice, working systematically through a cyclical quality improvement process. Services are expected to identify areas for improvement through thorough risk assessment processes, quality audits, and standards reviews, and to implement actions relevant to improving performance in identified areas. Improvement actions and outcomes should be evaluated to determine whether interventions or changes have been effective. It is expected that people using and interacting with the service are provided with opportunity to give feedback on the service received and to identify opportunities for improvement.

To meet this Standard, the health service is expected to ensure:

8.1. An ongoing quality improvement process is implemented to review clinical performance and outcomes, and to identify, implement and evaluate improvement activities.

8.2. Data about the effectiveness of palliative care delivery is collected, reviewed and reported locally.

8.3. System failures are systematically identified and investigated, and there are opportunities to learn from error.

8.4. The service engages in robust and rigorous clinical audit review.

8.5. The service is accredited to ensure achievement of governance and safety requirements.

8.6. The service participates in benchmarking processes to compare its service delivery over time and/or with external organisations.

8.7. The service supports staff to lead or participate in palliative care research wherever possible.

8.8. Specialist palliative care services support other services providing care to people at the end-of-life to improve the quality of that care.

8.9. The person, their family and carers and the community are provided with opportunities to provide input into the evaluation of the service via formal and informal feedback mechanisms.

Standard 9: Staff qualifications and training

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

Intent of the Standard

A defining feature of a specialist palliative care service is the employment of staff that have recognised qualifications or credentialing in palliative care. All services are expected to support their staff, both with respect to their ongoing professional development and in coping with the daily demands of working with people, their family and carers who require specialist palliative care.

Services must ensure that volunteer services are coordinated and supervised appropriately, and volunteers receive appropriate and regular training and support to fulfil their roles safely and competently.

To meet this Standard, the health service is expected to ensure:

9.1. The service employs a multidisciplinary team of health professionals with recognised qualifications, credentialing and experience to meet the physical, psychological, social, cultural and spiritual needs of the person, their family and carers.

9.2. Staff in clinical leadership and management positions have recognised qualifications and experience in relevant fields.

9.3. A formal assessment of palliative care education and training is undertaken for all members of the health service to identify professional development requirements.

9.4. Staff and volunteers receive appropriate supervision and support in accordance with an established professional development framework.

9.5. Staff undergo training to ensure delivery of culturally safe care.

9.6. Staff are trained in self-care strategies and advised on how to access personal support.

9.7. Volunteer programs are recognised, supported and managed in accordance with the relevant volunteer standards.

Mapping of the Standards to the NSQHC Standards (2nd edn)

The care of people recieving palliative care is guided by a number of different sets of standards including these Standards and the National Safety and Quality Health Service (NSQHS) Standards (2nd edn.).[1]

These Standards set out to articulate and promote a vision for compassionate and appropriate palliative care, where the NSQHS Standards aim to protect the public from harm and to improve the quality of health service provision.

The NSQHS Standards (2nd edn) includes a number of actions that overtly focus on supporting safe and high-quality end-of-life care (Actions 5.15 to 5.20). There are also a range of other actions that are relevant to the delivery of holistic and person-centred comprehensive care that includes palliative care. Consequently, health service organisations that are working towards meeting the actions in these Standards may also be contributing to related actions in the NSQHS Standards. Though the actions in the two sets of Standards are not always exactly equivalent, it is worth health services considering where the actions within these two sets of Standards relate as outlined in the table below.

STANDARD 1

Assessment of needs

Initial and ongoing assessment incorporates the person's physical, psychological, cultural, social and spiritual experiences and needs.

ELEMENT WITHIN THESE STANDARDS		ACTION WITHIN NSQHC STANDARDS
1.1	The initial and ongoing assessments are carried out by qualified interdisciplinary personnel.	1.20; 1.23; 1.24 4.5; 4.6 5.5; 5.6; 5.7; 5.8; 5.10; 5.11; 5.14; 5.15; 5.21; 5.22; 5.24; 5.29; 5.30; 5.31; 5.33; 5.34
1.2	The assessment is coordinated to reduce the burden of duplication on the person, family and carers.	2.10 5.5; 5.6; 5.7 6.3; 6.4; 6.7; 6.9
1.3	Clinical assessment tools are informed by the best available evidence and identify those approaching the end of life as well as those that are imminently dying.	1.27 5.15
1.4	The person's needs are reassessed on a regular basis.	2.6; 2.7 3.6 4.10 5.7; 5.10; 5.14 6.9 8.4; 8.5
1.5	Initial and ongoing assessments are documented in the person's clinical record.	1.16 4.5; 4.6; 4.7; 4.8; 4.10 5.12; 5.13 6.4; 6.11 8.4; 8.5
1.6	Ongoing assessments are used to inform the care plan and any subsequent changes to it.	2.10 4.6 5.13; 5.14; 5.15; 6.9; 6.11

Developing the care plan

The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan.

ELEMENT WITHIN THESE STANDARDS		ACTION WITHIN NSQHC STANDARDS
2.1	Care planning is informed by the assessment process and reflects a person-centred, holistic approach that incorporates cultural, spiritual, physical, psychological and social needs.	2.6; 2.7 5.4; 5.13; 5.14; 5.15; 5.20
2.2	The person, their family and carers are provided with up to date information appropriate to meet their needs and support informed participation in care planning and decision-making.	2.4; 2.6; 2.7; 2.8; 2.9; 2.10 4.11 5.13; 5.14;5.23; 5.26 6.9; 6.10
2.3	Systems are in place to identify a substitute decision maker if a person does not have the capacity to make decisions for themselves.	2.5
2.4	The person is supported to consider, document and update their future care goals, including in an advance care plan.	2.6; 2.7 5.9; 5.13; 5.14; 5.17 6.11
2.5	A system is in place for receiving, storing, accessing and sharing existing advance care plans.	1.16; 1.17; 1.18 5.17 6.11
2.6	Specific attention is paid to the needs of people who may be vulnerable or at risk, to support communication, goal setting and care planning. This includes, but is not limited to Aboriginal and Torres Strait Islanders, asylum seekers, people who have experienced torture and trauma, people who are experiencing homelessness; people living with mental illness, intellectual disabilities or dementia; paediatric populations or people from ethnically and culturally diverse backgrounds.	1.15; 1.21 2.6; 2.7; 2.8; 2.10; 2.13 5.7; 5.8; 5.10; 5.11; 5.21; 5.22; 5.23; 5.24; 5.25; 5.26; 5.27; 5.28; 5.29; 5.30; 5.31; 5.34; 5.35; 5.36 6.7; 6.9 8.5
2.7	Initial and ongoing discussions informing the care plan are documented and readily available to guide care delivery.	1.16 5.4; 5.8; 5.9; 5.12; 5.13; 5.17 6.1; 6.11 8.4; 8.5
2.8	The expectations and preferences of the person, their family and carers for the type and place of care are discussed, negotiated and an agreed plan is documented.	2.6; 2.7 5.4; 5.13; 5.20
2.9	The care plan is reviewed and updated regularly, on the basis of re-assessments of the person's condition, needs, and preferences, and in consultation with the person, their family and carers. Changes to the care plan are documented.	2.6; 2.7; 2.10 5.14 6.11
2.10	Care plans incorporate management for emergency and out-of-hours support, including certification of death and plans for the care and collection of the body where this is required after hours.	1.26 5.13; 5.20

