

National Palliative Care Standards for All Health Professionals and Aged Care Services

MARCH 2022

For professionals not
working in specialist
palliative care



PalliativeCare
AUSTRALIA

Acknowledgements

Palliative Care Australia (PCA) would like to acknowledge the people who contributed to the development of these standards. There were two key committees which provided guidance and governance for this work.

The Expert Steering Committee provided oversight of the project and contributed expertise and experience and made recommendations to the PCA board.

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Aspex Consulting were contracted to undertake consultations with a wide range of stakeholders and developed a draft document of standards for the PCA to consider and amend. The PCA would like to thank **Peter Nagel** and **Larissa Freeman** for their contribution to development of these standards.

PCA would like to thank and acknowledge the many health professionals and organisations who made contributions in a difficult pandemic environment in 2021.

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List of Abbreviations

CALD	Culturally and linguistically diverse
GP	General Practitioner
LGBTQI+	Lesbian, Gay, Bi-sexual, Trans, Questioning/Queer, and Intersex
NPCS	National Palliative Care Standards
NSAP	National Standards Assessment Program
PaCSA	Palliative Care Self-Assessment
PCA	Palliative Care Australia

Definitions and Terminology

A comprehensive list of terminology has been provided in Appendix 1. These include:

- » Palliative Care
- » Specialist Palliative Care
- » Generalist Palliative Care
- » End-of-life
- » End-of-life care
- » Community support
- » Person living with a life-limiting condition
- » Family and carers
- » Substitute decision-maker
- » Person and family-centred care
- » Advance care planning
- » Advance care directive
- » Comprehensive care plan
- » Goals of care
- » Non-beneficial treatments
- » Continuity of care
- » Integrated care
- » Spiritual care
- » Cultural Safety

Disclaimer

These Standards describe suggested practice for the provision of generalist palliative care in all settings apart from specialist palliative care services. It is a guiding document designed to inform healthcare providers and others of recommended practice. It is not a legal document, and health and aged care providers must continue to be aware of, and abide by, the laws of the jurisdiction in which they practise. Any inconsistency between the Standards and a law of a state, a territory or the Commonwealth will be resolved in favour of the relevant law.

Chair's Foreword

Palliative Care Australia (PCA) is pleased to publish the first edition of national palliative care standards for all health professionals and aged care services. The development of these standards is another important step in improving awareness and understanding that palliative care occurs in many settings outside of “specialist palliative care services”.

The aim of PCA's effort is to increase access for all Australians with a life limiting condition, to a quality palliative care approach, and to assist health professionals and services to provide improved palliative care services outside of, or in consultation with, specialist palliative care services.

PCA has established that improving access to the holistic palliative care approach in Australia not only improves health and social outcomes for people experiencing life-limiting conditions and their families, but also optimises the value of investment by Government for people at the end of their lives. PCA seeks to encourage innovative and adaptive approaches to increasing access to quality palliative care with these standards. Driving new partnerships and collaborations will be a key focus on PCA's work with health professionals and services in pursuing the delivery of quality palliative care outside specialist palliative care services.

These standards also support PCA's broader strategy to achieve better collaboration to deliver integrated models of care between Specialist Palliative Care and other specialist/primary health care and aged care. It is hoped these standards will help facilitate better awareness and coordination of care between the specialist and non-specialist palliative care services which will ensure we meet our goal to deliver high quality palliative care for all Australians.

I encourage health care services and professionals to consider these best practice standards and reflect on their practice to develop and improve their delivery of the palliative care approach.



Professor Meera Agar
Chair
Palliative Care Australia

Preface

The National Palliative Care Standards for All Health Professionals and Aged Care Services has been developed to complement the National Palliative Care Standards (NPCS) 5th Edition 2018¹ with the aim of supporting better experiences and outcomes for people receiving generalist palliative care. The scope is broad, and spans care across acute hospitals, ambulatory specialist clinics, primary care services, residential aged care services and people's homes.

These Standards were informed by a review of the evidence² and consultations nationally across the healthcare sector.

These are voluntary standards and are intended to guide healthcare providers to deliver high-quality palliative care.

The Standards are relevant to sole practitioners, as well as to larger tertiary acute hospitals – and to everything in between. They are generally normative standards but also incorporate aspirational components to support providers and services seeking to enhance capability and achieve best practice.

It is recognised that there will be organisational and practice differences so that alignment with the Standards is expected to vary in practice.

Core values of palliative care

Quality palliative care is delivered by healthcare providers, social, community and aged care workers, Aboriginal health workers, and family and carers of people with a life-limiting condition who:

- » Maintain the dignity of the person, their substitute decision-maker, their family³, and carers to use their strength to manage challenges;
- » Act with compassion and kindness towards the person, their family and carers, and substitute decision-maker(s);
- » Consider equity in the accessibility of services and in the allocation of resources;
- » Demonstrate respect for the person, their family and carers, and substitute decision-maker(s);
- » Provide culturally appropriate and Culturally Safe care, where culture is integral to social and emotional well-being;

- » Are inclusive and respectful of Aboriginal and Torres Strait Islander people, recognising the historic impact of colonisation on Aboriginal and Torres Strait Islander people and respecting the needs, priorities and aspirations of families and communities;
- » Are responsive to the specific needs of vulnerable populations;
- » Advocate on behalf of the expressed preferences of the person, their family, carers, their communities, and substitute decision-maker(s);
- » Are committed to the pursuit of excellence in the provision of holistic, evidence-based care and support; and
- » Are accountable to the person, their family, carers, and substitute decision-maker(s).

To ensure high quality, person-focused and evidence-based services are available to meet peoples' needs, healthcare providers should also:

- » Follow established practice standards and requirements for quality management such as leadership and governance, human resource management, safe practice, information management, and continuous quality improvement;
- » Adhere to professional and organisational codes of practice and ethics;
- » Reflect on and evaluate current practice, and incorporate new evidence into protocols, policies, and procedures; and
- » Participate in continuing professional development in the knowledge, attitudes, and skills required to deliver quality palliative care that is holistic, and Culturally Safe and responsive.

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1. The NPCS 2018 defines standards relevant for *specialist* palliative care services. PCA has implemented a self-assessment tool for use by specialist palliative care services in conjunction with the specialist standards.
2. Palliative Care Australia, 2021, Generalist palliative care: Background paper for the Addendum on Palliative Care.
3. The term *family* includes people identified by the person as family. This may include people who are biologically related, however it may not. People who joined the family through marriage or other relationships, such as kinship, as well as the chosen family, street family for those experiencing homelessness, and friends (including pets) may be identified by the person as family. A person may also choose to not to have their family or carers involved in their care, or a person may not have any family or carers.

Structure of the standards

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

The Standards are divided into two categories:

- » Care Standards (Standard 1 to 6) which describe the systems, processes, and enablers necessary to deliver high quality palliative care; and
- » Governance Standards (Standard 7 to 9), which describe expectations regarding quality management, quality improvement and benchmarking.

The purpose of each component of the Standard is as follows:

- » **Standard:** Contains the specific standards. There are nine 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 standards to which providers and services are encouraged to aspire.

Appendix 1 provides definitions and explanations of key terms used in the Standards.

What is generalist palliative care?

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 treatment goal is to optimise the quality of life.⁴

PCA's Service Development Guidelines⁵ differentiate between generalist palliative care and specialist palliative care as follows:

- » **Generalist palliative care:** All healthcare providers who provide care to people living with a life-limiting condition, their families and carers should have minimum core competencies in the provision of palliative care and understand the palliative approach to care.
- » **Specialist palliative care:** People will have different levels of need for palliative care. People with more complex needs should be able to access care provided by specialist palliative care services comprising multidisciplinary teams with specialised skills, competencies, experience, and training in palliative care. Palliative Care Australia refers to this type of care that is provided by specialist palliative care services as 'specialist palliative care'. PCA has specified service delivery standards for specialist palliative care.⁶

Further, the Service Development Guidelines define the following workforce envisaged as relevant to generalist palliative care:

- » The management and coordination of care for people living with a life-limiting condition may be undertaken by a wide range of care providers including General Practitioners (GPs) and other medical specialists such as oncologists, nurses, allied health professionals, Aboriginal and Torres Strait Islander health workers, aged care workers and pharmacists. These healthcare providers are 'generalists' with respect to palliative care, notwithstanding that many of them might be specialists in their own discipline.

The role of healthcare providers is summarised as follows:

- » To treat people living with a life-limiting condition, healthcare providers should have minimum core competencies to manage physical symptoms, support medication management, to provide or refer to psychosocial spiritual support services, and to discuss the goals of treatment and the person's prognosis.

An outline of the service capability expectations for healthcare providers is provided as Level One of the service capability framework of PCA's 2018 Service Development Guidelines.⁷

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4. Palliative Care Australia, 2018, National Palliative Care Standards, 5th edition.
5. Palliative Care Australia, 2018, National Service Development Guidelines.
6. Palliative Care Australia, 2018, National Palliative Care Standards, 5th edition.
7. Palliative Care Australia, 2018, Service Development Guidelines.

Scope of services relevant to the standards

The scope of generalist palliative care services is *comprehensive* and includes all settings in which a person receives palliative care, excluding specialist palliative care services. Quality palliative care is delivered by healthcare providers, social and community workers and family and carers of people with a life-limiting condition.

Services which may be involved in providing palliative care include, but are not limited to:

- » **Community-based palliative care:** Organisation of, and/or referral to, community nursing, allied health, identified Aboriginal and Torres Strait Islander health professionals, counselling, and other home care support services related to managing health care and functional needs; and
- » **Hospital-based palliative care:** Referral to hospital inpatient services and/or ambulatory (outpatient) services for the management of acute episodes and/or for people who are living with a life-limiting condition and whose care needs cannot be fully supported at home; services will be provided by the nearest available public or private hospital and care may be provided in acute or other beds (rather than in designated palliative care beds that are managed by specialist palliative care healthcare professionals).

Paediatrics

The care of infants (including in the perinatal period), children or adolescents with a life-limiting condition can have unique characteristics that differentiate this type of care from 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 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 need 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 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 in a safe environment, support for the family, the management of distress and symptoms, every opportunity to continue with education and hobbies, and provision of short breaks and care through to death.⁹

Who could be in the palliative care team to provide the greatest benefit to people with a life-limiting condition?

