



Palliative Care Social Work
Australia

Palliative &
End of Life Care
Social Work
Standards

2020

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Acknowledgment of Aboriginal and Torres Strait Islander peoples^{1,2}

Palliative Care Social Work Australia (PCSWA) acknowledge the Aboriginal and Torres Strait Islander peoples, the First Australians. We acknowledge their ongoing connection to land, sea and community. We acknowledge that the story and spirit of Aboriginal Nations are written in the landscape of this country and we pay respects to Elders, past, present and future for they hold the memories, traditions and values which deepen and enrich the life of our land, communities and our nation.

PCSWA acknowledges the pain and impact of dispossession from land and the interruption to intergenerational inheritance of culture. We recognise that this 'does not diminish cultural and spiritual connections to country'^{2[7]} but that it may have implications in the access to and provision of palliative care, end of life care and bereavement support.

PCSWA acknowledged the resilience and strengths of the Aboriginal and Torres Strait Islander peoples and adopts a position of cultural humility, making a commitment to promoting culturally competent, safe and sensitive practice in end of life care, sorry business and bereavement care.

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Palliative & End of Life Care Social Work Standards

Component of Social Work Practice	Standards
Values & Ethics	Social workers demonstrate that the values of social work are integral to their practice in palliative and end of life care, they uphold their ethical responsibilities and they act appropriately when faced with ethical problems, issues and dilemmas.
Professionalism	Social workers demonstrate active promotion and support of the social work profession in the provision of palliative and end of life care, act with integrity and ensure accountability.
Culturally Responsive & Inclusive Practice	Social workers have a good understanding and knowledge of cultural diversity in order to work in a culturally responsive and inclusive way in providing palliative and end of life.
Knowledge for Practice	Social workers have (and obtain) the knowledge required for effective practice in palliative and end of life care.
Applying Knowledge to Practice	Social workers demonstrate the skills required to implement knowledge into practice for the provision of palliative and end of life care, while being mindful of the social work commitment to the human rights perspective.
Communication & Interpersonal Skills	Social workers demonstrate skills required to communicate and work effectively with others in the delivery of palliative and end of life care.
Information Recording & Sharing	Social workers are accountable and responsible for the information they collect, share and keep in the provision of palliative and end of life care.
Professional Development & Supervision	Social workers demonstrate commitment to ongoing learning through supervision and continuing professional development of self and others. Professional supervision of social work practice is essential to working effectively in palliative and end of life care.

Preface

Research has identified the need for a framework to guide safe and competent practice for social workers in the provision of palliative and end of life care in Australia.³ As end of life and palliative care has been identified as a health care priority for State, Territory and National governments,⁴ this further emphasises the need for social work practice standards. In Australia, there are already established Standards to guide health services in the provision of quality end of life care, both in terms of clinical service provision and organisational governance requirements. The National Safety and Quality Health Service (NSQHS) Standards were created, and are mandated by, the Australian Commission on Quality and Safety in Health Care in accordance with the National Health Reform Act, 2011.⁵ The NSQHS standards provide the framework to assess health service compliance and accreditation outcomes. In addition to NSQHS Standards which apply to all health services, national palliative care standards were developed by Palliative Care Australia for specialist palliative care services and aim to guide the delivery of high quality palliative and end of life care.

The combination of research, policy, legislative changes and the need for enhanced professional practice have been the catalysts for the need to develop social work practice standards for palliative and end of life care. In 2018, a Steering Committee was established to create practice standards that could apply to social workers in specialist palliative care settings and social workers in broad range of roles and practice settings. The *Palliative and End of Life Care Social Work Standards* have been written to align directly with the *AASW Practice Standards 2013* and apply to social workers who provide palliative and end of life care across the lifespan. These *Palliative & End of Life Care Social Work Standards* are to be read in conjunction with:

- AASW's [foundation documents](#)
- Palliative Care Australia [National Palliative Care Standards, 2018](#),
- Australian Commission on Quality and Safety in Health Care [National Safety and Quality Health Service \(NSQHS\) Standards](#) and *National Consensus Statement: Essential elements for safe and high-quality end-of-life care* for [Adult](#) and [Paediatric](#) end of life care
- Aged Care Quality and Safety Commission [Aged Care Quality Standards](#)

Changing policy, legislative and practice landscapes have created an increasingly complex medico-legal-ethical environment and psychosocial complexity in palliative and end of life care. The *Palliative and End of Life Care Social Work Standards* provide the framework for person centred, family focused care. The *Palliative and End of Life Care Social Work Standards* provide a valuable framework to guide effective, professional and accountable social work practice in palliative and end of life care in Australia.

Introduction

End of life care is an integral component of health. There are 100,000 predictable adult deaths each year in Australia, 40,000 of which receive specialist palliative care.⁶ There is an estimated 32 children per 10,000 children aged 0-19 years living with a life limiting condition, with one child death for every sixty adult deaths in Australia.⁷ Social workers across the health care sector provide palliative and end of life care in a variety of health care settings and programs. Data from 2009 shows that over 17,000 social workers were employed in Australia and approximately 29% of these were employed in the health sector.^{8,9} In the context of palliative and end of life care, social workers provide support to individuals, carers, family and friends. There is thus the potential positive impact of the social work profession on the lives of a large population who will require palliative and end of life care.

Palliative care is an approach that improves quality of life for individuals and their families facing the problems associated with life-limiting illness. This is accomplished through the prevention and relief of suffering by means of early identification and comprehensive assessment and treatment of pain and other physical, psychosocial, and spiritual problems. Palliative care:

- provides relief from pain and other distressing symptoms.
- affirms life and regards dying as a normal process.
- intends neither to hasten nor to 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.
- enhances 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.¹⁰

Paediatric palliative care represents a unique, albeit closely related field to adult palliative care:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.¹⁰

Palliative and End of Life Care is a rapidly progressing area with increasing psychosocial and medico-legal complexity. The ongoing debate and introduction of voluntary assisted dying legislation in some states, along with end of life care for marginalised and vulnerable groups such as those with a lived experience of mental illness, developmental and physical disabilities, children, prisoners and the homeless, emphasise the need for practice standards to guide clinical practice. Palliative and end of life care practice standards need to reflect Australian contexts and the complexity of the values and attitudes, knowledge and skills that underpin social work in end of life and palliative care.

Social workers have unique skills and in-depth knowledge of working with individual, social, cultural and community diversity, providing interventions across the lifespan and during life transitions.¹¹ Social workers provide palliative and end of life care across a range of settings including hospitals, hospices, community and primary health, nursing homes, correctional facilities, group homes and other government and non-government agencies. When social workers are involved with individuals early in their illness trajectory, they have a positive impact on individual, carer and family outcomes.¹²

Social workers have expertise in working with complexity, assessing social determinants of health and providing psychosocial interventions. Social workers provide multidimensional symptom management, collaborate in interdisciplinary ways of working, engage with communities and navigate systems to influence service delivery, policy and legislation. Social workers adopt social justice approaches to influence resource allocation in order to address gaps and fragmentation across health and social care.

The role of social workers in palliative care is well established in Australia and internationally. Social workers are a crucial part of the multidisciplinary team that works in palliative care. When cure is no longer possible, a host of psychological, emotional, social, physical, practical and spiritual stressors arise. The specialist palliative care workforce is limited in meeting the significant demand for psychosocial care at end of life due to the growing ageing population, the number of people with multiple chronic illness and advancements in medical technology and treatments prolonging life expectancy.¹³ The need for social workers to be trained in palliative and end of life care is essential, irrespective of the workplace setting or role in which they work.

Framework for the Palliative & End of Life Care Social Work Standards

Alignment with AASW Values and Components of Social Work Practice¹

The *Palliative and End of Life Care Social Work Standards* is expressed in three ways

Component of Practice	There are eight components of practice that align with the <i>AASW Practice Standards, 2013</i> . Each component of practice is defined with a statement.
Standard	Each Standard has a statement that provides an overarching standard of professional practice and clinical care.
Indicators	Indicators for each Standard outline the required social work practice knowledge, skills and abilities.

Social work practiced in any field is committed to three core values which give rise to general and specific ethical responsibilities as outlined in the *Code of Ethics* (2010).¹ The values are:

- Respect for persons
- Social justice
- Professional integrity

The practice standards in this document are aligned with the *AASW Practice Standards 2013*¹ which are categorised under eight components of practice. The components of practice are:

1. Values and ethics
2. Professionalism
3. Culturally responsive and inclusive practice
4. Knowledge for practice
5. Applying knowledge to practice
6. Communication and interpersonal skills
7. Information recording and sharing
8. Professional development and supervision.