Caring for carers

The needs and preferences of the person's family and carers are assessed, and directly inform provision of appropriate support and guidance about their role.

ELEMENT WITHIN THESE STANDARDS		ACTION WITHIN NSQHC STANDARDS
3.1	At least one carer is identified for each person as far as possible and their specific needs, including their need for information, are assessed and documented.	2.6; 2.7; 2.10 5.13 6.3; 6.9
3.2	The service works with the family and carers to understand their needs and desired level of involvement in care. The potential benefits and risks around assisting with care are discussed with the person, their family and carers and there is ongoing assessment of their willingness and ability to participate in the provision of care.	2.6; 2.7; 2.10 5.13; 5.14; 5.20 6.9; 6.10
3.3	There are systems in place to ensure that the person's nominated family and carers are supported to participate in the provision of health care in accordance with the preferences of the person, their family and carers (taking into account privacy requirements).	2.6; 2.7; 2.8; 2.10 5.13; 5.14; 5.20 6.8; 6.9; 6.10 8.6; 8.7
3.4	The family and carers are provided with up to date information and resources that are adapted to meet their needs and that inform their participation in care planning and delivery. This may include information about accessing respite services, equipment, financial support and other services, as well as encouraging the involvement of personal support networks and self-care.	2.8; 2.10 5.20; 5.23; 5.25; 5.26 6.9
3.5	The family and carers are provided with a clear plan for emergency and out-of-hours events.	2.6; 2.7; 2.10 6.9 8.6; 8.7
3.6	Depending on the location of care and the person's needs and preferences, the family and carers are educated on how to safely assist with care, including managing risk, manual handling and activities of daily living.	2.6; 2.7; 2.10
3.7	The family and carers are provided with information about the signs and symptoms of approaching death and the steps to take following death, in a way that is appropriate for their age, culture and social situation.	2.8; 2.9; 2.10 5.20 6.9

Providing care

The provision of care is based on the assessed needs of the person, informed by evidence, and is consistent with the values, goals and preferences of the person as documented in their care plan.

ELEMENT WITHIN THESE STANDARDS		ACTION WITHIN NSQHC STANDARDS
4.1	Care is delivered promptly, in accordance with the changing needs of the person, their family and carers, their documented care plan and their goals and preferences.	2.6; 2.7 5.3; 5.14; 5.208.10; 8.11; 8.12; 8.13
4.2	The service takes practical steps to keep abreast with new and emerging evidence, and uses the best available evidence to inform clinical practice.	1.27; 1.28
4.3	Where care cannot be delivered in accordance with the goals and preferences of the person, this is discussed with the person, their family, and carers, and an agreed alternative plan is documented and communicated.	2.6; 2.7; 5.13; 5.20 6.3; 6.9; 6.10; 6.11
4.4	There are protocols and procedures in place for the escalation of care where required, based on assessed needs.	8.6; 8.7; 8.8; 8.9
4.5	The service aims to actively pre-empt distress to the best of their ability but when it occurs, the response to it is timely, appropriate and effective, and actions are documented.	1.302.6; 2.7; 2.10 5.16; 5.20; 5.30; 5.31; 5.32; 5.33; 5.34 8.6; 8.10; 8.12; 8.13
4.6	The effectiveness of care is measured according to established indicators and outcomes.	1.8; 1.28 5.14; 5.19

Transitions within and between services

Care is integrated across the person's experience to ensure seamless transitions within and between services.

ELEMENT WITHIN THESE STANDARDS		ACTION WITHIN NSQHC STANDARDS
5.1	There are policies and procedures in place that support and promote continuity of care across settings and throughout the course of the person's illness.	5.4; 5.5; 5.6; 5.20
5.2	The service has in place effective communication systems to support integrated care, including processes for communicating information about the care plan, goals of care, prognosis and death of the person within and between services.	1.16 2.10 3.7 5.4; 5.5; 5.20 6.4; 6.7; 6.8; 6.9; 6.10; 6.11
5.3	Care plans demonstrate appropriate actions to support seamless transition between care settings.	5.13; 5.14 6.4; 6.8; 6.9
5.4	Specialist palliative care services' admission criteria are clear, applied consistently, and communicated to the local health and wider community, and result in equitable access to services based on clinical need.	
5.5	Referrals from the specialist palliative care service are made to appropriate specialists or services that are able to meet the identified physical, social and spiritual needs of the person, their family and carers (for example acute pain services, mental health services, bereavement counsellors).	5.4; 5.13; 5.20 6.4; 8.12; 8.13
5.6	Discharging a person from a specialist palliative care service should allow adequate time for services to be put in place prior to discharge, and include a formal handover to ensure continuity of care and minimise risk. Plans should be discussed with the person, their family and carers to ensure that their needs and preferences are accommodated, and that they understand that the person may enter the service again if and when their needs change.	2.6; 2.7; 2.10 5.13; 5.20 6.4; 6.8; 6.9; 6.10; 6.11
5.7	Services assist local community-based service providers to build their capability to help people to be cared for in their home, where this aligns with the person's preferences.	
5.8	Policies for prioritising and responding to referrals in a timely manner are documented and audited regularly to identify improvement opportunities.	1.7; 1.8
5.9	The organisation has mechanisms in place to assess unmet needs, and uses this information to develop plans for future improvement of the service.	1.8; 1.9; 1.10; 1.11; 1.13; 1.14 2.11; 2.13 5.19

Grief support

Families and carers have access to bereavement support services and are provided with information about loss and grief.