- » **Medical practitioners** with knowledge and experience in palliative care who provide most medical care to the person living with a life-limiting condition – may be a GP, general physician, geriatrician, paediatrician, nephrologist, oncologist, cardiologist, respiratory physician, gastroenterologist, or other medical professional depending on the availability of health professionals in the community;
- » **Nurses** who may include nurse practitioners, registered nurses, and enrolled nurses who may work in community settings including people's homes and other residential care homes;
- » **Allied health professionals** including occupational therapists, physiotherapists, speech pathologists, dietitians, psychologists, spiritual care workers, and music and art therapists with knowledge or experience working with people receiving palliative care;
- » **Community Pharmacists** who provide a range of support services to optimise quality of medicines;
- » **Social Workers;**
- » **Aboriginal and Torres Strait Islander health workers, Liaison officers and identified nurses navigators;**
- » **Paramedics** who may provide transport for people receiving palliative care;
- » **Medical imaging professionals** who are often the key determinate of changes in care, or the denoting of the commencement of urgent care and **Radiation therapists** are involved in the provision of palliative radiation treatments;
- » **Personal care workers** who provide support in the person's home or other residential care home;
- » **Grief counsellors;** and
- » **Language Services** for access to appropriate support and advice for cultural diversity.

8. Palliative Care Australia & Paediatric Palliative Care Australia & New Zealand 2018, Policy Statement – Paediatric Palliative Care, Palliative Care Australia, Canberra.
9. Palliative Care Australia 2018, Paediatric Addendum – Palliative Care Service Development Guidelines, PCA, Canberra.

These Standards may be applicable to infants, children, or young people if they are receiving generalist palliative care, however there are acknowledged complexities in relation to paediatric, child and adolescent palliative care. These additional challenges in the paediatric context include considerations around clinical, developmental, social, educational, communication, information, and family needs, as well as the additional pain and suffering resulting from the prospect of the death of a young person.^{10,11} These complexities have not been highlighted in these Standards.

Care for people with diverse needs

There is a need for person-centred palliative care for all people, inclusive of those with diverse needs. Diverse populations often experience ongoing stress that comes from being marginalised. Individuals may also be members of more than one minority group and as a result may face compounding barriers to accessing appropriate palliative care.

Intersectionality¹² is a term used to describe the experiences of people that sit at the intersection of multiple minority identities (for example, LGBTIQ+ and Aboriginal and Torres Strait Islander people) and face additional systemic barriers in society as a result. It is important to understand different groups through an intersectional lens so that the palliative care needs of individuals can be better met.

Aboriginal and Torres Strait Islander people

For Aboriginal and Torres Strait Islander people, the time before, during and after passing often have several customary practices. These practices may be sacred and may not be widely discussed outside of the community.¹³ Research also suggests that traditions and practices as well as the significance of ceremony and practices at end of life, have been lost due to colonisation. Palliative care needs to be planned in partnership with community and decision makers to support the reclamation of these practices to enhance Culturally Responsive care. It should also be noted that cultures, customs, and practices vary across Australia. The time surrounding the end of someone's life is precious and needs to be respected and approached in a Culturally 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 substitute decision-makers about preferred terms and what they would like to know. In doing so, relevant information on the symptoms experienced by the person with a life-limiting condition, including pain, and the options to manage these symptoms, can be provided. The family, or community, may express specific preferences, such as use of traditional medicine, space to respect kinship and accommodate more than one person to stay overnight and room for multiple visitors at once.¹⁴ Health Professionals should ask the identified decision maker about the needs of the community, family and kin in developing a care plan for an Aboriginal and/or Torres Strait Islander person.

Cultural determinants of health are the social dimension of Indigenous peoples' lives and are life-giving values from which individuals, families and communities can draw strength, resilience, and empowerment.¹⁵ A cultural determinant of health approach has been shown to have a positive impact on the health and wellbeing outcomes of Aboriginal peoples. The cultural determinants include, among others, family/community, country and place, cultural identity, and self-determination. The Aboriginal community-controlled health organisations (ACCHOs) have long focused on this strength-based approach.¹⁶ Health services can improve the quality of palliative care provided to Aboriginal and Torres Strait Islander people, by ensuring they deliver "Culturally Responsive" care.¹⁷

Training in therapies and approaches adapted for working with Aboriginal and Torres Strait Islander peoples, such as narrative therapy or trauma-informed care, are available.¹⁸

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 can result in people being inadequately served by relevant specialties. People living with a mental illness may not want to engage with medical staff and so often do not receive a diagnosis until late in an illness trajectory, this may be further complicated by the person's legal decision-making capacity.¹⁹ They may also have poorly

10. Palliative Care Australia, 2018, National Palliative Care Standards, 5th edition.

11. Palliative Care Australia, 2018, Service Development Guidelines.

12. Victorian Government, understanding intersectionality Definition of intersectionality and how it can lead to overlapping of discrimination and marginalisation, 8 February 2021, available: <https://www.vic.gov.au/understanding-intersectionality>.

13. 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.

14. 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.

15. Verbunt, E., Luke, J., Kelaher, M., Cultural determinants of health for Aboriginal and Torres Strait Islander people – a narrative overview of reviews, International Journal for Equity in Health, 20, Article no: 181 (2021).

16. Verbunt, E., Luke, J., Kelaher, M., Cultural determinants of health for Aboriginal and Torres Strait Islander people – a narrative overview of reviews, International Journal for Equity in Health, 20, Article no: 181 (2021).

17. Indigenous Allied Health Australia, 2019 Policy Position statement, Cultural Safety through Responsive Health Practice.

18. <https://healthinonet.ecu.edu.au/key-resources/courses/?id=57> as of 15 February 2022

19. Australian Institute of Health and Welfare 2018, Mental health services in Australia, AIHW, Canberra.

met social, housing, income, and support needs. Consideration should be given to partnership models between palliative care and mental health services.²⁰

People living with addictions or substance abuse disorders

People living with addictions or substance abuse disorders can pose challenges for palliative care especially around medication (opioids/drugs of dependence) provision.²¹ Many people who have addictions and/or substance use disorders are also concurrently dealing with other diverse needs that may include mental illness, other comorbidities, cognitive impairment, dementia, an incarceration history, community parole with or without a security bracelet, live in supported accommodation or are homeless.²²

Alcohol and other drug use are increasing among older Australians and will be more and more relevant in generalist palliative care settings.²³

Where palliative care services are being provided to children and young people, including young adults, substance use issues may be involved. Alternatively, younger patients may be exposed to parents who have addiction issues and may be concurrently accessing multiple services, such as child protection services.

People living with dementia

A person living with dementia can require different care to people with other life-limiting conditions; 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.²⁴ Managing the needs of people with a life limiting condition, 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 remain the primary focus. For example, identifying and successfully managing symptoms such as pain for people living with dementia is difficult. These symptoms often present behaviourally and may be under-supported and treated.

Healthcare providers should always seek any existing Advance Care Directives. Healthcare providers 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.²⁵ Aids and equipment may help a person with their mobility and assistive technology may help them to communicate and these may help to improve the quality of life for the person living with dementia. Providing care to Aboriginal and Torres Strait Islander people living with dementia requires specialised skills in Culturally Responsive approaches.

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.²⁶ 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. There is only limited information available on the palliative care and decision-making preferences of this population.²⁷ The need for palliative care in prison custody is likely to increase given the increasing custodial population aged 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).²⁸

People with disability

Provision of palliative care for people with a disability is likely to require coordination of care between different services sectors, including disability and health, and where they may be receiving care, such as at home, in hospital, in residential aged care or supported accommodation. The staff engaged to support people living with a disability in residential services generally will not have additional health care training, unless

20. CareSearch 2017, Mental Illness, CareSearch, Adelaide. <https://www.caresearch.com.au/caresearch/ClinicalPractice/SpecificPopulations/MentalIllness/tabid/2030/Default.aspx>.

21. Merlin, J. S. et al 2020, 'Managing Opioids, Including Misuse and Addiction, in Patients With Serious Illness in Ambulatory Palliative Care: A Qualitative Study', *American Journal of Hospice and Palliative Medicine*, vol 37, no. 7, pp. 507-513.

22. Ebenau, A., Dijkstra, B., ter Huurne, C. et al 2019, 'Palliative care for people with substance use disorder and multiple problems: a qualitative study on experiences of patients and proxies'. *BMC Palliative Care*, vol 18, no. 56.

23. Australian Institute of Health and Welfare 2020, National Drug Strategy Household Survey 2019, AIHW, Canberra

24. Palliative Care Australia & Dementia Australia 2018, Policy Statement - Palliative Care and Dementia, PCA, Canberra.

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

26. 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.

27. 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.

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

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 in line with the palliative care approach.²⁹ For some people living with a disability, additional support may be required to assist them in understanding a diagnosis and prognosis, and address complications in symptom management. Staff may also need to be aware of non-verbal or alternative communication strategies to assist them in the provision of care.³⁰

Age-related hearing loss can impact care and therefore, it is important to screen for hearing loss and management approaches. Audiologists may provide diagnostic assessment, direct treatment and strategies, environmental modifications and devices or aids to support people receiving palliative care to be as active and independent as possible. This might include providing information on personal sound amplifiers, including how and when; optimising the physical environment so that it is free of distractions and has advantageous lighting; and employing tools and devices to enhance communication with others.

People experiencing homelessness

Some people who are at risk of or experiencing homelessness may require access to palliative care. It is important that healthcare providers are flexible enough to meet the needs of these deprived populations, especially given people may move around and not have a fixed location or address and have no identifiable family or carers. Partnership models between health and community services should be in place to ensure that the needs of people can be appropriately met.³¹

Culturally and linguistically diverse communities

People's beliefs, values and traditional health care practices are central to person-centred palliative care experiences. Quality, appropriate, and comprehensive care is culturally sensitive and requires healthcare providers 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.³²

Lesbian, gay, bisexual, transgender, queer or questioning and intersex people

Palliative care services must provide a safe environment for people who identify as LGBTIQ+ and have life-limiting conditions so that they can live and die with equity, respect, and dignity, and without fear of prejudice and discrimination.

Although there have been increasing levels of social acceptance and legislative improvements, people identifying as LGBTIQ+ continue to experience prejudice and discrimination in healthcare settings and often feel compelled to avoid or delay seeking treatment for fear of negative responses. This can be quite detrimental to their wellness for conditions such as HIV, which can be managed long-term with medication, allowing people to live relatively healthy and long lives.

Many people identifying as LGBTIQ+ face stigma, family rejection, exclusion, social isolation, and reduced access to advance care planning. The failure to recognise partners and rainbow families (chosen family) in health care planning and decision-making can be particularly challenging, and self-designated family and carer(s), which many people identifying as LGBTIQ+ refer to as their chosen family, should be treated with as much dignity and respect as biological relatives.