Palliative and End of Life Care Social Work Scope of Practice

The scope of social work in palliative and end of life care extends across many practice settings and populations, and requires intervention at the individual, family, group, community, and organizational levels. The social work profession has expertise in the psychological, emotional, social and spiritual dimensions of human experience throughout the life course. Social workers provide holistic psychological, social, cultural, emotional, spiritual and practical support to individuals, their carers and families throughout a persons' illness, at end of life and in bereavement and aim to improve and optimise quality of life for the person and their significant others. Social work practice occurs at the interface

between the individual and the environment: beginning with the individual, and extending to the contexts of family, social networks, community, and the broader society.

The person ('individual') and family as the 'Unit of Care'

At the level of engaging with the individual with advanced chronic, terminal or life-limiting illness, social work is concerned with assessment, intervention or treatment planning as well as progress and outcome monitoring. The specifics of these functions will be determined by the setting and role of the social worker. Some social workers are specialist palliative care providers who may work as part of a multidisciplinary team or unit and some may work as generalist social workers who provide palliative and end of life care support to individuals and their families in other settings. Irrespective of the setting, social workers collaborate with the relevant professionals and people who have an impact on the person's wellbeing.

Social context

At the level of 'social context', social work is concerned with the way each individual's social environment shapes their experience of palliative and end of life care. Its concerns include understanding

- the needs of carers and families
- the internal and external factors affecting vulnerability and resilience
- the strengths and stressors in family functioning, support networks, culture, community, class, ethnicity and gender
- the impact of wider social issues such as economic wellbeing, employment and housing.
- access to services.
- previous experience with health services.

Social work is committed to social justice and human rights, particularly in relation to health and social disparities and the impact this has on equitable access to palliative and end of life care and bereavement services. Social workers assess social determinants of health and target psychosocial interventions to enhance quality of life of individuals and families and address any structural barriers that impact on equitable access to support and care.

Vulnerable Groups

Throughout this document, there is reference to vulnerable groups. This term encompasses children, those individuals experiencing interpersonal violence (family and domestic violence and elder abuse), homelessness, mental health conditions, the aged, those with physical, intellectual and developmental disabilities, culturally diverse groups, incarcerated populations, individuals with low literacy and educational attainment and those who are socioeconomically disadvantaged.

About Palliative and End of Life Care

Palliative and end of life care are provided during a persons' illness trajectory and can be understood in the context of a persons' disease and the care they require, as depicted in *Figure 1*.^{13, 14, 15}

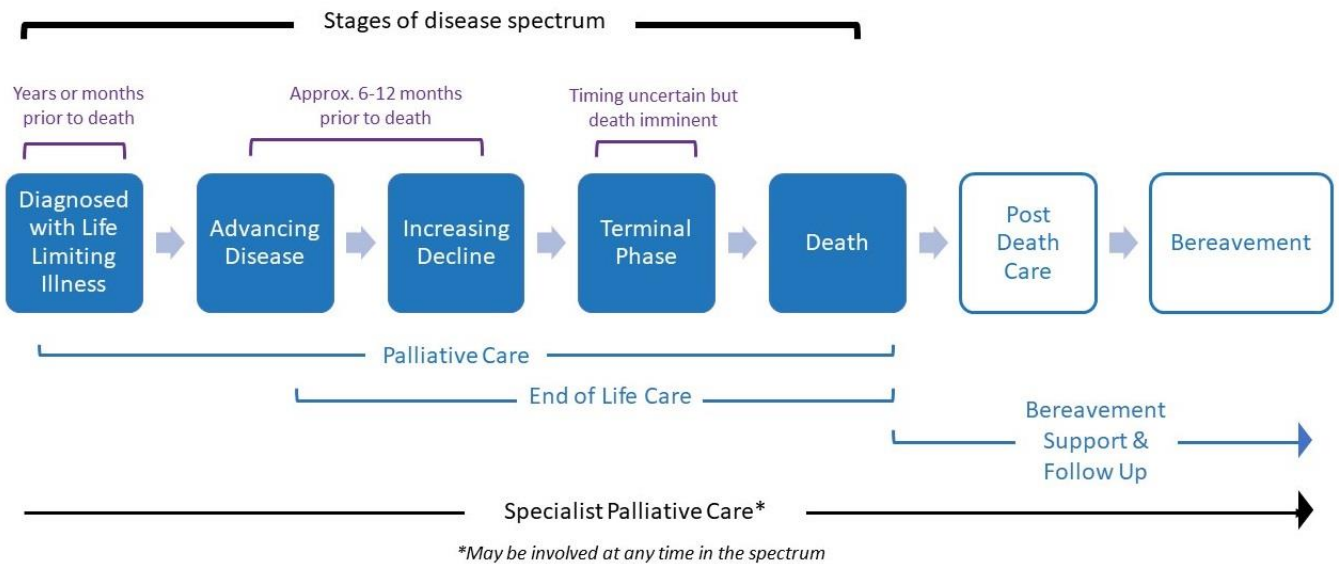


Figure 1: Stages of Disease Spectrum and Care Provision

The concepts from **stages in the disease spectrum** are described below.

Life-limiting illness

The term ‘life-limiting’ illness is used to describe illnesses where it is expected that death will be a direct consequence of the specified illness. Such illnesses 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 illness’ also incorporates the concept that people are actively living with such illnesses, often for long period of time, not simply dying.^{13,16,17}

Advancing Disease

There is evidence of progression of disease and/or increase symptoms. The disease may be referred to as advanced cancer or chronic disease.⁵

Increasing Decline

There is increasing symptom burden, increasing frailty and increasing psychosocial support needs and response to treatment is no longer as effective.⁵

Terminal Phase

The terminal phase refers to the stage in a person’s disease where death is imminent. The terminal phase can last for a period of hours, days or, occasionally, weeks.^{16,17}

Post Death Care

Post death care refers to the period after death where the deceased person is prepared for transfer to the mortuary or the funeral director's premises. The privacy and dignity of the deceased person is always maintained throughout. Depending on the protocols of the organisation and where culturally appropriate, the body of the deceased person may be washed by nurses and/or family members, the deceased person’s personal possessions are prepared and returned to their relatives. When deaths occur in the community with patients under the care of palliative care services, arrangements are made for certification of death, collection of equipment, education of family members on safe disposal of medications and sometimes

assistance is provided with liaising with funeral directors. Care after death includes honouring the spiritual or cultural wishes of the deceased person and their family and carers, while ensuring legal obligations are. Information on grief and bereavement and support services is usually given at this time.¹⁸

Bereavement

A bereaved person is any person who is experiencing grief following the death of a loved one and ‘encompasses the entire experience of family members and friends in the adjustment to living following the death of a loved one.’^{19,20} Bereavement can impact on an individual’s psychological and emotional wellbeing and on a range of social determinants that can lead to significant changes in their circumstances, wellbeing and quality of life.^{21,22}

The **care provided** throughout **the disease spectrum** will vary depending on the stage of where a person is and their care needs. These concepts are depicted in *Figure 1* and are outlined below.