ELEMENT WITHIN THESE STANDARDS		ACTION WITHIN NSQHC STANDARDS
6.1	Culturally appropriate information and resources about loss, grief and bereavement support services is routinely provided to families and carers before and after the death.	1.15; 1.21 2.8; 2.10 5.20
6.2	The service provides education about loss, grief and bereavement to staff, volunteers and other community providers.	1.20 5.18; 5.20
6.3	The service employs a structured assessment of bereavement that addresses emotional, behavioural, social, spiritual and physical domains.	
6.4	The risk assessment process begins on intake to the palliative care service and continues throughout the service's involvement with the person and beyond.	5.10; 5.11; 5.14 6.4; 6.9
6.5	The service uses validated tools to assess for signs and symptoms of persistent and intense distress in bereaved persons.	1.27 5.7; 5.10; 5.11; 5.20 8.6
6.6	The service develops strategies and referral pathways, in partnerships with other providers in the community, to assist families and carers in feeling more prepared for the death and to accommodate grief into their lives after bereavement.	2.10 5.20
6.7	Referrals to bereavement, specialist mental health and/or counselling professionals are made when clinically indicated.	2.10 5.4; 5.5; 5.6; 5.13 6.4; 8.10; 8.12
6.8	The organisation has mechanisms in place for the specialist palliative care team to access education, training and supervision to meet the loss, grief and bereavement needs of the family and carers.	1.20; 1.21; 1.22; 1.25; 1.26 5.16; 5.18

Service culture

The service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative care and end-of-life care.

ELEMENT WITHIN THESE STANDARDS		ACTION WITHIN NSQHC STANDARDS
7.1	The values and culture of the service explicitly support the provision of person-centred palliative care.	1.1; 1.2 2.1; 2.2 5.3
7.2	The philosophy and objectives of the service are documented and incorporated into clinical practice guidelines, policies and procedures.	1.1 2.1; 2.2
7.3	The care setting provides an appropriate environment to support people reaching the end of their lives, their family and carers.	1.29; 1.30; 1.32; 1.33 5.4
7.4	Services understand the community they serve, and use this information to both provide optimal specialist palliative care services and influence wider health, aged and social care systems that meet the needs of that community.	1.2; 1.4; 1.15 2.11; 2.13

Quality improvement

Services are engaged in quality improvement and research to improve service provision and development.

ELEMENT WITHIN THESE STANDARDS		ACTION WITHIN NSQHC STANDARDS
8.1	An ongoing quality improvement process is implemented to review clinical performance and outcomes, and to identify, implement and evaluate improvement activities.	1.8; 1.9; 1.10; 1.11; 1.12; 1.13; 1.14; 1.22; 1.28 2.11 5.19
8.2	Data about the effectiveness of palliative care delivery is collected, reviewed and reported locally.	1.8; 1.9 5.19
8.3	System failures are systematically identified and investigated, and there are opportunities to learn from error.	1.11; 1.12; 1.13; 1.14 5.19
8.4	The service engages in robust and rigorous clinical audit review.	1.28 5.19
8.5	The service is accredited to ensure achievement of governance and safety requirements.	
8.6	The service participates in benchmarking processes to compare its service delivery over time and/or with external organisations.	1.28
8.7	The service supports staff to lead or participate in palliative care research wherever possible.	
8.8	Specialist palliative care services support other services providing care to people at the end-of-life to improve the quality of that care.	5.16;5.20 6.4
8.9	The person, their family and carers and the community are provided with opportunities to provide input into the evaluation of the service via formal and informal feedback mechanisms.	1.8; 1.13; 1.14 2.11; 2.12; 2.13

Staff qualifications and training

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

NPC ELEMENT		ACTION WITHIN NSQHC STANDARDS
9.1	The service employs a multidisciplinary team of health professionals with recognised qualifications, credentialing and experience to meet the physical, psychological, social, cultural and spiritual needs of the person, their family and carers.	1.20; 1.21; 1.23; 1.24; 1.25; 1.26 4.4 5.5; 5.16 8.10; 8.11
9.2	Staff in clinical leadership and management positions have recognised qualifications and experience in relevant fields.	
9.3	A formal assessment of palliative care education and training is undertaken for all members of the health service to identify professional development requirements.	1.20; 1.22
9.4	Staff and volunteers receive appropriate supervision and support in accordance with an established professional development framework.	1.25; 1.26 5.16; 5.18
9.5	Staff undergo training to ensure delivery of culturally safe care.	1.20; 1.21
9.6	Staff are trained in self-care strategies and advised on how to access personal support.	5.18
9.7	Volunteer programs are recognised, supported and managed in accordance with the relevant volunteer standards.	

Mapping of the National Palliative Care Standards against Standards from other relevant agencies

To assist services to identify intersections and avoid duplication of effort, PCA has completed internal mapping of the National Palliative Care Standards (5[th]edn.) against the standards of various agencies.

The section below lists the relevant National Palliative Care Standard elements as it relates to these other standards.

Standard 1: Assessment of needs

National Palliative Care Standards 2005[5]	Std. 2 The holistic needs of the patient, their caregiver/s and family, re acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes. Std. 3 Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.
National Consensus Statement: Essential elements for safe high quality end of life care[2]	EE 1 Patient-centred communication & shared decision making • *Action 1.4 "individual preferences & needs of all patients [etc]"* EE 3 Components of care • *Action 3.1 "The psychosocial, cultural & spiritual needs of patients, families & carers should be assessed, and care should be provided in accordance with their wishes, values & needs."*
Accreditation Standards (residential aged care)[4]	Std. 2 Health & personal care • *2.5 Specialised nursing needs "Care recipients' specialised nursing care needs are identified and met by appropriately qualified nursing staff."* Std. 3 Care recipient lifestyle • *3.8 Cultural & spiritual life "Individual interests, customs, beliefs and cultural and ethnic backgrounds are valued and fostered."* • *3.9 Choice & decision-making "Each care recipient (or his or her representative) participates in decisions about the services the care recipient receives…"*
National Consensus Statement: Essential elements for safe high quality paediatric end of life care[3]	EE 1 Family-centred communication and shared decision-making • *Action 1.4 Clinicians should be respectful, sensitive and responsive to the preferences and needs of individual children and their families, regardless of aspects of identity such as culture, religious belief, gender or sexual preference.* EE 3 Components of care • *Action 3.1 Clinicians should assess the psychosocial, cultural and spiritual needs of the child. Support should be offered for families who wish to include cultural or religious practices in the care of the child, such as particular foods, singing, ceremonies or healing.* • *Action 3.5 Clinicians should revisit the goals of care, treatment plan and any limitations of medical treatment when significant changes in the child's condition, preferences, or circumstances occur – for example, when the child is in transition to the terminal phase.*