People identifying as LGBTIQ+ who require carers at end-of-life are often supported by their partners who also identify as LGBTIQ+. These partners also face ongoing stress and may experience increased pressure, providing longer and more intense care, due to their partners avoiding or delaying care because of fear of stigma and discrimination.

As a result of the barriers they face, many people identifying as LGBTIQ+ face worse health outcomes and die without having their end-of-life preferences met and without care suitable to their needs.

People identifying as LGBTIQ+ have diverse life experiences, and the barriers that are faced by some population groups may be different to others – for example, lesbians and gay people face different challenges to transgender people. Intersex people can face distinct barriers to accessing appropriate health care services. It is important to note that many intersex people are heterosexual and cisgender and may not consider themselves to be part of LGBTIQ+ communities.³³

29. 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.

30. CareSearch 2018, Intellectually Disabled, CareSearch, Adelaide.

31. CareSearch 2017, Homelessness, CareSearch, Adelaide.

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

33. LGBTIQ+ Health Australia - written submission to PCA during consultation phase.

Precursor

A frequent challenge for effective palliative care is the timely identification of people who have been diagnosed with a life-limiting condition. Understandably, it is seldom easy for healthcare providers to initiate a conversation about palliative care, as this may be unexpected and confronting for many people. Nonetheless, sensitive, and compassionate conversations with trusted and knowledgeable healthcare providers enables people, their families, carers and substitute decision-maker(s) to be informed at an early stage about palliative care planning and the person to be supported to live as well as they can. A series of conversations may be needed to elicit the goals, values, and preferences of the person now and for the future and reach shared decisions about the appropriate plan for their care.³⁴ This is essential to informed decision-making.³⁵ Such conversations should be ongoing, as the person's needs change, and as their care plan needs to be continually revisited.

Informed decision-making about palliative care planning also involves healthcare providers identifying people systematically and on a timely basis.³⁶ Examples of tools that may be used to identify people who are likely to be approaching the end of their life include the Gold Standards Framework,³⁷ the Amber Care Bundle³⁸ or the Supportive and Palliative Care Indicators Tool (SPICT).³⁹

The focus of these Standards is the provision of quality palliative care across a range of settings. A patient's decision to access voluntary assisted dying does not change their right nor their access to high quality palliative care.⁴⁰

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34. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC, 2015, p. 10.

35. NICE Guideline 142, 2019, End-of-life care for adults: service delivery.

36. NICE Guideline 142, 2019, End-of-life care for adults: service delivery.

37. Thomas.K et al, Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011, The Gold Standards Framework Centre In End of Life Care CIC, UK

38. Carey I, Shouls S, Bristowe K, et al. Improving care for patients whose recovery is uncertain. The AMBER care bundle: design, implementation, and clinical outcomes. *BMJ Support Palliat Care* 2015; 5(1): 12-18.

39. SPICT 2019, The University of Edinburgh.

40. Palliative Care Australia, September 2019, Palliative Care and Voluntary Assisted Dying, Position Statement.

The standards – an overview

STANDARD 1

Comprehensive assessment of needs

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

- 1.1 The initial and ongoing assessments are carried out by a qualified healthcare provider in partnership with the members of the care team, wherever feasible. The person may be supported by their family, carer or substitute decision-maker(s), and any other services which may assist with supported decision-making.
- 1.2 Initial and ongoing assessments are coordinated to reduce the burden of duplication on the person, family, and carers and substitute decision-maker(s).
- 1.3 Assessments are documented in the person's clinical record and communicated to all members of the care team, including the person and their family and carers and any substitute decision-maker(s).
- 1.4 Processes are in place for healthcare providers to identify people who have been diagnosed with a life limiting condition to enable proactive and timely palliative care and advance care planning for their future.
- 1.5 Processes include clinical assessment tools, informed by the best available evidence, where these are available.
- 1.6 People managing and delivering generalist palliative care should develop processes to ensure a person's needs are reassessed on a regular basis.

STANDARD 2

Developing the comprehensive care plan

The person, their family and carers and substitute decision-maker(s) work in partnership with multidisciplinary teams to communicate, plan, set goals of care and support informed decisions about the comprehensive care plan

- 2.1 Care planning is informed through an assessment process.
- 2.2 The person, their family and carers and substitute decision-maker(s) are provided with evidence-based information appropriate to meet their

needs and to support informed participation in care planning and decision-making, including advance care planning. There should be ongoing review and anticipation of the information needs and preferences as circumstances change. It is important to meet a careful balance between the needs of a child or young person with a life limiting condition and their parents and carers.

- 2.3 Initial and ongoing discussions informing the comprehensive care plan are documented and readily available to guide care delivery. Whenever possible, healthcare providers should ensure that the person, their key family members, substitute decision-maker(s) and carers are present during discussions, ensuring consistent messages are given about treatment options, their likelihood of success, risks, and prognosis.
- 2.4 There is appropriate use of interpreters to support those from culturally and linguistically diverse backgrounds to communicate, plan and set goals of care.
- 2.5 There is appropriate use of assistive devices for hearing, sight, and cognitively impaired individuals to ensure communication is optimised i.e., hearing aids/sign language/speech boards etc.
- 2.6 The expectations, values and preferences of the person, their family and carers and substitute decision-maker(s) for the type and place of care are discussed, negotiated, and documented in the comprehensive care plan.
- 2.7 Processes are in place to enable healthcare providers to identify the person's substitute decision-maker (whether legally appointed by the person, appointed by tribunal, or assigned to a person by a statutory hierarchy) upon entry to the health service, and processes are in place to ensure a person can formally appoint a substitute decision-maker if they desire.
- 2.8 The comprehensive care plan and any limitations of medical treatment should be revisited with the person, family, carers and substitute decision-maker, when significant changes in the person's condition or circumstances occur, for example when the person is admitted to hospital, or they are in transition to the terminal phase. The person's holistic needs should be considered and the person, family, carers and substitute decision-maker, should be empowered to request further discussion and a review of the plan at any time.

- 2.9** Processes are in place to enable person and family-centred palliative care planning.
- 2.10** Processes are in place to prepare, review and/or update advance care directives, according to the current values and preferences of the person.
- 2.11** Processes are in place for receiving, storing, accessing, and sharing existing advance care planning documents.
- 2.12** Processes are in place to assess individual values, preferences and needs of all people inclusive of aspects of identity such as culture, gender, sexuality and bodily diversity, other vulnerable populations.
- 2.13** There is appropriate use of e-technology or e-platforms for assessment and to support decision making. These may also contribute to staff competency in these modalities.
- 3.5** There are processes in place to ensure that the person's nominated family and carers and substitute decision-maker(s) are supported to participate in the provision of health care in accordance with the preferences of the person, their family and carers and substitute decision-maker(s). It is important to recognise however, that some family situations may be complex and involve a fractured relationship between the person and parents or siblings.
- 3.6** Family and carers and substitute decision-maker(s) should be supported to spend time with a dying person in accordance with their preferences, including in the period immediately after death. The family and carers and substitute decision-maker(s) 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, religion and social situation.
- 3.7** There are processes in place to provide a safe working environment for family, carers, substitute decision-maker(s) and healthcare providers. Stress and impacts of changed behaviours, in for example dementia, is not only a consideration for the dying but for those around them.

STANDARD 3

Caring for carers

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

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- 3.1** At least one carer is nominated by the person and the carer's specific needs, including their need for information, are assessed and documented. Consideration should be given to factors such as a carer's age, ability, culture, social situation, sexual orientation, body diversity and gender identity, concerns about employment and any other factors that may be relevant.
 - 3.2** The healthcare providers work with the family and carers and substitute decision-maker(s) 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 substitute decision-maker(s) and there is ongoing assessment of their willingness and ability to participate in the provision of care.
 - 3.3** The family, carers and substitute decision-maker(s) 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.
 - 3.4** Depending on the location of care and the person's needs and preferences, the family and carers and substitute decision-maker(s) are educated about how to safely assist with care, management of medications, managing risk, manual handling, and activities of daily living.

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.

- 4.1** The healthcare providers with overall responsibility for leading and coordinating a person's care must be clearly identified and documented in the person's comprehensive care plan. The leading healthcare provider may delegate this coordination role to someone else in the care team.
- 4.2** Care is responsive and delivered promptly, in accordance with changing needs of the person, their family and carers and any substitute decision-maker(s), their documented comprehensive care plan and their goals, values and preferences.
- 4.3** Where care cannot be delivered in accordance with the goals, values, and preferences of the person, this is discussed with the person, substitute decision-maker, their family, and carers, and an agreed alternative plan is documented and communicated.
- 4.4** Evidence-based policies for reviewing treatment within all specialties and reducing unnecessary prescribing, with deprescribing when appropriate, are developed to meet the changing needs of people approaching the end of their life and to reduce the burden of unhelpful treatments.
- 4.5** There are protocols and procedures in place for the escalation of care including referral to specialist palliative care where required, based on assessed needs and the availability of a specialist palliative care team.
- 4.6** The healthcare providers aim to actively pre-empt distress to the best of their ability.
- 4.7** Anticipatory planning should be undertaken by the lead healthcare provider so that people approaching the end of their life, their family and carers and substitute decision-maker(s) have access to:
 - » Appropriate care available 24 hours a day, 7 days a week, allowing access to the person's records and advance care directive, and to informed decisions about changes to care, and to certify death;
 - » An out-of-hours palliative care advice line;
 - » Community support and respite care;
 - » Predictable medications for symptom management; and
 - » Grief support.

STANDARD 5

Transitions within and between services

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

- 5.1** Healthcare providers provide clear communication so that people are aware of why they are being transferred, where they are being transferred to and how the transfer may be avoided if, for example, additional supports could be put in place.
- 5.2** Healthcare providers take steps so that transfers are minimised to maximise the opportunity for people to stay in their preferred place, so that they can age and die in place.
- 5.3** There are policies and procedures in place that support and promote continuity of care across settings throughout the course of the person's condition. This is reinforced through the comprehensive care plans.
- 5.4** Policies for prioritising and responding to referrals for people with a life-limiting condition in a timely manner are documented and audited regularly to identify improvement opportunities.
- 5.5** The healthcare providers have effective communication processes to support integrated care, to enable information to be reviewed, updated, and shared efficiently within and between teams of generalist or specialist palliative care providers, across different services and organisations
- 5.6** Notification of death of the person within and between services is important as it helps to prevent anyone inadvertently recalling a patient for a consult after they have already died, which can be very distressing for the family as well as staff.
- 5.7** Processes should be in place to adequately assess unmet need and where this cannot be managed by the healthcare providers, a referral to specialist palliative care occurs. This may include off-site access via videoconferencing or teleconferencing.
- 5.8** Referrals are made to appropriate specialists or services that can meet the identified physical, social, cultural, and spiritual needs of the person, their family and carers and substitute decision-maker(s).
- 5.9** When a person is to be discharged from a specialist palliative care service, community-based healthcare providers collaborate to ensure continuity of care and minimise risk, to enable swift access to community-based health, pharmacy, and community support services.
- 5.10** Healthcare providers support people to reengage with specialist palliative care in accordance with their needs and preferences.