Palliative Care

Palliative care is an approach to care that is person and family-centred and aims to improve quality of life. Palliative care is care provided to a person who has a progressive, advanced illness with little or no prospect of cure and is expected to cause the death of the person. The primary treatment goal is to optimise the quality of life through the prevention and relief of suffering and the treatment of pain, other symptoms and psychosocial-spiritual issues.^{13,16,17,23}

End of life care

End of life care can be provided by a broad set of health and community services to address physical, psychological, emotional, social, cultural, spiritual and practical needs. Quality end of life care is optimal when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists and support care providers and the community – working together to meet the needs of people requiring care. This includes the support of families and carers of the person with a life limiting illness. It is generally accepted that 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 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
- Life-threatening acute conditions caused by sudden catastrophic events^{13, 16(33),23}

*Palliation

Although this is not included in *Figure 1*, some health care professionals use this term to describe the care that is provided, often in the last hours, days or weeks of life. Palliation refers to the relief of symptoms and suffering and aims to help a person feel more comfortable. Palliation of symptoms is a key goal of care for both end of life and palliative care.¹⁷

Specialist Palliative Care

Specialist palliative care is provided by services with medical, nursing and allied health clinicians who have recognised qualifications or accredited training in palliative care. They provide direct

care and consultation services to advise, support and educate non-specialist clinicians who provide palliative care. Specialist palliative care is generally indicated where complex palliative care needs are identified.¹⁷

Specialist Palliative Care Services in Australia are currently categorised into three service levels that outline expectations of workforce and system capabilities required to deliver effective palliative care.¹³ State and Territory Health Department Clinical Services Capability Frameworks are used to guide health service planning and delivery. Combining Palliative Care Australia (PCA) Service Levels and respective State Department of Health *Clinical Services Capability Framework* can provide guidance on expectations for social work workforce requirements (*Appendix*).¹³

Bereavement Support and Follow Up

Bereavement support is part of the palliative care continuum. Bereavement follow up and support adopts an interdisciplinary approach to support the needs of the bereaved and identify those more vulnerable of adverse outcomes as a result of their bereavement, with referral to specialist care where indicated. The provision of bereavement follow-up and support typically involves the provision of a range of interventions along a continuum from less intensive (eg. providing information, follow up phone calls, sympathy letters, memorial service invitations) to more intensive (eg. Counselling or therapy, referral for other specialist interventions).^{24,25}

The role of social work is applicable across the disease spectrum and the breadth of interventions that social work provides varies greatly, depending on their role and setting in which they work. Social workers bring particular expertise in working with complexity and addressing social determinants of health, grief, loss and bereavement and responsive and anticipatory psychosocial care. These concepts are described below.

Grief

Grief is multi-faceted and includes emotional, psychological physical, spiritual and behavioural dimensions, which may begin before the death. Individuals, their carers and families experience grief as a result of many losses throughout an individuals' illness. The person with a life-limiting illness can experience a range of losses such as a loss of independence, security (for example employment, financial, housing security), their social role and networks, intimacy and a decline in body function. Carers can experience similar losses. Grief is a normal reaction to loss. Most people cope in their grief however, grief can result in difficulties when prolonged features impact on a person's ability to function.²⁶ Social workers provide grief support throughout a person's illness and to carers, families and others in their bereavement.

Anticipatory Psychosocial Care

Anticipatory psychosocial care occurs when issues are identified and interventions aim to pre-empt adverse outcomes. Anticipatory psychosocial care aims to strengthen an individual's sense of control and personal efficacy early in the palliative care continuum to mitigate against adverse outcomes as their disease progresses and to minimise adverse outcomes for carers and families throughout a person's illness and during bereavement. Assessment and interventions are ongoing and dynamic across the care continuum.^{21,27}

Social Determinants of Health

The Social Determinants of Health [SDOH] are "conditions in the environments in which people are born, live, learn, work, play, worship, and age."²⁸ SDOH affect a person's health, level of function and quality of life through the unequal distribution of resources.²⁹ Other factors that

impact on a persons' quality of life and access to care include the persons' environment (community and social contexts), economic stability, education, geography and the physical environment and access to health care.^{30,31} To improve access to quality of care and outcomes for people who receive palliative and end of life care, social work interventions take into account social determinants of health in the context of political and power structures and work to address issues that impact a persons' structural vulnerability and disadvantage.^{32,33}

Specialist Palliative Care Social Work: Australian contexts

In accordance with Level 3 Palliative Care Australia Service levels and Level 5 and/or 6 State Health Services Capability Frameworks for Palliative Care Services (*see Appendix*),¹³ social workers who work in these specialist palliative care services have formal specialist qualifications and extended training in palliative, end of life and bereavement care and are considered to be advanced practitioners. Social workers in specialist palliative care services:^{34,35}

- have their core activity limited to the provision of palliative care to individuals with more complex and demanding biopsychosocial-spiritual care needs.
- have advanced knowledge of life limiting illness, disease trajectories and treatment options as well as complex medico-ethical-legal issues.
- use this knowledge to engage in anticipatory psychosocial interventions to mitigate adverse outcomes along the disease trajectory and in bereavement.
- have a multidimensional role as clinicians, educators, researchers, advocates and community and sector leaders and provide consultation on end of life policy, practice standards and clinical pathways at state and national levels.

Statement of Intent

The intent of these Standards is to provide a framework that outlines the knowledge, skills and abilities required of social workers to provide competent and effective palliative and end of life care.

These Standards adopt a lifespan approach, acknowledging that palliative and end of life care is provided to individuals and families of all ages by social workers who are employed across an array of roles and organisations.

Social Workers who work with specific populations, such as with children and adolescents, or in aged care, should apply the Standards accordingly of developing competence. It is also acknowledged that different skills are required for different settings and that some skills outlined within, require a commitment to ongoing skill development.

For social workers working in rural practice or in a generalist role, there is sufficient variability within the standards to allow for discretion around adaptability across geographical locations and available resources.

There is a cross over of indicators between some standards. They are included in each area of relevancy, so that a standard can be considered on its own, rather than all standards having to be read altogether.

Social workers demonstrate that the values of social work are integral to their practice in palliative and end of life care, they uphold their ethical responsibilities and they act appropriately when faced with ethical problems, issues and dilemmas.

STANDARD 1.1

Empower individuals, carers and families to make informed decisions about palliative and end of life care and to direct their care based on their individual needs.

Indicators:

- a. Encourage and promote self-determination and autonomy where possible, within the context of life limiting illness, therapeutic alliance and the parameters of resources and care provision available.
- b. Support and build individual and family strengths and capacity to make informed choices about palliative and end of life care and to document those choices.
- c. Support individuals, carers, families and care teams in honouring difficult decisions related to treatment options and end of life care preferences.
- d. Understand the importance of enhancing an individual's self-determination and choice in end of life decision making; recognising the balance between individual self-determination and the capacity of the health care, family and carer systems to meet the individuals' wishes and needs and managing conflict when an individuals' decisions may differ from professional opinions.
- e. Support family focused decision making in paediatric palliative care, adopting a triadic model in which the child (according to their ability and capacity), the child's parents or guardians and the health care team are involved in decisions regarding the medical care of the child.
- f. Understand the concept of Gillick Competency that affirms the capacity of 'mature minors' to make their own decisions about medical treatment without parental involvement.
- g. Support individuals, carers and families to source accurate information when utilising information technologies to learn about disease processes and trajectories, resources available and treatment options, facilitating access to information which is accessible and useful to the patients, families and carers
- h. Maintain professional boundaries and ensure compliance with organisational policies when using technologies to deliver social work services with individual, carers and families (ie. Telehealth, Videoconferencing, social media platforms, texting etc.).

STANDARD 1.2

Demonstrate a commitment to promoting social justice, ensuring individuals, carers and families have equitable access to resources to meet their biopsychosocial-spiritual needs for palliative and end of life care.

Indicators:

- a. Understand how various systems function (healthcare, policy, clinical practice and the broader community, socio-political and legislative systems) to support advocating for individual, carer and family needs and resources required for safe and optimum end of life and palliative care service delivery.
- b. Work effectively with health and social care systems, adopting multi-level advocacy techniques, to identify and address gaps that create barriers to palliative and end of life care, including financial and resource inequities.

- c. Promote principles of equality, addressing the impact of diversity, discrimination and disparities across cultures and marginalised and vulnerable groups and reduce barriers for equitable access to palliative and end of life care.
- d. Possess the ability to articulate social work, palliative and end of life ethical principles and practice in accordance with professional and organisational codes of conduct and standards, regulatory and accreditation standards which govern settings that provide palliative and end of life care.
- e. Possess contemporary knowledge of ethical issues that may arise in palliative and end of life care and utilise ethical principles to inform decision making and address dilemmas, particularly in relation to resuscitation orders, withdrawal or withholding treatment, palliative sedation and requests for voluntary assisted dying.
- f. Demonstrate anti-oppressive practice through empowering and enabling individuals and families to express and achieve their choices and facilitate the interprofessional team's understanding of and commitment to these.
- g. Promote the principle of veracity and the duty to tell the truth, ascertaining what the individual, carer and family understand and what they would like to know when sharing information, within a culturally competent framework, recognising that individuals have a right to truthful, clear and understandable information about their condition and care options available, if they so wish.