Standard 2: Developing the care plan

National Palliative Care Standards 2005[5]	Std. 1 Care, decision-making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patient, their caregiver and family's needs and wishes are acknowledged and guide decision-making and care planning.
National Consensus Statement: Essential elements for safe high quality end of life care[2]	EE 1 Patient-centred communication & shared decision making • Action 1.1 *"Clinicians and patients should identify opportunities for proactive and pre-emptive end-of-life care discussions"* • Action 1.2 *"The clinical team should work with the patient, family and carers to identify [who] the patient wishes to be involved in discussions about their care."* • Action 1.3 *"Culturally appropriate decision makers should be identified"* • Action 1.4 *"Clinicians should seek to understand … be responsive to, the individual preferences & needs of all patients [etc]"* • Action 1.6 *"The patient [etc] should be provided with written information"* • Action 1.7 *"Clinicians should work with patients, families & carers to ensure key [people] are present during end-of-life discussions"* • Action 1.9 *"Clinicians should … allow adequate time for those involved to absorb, process and react to the information they are being given."* • Action 1.8 *"Clinicians should provide an honest and straight forward summary … Clinicians should be compassionate and sensitive, use plain language, and avoid the use of medical jargon."* • Action 1.11 *"patients, families & carers … provided with sufficient support to make decisions"* EE 2 Teamwork & coordination of care • Action 2.2 *"The roles and responsibilities of different understood by all those involved in a patient's care, including the patient themselves, and their substitute decision-maker, family and carers."* • Action 2.3 *"If there is disagreement or ambiguity … the range of views and the reasons for them should be discussed with the patient [etc]."* EE 3 Components of care • Action 3.5 *The goals of care … should be appropriately discussed with the patient [etc]."* • Action3.7 *"The goals of care, treatment plan and any limitations of medical treatment should be revisited with the patient [etc]"* • Action 3.8 *"Information about the advance care plan … the patient's treatment preferences should be readily available to all clinicians [etc]"*
Accreditation Standards (residential aged care)[4]	Std. 1 Management systems, staffing and organisational development • *1.8 Information systems "Effective information management systems are in place."* Std. 3 Care recipient lifestyle • *3.6 Privacy and dignity "Each care recipient's right to privacy, dignity and confidentiality is recognised and respected."* • *3.8 Cultural & spiritual life "Individual interests, customs, beliefs and cultural and ethnic backgrounds are valued and fostered."* • *3.9 Choice & decision-making "Each care recipient (or his or her representative) participates in decisions about the services the care recipient receives"*

National Consensus Statement: Essential elements for safe high quality paediatric end of life care[3]	EE 1 Family-centred communication and shared decision-making
	• Action 1.1 The interdisciplinary team should identify the person/s with parental responsibility.
	• Action 1.2 Clinicians should assess the capacity of the child to be involved in discussions and decision-making about their care. This capacity may change across the illness trajectory and as the child develops.
	• Action 1.5 Clinicians, the child and their parents should identify opportunities for proactive and pre-emptive end-of-life care discussions to increase the likelihood of delivering high-quality end-of-life care aligned with the child and their parents' values and preferences, and to reduce the need for urgent, after-hours discussions in emergency situations.
	• Action 1.13 Clinicians should check that the child and their parents have been provided with sufficient support to make decisions. This includes support for children and parents who have communication difficulties, cultural, spiritual or linguistic needs, or decision-making difficulties associated with disability, mental illness or cognitive impairment.
	• Action 1.14 Clinicians should clearly document the content of discussions and any agreed plan of care in the patient clinical record. Any unresolved issues that require further follow-up should be documented, along with a plan for follow-up.
	EE 3 Components of care
	• Action 3.2 Clinicians should inform families about the process and purpose of advance care planning. This process should be undertaken using age-appropriate advance care planning documents where available.
	• Action 3.4 Clinicians should document the outcomes of the decision-making process in the child's clinical record. These outcomes include the goals of care, the agreed treatment plan…
	• Action 3.5 Clinicians should revisit the goals of care, treatment plan and any limitations of medical treatment when significant changes in the child's condition, preferences, or circumstances occur – for example, when the child is in transition to the terminal phase.
	• Action 3.8 Information about the advance care plan, clinical treatment plan, goals of care, any limitations of medical treatment, and the child and parents' treatment preferences should be readily available to all clinicians involved in the child's care, including those involved in caring for the child in emergencies, after hours, through ambulance services and, where relevant, in the community.
	EE 10 Systems to support high-quality care
	• Action 10.1 The health service organisation should ensure that systems are in place to support clinicians to work with children and their families to receive, prepare, review and/or update age-appropriate advance care plans, according to the wishes of the child and their family. These systems should align with NSQHS Standard 1 (Governance for safety and quality in health service organisations) and Standard 9 (Recognising and responding to clinical deterioration in acute health care).
	• Action 10.5 The health service organisation should work with community care providers to ensure that systems are in place for communicating and accessing advance care plans developed in community care settings.