STANDARD 6

Grief support

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

- 6.1** Culturally appropriate information and resources about loss and grief support is routinely provided to families, carers, and substitute decision-maker(s) before and after the death. These should be available in multiple languages for CALD populations.
- 6.2** Organisations provide access to education about loss and grief to staff, volunteers, and other community providers working in generalist palliative care.
- 6.3** Healthcare providers use validated tools to assess for signs and symptoms of persistent and intense distress in grieving or bereaved persons.
- 6.4** Healthcare providers develop strategies and referral pathways, in partnership with other providers in the community, to assist families, carers and substitute decision-maker(s) in feeling more prepared for the death, and to accommodate grief into their lives.
- 6.5** Referral to grief counsellors, specialist mental health and/or counselling professionals are made when clinically indicated.

STANDARD 7

Service culture

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

- 7.1** The values and culture of an organisation providing generalist palliative care explicitly support the provision of person and family-centred palliative care to the person's family and carers and any substitute decision-maker(s).
- 7.2** There is evidence of person and family-centred care principles within clinical practice guidelines, policies, and procedures.
- 7.3** The care setting provides an appropriate environment to support people receiving palliative care, their family, carers, and substitute decision-maker(s).
- 7.4** Healthcare providers understand the community they serve and use this information to both provide optimal palliative care services and influence wider health, aged care, and community support systems to optimally meet the needs of that community.
- 7.5** Organisations support the mental health and wellbeing of their staff working in generalist palliative care.

STANDARD 8

Quality improvement

Services are engaged in quality improvement and research, based on best practice and evidence, to improve service provision and development.

- 8.1** Palliative care is explicitly addressed as part of an organisation's quality improvement framework(s). The palliative care quality improvement framework is implemented to enable review of clinical performance, outcomes, and experience of care provision, and to identify, implement and evaluate improvement activities.
- 8.2** Data about the effectiveness of palliative care provision is collected, reviewed, and reported locally.
- 8.3** An organisation providing generalist palliative care is accredited to ensure achievement of governance and safety requirements.
- 8.4** The organisation includes palliative care within the ambit of its research focus and supports opportunities for staff to lead or participate in palliative care research. Consultation and collaboration with academics will ensure the research is conducted in an ethical manner.
- 8.5** Healthcare providers establish links with specialist palliative care services and other specialists to provide integrated care and to improve the quality of that care.
- 8.6** The person, their family, carers and substitute decision-maker(s), and health professionals are invited to co-design the evaluation of the service via formal and informal feedback mechanisms. Access to language services should be available where necessary to encourage feedback from CALD populations.

STANDARD 9

Staff qualifications and training

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

- 9.1** Healthcare providers have the skills to meet the physical, psychological, social, cultural, and spiritual needs of the person, their family and carers and substitute decision-maker(s). Healthcare providers working as part of a team to deliver generalist palliative care should receive education about their roles and responsibilities in relation to local processes and processes for recognising and enabling optimal palliative care.
- 9.2** Staff and volunteers should receive training that includes providing culturally safe palliative care for paediatrics, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, LGBTQI+ people and anyone else deemed vulnerable.
- 9.3** Staff and volunteers receive appropriate supervision and support in accordance with an established professional development framework.
- 9.4** Education for health care professionals should include how to recognise and resolve feelings of moral distress and burnout in themselves and their colleagues, as well as information about how to seek help, if required.
- 9.5** Staff should receive training in the law relating to palliative care and end-of-life care.
- 9.6** Generalist volunteer programs are recognised, supported, and managed in accordance with the relevant volunteer standards.
- 9.7** Experienced team members are responsible for providing supervision, leadership, support, mentorship and teaching to develop the skills and capacity of all team members in relation to palliative care and end-of-life care.
- 9.8** A formal assessment of palliative care education and training is undertaken for all members of the health service to identify professional development requirements.

Comprehensive assessment of needs

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

Intent of Standard 1

Timely assessment of care needs during a person's disease trajectory enables the right support to be provided to the person and their carers when it is needed. The person, their family* and carers and any substitute decision-maker(s), should be actively involved in the early initial and ongoing person and family-centred assessments which focus on their physical, psychological, cultural, social, and spiritual needs.

An individual person's health can fluctuate unpredictably, with periods of deterioration, stabilisation and sometimes improvement. In addition to changes in their physical condition, a person's psychological, social, spiritual, financial, and other support needs will vary over time. This reinforces the need for regular reviews of care or other forms of support.⁴¹ Repeating holistic needs assessments and reviews of advance care directives helps to ensure that people continue to receive culturally appropriate care and support at the right time.⁴²

It is important that everyone recognise there may be differing views about life limiting conditions, their implications, and consequent approaches to comprehensive care. In some culturally and linguistically diverse (CALD) communities, the meaning of shared decision-making does not necessarily align with other interpretations. Some cultures delegate responsibility for decision making to others or support a belief that it is inappropriate to share a diagnosis of a life-limiting condition with the affected person. Awareness of a person's cultural beliefs should be identified as early as possible so that strategies can be put in place for obtaining input into discussions about palliative care.⁴³

When providing person and community and family-centred care to Aboriginal and Torres Strait Islander people, it is important to ask who should be involved in discussions and decisions regarding the person's care as there may be kinship responsibilities, or other people considered family who should be involved.⁴⁴ Involving Aboriginal or Torres Strait Islander Health Workers or Liaison Officers in these conversations may be helpful. It is important that these conversations are self-determined, build trust and connectedness, and reflect culturally responsive care.

LGBTIQ+ people often have a broader definition of family and often opt to be supported by those they consider to be their chosen family. This may have come about due to rejection from their family of origin because of their LGBTIQ+ status. Some people may request the presence of religious leaders (priests, imams, etc.,) for support.

Shared decision-making is a critical part of making sure that people approaching the end of their lives are partners in their own care, consistent with their cultural expectations.

Healthcare providers should use their clinical skills and experience, and their knowledge of the person's values, culture, and preferences to make recommendations that inform the collaborative decision-making process.⁴⁵ However, information about a person may not always be disclosed to healthcare providers, for example where a person receiving palliative care may not be open about their LGBTIQ+ status with all the people involved in their care.

41. NICE Guideline 142, 2019, End-of-life care for adults: service delivery.

42. NICE Guideline 142, 2019, End-of-life care for adults: service delivery.

43. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015. p. 11.

44. Program of Experience in the Palliative Approach (2020). Cultural considerations: providing end-of-life care for Aboriginal peoples and Torres Strait Islander peoples (pp. 34). Canberra: Program of Experience in the Palliative Approach.

45. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015.

* The term *family* includes people identified by the person as family. This may include people who are biologically related, however it may not. People who joined the family through marriage or other relationships, such as kinship, as well as the chosen family, street family for those experiencing homelessness, and friends (including pets) may be identified by the person as family. A person may also choose to not to have their family or carers involved in their care, or a person may not have any family or carers.

Support should be provided to people to enable them to actively participate in decision-making by having in place:

- » Processes to establish the amount and type of information they would prefer;
- » Information that meets their communication needs and preferences and for how it is given – whether verbally or paper-based, by text, email, or other assistive technologies; and
- » Arrangements to review and anticipate their information needs and preferences as circumstances change.⁴⁶

Maximising the input and voice of people with life limiting conditions, and, where appropriate, their family members/carers and substitute decision-maker(s), is an obligation for all healthcare providers. However, those with cognitive or intellectual impairment, those who are young, or those with severe mental illness may not be able to participate fully in decision-making, and their capacity to participate in decisionmaking may fluctuate. Supported decision-making may be necessary for such people.

Supported decision-making means that healthcare providers assess the person's decisionmaking capacity and maximise opportunities for participation by people with impaired capacity, potentially with help from other professionals such as language services, social workers, or speech pathologists. Healthcare providers should work with carers and families to support people to be as involved in decision-making as their capacity at the time will allow.⁴⁷

A comprehensive and holistic documented 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 healthcare provider may be involved, care is taken to ensure that assessment is co-ordinated, and the information gathered is communicated effectively among the multiple healthcare and other professionals involved in the care team and stored in a digital health record/ electronic medication management system appropriate to the care setting.

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46. NICE Guideline 142, 2019, End-of-life care for adults: service delivery.

47. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015 p.11.

Reassessment should occur regularly, particularly when care requirements and goals of treatment change. This includes identifying when the person is imminently dying and incorporating assessment of the specific needs associated with this phase.

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To meet this standard, the healthcare provider managing or delivering services is expected to ensure:

- 1.1** The initial and ongoing assessments are carried out by a qualified healthcare provider in partnership with the members of the care team, wherever feasible. The person may be supported by their family, carer or substitute decision-maker(s), and any other services which may assist with supported decision-making.
- 1.2** Initial and ongoing assessments are coordinated to reduce the burden of duplication on the person, family, and carers and substitute decision-maker(s).
- 1.3** Assessments are documented in the person's clinical record and communicated to all members of the care team including the person and their family and carers and any substitute decision-maker(s).
- 1.4** Processes are in place for healthcare providers to identify people who have been diagnosed with a life limiting condition to enable proactive and timely palliative care and advance care planning for their future.
- 1.5** Processes include clinical assessment tools, informed by the best available evidence, where these are available.
- 1.6** People managing and delivering generalist palliative care should develop processes to ensure a person's needs are reassessed on a regular basis.

Developing the comprehensive care plan

The person, their family and carers and substitute decision-maker(s) work in partnership with multidisciplinary teams to communicate, plan, set goals of care and support informed decisions about the comprehensive care plan.

Intent of Standard 2

The person should have an active role in their palliative care planning. Family* members and carers, where this is consistent with a person's wishes, should also have opportunities for involvement in care planning. Where the person is not able to participate in care planning or decision-making due to young age, cognitive impairment, or incapacity, 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.

Comprehensive assessment provides the foundation for care planning. Each re-assessment should inform a re-evaluation of the comprehensive care plan. In addition, the person should be supported to consider and document their future care goals, values, and preferences in an advance care directive and/or Goals of Care document. Access to such a comprehensive care plan needs to be assured and made known to all current and incoming healthcare providers.