STANDARD 1.3

Social workers practicing in States and Territories in which Voluntary Assisted Dying (VAD) is legislated will be guided by their commitment to palliative care principles, professional practice standards, the philosophical position of the organisation in which they work and the relevant legislation.

Indicators:

- a. Understand that the introduction of Voluntary Assisted Dying legislation does not detract, deter or diminish social workers capacity to provide optimal palliative and end of life care.
- b. Understand that a person requesting Voluntary Assisted Dying is not excluded from receiving or being supported by palliative and end of life care services.
- c. Promote equity of resources to ensure requests for Voluntary Assisted Dying are not made in the context of limited support or resources.
- d. Demonstrate a commitment to treating individuals, carers and families with respect and dignity as their individual values, beliefs, culture and personal views are expressed in relation to Voluntary Assisted Dying.
- e. Act with respect and cooperation with health and care professionals recognising the many ethical, personal and professional values held towards Voluntary Assisted Dying.
- f. Understand that social workers, whose values and beliefs conflict with Voluntary Assisted Dying, may conscientiously object and not engage in any part of Voluntary Assisted Dying while ensuring that no individual is impeded or disadvantaged in accessing appropriate information, material, guidelines and support.
- g. Understand the scope and limitations of the Social Work role in Voluntary Assisted Dying, have knowledge of the legal frameworks, processes and referral pathways should an individual wish to explore Voluntary Assisted Dying.

Social workers demonstrate active promotion and support of the social work profession in the provision of palliative and end of life care, act with integrity and ensure accountability.

STANDARD 2.1

Represent and promote the social work profession in palliative and end of life care with integrity, ensuring the values, ethics and standards of the profession are upheld.

Indicators:

- a. Demonstrate knowledge and expertise of Social Work in the care of individuals, their carers and families receiving palliative and end of life care and promote the profession's expertise in addressing social determinants of health and psychosocial care.
- b. Possess the ability to identify appropriate assessment and screening tools, draw on professional knowledge and best practice to develop case formulations, care planning and therapeutic or psychosocial interventions for palliative and end of life care.
- c. Integrate evidence-based knowledge and best practice guidelines into palliative and end of life care practice and service delivery models across care settings.

STANDARD 2.2

Social Workers are part of the interprofessional team dedicated to the holistic and psychosocial care of individuals, carers and their families.

Indicators:

- a. Advocate for the inclusion of the social work role within interprofessional teams in the provision of generalist palliative and end of life care and promote the profession's integral and essential role in specialist palliative care teams.
- b. Possess knowledge of the diversity and overlap between interdisciplinary team roles, responsibilities and professional boundaries of individuals and professional groups.
- c. Demonstrate a commitment to professional practice that reflects transparency, accountability, autonomy and confidentiality in an interprofessional team context.
- d. Promote the significant role of social work in maintaining a dual focus on the individual, family and contextual domains, viewing the individual, carer and family as a 'unit of care'.
- e. Promote the professions expertise in psychosocial care, case formulation and treatment planning, ensuring psychosocial-spiritual care is a fundamental aspect of all care planning.
- f. Advocate for the role that social workers have in mental health assessment and delivery of quality, evidence based psychological therapies and strategies for individuals receiving palliative and end of life care and their families.

STANDARD 2.3

Demonstrate a level of professional behaviour, emotional intelligence and leadership consistent with the qualities and conduct expected of the Social Work profession.

Indicators:

- a. Possess the ability to recognise different agendas (personal, structural and organisational) and power imbalances that impact the care of individuals and influence decision making.
- b. Promote the multi-faceted role of palliative care social work in being an agent of change across the health system in meeting the needs of culturally diverse, marginalised and underserved populations, through education, advocacy and collaboration.
- c. Possess knowledge of the role of emotional intelligence in self-care, in interactions with individuals' and families and within the interprofessional team in managing emotional labour, moral distress, facilitating difficult conversations and responding to conflict.
- d. Contribute to national platforms which seek to identify critical issues pertaining to palliative and end of life care and the process of quality improvement and research agendas across care settings and with population groups, including underserved, vulnerable and marginalised groups and communities.
- e. Advocate for progressive development programs that encourage interest in the palliative and end of life care clinical speciality in both specialist and generalist settings.

Social workers have a good understanding and knowledge of cultural diversity in order to work in a culturally responsive and inclusive way in providing palliative and end of life.

STANDARD 3.1

Understand how illness, death, palliative and end of life care are conceptualised in an individual's culture of origin.

Indicators:

- a. Demonstrate knowledge of, and respect for, the diversity of cultures, religions and backgrounds of individuals, carers and families referred to palliative care and adapt practice accordingly.
- b. Demonstrate understanding of the barriers to palliative care faced by individuals from marginalised and vulnerable populations and culturally diverse groups.
- c. Critically reflect on cultural competence in relation to family systems, cultural and religious diversity.
- d. Possess advanced knowledge of the meaning and concepts attached to illness, interventions, death and associated customs and rituals, as influenced by the individual's cultural, spiritual and familial background.
- e. Demonstrate sensitivity and understanding of the influence that culture and religion have on grief responses to death and dying and how this might impact on an individual's and/or family's bereavement response and support needs.

STANDARD 3.2

Work respectfully and inclusively with cultural difference and diversity in palliative and end of life care.

Indicators:

- a. Demonstrate the ability to undertake comprehensive and holistic assessments, utilising interpreter and translation services where appropriate, to support ongoing care planning that identifies needs from the individual, carer and families' perspective, which acknowledges the diversity of cultural, religious and spiritual beliefs.
- b. Demonstrate the ability to engage with individuals, their carers and families within the complexity of cultural/religious and familial diversity with a knowledge of when and how to consult further cultural expertise when required.
- c. Promote the right to self-determination of individuals, respecting their wishes about their care and options/preferences consistent with cultural/religious and familial practices while recognising that 'duty of care' may override the demands of social customs, law and religion when pre and post death care may impact on cultural traditions and social mores.
- d. Maintain a commitment to represent, and advocate for the unique needs, values and wishes of culturally diverse groups within interprofessional teams, services and health care policy arenas, to ensure equitable service provision and address barriers to palliative care.
- e. Recognise and appropriately challenge discriminatory and oppressive practice in relation to culturally diverse groups in the context of palliative and end of life care.

- f. Seek opportunities to build and develop community and local resources through developing collaborative partnerships to enhance culturally sensitive and appropriate services and support.



STANDARD 3.3

Understand how illness, dying and death are conceptualised in Aboriginal and Torres Strait Islander peoples' culture of origin.

Indicators:

- a. Demonstrate an understanding of the historical and ongoing systems of disadvantage and oppression, and how these affect Aboriginal and Torres Strait Islander peoples' access to and utilization of palliative and end of life care.
- b. Demonstrate an understanding and respect for the concept of health, illness and wellbeing in terms of Aboriginal and Torres Strait Islander peoples' culture in relation to finishing up, sorry business and returning to country, and how this impacts delivery of information and care.
- c. Identify where there is discordance between bio-medical models and social models of health impacting on access to, and utilisation of, palliative and end of life care services for Aboriginal and Torres Strait Islander peoples.
- d. Develop collaborative relationships with local service providers within Australian and Torres Strait Islander peoples' local communities to enhance opportunities for engagement with appropriate palliative and end of life care supports.
- e. Maintain a commitment to culturally safe and responsive care that considers the trauma history of Aboriginal and Torres Strait Islander people and the intergenerational impact this may have on the present experience of grief and loss.
- f. Ensure that a 'one size fits all' approach is not adopted and show respect and knowledge for the diversity of beliefs and practices within sub-cultures and tribes throughout all communities in metropolitan, regional, rural and remote settings.

Social workers have (and obtain) the knowledge required for effective practice in palliative and end of life care.

STANDARD 4.1

Social workers possess contemporary knowledge of palliative and end of life care principles of practice.