Standard 3: Caring for carers

National Palliative Care Standards 2005[5]	Std. 5 The primary caregiver/s is provided with information, support and guidance about their role according to their needs and wishes. Std. 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.
National Consensus Statement: Essential elements for safe high quality end of life care[2]	EE 1 Patient-centred communication & shared decision making • *Action 1.3 "Culturally appropriate decision makers should be identified"* • *Action 1.4 "Clinicians should seek to understand … be responsive to, the individual preferences & needs of all patients [etc]"* • *Action 1.6 "The patient [etc] should be provided with written information"* • *Action 1.7 "Clinicians should work with patients, families & carers to ensure key family members, substitute decisions-makers & carers are present during end-of-life discussions"* • *Action 1.11 "patients, families & carers … provided with sufficient support to make decisions"* EE 3 Components of care • *Action 3.1 "The psychosocial, cultural & spiritual needs of patients, families & carers should be assessed, and care should be provided in accordance with their wishes, values & needs."* • *Action 3.5 "The goals of care … should be appropriately discussed with the patient, and their substitute decision-maker, family and carers"* • *Action 3.6 "The rationale for medical decisions should be clearly communicated with the patient, family and carers."* • *Action 3.7 "The patient, substitute decision-maker, family and carers should be empowered to request further discussion and a review of the plan at any time."* • *Action 3.9 "The patient, family and carers should not feel abandoned by the healthcare team"* • *Action 3.12 "Family and carers should be supported to spend time with a dying patient in accordance with their wishes"* • *Action 3.13 "Bereaved family and carers should be provided with written information about how to access bereavement support"* EE 5 Response to concerns • *Action 5.2 "The patient, substitute decision-maker, family and carers should understand the triggers and process for requesting an urgent review, and the process for responding to their request."* • *Action 5.3 "Processes should be in place to enable patients, substitute decision-makers, families, carers … to escalate concern until a satisfactory resolution is achieved."* EE 6 Leadership & governance • *Action 6.1 Patients, and their families and carers should be partners in the development and governance of organisational systems for delivering end-of-life care.*
Accreditation Standards (residential aged care)[4]	Std. 3 Care recipient lifestyle 3.6 Privacy and dignity "Each care recipient's right to privacy, dignity and confidentiality is recognised and respected." 3.9 Choice and decision-making "Each care recipient (or his or her representative) participates in decisions about the services the care recipient receives, and is enabled to exercise choice and control over his or her lifestyle…"
National Consensus Statement: Essential elements for safe high quality paediatric end of life care[3]	EE 1 Family – centred communication and decision-making • *Action 1.1 The interdisciplinary team should identify the person/s with parental responsibility.* • *Action 1.4 Clinicians should be respectful, sensitive and responsive to the preferences and needs of individual children and their families, regardless of aspects of identity such as culture, religious belief, gender or sexual preference.* • *Action 1.9 Clinicians should work with parents to ensure that key family members are present during end-of-life discussions or that appropriate follow-up meetings are offered. This will ensure that consistent messages are given about treatment options, their likelihood of success, risks and prognosis.* EE 3 Components of care • *Action 3.9 … Clinicians should communicate openly about comfort care and what to expect in the terminal phase.* • *Action 3.15 Clinicians should support parents and families to care for their dying child, and provide information about what to expect during the dying process.*

Standard 4: Providing care

National Palliative Care Standards 2005[5]	Std. 2 The holistic needs of the patient, their caregiver/s and family, re acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.
	Std 3. Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.
	Std. 6 The unique needs of dying patients are considered, their comfort maximized and their dignity preserved.
National Consensus Statement: Essential elements for safe high quality end of life care[2]	EE 3 Components of care • *Action 3.1 "The psychosocial, cultural & spiritual needs of patients, families & carers should be assessed, and care should be provided in accordance with their wishes, values & needs."* EE 7 Education and training • *Action 7.5 Clinicians should receive ongoing education about disease-specific symptom assessment and evidence-based symptom management relevant to their area of practice.*
Accreditation Standards (residential aged care)[4]	Std. 2 Health & personal care • *2.1 Continuous improvement "The organisation actively pursues continuous improvement."* • *2.4 Clinical care "Care recipients receive appropriate clinical care."* • *2.5 Specialised nursing care needs "Care recipients' specialised nursing care needs are identified and met by appropriately qualified nursing staff."* • *2.6 Other health and related services "Care recipients are referred to appropriate health specialists in accordance with the care recipient's needs and preferences."* • *2.9 Palliative care "The comfort and dignity of terminally ill care recipients is maintained."*
National Consensus Statement: Essential elements for safe high quality paediatric end of life care[3]	EE 3 Components of care • *Action 3.9 Clinicians should manage physical symptoms in alignment with the child and their parents' wishes, and review treatment regularly.* EE 5 Response to concerns • *Action 5.1 Members of the interdisciplinary team should escalate concerns as required and in line with relevant policies and procedures until a satisfactory resolution is achieved. This may include accessing a second opinion if there are concerns that end-of-life care needs are not being adequately recognised or addressed.* • *Action 5.3 Clinicians should conduct an interdisciplinary review of the goals of care and the treatment plan when concerns are raised that a child has unmet end-of-life care needs including physical, psychosocial or spiritual distress. Plan and document required follow-up and ongoing communication with the child, parents, and other clinicians.* • *Action 5.4 Clinicians should know how to get rapid access to specialist paediatric palliative care advice 24 hours a day and seven days a week. This may include access by telephone or videoconference.* EE 10 Systems to support high-quality care • *Action 10.2 The health service organisation should ensure that systems are in place to provide clinicians with access to essential palliative medications 24 hours a day and seven days a week. These systems should align with NSQHS Standard 4 (Medication safety).* • *Action 10.3 The health service organisation should ensure that systems are in place to provide timely access to input from specialist paediatric palliative care clinicians, when required for children with complex palliative care needs or as a supportive resource for other clinicians. This may include off-site access via videoconferencing or teleconferencing.*

Standard 5: Transitions within and between services

National Palliative Care Standards 2005[5]	Std. 4 Care is coordinated to minimise the burden on patient, their caregiver/s and family.
	Std. 9 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
	Std. 10 Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography
National Consensus Statement: Essential elements for safe high quality end of life care[2]	EE 1 Patient-centred communication & shared decision making
	• Action 1.6 *"The patient, substitute decision-maker, family and carers should be provided with written information about which clinician is responsible for leading and coordinating their care. Whenever possible, this clinician should be directly involved in discussions about the patient's end-of-life care."*
	• Action 1.13 *"The content of the discussion and plan of care ... should be communicated to all teams involved in the patient's care"*
	EE 2 Teamwork & coordination of care
	EE 3 Components of care
	• Action 3.8 *Information about the advance care plan, clinical treatment plan, goals of care... should be readily available to all clinicians involved in the patient's care, including those involved in caring for the patient in emergencies, after hours and, where relevant, in the community.*
	• Action 3.9 *The patient, family and carers should not feel abandoned by the healthcare team...*
	• Action 3.14 *Clinicians should explore and discuss alternatives to hospital-based care... this could include the patient's usual residence, a local hospital, a community or residential aged care facility, or a hospice or other palliative care facility.*
	• Action 3.15 *Clinicians should liaise with other relevant services and provide referral, as necessary*
	EE 5 Response to concerns
	• Action 5.9 *If the responder is not part of the clinical team, they should communicate with the responsible medical officer ... and the plan for follow-up or further review of the patient.*
	EE6 Leadership & governance
	• Action 6.2 *The health service executive should consider how best to allocate resources within the context of the organisation's strategic plan to support the delivery and effective functioning of systems for providing end-of-life care.*
	• Action 6.3 *A formal policy framework should exist, outlining the organisational approach to end-of-life care. It should include...the interface with external services, such as community and social care providers, residential aged care facilities and external hospice providers*
	• Action 6.9 *Organisations should work with local community-based service providers to build capacity for people to be cared for in their preferred place of death (e.g. at home).*
	EE 10. Systems to support high-quality care
	• Action 10.4 *Organisations should implement processes to improve communication between health services at transitions of care.*
Accreditation Standards (residential aged care)[4]	Std. 1 Management systems, staffing and organisational development
	• 1.1 Continuous improvement *"The organisation actively pursues continuous improvement."*
	• 1.8 information systems *"Effective information management systems are in place."*
	Std. 2 Health & personal care
	• 2.6 Other health and related services: *Care recipients are referred to appropriate health specialists in accordance with the care recipient's needs and preferences.*
	• 2.9 Palliative care *"The comfort and dignity of terminally ill care recipients is maintained."*
	Std. 3 Care recipient lifestyle
	• 3.8 Cultural and spiritual life *"Individual interests, customs, beliefs and cultural and ethnic backgrounds are valued and fostered."*

| National Consensus Statement: Essential elements for safe high quality paediatric end of life care[3] | EE 1 Family-centred communication and shared decision-making