People with a life limiting condition should be informed about the process and purpose of advance care planning and asked if they would like to instigate an advance care directive. Any substitute decision-maker, family members and carers, where this is consistent with a person's wishes, should also have opportunities for involvement in care planning. For those with an advance care directive, people should have the opportunity to revise this over time.⁴⁸ Where possible, legally binding advance care directives should be promoted.

To enable ready access to the advance care planning document by the care team, people should be advised of the option of uploading their advance care planning information to My Health Record. People managing and delivering services should have processes in place to ensure that people approaching the end of their life each have a copy of their advance care plan or directive

available in their place of residence, to avoid unwanted transport to acute hospital services, or with them if admitted to a hospital, residential aged care service or other accommodation setting.⁴⁹

The person's future care goals and comprehensive care plan are documented in their clinical record and communicated to all involved in care. Healthcare providers should clearly document the content of the discussion and any agreed plan of care in the person's clinical record, or any recorded conversations with accredited interpreters for non-English speaking people. Any unresolved issues that require further follow-up should also be managed and documented, along with a plan for follow-up.⁵⁰

Healthcare providers should offer information to the person approaching the end of their life, their carers, family, and substitute decision-maker(s) about who the team members are (including the lead healthcare provider), the roles of the team members and how their service is accessed.⁵¹

Care of the dying is urgent care. Timely recognition of a person's transition to the terminal phase of life must be documented and communicated to them, their substitute decision-maker, their families, carers, and other healthcare providers by the team involved in generalist palliative care. The care plan must be specifically revised to meet the unique needs of the person, family and carers and substitute decision-maker(s) during this phase.⁵² The person's preferred place of care, which is appropriate to their age and development, should be re-confirmed, and explicit consideration given to what is needed to support this to occur. This may include the person's community pharmacist if the person will be going home, and the pharmacist will be managing medication for end-of-life. Other factors of consideration will include the person's will, after-death wishes and support for bereaved family and carers.

48. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015. section 3.2.

49. NICE Guideline 142, 2019, End-of-life care for adults: service delivery.

50. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015. section 1.12.

51. NICE Guideline 142, 2019, End-of-life care for adults: service delivery, 1.10.4.

52. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015. p. 4.

* The term *family* includes people identified by the person as family. This may include people who are biologically related, however it may not. People who joined the family through marriage or other relationships, such as kinship, as well as the chosen family, street family for those experiencing homelessness, and friends (including pets) may be identified by the person as family. A person may also choose to not to have their family or carers involved in their care, or a person may not have any family or carers.

Recognising that every person is unique, that their experiences 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.⁵³ For example for Aboriginal and Torres Strait Islander populations, extra support with social work referral, guardianship and other support may be necessary. Health and aged care providers should seek to understand and respect the individual preferences and needs of the person, their substitute decision-maker(s), families and carers.

To meet this Standard, the healthcare provider managing or delivering services is expected to ensure:

- 2.1** Care planning is informed through an assessment process.
- 2.2** The person, their family and carers and substitute decision-maker(s) are provided with evidence-based information appropriate to meet their needs and to support informed participation in care planning and decision-making, including advance care planning. There should be ongoing review and anticipation of the information needs and preferences as circumstances change. It is important to meet a careful balance between the needs of a child or young person with a life limiting condition and their parents and carers.
- 2.3** Initial and ongoing discussions informing the comprehensive care plan are documented and readily available to guide care delivery. Whenever possible, healthcare providers should ensure that the person, their key family members, substitute decision-maker(s) and carers are present during discussions, ensuring consistent messages are given about treatment options, their likelihood of success, risks, and prognosis.
- 2.4** There is appropriate use of interpreters to support those from culturally and linguistically diverse backgrounds to communicate, plan and set goals of care.
- 2.5** There is appropriate use of assistive devices for hearing, sight, and cognitively impaired individuals to ensure communication optimised i.e., hearing aids/sign language/speech boards etc.
- 2.6** The expectations, values and preferences of the person, their family and carers and substitute decision-maker(s) for the type and place of care, are discussed, negotiated, and documented in the comprehensive care plan.
- 2.7** Processes are in place to enable healthcare providers to identify the person's substitute decision-maker (whether legally appointed by the person, appointed by tribunal, or assigned to a person by a statutory hierarchy) upon entry to the health service, and processes are in place to ensure a person can formally appoint a substitute decision-maker if they desire.
- 2.8** The comprehensive care plan and any limitations of medical treatment should be revisited with the person, substitute decision-maker, family, and carers when significant changes in the person's condition or circumstances occur, for example, when the person is admitted to hospital, or they are in transition to the terminal phase. The person's holistic needs should be considered and the person, substitute decision-maker, family and carers should be empowered to request further discussion and a review of the plan at any time.
- 2.9** Processes are in place to enable person and family-centred palliative care planning.
- 2.10** Processes are in place to prepare, review and/or update advance care directives, according to the current values and preferences of the person.
- 2.11** Processes are in place for receiving, storing, accessing, and sharing existing advance care planning documents.
- 2.12** Processes are in place to assess individual values, preferences and needs of all people inclusive of aspects of identity such as culture, gender sexuality and bodily diversity, as well as to other vulnerable populations.
- 2.13** There is appropriate use of e-technology or e-platforms for assessment and to support decision making. These may also contribute to staff competency in these modalities.

53. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015. section 3.1.

Caring for carers

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

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Intent of standard 3

The person's family* and carers and substitute decision-maker(s) play a vital role in providing physical, emotional, social, and spiritual support and advocating on behalf of the person with a life-limiting condition. They have insights and experience of the person's circumstances and support needs. It is important that services value this role, appreciate its importance, and support the person's family and carers and substitute decision-maker(s) by working with them to understand the level of care that they are willing and able to provide, where this accords with the person's current values and preferences. In some circumstances, the person diagnosed with a life-limiting condition is a carer themselves, such as a parent with young children, and in this case their support needs may include caring for others.

Identifying carers' support needs can contribute to improved carer outcomes, such as maintaining quality of life and reducing carer burden. Understanding the carers' context includes a recognition that the support needs of carers can be different. For example, support needs of a young carer are likely to be different to those of an older carer, and LGBTIQ+ partners may face a higher carer burden.⁵⁴ If support for carers cannot always be provided face-to-face, telehealth or phone support are two effective alternative means.

The needs and preferences of the family, carers and any substitute decision-maker(s), including their need for information, should be assessed independently from that of the person and directly inform provision of appropriate support and guidance about their role, to be active partners in the care team and to reduce associated stress.

To enhance their support role, family, carers, and substitute decision-maker(s) should be provided with a clear, documented plan for the management of 24-hour 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. Conversely, some family situations may be complex and involve a fractured relationship between the person and one or both parents or siblings. It may also be that a person does not have any carers, in which case the healthcare providers may need to support the person through a care coordination role, and access additional resources to support the person.

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. In Aboriginal and Torres Strait Islander contexts (and other culturally and linguistically diverse groups) this can include gender considerations in providing certain types of care and support. In some cases, due to colonisation, family connections are lost or fragmented and referral to healing and support services might need to be considered. Clear identification of these individuals is necessary to enable effective communication and avoid distress caused by inadequate communication.

54. NICE Guideline 142, 2019, End-of-life care for adults: service delivery.

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To meet this Standard, the healthcare provider managing or delivering services is expected to ensure:

- 3.1** At least one carer is nominated by the person and the carer's specific needs, including their need for information, are assessed, and documented. Consideration should be given to factors such as a carers' age, ability, culture, social situation, sexual orientation, bodily diversity and gender identity, concerns about employment and any other factors that may be relevant.
- 3.2** The healthcare providers work with the family and carers and substitute decision-maker(s) 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 substitute decision-maker(s) and there is ongoing assessment of their willingness and ability to participate in the provision of care.
- 3.3** The family, carers and substitute decision-maker(s) 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.
- 3.4** Depending on the location of care and the person's needs and preferences, the family and carers and substitute decision-maker(s) are educated about how to safely assist with care, management of medications, managing risk, manual handling, and activities of daily living.
- 3.5** There are processes in place to ensure that the person's nominated family and carers and substitute decision-maker(s) are supported to participate in the provision of health care in accordance with the preferences of the person, their family and carers and substitute decision-maker(s).
- 3.6** Family and carers and substitute decision-maker(s) should be supported to spend time with a dying person in accordance with their preferences, including in the period immediately after death. The family and carers and substitute decision-maker(s) 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, religion and social situation.
- 3.7** There are processes in place to provide a safe working environment for family, carers, substitute decision-maker(s) and healthcare providers. Stress and impacts of changed behaviours, in for example dementia, is not only a consideration for the dying but for those around them.

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.

4

Intent of Standard 4

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 comprehensive 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.

Healthcare providers should have the skills to:

- » Identify a person's needs and identify multidisciplinary team members to meet these needs;
- » Anticipate and prevent or minimise crises; and
- » Support people's preferences for where they would like to be cared for and die.⁵⁵

It may not always be possible to provide care that matches a person's values and preferences. Where the person's values and preferences cannot be met, the service is expected to explain the reasons for this to them, their substitute decision-maker, their family,* and carers, and to discuss acceptable alternatives. The criteria and processes for accessing help for issues that are causing concern should be clearly defined in relevant policies and procedures and communicated to the person, their substitute decision-maker(s), families, and carers.

Consideration should be given to changes that optimise care and improve a person's quality of life. For ethical reasons, it is important not to harm people receiving palliative care, by providing burdensome investigations and treatments that can be of no benefit.⁵⁶

For example, optimal care could involve:

- » Reducing the number of unnecessary routine appointments;
- » Organising appointments closer to or in the person's home;
- » Starting new treatments or stopping unhelpful treatments;
- » Measurements to ensure timely access to medications; and
- » Discussion of community support available to help with their care.⁵⁷

Coordination of care is important so that the goals of care are agreed and understood by the person, their family and carers and substitute decision-maker(s) and communicated to all members of the care team. For people in inadequately served and vulnerable groups, additional support should be provided to address the challenges of providing and coordinating care for people in these groups.⁵⁸

The criteria and processes for accessing help for issues that are causing concern should be clearly defined in relevant policies and procedures and communicated to the person, their families, and carers.

55. NICE Guideline 142, 2019, End-of-life care for adults: service delivery, 1.9.1.

56. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015. p.5.