Indicators:

- a. Understand the typical and expected trajectories of advanced chronic, terminal and life-limiting conditions and can anticipate emergent and future needs of individuals, carers and their families (ie. Anticipatory psychosocial care).
- b. Possess knowledge about the complex and interconnected lives and domains of individuals, carers and families, such as the psychological, emotional, social, spiritual, existential, cultural, and practical domains as well as the biomedical, pharmacological, economic, geographic and political factors that impact on their experience of chronic, terminal and life limiting illness, palliative and end of life care, death and bereavement.
- c. Maintain an understanding of how capacity to make decisions may change across the illness continuum in the context of life-limiting conditions and disease trajectories.
- d. Possess knowledge of the dying process (terminal phase) and post death care procedures and provide compassionate emotional and psychological support to individuals, carers, families and friends during this time.
- e. Demonstrate and maintain an awareness of the benefit of timely and appropriate access to specialist palliative care services.
- f. Recognise the capacity of each person and family to identify and draw on individual and collective knowledge, strengths and resources in bereavement.
- g. Maintain comprehensive knowledge of health, social and community services and resources available to assist individuals, carers and families in order to supplement or augment those provided by palliative and end of life care services.
- h. Understand the causation, significance and impact of symptoms on the individual's perception of any intervention and delivery of care, noting the diverse range of interventions including contemporary medicine, complementary medicine, psychological therapies and community care packages.
- i. Possess an awareness of alternative and complementary therapies available to and employed by, individuals experiencing advanced chronic, terminal and life limiting illness and the impact these may have on their treatment and quality of life.
- j. Possess an awareness that care planning is dynamic, continuous, collaborative and holistic and is responsive to the needs and expectations of all systems and stakeholders involved with an individual's care and support.
- k. Recognise the important role, needs, strengths, challenges and limitations of carers within palliative and end of life care.

STANDARD 4.2

Has contemporary knowledge of ethical, legal and moral issues relevant to palliative and end of life care.

Indicators:

- a. Demonstrate an awareness of complex bioethical and legal issues present in palliative and end of life care, including but not limited to the right to refuse treatment; assisted and proxy decision making; withdrawal or withholding of treatment, termination of ventilator support, withdrawal of fluids and nutrition and Voluntary Assisted Dying.
- b. Demonstrate awareness and understanding of the legal requirements and implications of Advance Care Planning processes across States and Territories in Australia.
- c. Possess knowledge of the impact of advanced chronic disease, terminal and life limiting illness on sexuality, libido, functionality and intimacy between individuals and partners, and its influence on physical, psychological and emotional wellbeing.
- d. Demonstrate an awareness and understanding of the unique social, legal, financial, health and mental health issues for Lesbian, Gay, Bisexual, Transgender, Queer, Intersex (LGBTQI) and non-binary gender individuals receiving palliative and end of life care.
- e. Possess knowledge of the complexity of issues related to estrangement, reconciliation and reunification in the context of interpersonal and family systems at end of life.
- f. Possess knowledge of the legal and procedural requirements and systems in place to protect vulnerable adults and children.
- g. Possess knowledge of issues of capacity, competence and legal requirements related to decision making and the impact of progressive illness on decision making capacity, including awareness of Gillick Competency when working with children and young people receiving palliative care.
- h. Demonstrate an awareness of power, control and ethical issues in decision making within palliative and end of life care, including the influence of elder abuse and family and domestic violence.
- i. Demonstrate knowledge of relevant legislation and policies that underpin palliative and end of life practice and service delivery.
- j. Demonstrate an awareness of the complex legal, moral and ethical considerations around Voluntary Assisted Dying.
- k. Maintain an awareness of the processes surrounding coroners' cases, body/organ/tissue donation, deceased body preparation, viewings, funerals/memorials and how to inform and assist people to know their choices and to meet their needs around these situations.
- l. Demonstrate awareness of legislation and processes guiding organ and tissue donation and, in collaboration with the relevant treating team (e.g. Intensive Care Unit) and donation specialist, provide support to the families and significant others of organ and tissue donors before, during and after the decision and procedure.
- m. Maintain an awareness of protocols and processes for donating body to science to assist individuals to initiate this process if requested.

STANDARD 4.3

Understand and articulate social work and other relevant theories and practice modalities relevant to palliative and end of life care practice.

Indicators:

- a. Demonstrate and promote an understanding of a range of social work and other theories related to systems, families, human behaviour, attachment, personality and life cycle development, and their application to palliative and end of life care, dying, death and bereavement practice.
- b. Understand and recognise the unique professional knowledge base that social work brings to the palliative and end of life care setting, specifically the strength of the psychosocial, systems and person-centred practice perspective.
- c. Possess knowledge of teamwork theory, and collaborative practice within and across care settings in order to achieve high level inter and intra disciplinary practice in palliative and end of life care and service delivery.
- d. Possess knowledge of, and develop competence and confidence in, the use of contemporary psychological and existential therapeutic interventions relevant and specific to palliative and end of life care contexts which are congruent with an individuals' life and developmental stages and the illness trajectory.
- e. Possess specific knowledge in paediatric palliative care of child development stages as they relate to a child or young person's understanding of death and dying.
- f. Understand that the needs of siblings of children receiving palliative care are an integral part of each child/family plan of care.

STANDARD 4.4

Awareness of the impact of trauma experiences in palliative and end of life care practice.

Indicators:

- a. Demonstrate a knowledge of contemporary theories, models and practice interventions related to the experience of trauma.
- b. Possess awareness of trauma issues that may impact on an individual at end of life including historical experiences of trauma, exposure to traumatic environmental events, childhood trauma, abuse, diagnostic and medically associated trauma and other traumatic stress factors.
- c. Recognise the widespread experience and impact of trauma and potential pathways for recovery.
- d. Understand how the experiences of trauma can affect an individual's mental health, wellbeing, recovery, and behaviour, symptoms and experience of pain and distress at end of life.
- e. Maintain a commitment to the promotion and integration of trauma informed care strategies into policies and practices within palliative and end of life care settings.
- f. Develop competency in screening and assessment of intergenerational trauma, historical trauma and chronic trauma and the development of intervention and treatment plans to ensure that individuals receive appropriate psychological therapy and support in a timely and compassionate manner.

STANDARD 4.5

Understand and articulate historical and contemporary theories, concepts and practice models related to loss, grief and bereavement care.

Indicators:

- a. Understand that grief is a natural and appropriate response to loss and is the psychological, behavioural and cognitive response to loss that is individually and socially experienced.
- b. Possess knowledge of historical and contemporary theories, models and intervention strategies related to the experience of loss, grief and bereavement.
- c. Identify the social, emotional, psychological, developmental, practical, economic, spiritual, cultural and existential factors that may impact on an individual's experience of loss and grief.
- d. Recognise the factors which may place an individual at risk of encountering difficulties in their grief, whilst also remaining aware of the resources and resiliencies that are unique to each person, family and community.
- e. Develop competency in screening and assessment, differentiating between grief reactions and other mental health presentations such as depression, dysphoria, demoralisation syndrome and psychosocial distress.
- f. Understand the relationship between loss and grief experiences associated with physical, functional and mental health difficulties and an individuals' experience of the health system.
- g. Understand how culture, gender, developmental stages and disability influence the experience of loss, grief, and bereavement.
- h. Recognise that prospective support interventions or anticipatory psychosocial care initiated early in palliative and end of life care delivery and continued throughout the illness trajectory can mitigate potential adverse outcomes in bereavement.
- i. Recognise the importance of bereaved individuals providing informed consent for any interventions and recorded information.
- j. Understand the different applications of technology and social media in people's communication and response to loss and bereavement support.

STANDARD 4.6

Understand systemic influences on palliative and end of life care and service delivery

Indicators:

- a. Recognise the positioning of palliative and end of life care service delivery and practice within the broader health, disability and aged care systems, the nature of the systems within which palliative and end of life care can be provided and the role of specialist palliative care services to build capacity for end of life care within the broader health and disability and aged care community.
- b. Understand social determinants of health, power and disadvantage and the impact of these on access to palliative care support and resources at micro, meso and macro levels of practice.
- c. Possess knowledge of how diversity and discrimination based on culture, gender, ethnicity, age, developmental and physical disability, sexuality, religion and economic status can impact on access and receptiveness to palliative and end of life care.

- d. Understand the impact of systemic influences on access, receptivity and utilisation of palliative and end of life care services by marginalised and vulnerable population groups (including children, carers, people with intellectual disabilities and communication limitations, people experiencing mental health difficulties, LBGTQI, incarcerated people, refugees and migrants, Aboriginal and Torres Strait Islander people and homeless people).

STANDARD 4.7

Understand the role of research and evaluation methods in obtaining and generating new knowledge of practice in relation to palliative and end of life care.