• *Action 1.7 Clinicians should provide parents with written information about which clinician is responsible for leading and coordinating their child's care. Whenever possible, this clinician should be directly involved in discussions about the child's end-of-life care.*

• *Action 1.15 Clinicians should communicate the content of the discussion and plan of care, including any limitations of medical treatment, to all teams involved in the child's care, including relevant community care providers.*

EE 2 Teamwork and coordination of care

EE 3 Components of care

• *Action 3.8 Information about the advance care plan, clinical treatment plan, goals of care, any limitations of medical treatment, and the child and parents' treatment preferences should be readily available to all clinicians involved in the child's care...*

• *Action 3.9 The child and their parents should not feel abandoned by the healthcare team...*

• *Action 3.12 Clinicians should explore and discuss alternatives to hospital-based care, when possible and appropriate, and as preferred by the child and their parents. This could include providing appropriate referrals, equipment and support to deliver care in the family home, the child's local hospital, a hospice or other palliative care facility.*

• *Action 3.13 Clinicians should liaise with, and provide referral to, other relevant services as necessary – for example, to children's hospice, specialist inpatient or community palliative care services.*

EE 6 Leadership and governance

• *Action 6.2 The health service executive should consider how best to allocate resources within the context of the organisation's strategic plan to support the delivery and effective functioning of systems for providing paediatric end-of-life care.*

• *Action 6.3 The health service organisation should create a formal organisational policy framework for paediatric end-of-life care which applies across the acute health service, including... the interface with external services, such as community and social care providers, and external hospice providers*

• *Action 6.8 The health service organisation should work with local community-based service providers and families to build capacity for children to be cared for in the preferred place of care (e.g. at home).*

EE 10 Systems to support high-quality care

• *Action 10.4 The health service organisation should implement processes to improve communication between health services at transitions of care...* |

Standard 6: Grief support

National Palliative Care Standards 2005[5]	Std. 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.
National Consensus Statement: Essential elements for safe high quality end of life care[2]	EE 1 Family-centred communication and shared decision-making • *Action 1.3 In some cultures, mainstream assumptions about death and dying, and about patients and families as decision-makers may not be correct. Culturally appropriate decisionmaker(s) should be identified as early as possible so that strategies can be put in place for obtaining their input into discussions about end-of-life care.* EE 3 Components of care • *Action 3.13 Bereaved family and carers should be provided with written information about how to access bereavement support when they have left the health service.*
Accreditation Standards (residential aged care)[4]	Std. 1 Management systems, staffing and organisational development • *1.3 Education and staff development "Management and staff have appropriate knowledge and skills to perform their roles effectively."* Std. 2 Health & personal care • *2.4 Clinical care "Care recipients receive appropriate clinical care."* • *2.6 Other health and related services: Care recipients are referred to appropriate health specialists in accordance with the care recipient's needs and preferences.* Std. 3 Care recipient lifestyle • *3.8 Cultural and spiritual life "Individual interests, customs, beliefs and cultural and ethnic backgrounds are valued and fostered."*
National Consensus Statement: Essential elements for safe high quality paediatric end of life care[3]	EE1 Family-centred communication and shared decision-making • *Action 1.10 In some cultures, mainstream assumptions about death and dying may not be correct. Clinicians should work with parents to identify as early as possible any culturally appropriate decision-makers to include in discussions about end-of-life care.* EE 3 Components of care • *Action 3.18 Clinicians should provide bereaved parents, siblings and other family members with written information about how to access bereavement support from the time the child receives a life-limiting diagnosis. This may include providing support to the child's friends or, for an adolescent, boyfriend or girlfriend.*

Standard 7: Service culture

National Palliative Care Standards 2005[5]	Std. 7 The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care. Std. 9 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
National Consensus Statement: Essential elements for safe high quality end of life care[2]	Guiding principle 4. Recognising when a patient is approaching the end of their life is essential to delivering appropriate, compassionate and timely end-of-life care. EE 1 Patient-centred communication & shared decision making • *Action 1.8 "Clinicians should be compassionate and sensitive, use plain language, and avoid the use of medical jargon."* EE 3 Components of care • *Action 3.9 "Care, compassion, open and honest communication about what to expect, and the comfort of the dying patient remain priorities."* EE 6 Leadership and governance • *Action 6.3 A "formal policy framework should exist, outlining the organisational approach to end-of-life care. It should include…"* • *Action 6.8 "Organisations should have systems in place to ensure that essential resources required for the provision of safe and high-quality end-oflife care (e.g. private space for family meetings, equipment and medications) are always operational and available."* • *Action 6.9 "Organisations should work with local community-based service providers to build capacity for people to be cared for in their preferred place of death (e.g. at home)."* EE 7 Education and training • *Action 7.6 Education should cover ethical and medico-legal issues, including the relevant professional ethical frameworks, and the relevant legislation.*
Accreditation Standards (residential aged care)[4]	Std. 1 Management systems, staffing and organisational development • *1.5 Planning and leadership: The organisation has documented the residential care service's vision, values, philosophy, objectives and commitment to quality throughout the service.* • *1.6 Human resource management: There are appropriately skilled and qualified staff sufficient to ensure that services are delivered in accordance with these standards and the residential care service's philosophy and objectives.* Std. 4 Physical environment and safe systems • *4.4 Living environment "Management of the residential care service is actively working to provide a safe and comfortable environment consistent with care recipients' care needs."*
National Consensus Statement: Essential elements for safe high quality paediatric end of life care[3]	Guiding principle 6 - Care of the dying is urgent care. Recognising when a child is approaching the end of their life is essential to delivering appropriate, compassionate and timely end-of-life care. EE 1 Patient-centred communication & shared decision making • *Action 1.11 "Clinicians should …Be compassionate and sensitive, use plain language, and avoid the use of medical jargon."* EE 6 Leadership and governance • *Action 6.3 The health service organisation should create a formal organisational policy framework for paediatric end-of-life care which applies across the acute health service…* • *Action 6.7 The health service organisation should develop systems to ensure that essential resources required for the provision of safe and high-quality paediatric end-of-life care (e.g. private space for family meetings, equipment and medications, memory making materials, access to toys and education resources) are always operational and available.* • *Action 6.8 The health service organisation should work with local community-based service providers and families to build capacity for children to be cared for in the preferred place of care (e.g. at home).* EE 7 Education and training • *Action 7.6 Education should cover ethical and medico-legal issues, including the relevant professional ethical frameworks, and the relevant legislation in the state or territory of clinical practice.*