57. NICE Guideline 142, 2019, End-of-life care for adults: service delivery, 1.5.3.

58. NICE Guideline 142, 2019, End-of-life care for adults: service delivery, 1.10.2.

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Concern or worry that a person has unmet care needs should prompt review of the goals of care and the treatment plan by the care team, leading to appropriate recommendations for follow-up and ongoing communication. This applies regardless of whether the concern is raised by the person; their substitute decision-maker, family, or carers; or a healthcare provider.⁵⁹ The lead healthcare provider should implement recommendations in a timely way. Distress caused by symptoms and treatment, including physical, psychosocial, cultural, spiritual distress, or the social determinants of health should be actively pre-empted, and when it occurs, the response should be timely and effective. This includes prompt response to needs, regularly reviewing the effectiveness of treatment, and ensuring the person, their family and carers and substitute decision-maker(s) have timely access to generalist palliative care at all times. For Aboriginal and Torres Strait Islander peoples, care that is delivered to support self-determination should be incorporated.

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To meet this Standard, the healthcare provider managing or delivering services is expected to ensure:

- 4.1** The healthcare provider with overall responsibility for leading and coordinating a person's care must be clearly identified and documented in the person's comprehensive care plan. The leading healthcare provider may delegate this coordination role to someone else in the care team.
- 4.2** Care is responsive and delivered promptly, in accordance with changing needs of the person, their family and carers and any substitute decision-maker(s), their documented comprehensive care plan and their goals, values and preferences.
- 4.3** Where care cannot be delivered in accordance with the goals, values, and preferences of the person, this is discussed with the person, substitute decision-maker, their family, and carers, and an agreed alternative plan is documented and communicated.

- 4.4** Evidence-based policies for reviewing treatment within all specialties and reducing unnecessary prescribing, with deprescribing when appropriate, are developed to meet the changing needs of people approaching the end of their life and to reduce the burden of unhelpful treatments.
- 4.5** There are protocols and procedures in place for the escalation of care including referral to specialist palliative care where required, based on assessed needs and availability of a specialist palliative care team.
- 4.6** The healthcare providers aim to actively pre-empt distress to the best of their ability.
- 4.7** Anticipatory planning should be undertaken by the lead healthcare provider so that people approaching the end of their life, their family and carers and substitute decision-maker(s) have access to:
- » Appropriate care available 24 hours a day, 7 days a week, allowing access to the person's records and advance care directive, and to informed decisions about changes to care, and to certify death;
 - » An out-of-hours palliative care advice line;
 - » Community support and respite care;
 - » Predictable medications for symptom management; and
 - » Grief support.

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59. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015 section 5.4.

Transitions within and between services

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

5

Intent of Standard 5

People may receive care from multiple services. Understanding the values, goals and preferences of the person, their family* and carers and substitute decision-maker(s) and communicating these effectively during movements within and between care settings will support delivery of effective, person-centred and coordinated care.

Verbal communication between healthcare including aged care providers should be supported by sufficient written information on the person's condition, and for people with a disability, guidance on their needs. All services providing palliative care, including private practitioners or services, should make information available to local and wider health services. This should include the person's advance care planning information and goals of care, and a reconciled medication list to ensure seamless care and to avoid the provision of ineffective care or care that does not align with the person's values and preferences. This may be shared electronically and uploaded to the national My Health Record to facilitate sharing with other health professionals.

When working in partnership with other services, clear strategies for referral, communication and designated areas of responsibility are essential. Different services should work together and share information about treatment reviews. Generalist palliative care services should seek the advice, guidance and direction of specialist palliative care as needed.

When considering discharge and transfer from hospital to home or the person's place of residence, delay can be distressing to the person, their family, carers and substitute decision-maker(s). To ensure prompt discharge with care and compassion there should be clear communication processes between services providing care in both settings and to those providing transport.⁶⁰

The coordination of palliative care should be facilitated through either the person's carer, if this is possible, or their GP, specialist or other healthcare provider.⁶¹ An agreed transfer policy between ambulance service providers and acute care, home care and aged care and other community and primary care providers should be in place to enable the rapid transfer of people to the place where they would like to be cared for.⁶² Similarly, the care team should coordinate access to care packages, such as for allied health professionals and equipment, for the person to optimise quality of life.⁶³

For Aboriginal and Torres Strait Islander people, health providers should initiate early discussions to identify multiple referral pathways to support individuals who may move between jurisdictions to connect to family and culture whilst needing palliative care.

60. NICE Guideline, 2019, End-of-life care for adults: service delivery, pg. 24-37.

61. NICE Guideline, 2019, End-of-life care for adults: service delivery, 1.10.1.

62. NICE Guideline, 2019, End-of-life care for adults: service delivery, 1.11.3.

63. NICE Guideline, 2019, End-of-life care for adults: service delivery, 1.11.2.

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To meet this Standard, the healthcare provider managing or delivering services is expected to ensure:

- 5.1** Healthcare providers provide clear communication so that people are aware of why they are being transferred, where they are being transferred to and how the transfer may be avoided if, for example, additional supports could be put in place.
- 5.2** Healthcare providers take steps so that transfers are minimised to maximise the opportunity for people to stay in their preferred place, so that they can age and die in place.
- 5.3** There are policies and procedures in place that support and promote continuity of care across settings throughout the course of the person's condition. This is reinforced through the comprehensive care plans.
- 5.4** Policies for prioritising and responding to referrals for people with a life-limiting condition in a timely manner is documented and audited regularly to identify improvement opportunities.
- 5.5** The healthcare providers have effective communication systems to support integrated care, to enable information to be reviewed, updated, and shared efficiently within and between teams of generalist or specialist palliative care providers, across different services and organisations.
- 5.6** Notification of death of the person within and between services is important as it helps to prevent anyone inadvertently recalling a patient for a consult after they have already died, which can be very distressing for the family as well as staff.
- 5.7** Processes should be in place to adequately assess unmet need and where this cannot be managed by the healthcare providers, a referral to specialist palliative care occurs. This may include off-site access via videoconferencing or teleconferencing.
- 5.8** Referrals are made to appropriate specialists or services that can meet the identified physical, social, cultural, and spiritual needs of the person, their family and carers and substitute decision-maker(s).
- 5.9** When a person is to be discharged from a specialist palliative care service, community-based healthcare providers collaborate to ensure continuity of care and minimise risk, to enable swift access to community-based health, pharmacy, and community support services.
- 5.10** Healthcare providers support people to reengage with specialist palliative care in accordance with their needs and preferences.

Grief support

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

6

Intent of Standard 6

Grief is a normal reaction to loss and its course and consequences will vary for everyone. Personal and social circumstances, including for example culture, may place some family* members, carers and substitute decision-maker(s) at increased risk of experiencing problems in the lead up to and after a person's death. These may be emotional, spiritual, or psychosocial problems, or more practical issues such as seeking new employment, financial insecurity, or risk of homelessness. Disenfranchised grief,⁶⁴ which is unacknowledged or unvalidated grief by social norms, is a particular risk for LGBTIQ+ people. It is important that healthcare providers recognise this risk and make appropriate referrals and ensure supports are in place.

Support for family members, carers, and substitute decision-maker(s) in preparing for cumulative changes, the death and in understanding the process of dying, as well as grief support at designated timeframes after a death may assist in reducing physical and psychosocial ill-health associated with loss and grief. There should be multiple opportunities for grieving and bereaved people to self-identify their requirement for grief support. Families and carers can experience significant impacts that extend beyond the overwhelming emotions of grief, and these can include changes to their financial status (through reduced work), their own health and social supports.

Pre-death grief is common among people who are facing their own death or the death of someone close to them. In contrast to grief after death this type of grief includes many losses which are often cumulative, such as changing roles in the family, fear of abandonment, fear of financial changes, and the loss of dreams of what could be.

Most people who experience grief do not require specialist counselling, but would benefit from reassurance, acknowledgement of their losses, and access to information. A proportion of people who grieve may experience intense distress over a prolonged period. Culture plays a major role in the expression of grief. For Aboriginal and Torres Strait Islander people, culturally specific care for grief and loss should be explored. Whilst it has been shown that treatment interventions can diminish the symptoms of prolonged intense distress, as yet evidence has not shown preventive interventions to be effective.⁶⁵

Health and aged care providers should develop partnerships with a range of community organisations that are able to support people who are anticipating or living with loss. People who experience intense distress over a prolonged period can be referred to:

- » Specialist grief counsellors and allied health;
- » Mental health professionals with appropriate counselling skills;⁶⁶ and
- » Other social and emotional wellbeing professionals.

Care for families and carers extends to the period after the person has died.⁶⁷

64. Australian Centre for Grief and Bereavement, The Rosemary Branch, 2015, available <https://www.grief.org.au/uploads/uploads/Rosemary-Branch-Autumn-2015.pdf>

65. Caresearch, Palliative Care Knowledge Network, Bereavement and Grief <https://www.caresearch.com.au/caresearch/ClinicalPractice/PsychologicalSocialSpiritual/BereavementandGrief/tabid/1345/Default.aspx>

66. Caresearch, Palliative Care Knowledge Network, Bereavement and Grief

67. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015.

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To meet this Standard, the healthcare provider managing or delivering services is expected to ensure:

- 6.1** Culturally appropriate information and resources about loss and grief support is routinely provided to families, carers, and substitute decision-maker(s) before and after the death. These should be available in multiple languages for CALD populations.
- 6.2** Organisations provide access to education about loss and grief to staff, volunteers, and other community providers working in generalist palliative care.
- 6.3** Healthcare providers use validated tools to assess for signs and symptoms of persistent and intense distress in grieving or bereaved persons.
- 6.4** Healthcare providers develop strategies and referral pathways, in partnership with other providers in the community to assist families, carers and substitute decision-maker(s) in feeling more prepared for the death, and to accommodate grief into their lives.
- 6.5** Referral to grief counsellors, specialist mental health and/or counselling professionals are made when clinically indicated.

Service culture

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

Intent of Standard 7

Organisations providing generalist palliative care should have a clearly stated philosophy, strategy, set of values and culture that guides the delivery of high-quality palliative care. The strategy for person and family-centred palliative care should ensure healthcare providers are able to address the cultural, spiritual, and psychosocial needs of people receiving care as well as meeting their physical needs. Person and family-centred palliative care should be aligned with the values, needs, beliefs, and current values and preferences of the person, and their family,* carers and substitute decision-maker(s). Such care should consider the person's expressed preferences regarding the circumstances, environment, and place in which they want to live until death.⁶⁸

Healthcare providers should seek opportunities to facilitate the delivery of palliative care across various settings, through collaboration and partnerships. Partnerships should be sought with services that provide support to Aboriginal and Torres Strait Islander, culturally and linguistically diverse, LGBTIQ+ and other vulnerable populations.