Indicators:

- a. Identify key issues for research in palliative, end of life and bereavement care and have knowledge of ethical guidelines in research with individuals who have terminal and life limiting conditions, as well as their carers and families.
- b. Demonstrate an ability to articulate research related to the benefits of social work inclusion in palliative and end of life care service delivery, across care settings and health care teams.
- c. Attain knowledge of social work evaluation and research theory and methodologies to enhance practice and service outcomes.
- d. Understand that evaluation is integral to social work practice, at the micro, meso and macro levels and contribute to evaluation of services, including a commitment to involve individuals, carers and families who use these services.
- e. Recognise the importance of understanding and contributing to evaluation and quality improvement initiatives in the context of palliative and end of life care.

Social workers demonstrate the skills required to implement knowledge into practice for the provision of palliative and end of life care, while being mindful of the social work commitment to the human rights perspective.

STANDARD 5.1

Apply palliative and end of life care principles to social work practice.

Indicators:

- a. Possess the ability to adopt person and family centred practice and interventions in palliative and end of life consultations through the use of advanced communication skills.
- b. Promote and facilitate early referral to a palliative approach to care to improve outcomes for the individual, their carer and their family.
- c. Advocate for the social determinants of health and mental health to be included in the assessment of an individuals' and family's needs and the impact these may have on behaviour, illness and premature death.
- d. Ensure care planning and interventions reflect the holistic needs of the individual and their family – the biological, psychological, social, developmental, emotional and existential factors as well as the impact environment has on an individual's social and cognitive functioning.
- e. Advocate for the integration of palliative and end of life care principles in non-traditional areas of palliative and end of life care where appropriate, where social work has a presence, such as through government and community programs including Centrelink, My Aged Care, NDIS, Primary Health Networks, Aged Care Facilities, Defence Organisations and Prisons.

STANDARD 5.2

Apply knowledge and theory of loss, grief and bereavement in assessment and care planning.

Indicators:

- a. Undertake a holistic screening and assessment process informed by theory and research of loss and bereavement acknowledging grief as a normal response to loss which incorporates physical, psychological, spiritual, emotional and social responses.
- b. Possess an ability to provide anticipatory grief support for children and vulnerable adults in partnership with parents, guardians and other family members and extend care into bereavement.
- c. Demonstrate competence in developing a therapy and intervention plan to respond to the psychological, social, emotional, developmental and spiritual needs of the individual and their family.
- d. Demonstrate an ability to provide anticipatory interventions for individuals, carers and families with a view to mitigate adverse outcomes in bereavement, including domains related to social determinants of health (ie. psychological, emotional, social, environmental and practical factors).
- e. Facilitate ongoing access to bereavement information and support while acknowledging grief as an evolving and dynamic process that includes anticipatory grieving before a death.
- f. Promote and support strategies that enhance self-determination, self-mastery and self-efficacy in the bereaved.

STANDARD 5.3

Provide social work consultancy to the palliative care interdisciplinary team to enable a holistic approach to care and effective team functioning.

Indicators:

- a. Provide bio-psycho-social-spiritual consultancy across the interdisciplinary team to inform assessments, decision making, interventions and treatment plans.
- b. Demonstrate high level knowledge of interprofessional team functioning and self-reflective practice to enable the strengths and potential of inter- and intra- team collaboration, quality improvement and program development.
- c. Demonstrate an ability to apply conflict resolution to manage differences within the interdisciplinary team.

STANDARD 5.4

Collaborate with individuals, carers and service providers to build capacity in palliative care in the community, health and social care system.

Indicators:

- a. Demonstrate an ability to work collaboratively with individuals, carers, service providers and within the interdisciplinary team to develop a continually evolving person-centred plan of care that enables the individual, carer and family to establish, maintain and review realistic goals.
- b. Demonstrate appropriate community practice approaches by engaging the skills, resources, knowledge, strengths and capacity of communities (eg. Compassionate Communities), to address the diverse needs of individuals and families.
- c. Advocate for the development or enhancement of systems for communicating and working with communities and within organisations to improve the provision and awareness of palliative and end of life care.
- d. Possess the knowledge and capacity to undertake service mapping within and across communities and organisations in order to identify service and knowledge gaps in the provision of palliative and end of life care and bereavement.
- e. Possess or build on the knowledge and capacity of organisations and communities to initiate projects that enhance knowledge of palliative and end of life care within communities and organisations.

STANDARD 5.5

Conducts assessment and care planning with individuals and their families which offer comprehensive and holistic options in palliative and end of life care.

Indicators:

- a. Demonstrate the ability to undertake comprehensive, holistic and ongoing assessments to identify the strengths and challenges of the individual, carer and family and collate key information to devise a care plan to meet their needs with their consent, including family constellation and roles,

communication styles and decision making, cultural beliefs and values, spirituality or religious faith, social supports, and past experience with loss, disability, dying and death.

- b. Demonstrate competence in assessing and identifying significant risk factors that may prevent access to timely palliative and end of life care.
- c. Respond to identified risk factors, including the development of strong advocacy and leadership, in ensuring availability of palliative and end of life care to 'at risk' individuals and populations (this may include people with severe and enduring mental illness, people experiencing homelessness, people experiencing any form of abuse or neglect, and caregiver stress and burden).
- d. Ability to identify and respond to indicators or symptoms of distress, burden and demoralisation (individual, carer and family) throughout the illness trajectory and show an appreciation of the under-recognition, under-diagnosing and under-treatment of psychological distress and mental health concerns of individuals, their carers and families.
- e. Demonstrate the ability to undertake assessment of psychological wellbeing (mental health) and interventions, incorporating these into careplans to capture the biopsychosocial dimensions and determinants of health in the context of palliative and end of life care and advocate for specialist mental health assessment where indicated.
- f. Utilise advanced clinical skills to undertake assessment inclusive of the impact of disease and treatments on sexuality and intimacy, including body image and self-concept, social and relational concerns, changes in sexual functioning and desire and systemic barriers, including those that impede sexual expression and provide interventions that support and promote interpersonal intimacy, sexual satisfaction and identity.
- g. Conduct psychosocial assessments that consider the individual, carer and family views, knowledge and abilities to use technologies and ways in which they use technology (including needs, strengths, risks and challenges).
- h. Advocate for access to technology and resources for individuals and families with limited financial means, who lack familiarity with technology or who come from vulnerable populations such as people with disabilities, limited proficiency in English or other underserved and marginalised groups.
- i. Possess the ability to respond to the changing pain, symptoms and other needs of an individual with a life-limiting illness in a timely and constructive manner, meeting priorities and wishes of the individual, carer and family.
- j. Demonstrate competence to utilise culturally sensitive, person- and family-centred approaches to engage individuals, carers and families in sensitive conversations pertaining to the biological, psychological, social and spiritual impact of a life-limiting condition.
- k. Develop an end of life care plan in partnership with individual, carer, family, friends and relevant professionals or specialists, to provide optimal and effective therapies and support that optimise the comfort of the individual and respects their wishes.
- l. Demonstrate a commitment to ensure that care planning is regularly reviewed in response to the dynamic nature of the illness trajectory and individual, carer or family preferences.
- m. Ability to discuss Advance Care Planning in a timely manner at the level of an individuals' understanding while being mindful of the principle of Informed Consent.
- n. Advocate for and integrate where appropriate the voice of the child and young person with a life limiting condition in conversations around Advance Care Planning.

- o. Ability to support school community and classmates to understand how they can contribute to the wellbeing of paediatric and adolescent individuals receiving palliative care and their families (with permission of the family).
- p. Demonstrate a commitment to ensuring educational needs of children and/or their siblings where possible by supporting access to schooling and opportunities to socialise with peers.
- q. Demonstrate a capacity to undertake assessment of inter-personal and family relationships and the impact of estrangement on family relations and the individual.
- r. Possess high level communication skills to facilitate interpersonal reconciliation and reunification and in building family relationships if this is the expressed wish of the individual receiving palliative and end of life care.
- s. Communicate and employ strategies to support carers needs across the illness trajectory and into bereavement; consider referral to groups for carers or bereaved carers where available or initiate such groups if indicated.

STANDARD 5.6

Implement intervention plans informed by assessments that reflect an individuals' abilities and decisions in palliative and end of life care.