Standard 8: Quality improvement

National Palliative Care Standards 2005[5]	Std. 11 The service is committed to quality improvement and research in clinical and management practices.
National Consensus Statement: Essential elements for safe high quality end of life care[2]	EE 6 Leadership and governance • *Action 6.3 A formal policy framework should exist, outlining the organisational approach to end-of-life care. It should include…evaluation, audit and feedback processes, and reporting requirements.* EE 7 Education and training • *Action 7.3 Patients, families and carers should be invited to participate in providing education about end-of-life care, since patient stories can be powerful tools for teaching. It is important that patients, families and carers are adequately supported to share their experiences* EE 9 Evaluation, audit & feedback • *Action 9.1 Data about the effectiveness of processes and systems for delivering end-of-life care should be collected, reviewed and reported locally (including over time).* • *Action 9.2 Clinicians must lead evaluation and audit, and feed back aggregate, de-identified data to their peers and colleagues.* • *Action 9.3 Monitoring and evaluation strategies should be developed to capture feedback about the quality of end-of-life care from multiple disciplines* • *Action 9.7 All deaths should be routinely reviewed to determine whether the safety and quality of the patient's end-of-life care were acceptable, and how they could have been improved.*
Accreditation Standards (residential aged care)[4]	Std. 1 Management systems, staffing and organisational development • *1.1 Continuous improvement "The organisation actively pursues continuous improvement." (also 2.1, 3.1, 4.1)* • *1.2 Regulatory compliance "The organisation's management has systems in place to identify and ensure compliance with all relevant legislation, regulatory requirements, professional standards and guidelines." (also 2.2, 3.2, 4.2)* • *1.4 Comments and Complaints "Each care recipient (or his or her representative) and other interested parties have access to internal and external complaints mechanisms."*
National Consensus Statement: Essential elements for safe high quality paediatric end of life care[3]	EE 6 Leadership and governance • *Action 6.3 A formal policy framework should exist, outlining the organisational approach to end-of-life care. It should include…evaluation, audit and feedback processes, and reporting requirements.* EE 7 Education and training • *Action 7.3 The health service organisation should invite children and families to participate in providing education about paediatric end-of-life care, since patient stories can be powerful tools for teaching. It is important that children and families are adequately supported to share their experiences.* EE 9 Evaluation, audit and feedback • *Action 9.1 The health service organisation should collect, review and report locally (including over time) data about the effectiveness of processes and systems for delivering paediatric end-of-life care.* • *Action 9.2 The health service organisation should ensure that clinicians lead evaluation and audit, and feed back aggregate, de-identified data to their peers and colleagues.* • *Action 9.3 The health service organisation should develop monitoring and evaluation strategies to capture feedback about the quality of paediatric end-of-life care from multiple disciplines (e.g. medicine, nursing, social work), as well as from children and their families.* • *Action 9.7 The health service organisation should implement processes to routinely review the safety and quality of all deaths and determine if end-of-life care could have been improved.*

Standard 9: Staff qualifications and training

National Palliative Care Standards 2005[5]	Std. 12 Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.
	Std. 13 Staff and volunteers reflect on practice and initiate and maintain effective self-care strategies.
National Consensus Statement: Essential elements for safe high quality end of life care[2]	Guiding principle 7. Safe and high-quality end-of-life care requires the availability of appropriately qualified, skilled and experienced interdisciplinary teams.
	EE 6 Leadership and governance
	• *Action 6.3 A formal policy framework should exist, outlining the organisational approach to end-of-life care. It should include...training and education requirements, access to professional clinical supervision, and formal and informal debriefing, to suit the varied needs of clinicians, access to support and debriefing for nonclinical staff*
	EE 7 Education & training
	• *Action 7.5 Clinicians should receive ongoing education about disease-specific symptom assessment and evidence-based symptom management relevant to their area of practice.*
	• *Action 7.7 Education should include specific competencies for providing culturally responsive end-of-life care to Aboriginal and Torres Strait Islander people, and to people from other culturally and linguistically diverse communities.*
	• *Action 7.8 Education should include specific training for providing end-of-life care to people with limited capacity to participate in decision-making – for example, those with mental illness, disability or cognitive impairment.*
	• *Action 7.9 Ongoing formal training in communication skills should be offered to clinicians at all levels, as these skills are critical to the delivery of end-of-life care.*
	• *Action 7.10 All members of the interdisciplinary team should receive education about how to recognise and resolve feelings of moral distress and burnout in themselves and their colleagues. They should also receive information about how to seek help, if required*
	EE 8 Supervision and support for interdisciplinary team members
Accreditation Standards (residential aged care)[4]	Std. 1 Management systems, staffing and organisational development
	• *1.3 Education and staff development "Management and staff have appropriate knowledge and skills to perform their roles effectively." (also 2.3, 3.3, 4.3)*
	• *1.6 Human resource management "There are appropriately skilled and qualified staff sufficient to ensure that services are delivered in accordance with these standards and the residential care service's philosophy and objectives."*
	Std. 4 Physical Environment and Safe Systems
	• *4.5 Occupational health and safety "Management is actively working to provide a safe working environment that meets regulatory requirements."*

| National Consensus Statement: Essential elements for safe high quality paediatric end of life care[3] | Guiding principle 7 Safe and high-quality end-of-life care requires the availability of appropriately qualified, skilled and experienced interdisciplinary teams.