An organisation dealing with the care of people in need of generalist palliative care maintains or provides access to information on relevant health and community support services or refers people to other places to attain local service provider information.

To meet this Standard, the healthcare organisation is expected to ensure:

- 7.1 The values and culture of an organisation providing generalist palliative care explicitly support the provision of person and family-centred palliative care to the person's family and carers and any substitute decision-maker(s).
- 7.2 There is evidence of person and family-centred care principles within clinical practice guidelines, policies, and procedures.
- 7.3 The care setting provides an appropriate environment to support people receiving palliative care, their family, carers, and substitute decision-maker(s).
- 7.4 Healthcare providers understand the community they serve and use this information to both provide optimal palliative care services and influence wider health, aged care, and community support systems to optimally meet the needs of that community.
- 7.5 Organisations support the mental health and wellbeing of their staff working in generalist palliative care.

68. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015.

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Quality improvement

Services are engaged in quality improvement and research, based on best practice and evidence, to improve service provision and development.

8

Intent of Standard 8

To maintain and continuously improve the standard of palliative care delivery in Australia, healthcare and aged care providers are expected to engage in quality improvement and to lead or participate in research. Organisations providing generalist palliative care are encouraged to engage in research and quality improvement activities aimed at developing new evidence for practice. Where relevant, these activities should contribute to the quality improvement approach and/or policy of the broader organisation.

All healthcare providers are expected to embed quality improvement activities into their daily practice, working systematically through a cyclical quality improvement process and under a clinical governance framework. Healthcare providers should identify areas for improvement through comprehensive risk assessment processes, quality audits, standard reviews, and through co-design with users, and implement actions relevant to improving performance in identified areas. Examples include: health record and organisational systems audits; medication chart safety reviews by a suitably qualified health professional; review with families,* carers, substitute decision-maker(s) and other advocates; review of healthcare providers and other practitioners involved in care; review of complaints and complaint processes; review of Cultural Safety; and monitoring the quality of care and the person's outcomes and experience of care.⁶⁹

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 healthcare providers are provided with opportunities to give feedback on the service received and to identify opportunities for improvement. Ideally, this information and feedback would be shared across settings to maximise the learnings.

Service providers should consider Aboriginal and Torres Strait Islander informed research approaches and strategies in seeking feedback and implementing culturally appropriate practice in palliative care services.

To meet this Standard, the healthcare organisation is expected to ensure:

- 8.1** Palliative care is explicitly addressed as part of an organisation's quality improvement framework(s). The palliative care quality improvement framework is implemented to enable review of clinical performance, outcomes, and experience of care provision, and to identify, implement and evaluate improvement activities.
- 8.2** Data about the effectiveness of palliative care provision is collected, reviewed, and reported locally.
- 8.3** An organisation providing generalist palliative care is accredited to ensure achievement of governance and safety requirements.
- 8.4** The organisation includes palliative care within the ambit of its research focus and supports opportunities for staff to lead or participate in palliative care research. Consultation and collaboration with academics will ensure the research is conducted in an ethical manner.
- 8.5** Healthcare providers establish links with specialist palliative care services and other specialists to provide integrated care and to improve the quality of that care.
- 8.6** The person, their family, carers and substitute decision-maker(s), and healthcare providers are invited to co-design the evaluation of the service via formal and informal feedback mechanisms. Access to language services should be available where necessary to encourage feedback from CALD populations.

69. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015. Section 9.6.

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Staff qualifications and training

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



Intent of Standard 9

Safe and high-quality palliative care requires an educated and suitably skilled and qualified workforce, to provide seamless care between multiple disciplines and teams. Education and training should enable healthcare and aged care providers to have the appropriate skills to manage Standards 1 to 6 of these standards. This may be gained through certificate or undergraduate degrees, or via workplace learning or specific learning packages. Carers and those caring for people with diverse needs may also require specific training.

Education should include specific training for providing palliative care to people with limited capacity to participate in decision-making – for example, those with mental illness, disability, or cognitive impairment. This should include education about the role and legal status of families, carers, and substitute decision-maker(s) and cultural safety training.⁷⁰ Services should adopt a culture of life-long learning.

All services are expected to support their staff, both in terms of continuing professional development and in coping with the daily demands of working with people who require palliative care. As workforces include people with culturally and linguistically diverse backgrounds, staff may have their own cultural understandings of decision making, the meaning of family, end-of-life issues, dementia, grief, etc., and training may need to be targeted to the individual context.

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

Healthcare providers and other staff members who are in contact with the person and their families* and carers should know when and how to access peer support, mentoring, clinical supervision, and clinical ethics advice. This information should be provided at the start of employment and as part of regular refresher training.⁷¹

Healthcare providers should know how to access support after particularly distressing or problematic episodes of care. This may involve accessing external services for formal counselling or debriefing.⁷²

Healthcare providers should also be supported to develop skills in self-care, reflective learning and providing peer support to colleagues.⁷³ Organisational structures to support the wellbeing of healthcare providers needs to be in place and unsustainable workloads and pressures should be monitored.

Education for healthcare providers should include how to recognise and resolve feelings of moral distress and burnout in themselves and their colleagues as well as information about how to seek help, if required.⁷⁴

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70. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC 2015. p. 25
 71. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015. section 8.2.
 72. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015. section 8.3.
 73. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015. section 8.4.
 74. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC 2015. section 7.10.

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To meet this Standard, the healthcare organisation is expected to ensure:

- 9.1** Healthcare providers have the skills to meet the physical, psychological, social, cultural, and spiritual needs of the person, their family and carers and substitute decision-maker(s). Healthcare providers working as part of a team to deliver generalist palliative care should receive education about their roles and responsibilities in relation to local systems and processes for recognising and enabling optimal palliative care.
- 9.2** Staff and volunteers should receive training that includes providing culturally safe palliative care for paediatrics, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, LGBTQI+ people and anyone else deemed vulnerable.
- 9.3** Staff and volunteers receive appropriate supervision and support in accordance with an established professional development framework.
- 9.4** Education for health care professionals should include how to recognise and resolve feelings of moral distress and burnout in themselves and their colleagues, as well as information about how to seek help, if required.
- 9.5** Staff should receive training in the law relating to palliative care and end-of-life care.
- 9.6** Generalist volunteer programs are recognised, supported, and managed in accordance with the relevant volunteer standards.
- 9.7** Experienced team members are responsible for providing supervision, leadership, support, mentorship and teaching to develop the skills and capacity of all team members in relation to palliative care and end-of-life care.
- 9.8** A formal assessment of palliative care education and training is undertaken for all members of the health service to identify professional development requirements.

Appendix 1: Terminology

This appendix defines the key terms that are used throughout these Standards.

Advance care planning documents

A catch all term to include documents that result from advance care planning. This includes Advance Care Directives and Advance Care Plans, as detailed below.^{75,76}

Advance care directives

This term includes, but is not limited to, *Advance Care Directives*, Advance Health Directive, Statement of Choices – Competent Person, Advance Personal Plan, Health Direction, Enduring Powers of Attorney, Enduring Guardian, Medical Treatment Decision-Maker, or any other similar *Advance Care Directives* in legislation.

Advance Care Directives is used in this document as a catch-all term to refer to the instruments which are recognised in each jurisdiction under advance care directive legislation or common law.

They are voluntary, person-led documents completed and signed by a competent person that focus on an individual's values and preferences for future care decisions, including their preferred outcomes and care. *Advance Care Directives* are recognised by specific legislation (statutory) or under common law (non-statutory). They come into effect when an individual loses decision-making capacity.

Advance Care Directives can also appoint substitute decision-makers who can make decisions about health or personal care on the individual's behalf. *Advance Care Directives* are focused on the future care of a person, not on the management of his or her assets.

Common law (non-statutory) *Advance Care Directive* is a structured document that is completed and signed by a competent adult and that is not a legislated statutory document.

This includes a document completed and signed by a competent person in a jurisdiction which does not have legislation authorising an *Advance Care Directive* regarding preferences for care (that is, New South Wales and Tasmania).

An instruction or directive completed and signed by a competent person, in a jurisdiction with advance care planning legislation, but where the document does not

comply with the requirements set out in this legislation and is recognised instead by common law.

Statutory *Advance Care Directive* is a signed document that complies with the requirements set out by a jurisdiction's legislation.⁷⁷

Advance Care Plans

Advance care plans, including but not limited to, Statements of Choice; Statement of Choices – No Legal Capacity, are often very helpful in providing information for substitute decision-makers of a non-competent person, and health practitioners and may guide care decisions but are not legally binding. An Advance Care Plan may be oral or written, with written being preferred. A substitute decision-maker named in an Advance Care Plan is not a statutory appointment.⁷⁸ *Advance care plans are also known as Advance Care Directive or Advance Personal Plan in different States and Territories in Australia.*

Capacity

Capacity is the ability to make a decision for oneself. Decision-making *capacity* can be assessed by trained professionals, and its assessment depends on the type and complexity of the decision to be made. *Capacity* assessment does not assess whether the decision is considered "good" or "bad" by others such as health practitioners or family, but rather considers the person's ability to make a decision and comprehend its implications.

Generally, when a person has capacity to make a particular decision, they can do all the following:

- » Understand and believe the facts involved in making the decision
- » Understand the main choices
- » Weigh up the consequences of the choices
- » Understand how the consequences affect them
- » Make their decision freely and voluntarily
- » Communicate their decision.

By default, people are assumed to have capacity, unless there is evidence to the contrary.^{79,80}

75. Advance Care Planning Australia. <https://www.advancecareplanning.org.au>
76. Advance Care Planning Australia - written submission during consultation phase
77. Advance Care Planning Australia. <https://www.advancecareplanning.org.au>
78. Advance Care Planning Australia. <https://www.advancecareplanning.org.au>
79. Advance Care Planning Australia. <https://www.advancecareplanning.org.au>
80. Advance Care Planning Australia - written submission during consultation phase

Community support

Community Support includes services that provide the support needed for a person with disability to live in a non-institutional setting.⁸¹

Comprehensive care plan

Including, but not limited to clinical care plans, clinical pathway, or medical order.

A document or electronic view which describes agreed goals of care, and outlines planned medical, nursing, and allied health activities for a patient. *Comprehensive care plans* reflect shared decisions made with patients, carers and families about the tests, interventions, treatments, and other activities needed to achieve the goals of care. The content of *comprehensive care plans* will depend on the setting and the service that is being provided and may be called different things in different health organisations. For example, a care or clinical pathway for a specific intervention may be considered a *comprehensive care plan*.