Indicators:

- a. Understand the importance of and support the integration of screening and assessment tools for a range of psychological, social, emotional and existential issues and concerns and respond to these in collaboration with individuals, their family and the treating team.
- b. Possess the ability to plan and devise a range of interventions and approaches informed by ongoing assessments to meet changing care needs along the disease trajectory, and in other circumstances such as family conflict and complex family situations.
- c. Demonstrate an ability to implement interventions and maintain continuity of care that is holistic and comprehensive, using multiple generalist social work skills such as case management, reassessments, evaluation, advocacy, referral, discharge planning, knowledge of barriers to access resources to support individuals, carers and families.
- d. Demonstrate the ability to use high level communication and negotiation skills in the facilitation of family-team conferences to discuss changes in goals of care, the impact of intervention plans and future care needs.
- e. Ability to recognise the signs and symptoms of the terminal phase and in conjunction with the other team members, provide support and psychoeducation to carers, families and other significant persons pertaining to dying, death and post death care.
- f. Utilise standardised evidence-based assessment tools to promote best practice and use data from assessment tools to drive change and improve clinical care.
- g. Demonstrate an ability to provide social work interventions and services using a variety of electronic and multimedia platforms including email, text messages, videoconferencing, social media and electronic social networks and self-guided web-based interventions to communicate with and support individuals, carers and their families.
- h. Offer support to individuals in legacy and meaning making activities such as life review, dignity therapy, hand and footprints, memory boxes or ethical wills to reduce existential distress and demoralisation.

STANDARD 5.7

Apply information collected in assessments to enable individuals, carers and their families to make decisions applicable to their end of life care circumstances.

Indicators:

- a. Identify and incorporate factors identified throughout the assessment process that can influence decision making such as specific disease trajectories, personal and family conflicts, power differentials, psychosocial needs and other factors.
- b. Ensure individual self-determination and autonomy are integrated during the decision making processes in a non-judgemental manner, recognising issues of capacity, competence and legal frameworks.
- c. Empower the voice of children and young people where appropriate in decision making processes around treatment and wishes at end of life.
- d. Ensure information provided on organ and tissue donation or donating body to science is accurate, facilitating discussions with individuals, carers and families, to promote informed decision making and assist with timely planning if requested.
- e. Possess the ability to use outcome measures to determine effectiveness of interventions and be able to communicate these to the treating team and the individual, carer and their family in order to guide and monitor therapeutic interventions.

STANDARD 5.8

Undertake evaluation and research in the area of palliative and end of life care.

Indicators:

- a. Participate in, promote and lead research into social work interventions, theoretical approaches and general knowledge to enhance the social work profession's understanding and response to the psychosocial needs of individuals, carers, families and communities requiring palliative and end of life care.
- b. Demonstrate skills in critically appraising research, integrating research into practice and evaluating outcomes and research from the perspective of the individual, carer and family.
- c. Contribute to research initiatives that demonstrate the efficacy of the social work profession and social work interventions, which promote the importance of identifying and addressing psychological, social, emotional, spiritual and practical needs in palliative and end of life care.
- d. Work collaboratively with social work peers and other disciplines to conduct evaluations and research that enhance knowledge and practice in palliative and end of life care and services.
- e. Demonstrate aptitude in the use of relevant tools and strategies for the evaluation of individual, family and group interventions.
- f. Facilitate ethical engagement of individuals, carers and families in the development and evaluation of palliative and end of life service provision where appropriate.
- g. Integrate critical thinking with data collection and technology solutions to monitor and enhance the quality of social work practice and enhance experiences and outcomes for individuals, carers and families.

- h. Collaborate with external services and communities to develop palliative and end of life care and bereavement services, using evidence-based approaches and education.
- i. Evaluate service delivery, practice standards, clinical care pathways and individual, carer and family outcomes against established palliative and end of life care standards and guidelines, to ensure that evidence-based practice, guides quality clinical practice.
- j. Identify appropriate data to inform clinical and systemic level decision making and service development when planning and developing programs for palliative and end of life care across health settings and health and aged care teams.
- k. Facilitate engagement with individuals, carers and their families in the development of quality clinical practice and evaluate outcome measures which contribute to the development of palliative care service delivery

Social workers demonstrate skills required to communicate and work effectively with others in the delivery of palliative and end of life care.

STANDARD 6.1

Possess well-developed engagement and rapport building skills and effectively address all psychosocial concerns with awareness of diversity and sociocultural contexts.

Indicators:

- a. Demonstrate the ability to develop rapport, engage and establish a professional therapeutic alliance with individuals, their carers, families and significant others.
- b. Understand the importance of using strategies that empower effective communication including active listening, plain language, appropriate tone, clarifying statements, inviting questions and able to provide information at a reasonable rate as to not overwhelm the individual, carer and family.
- c. Demonstrate competence in the use of micro-skills to establish a rapport including reflecting feelings, reframing, constructively confronting and purposeful self-disclosure and attunement to individuals, self and the environment.
- d. Practice with humility, maintaining sensitivity to the impact of a life limiting illness on individuals, carers and significant others, listen to their concerns and priorities in a non-judgemental and respectful way, demonstrating attunement as they adapt to the changes in their condition.
- e. Remain attentive to the individual through careful listening, ensuring the person feels heard and their experience validated, communicating with warmth, empathy and concern to the individual and their family.
- f. Demonstrate cultural awareness and respect for diversity in all interpersonal communication, employing interpreters when appropriate.
- g. If using E-technology and E-platforms, ensure demonstrable skills in establishing a therapeutic alliance and the transmission of information, warmth and empathy through these mediums.

STANDARD 6.2

Effectively adapt communication styles in accordance to the individual's characteristics and situation.

Indicators:

- a. Possess knowledge of different communication styles and tools that can be utilised in an array of situations and demonstrate an ability to adapt these skills to each individual interaction, including the use of technologies for hearing, sight and cognitively impaired individuals, their carers and families.
- b. Understand and respect that individuals and families have their own communication styles, particularly in the context of illness, dying and death.
- c. Demonstrate the capacity to effectively engage children and young people through a range of developmentally appropriate communication strategies such as play, music and art.
- d. Demonstrate an ability to consider the individual, carer and family's cultural, spiritual and religious values and beliefs and adapt communication in accordance to their world view.

- e. Demonstrate an ability to recognise the impact of disease and treatment and its influence on an individual's capacity and ability to comprehend information provided and respond or communicate their needs, wishes and concerns.

STANDARD 6.3

Possess advanced knowledge on the role of communication and decision making, effectively initiating and discussing sensitive issues relating to end-of-life care, with awareness of how the situation is impacting the individual, carers family.

Indicators:

- a. Demonstrate ability and confidence to initiate conversations about prognosis, Advance Care Planning and other sensitive and personal issues in preparation for dying and death.
- b. Demonstrate ability to support Parents/Guardians/Families in sharing news that may be difficult to deliver to children and vulnerable adults and additionally an awareness and demonstrable skill of age appropriate communication techniques for children and young people.
- c. Demonstrate an awareness of the impact of death, dying and bereavement on the individual, family and carer and facilitate discussions about prognosis to allow for early discussions to prepare for anticipated changes and treatment choices (ie. cessation of active treatment, and discussions about fears, concerns related to disease progression and preferences for places for care).
- d. Understand that communication needs of individuals, carers and families will vary throughout a person's disease trajectory and can be impacted by treatment options.
- e. Possess the ability to communicate effectively in situations of ambiguity, distress, dissatisfaction and heightened emotions.
- f. Demonstrate compassion and sensitivity to individuals, carers and families with the ability to remain present and non-judgemental, when bearing witness to emotional, existential and spiritual suffering.
- g. Understand that communication of information changes the individuals' understanding of their situation and/or influences their decision making.
- f. Demonstrate competence in facilitating communication between individuals, carers, family members, and members of the care team during the decision making process, using creativity and advocacy in developing strategies and using a variety of methods to enhance communication between service providers and care settings (eg. home diary, phone apps).

STANDARD 6.4

Possess advanced knowledge on how structural institutions impact on an individuals' situation and can communicate accordingly.

Indicators:

- a. Demonstrate an ability to appraise and communicate the impact that structural institutions and organisational systems have on people and their situation.
- b. Possess the ability to effectively communicate issues relating to health policy, organisational policy and legislative requirements to individuals, carers and families.
- c. Demonstrate an understanding of the impact that government and community programs have on individuals, carers and families and show capacity to navigate and communicate complex systems to enable equitable access and knowledge.

STANDARD 6.5

Assist individuals who have capacity to discuss, review and record their wishes and decisions about their current and future treatment and care.