EE 6 Leadership and governance
• *Action 6.3 A formal policy framework should exist, outlining the organisational approach to end-of-life care. It should include...training and education requirements, access to professional clinical supervision, and formal and informal debriefing, to suit the varied needs of clinicians, access to support and debriefing for nonclinical staff*

EE 7 Education and training
• *Action 7.5 The health service organisation should ensure that clinicians receive ongoing education about disease-specific symptom assessment and evidence-based symptom management relevant to their area of practice.*
• *Action 7.7 Education should include specific competencies for providing culturally responsive end-of-life care to Aboriginal and Torres Strait Islander people, and to people from other culturally and linguistically diverse communities.*
• *Action 7.8 Education should include specific training for providing end-of-life care to children of different ages and developmental stages. This should include those with limited capacity to participate in decision-making – for example, those with mental illness, disability or cognitive impairment. This should include education about parental responsibility and making decisions in the best interests of the child.*
• *Action 7.9 Ongoing formal training in communication skills should be offered to clinicians at all levels, as these skills are critical to the delivery of end-of-life care.*
• *Action 7.10 All members of the interdisciplinary team should receive education about how to recognise and resolve feelings of moral distress and burnout in themselves and their colleagues. They should also receive information about how to seek help, if required.*

EE 8 Supervision and support for interdisciplinary team members |

References

1. Australian Commission on Safety and Quality in Health Care 2017, *National Safety and Quality Health Services Standards*, 2nd edn., ACSQHC, Sydney

2. Australian Commission on Safety and Quality in Health Care 2015, *National consensus statement: essential elements for safe and high-quality end-of-life care,* ACSQHC, Sydney.

3. Australian Commission on Safety and Quality in Health Care 2016, *National consensus statement: essential elements for safe and high-quality paediatric end-of-life care*, ACSQHC, Sydney.

4. *Quality of Care Principles 2014* (Cwlth), viewed 1 June 2018, http://www.legislation.gov.au

5. Palliative Care Australia 2005, *Standards for Providing Quality Palliative Care for all Australians*, PCA, Canberra.

6. Palliative Care Australia 2018, *Palliative Care Service Development Guidelines*, PCA, Canberra.

7. Palliative Care Australia 2018, *Paediatric Addendum – Palliative Care Service Development Guidelines*, PCA, Canberra.

8. Palliative Care Australia & Paediatric Palliative Care Australia & New Zealand 2018, *Policy Statement – Paediatric Palliative Care*, PCA, Canberra.

9. Palliative Care Australia 2018, *Paediatric Addendum – Palliative Care Service Development Guidelines*, PCA, Canberra.

10. State of Queensland (Queensland Health) 2015, *Sad news, sorry business: guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying (version 2)*, Queensland Health, Brisbane.

11. Program of Experience in the Palliative Approach 2014, *Cultural considerations: providing end of life care for Aboriginal people and Torres Strait Islander peoples*, PEPA, Queensland.

12. Australian Indigenous HealthInfoNet & Palliative Care Australia n.d., *Culturally appropriate palliative care and end-of-life care*, AIH, Western Australia, viewed 1 November 2018, https://healthinfonet.ecu.edu.au/learn/health-system/palliative-care/culturally-appropriate/

13. Australian Institute of Health and Welfare 2018, *Mental health services in Australia*, AIHW, Canberra, viewed 1 November 2018, https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/report-contents/summary/prevalence-and-policies#references

14. CareSearch 2017, *Mental Illness*, CareSearch, Adelaide, viewed 1 November 2018, https://www.caresearch.com.au/caresearch/ClinicalPractice/SpecificPopulations/MentalIllness/tabid/2030/Default.aspx

15. Palliative Care Australia & Dementia Australia 2018, *Policy Statement – Palliative Care and Dementia*, PCA, Canberra.

16. Dementia Australia 2017, *Palliative Care and Dementia*, prepared by Parker, D, Lewis, J, & Gourlay, K, Dementia Australia, Melbourne.

17. Palliative Care Australia, Alzheimer's Australia, COTA, Aged & Community Services Australia, Catholic Health Australia, Leading Age Services Australia & Aged Care Guild n.d. *Principles for Palliative and End-of-Life Care in Residential Aged Care*, PCA, Canberra.

18. Australian Institute of Criminology 2018, *Prison Custody*, viewed 1 November 2018, http://crimestats.aic.gov.au/NDICP/1_prison-custody/#numberCause

19. Australian Institute of Criminology 2018, *National Deaths in Custody Program*, viewed 1 November 2018, http://crimestats.aic.gov.au/NDICP/

20. Sax Institute 2015, *Managing the health of an ageing prison population – a review of the challenges to be addressed by effective models of care: an evidence check rapid review*, prepared by Baidawi, S, Monash University, Australia.

21. Ginnivan, N, Butler, T & Withall, A 2018, 'The rising health, social and economic costs of Australia's ageing prisoner population', T*he Medical Journal of Australia*, vol. 209, no. 10, pp. 422 – 424.

22. Victorian Government Department of Human Services 2009, *Disability Residential Services Palliative Care guide – end-of-life care for residents of disability residential services*, State of Victoria, Melbourne.

23. CareSearch 2018, *Intellectually Disabled*, CareSearch, Adelaide, viewed 1 November 2018, https://www.caresearch.com.au/caresearch/tabid/233/Default.aspx

24. CareSearch 2017, *Homelessness*, CareSearch, Adelaide, viewed 1 November 2018, https://www.caresearch.com.au/caresearch/tabid/231/Default.aspx

25. Palliative Care Australia n.d., *Palliative Care and Culturally and Linguistically Diverse Communities – Position Statement*, PCA, Canberra.

26. Palliative Care Australia & National LGBTI Health Alliance 2015, *Palliative Care for Lesbian, Gay, Bisexual, Transgender People and People with Intersex Characteristics (LGBTI) – Position Statement*, PCA, Canberra.

27. Hall, C, Hudson, P & Boughey, A 2012, *Bereavement support standards for specialist palliative care services*, Department of Health, State Government of Victoria, Melbourne.

28. Hudson, P, Hall, C, Boughey, A & Roulston, A 2018, 'Bereavement support standards and bereavement care pathway for quality palliative care', *Palliative and Support Care*, vol. 16, pp. 375 - 387.

29. Maercker, A, Brewin, C, Bryant R, Cloitre, M, van Ommeren, M, Jones, L, Humayan, A, Kagee, A, Llosa A, Rousseau, C, Somasundaram, D, Souza, R, Suzuki, Y, Weissbecker, I, Wessely, S, First, M & Reed, G 2013, 'Diagnosis and classification of disorders specifically associated with stress: proposals for ICD-11', *World Psychiatry*, vol. 12, no. 3, pp. 198 - 206.

Palliative Care Australia is funded by the Australian Government.