A *comprehensive care plan* is different to an Advance Care Directive. While an Advance Care Directive is completed by an individual and recognised within legislation, a comprehensive care plan is written by health practitioners together with the individual through shared decision-making (wherever possible). It is appropriate that *comprehensive care plans* be put in place whether the person has made an Advance Care Directive or Advance Care Plan, but when there is an existing document that records directions about care, the *comprehensive care plan* complements, and therefore should be informed by the person's documented preferences.⁸²

Continuity of care

The term *continuity of care* is the degree to which a series of discrete health care events is experienced by people as coherent and interconnected over time and consistent with their health needs and preferences.⁸³

Cultural Safety

Cultural Safety is determined by Aboriginal and Torres Strait Islander individuals, families, and communities. Culturally Safe practise is the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible, and responsive healthcare free of racism.⁸⁴

Cultural Responsiveness

Cultural responsiveness is the active approach taken by individuals, organisations and systems to promote and maintain Cultural Safety.⁸⁵

Decision-making

Contemporaneous *decision-making* is a decision made in the present time. Individuals with competency and capacity may make contemporaneous decisions about their care and these may differ from those decisions recorded in an Advance Care Directive. Foremost respect should be given to contemporaneous decisions.

End-of-life

The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke, or trauma.⁸⁶

Many Aboriginal tribal groups share the belief that this life is only part of a cyclic approach to life and death. It is important to ask the family or the Aboriginal Elders, Health Workers or Liaison Officers what terms they wish to use for this time and preparation process, e.g., "finishing up", "journey to dreaming", "sad news" or "sorry business".

End-of-life care

End-of-life care includes physical, spiritual, and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the person's body after their death. People are 'approaching the end-of-life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- » advanced, progressive, incurable conditions;
- » general frailty and co-existing conditions that mean that they are expected to die within 12 months;
- » existing conditions, if they are at risk of dying from a sudden acute crisis in their condition; and
- » life-threatening acute conditions caused by sudden catastrophic events.⁸⁷

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81. Australia's Welfare 2019, Glossary <https://www.aihw.gov.au/reports-data/australias-welfare/australias-welfare-snapshots/glossary>

82. Advance Care Planning Australia. <https://www.advancecareplanning.org.au>

83. Continuity and coordination of care: a practice brief to support implementation of the WHO Framework on integrated people-centred health services. Geneva: World Health Organization; 2018. Licence: CC BY-NC-SA 3.0 IGO.

84. Australian Health Practitioners Regulation Agency, The National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020-2025.

85. Indigenous Allied Health Australia, 2019 Policy Position statement, Cultural Safety through Responsive Health Practice.

86. General Medical Council, Treatment and care towards the end-of-life: good practice in decision making, from the Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and highquality end-of-life care. Sydney: ACSQHC, 2015

87. Australian Government Department of Health, National Palliative Care Strategy 2018, Available: www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018.

Family and carers

The term *family* includes people identified by the person as family. This may include people who are biologically related, however it may not. People who joined the family through marriage or other relationships, such as kinship, chosen family, street family for those experiencing homelessness, and friends (including pets) may be identified by the person as family.

The term *carers* may include family members and other members of the person's community (such as close friends, neighbours, or people from the community) who the person agrees to being involved in their care.⁸⁸ A person may also choose to not to have their family or carers involved in their care, or a person may not have any family or carers.

Generalist Palliative Care

Generalist palliative care is care provided to people living with a life-limiting condition, their families and carers by healthcare providers who are not specialist palliative care providers.⁸⁹

The medical management and coordination of care for people living with a life-limiting illness may be undertaken by a wide range of health professionals including GPs, geriatricians, physicians, oncologists, paediatricians, renal specialists, cardiologists, endocrinologists and other specialists. Other essential team members will include nurses, allied health professionals, Aboriginal and Torres Strait Islander Health Workers and Liaison Officers, and pharmacists. These health professionals are 'generalists' with respect to palliative care, notwithstanding that many of them may be specialists in their own discipline.⁹⁰

Goals of care

Clinical and other goals of a patient's episode of care that are determined in the context of a shared decision-making process. Other goals may involve maximising quality, fulfilment, and wellbeing.

Goals of care may change over time, particularly as the patient enters the terminal phase and during end-of-life care.

Medical goals of care may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying patient.

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88. Palliative Care Australia. Palliative Care Service Development Guidelines. 2018

89. Palliative Care Australia. Palliative Care Service Development Guidelines. 2018

90. Palliative Care Australia. Palliative Care Service Development Guidelines. 2018

91. Advance Care Planning Australia. <https://www.advancecareplanning.org.au>

92. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Primary and Community Healthcare Standards. Sydney: ACSQHC; 2021

93. WHO global strategy on integrated people-centred health services 2016-2026, https://apps.who.int/iris/bitstream/handle/10665/180984/WHO_HIS_SDS_2015.20_eng.pdf?sequence=1

94. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney, ACSQHC, 2015.

Non-medical goals of care articulated by the person may include returning home or reaching a particular milestone, such as participating in a family event.

Goals of care documents are different to Advance Care Directives. Goals of care are completed by medical practitioners but should align with the preferred health outcomes and treatment decisions made by the individual (to the capacity they have to participate in shared decision-making). The person may or may not have previously completed an Advance Care Directive. Where an Advance Care Directive has been completed, and the individual no longer has decision-making capacity, the goals of care should reflect the Advance Care Directive and should include a discussion with the person's substitute decision-maker.⁹¹

Healthcare provider

A *healthcare provider* is an individual who practises a profession relating to the provision of health care. Healthcare providers may be required to maintain profession-specific registration with a national board under the National Registration and Accreditation Scheme or be self-regulated.⁹²

Integrated care

Integrated care is the management and delivery of health services such that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation, and palliative care services, through the different levels and sites of care within the health system, and according to their needs throughout the life course.⁹³

Non-beneficial treatments

Interventions that will not be effective in treating a person's medical condition or improving their quality of life. *Non-beneficial treatment* may include interventions such as medical imaging, pathology tests, medications, artificial hydration and nutrition, intensive care, and medical or surgical procedures. *Non-beneficial treatment* is sometimes referred to as futile treatment, but this is not a preferred term.⁹⁴

Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of

early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. *Palliative care*:

- » Provides relief from pain and other distressing symptoms;
- » Affirms life and regards dying as a normal process;
- » Intends neither to hasten or postpone death;
- » Integrates the psychological and spiritual aspects of patient care;
- » Offers a support system to help patients live as actively as possible until death;
- » Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- » Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- » Will enhance quality of life, and may also positively influence the course of illness; and
- » Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.⁹⁵

Person and family-centred care

Person and family-centred care strives to make the whole person and their family visible and prioritises the satisfaction of spiritual, existential, social, cultural, and psychological needs to the same extent as physical needs.⁹⁶ Person and family-centred care is an integral part of palliative care.

Person living with a life-limiting condition

The term *life-limiting condition* is used to describe conditions where it is expected that death will be a direct consequence of the specified condition. Such conditions may include, but are not limited to cancer, heart disease, chronic obstructive pulmonary disease, dementia, heart failure, neurodegenerative disease, chronic liver disease and renal disease. The term *person living with a life-limiting condition* also incorporates the concept that people are actively living with, not simply dying from, such conditions.⁹⁷

Specialist Palliative Care

People will have different levels of need for palliative care. People with more complex needs should be able to access care provided by *specialist palliative care* services comprising multidisciplinary teams with specialised skills, competencies, experience, and training in palliative care.⁹⁸

Substitute decision-maker

Substitute decision-maker(s) are people appointed or identified by law to make substitute decisions on behalf of a person whose decision-making capacity is impaired. Substitute decision-maker(s) have legal authority to make these decisions; the relevant legislation varies between jurisdictions (states and territories). A document that appoints a substitute decision-maker to make health, medical, residential, and other personal decisions (but not financial or legal decisions) is an advance care directive. More than one substitute decision-maker may be appointed under an advance care directive.

There are three categories of substitute decision-maker(s):

- » substitute decision-maker(s) chosen by the person (e.g., one or more enduring guardians appointed under a statutory advance care directive, or a nominated substitute decision-maker in a common law advance care directive);
- » substitute decision-maker(s) assigned to the person by the law in the absence of an appointed substitute decision-maker (e.g., family member, carer or 'person responsible'); and
- » substitute decision-maker(s) appointed for the person (e.g., a guardian appointed by a guardianship tribunal).⁹⁹

When providing person-centred or family-centred care to Aboriginal and Torres Strait Islander people, it is important to ask the person or family who should be involved in discussions about the health care as there may be community decision makers or spokespersons who should be involved in all discussions and decisions regarding that person's care. In paediatric care, for example, the parents may not be the decision makers for a child's health care. If this is the case, it should be clearly documented in the person's records.¹⁰⁰

95. WHO. National Cancer Control Programs: Policies and Managerial Guidelines, 2nd ed. Geneva: WHO, 2002.

96. Bökberg, Christina, et al. "Evaluation of person-centeredness in nursing homes after a palliative care intervention: pre-and post-test experimental design." *BMC palliative care* 18:1 2019: 1-10.

97. Palliative Care Australia. Palliative Care Service Development Guidelines. 2018

98. Palliative Care Australia, 2018, National Palliative Care Standards, 5th edition.

99. Working Group of the Clinical Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. A national framework for advance care directives. Adelaide: Australian Health Ministers' Advisory Council, 2011.

100. Queensland Aboriginal & Torres Strait Islander Health Branch (2015). Sad news, sorry business: guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying. Brisbane: Queensland Health.

Supported decision-making

Supported *decision-making* is the process of enabling a person who requires *decision-making* support to make, and/or communicate, decisions about their own life. The *decision-making* is supported, but the decision is theirs.¹⁰¹

Spiritual care

Spiritual care is an essential domain of palliative care, which focuses on the needs of the whole person and their family. Spirituality is a fundamental element of human experience. It encompasses the individual's search for meaning and purpose in life and the experience of the transcendent. For some people spirituality can be largely faith based, for others it may be their relationship with nature or the profound connections they have with other people and culture/customs.¹⁰²

For Aboriginal and Torres Strait Islander peoples spiritual care includes the whole person and their social, cultural, emotional and spiritual wellbeing.

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101. Advance Care Planning Australia. <https://www.advancecareplanning.org.au>
102. Palliative Care Victoria. For Healthcare Professionals. Spiritual Care.

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Palliative Care Australia is funded by the Australian Government.