Indicators:

- a. Possess an understanding of Advance Care Planning and assessment, integrating person centred care and preserving choice where possible as the individual's disease trajectory changes.
- b. Demonstrate an ability to engage individuals to discuss, review and record their wishes and decisions about their current and future care needs, encouraging review of preferences whilst the individual retains capacity to do so.
- c. Demonstrate an ability to encourage and support individuals to utilise their Advance Care Plans with service providers across different settings of care.
- d. Refer to an individual's Advance Care Plan document to communicate clearly to professionals, carers and families when an individual no longer has capacity to make their own decisions.

Social workers are accountable and responsible for the information they collect, share and keep in the provision of palliative and end of life care.

STANDARD 7.1

Record and maintain Advance Care Planning information, facilitating its availability, distribution and use when needed.

Indicators:

- a. Demonstrate knowledge and competence in documenting any adjustments and limitations in approach required to work within individuals' existing decision making capacity and emotional state.
- b. Demonstrate an ability to sensitively share information, maintaining the dignity of an individual in relation to their Advance Care Plan choices and preferences and sharing this information respectfully in accordance with the individuals' consent and legislative requirements.

STANDARD 7.2

Information is gathered and recorded expressing individual, carer and family perspectives and goals of care, honouring cultural differences and diversity when sharing information.

Indicators:

- a. Demonstrate an ability to formulate an individualised approach to information gathering and sharing that respects personal, developmental and age appropriate and cultural uniqueness of individuals, carers, their family, and other social networks.
- b. Demonstrate an ability to modify communication and information sharing techniques and strategies when working with individuals who may experience challenges with communication such as those with learning or speech disability, mental health issues, low literacy and or low proficiency in English.
- c. Recognise and respect an individual's preferences or cultural beliefs regarding 'family' and family involvement and demonstrate sensitivity and empathy in sharing information to those authorised persons identified by the individual in relation to communicating about their care, illness, dying or death.
- d. Recognise and respond to cultural differences about information sharing, specific cultural traditions and ceremonies relative to palliative and end of life care, such as post death care and burial requirements, and ensure these are documented and facilitated to the extent possible.
- e. Demonstrate an ability to articulate individual, family and carer biopsychosocial, economic and spiritual perspectives in documentation, case discussion, referral processes and direct engagement with individuals, carers, families and social networks.
- f. Demonstrate an awareness of the necessity of recording individuals' preferences and effective communication strategies such as use of interpreting, translation, communication devices or modified communication styles.
- g. Demonstrate an ability to accurately document mental health and psychological concerns (eg. death anxiety) and communicate these to the appropriate team members.
- h. Identify, apply and appropriately document the use of validated measuring and assessment tools, noting any limitations or restrictions.

- i. Ensure that the information gathered throughout the care continuum of palliative and end of life care informs post death care and bereavement assessment and interventions for the carers and family.

STANDARD 7.3

Use information to facilitate empowerment, providing effective advocacy and outcomes for individuals, carers and families.

Indicators:

- a. Maintain professionalism when using information to respectfully challenge opinions and processes within team and family environments to support palliative and end of life care for individual, carer and family outcomes.
- b. Understand how information collection, provision and administration processes can contribute to oppression for individuals from vulnerable backgrounds and how these can impact on an individual, carer or family's utilisation of services.

STANDARD 7.4

Apply legislation, ethical and professional codes of conduct in information collection and dissemination.

Indicators:

- a. Ensure documentation reflects an ethical and respectful regard for professional knowledge and expertise of other disciplines involved in an individual, carer and families' lives.
- b. Ensure appropriate levels of consent are obtained that are age and developmentally appropriate, culturally competent, inclusive of capacity and competency issues and concerns; ensure this consent is recorded and communicated in an appropriate manner.
- c. Ensure information derived from risk assessments and interventions are managed in accordance with organisational policy, accreditation standards and legislation, including (but not limited to) privacy and record keeping.
- d. Demonstrate a commitment to an individuals' confidentiality within the parameters of safety, informed decision making, information sharing and interdisciplinary team contexts, ensuring information and data storage and protection complies with Australian Data, Privacy, Record Management and other legislative requirements.
- e. Ensure the use of technologies for the collection, maintenance, use and dissemination of data and information using data management complies with ethical, legal and privacy guidelines and policies.

Social workers demonstrate commitment to ongoing learning through supervision and continuing professional development of self and others. Professional supervision of social work practice is essential to working effectively in palliative and end of life care.

STANDARD 8.1

Engage in continuing professional development to enhance skills and knowledge in palliative and end of life care and to be able to mentor others.

Indicators:

- a. Demonstrate a commitment to continuing education and professional development plans, including undertaking higher education and advanced training, to support professional development in palliative and end of life care.
- b. Demonstrate an ability to orientate, educate and mentor others about psychosocial needs in palliative and end of life care using knowledge of various education strategies to meet diverse learning needs.

STANDARD 8.2

Actively participate in professional supervision.

Indicators:

- a. Demonstrate a commitment to seeking and receiving regular professional supervision, knowing when and how to access support and actively seek and act on feedback from individuals, colleagues, mentors and managers to facilitate reflective practice.
- b. Provide supervision and mentorship to practising social workers and students, contributing to enhancing their skills, knowledge and competence; integrating relevant theories into practice; recognising and responding to ethical dilemmas and consolidating learning and reflections into clinical practice.
- c. Utilise a variety of media and technologies to facilitate supervision, meetings and consultation, ensuring appropriate safeguards are in place to protect confidentiality.

STANDARD 8.3

Maintain a critical reflective approach to practice in palliative and end of life care with the aim to enhance care provision.

Indicators:

- a. Possess a commitment to integrate self-reflection into practice, in order to provide excellence in service provision and as an essential part of self-care.
- b. Demonstrate an ability to manage one's own emotional responses to death and dying and a recognition of the importance of reflection on one's own strengths, vulnerabilities, limitations and personal history and their impact on practice and a willingness to seek support from colleagues as required.
- c. Ability to seek out and integrate feedback into practice whilst maintaining an understanding on the role of supervision, and how it can safeguard best practice in palliative and end of life care, ensuring

organisational and professional requirements are met and opportunities to strengthen knowledge and expertise are identified and utilised.

STANDARD 8.4

Recognise the importance of a culture of self-awareness and self-care in working in the field of palliative and end of life care and work within appropriate professional boundaries.

Indicators:

- a. Incorporate self-awareness into one's own practice as an evolving and continuing process, demonstrating a commitment to developing self-care strategies and to attending to any impact that working with individuals with advanced chronic, terminal and life-limiting conditions and their families may have personally.
- b. Possess a level of self-awareness of personal experiences of loss and beliefs, values and feelings in relation to death and dying, and how this may influence practice with individuals with a life-limiting condition and their carer and family.
- c. Demonstrate compassion and sensitivity to individuals, carers and families with the ability to remain present and non-judgemental, when bearing witness to emotional existential and spiritual suffering.
- d. Maintain a commitment to exercising self-awareness by observing boundaries when faced with other people's sorrow, pain and suffering; minimising transference, countertransference and triangulation.
- e. Maintain self-awareness and transparency about one's own assumptions, experiences and bias in relation to palliative and end of life care, grief, loss and bereavement.
- f. Possess awareness of compassion fatigue and vicarious trauma and take responsibility for mitigating this risk by engaging in good self-care practices, and the use of personal coping strategies and professional supervision.
- g. Provide leadership to the interdisciplinary team and social work peers in recognising, responding to and managing moral distress that arises from situations where there is perceived futility or enduring suffering (eg. situations in which there is continued aggressive treatment or, where treatment wishes of a family are incongruent with an individual's wishes or care).
- h. Advocate for a culture of self-awareness and self-care in the interprofessional team and provide leadership in this area.

STANDARD 8.5

Understand and articulate how and when theories, knowledge bases and knowledge sources inform practice in a palliative care and end of life setting.

Indicators:

- a. Demonstrate a commitment to ongoing knowledge and skill development from a range of sources to inform practice (including practice evidence; practice experience; personal and community knowledge; research evidence; organisational policy and legal and ethical knowledge).
- b. Utilise research, theory and other sources of knowledge to inform professional development, education and research activities.
- c. Maintain a commitment to the dissemination of practice wisdom and research knowledge on palliative and end of life care through seminars, publications, education and conferences.

STANDARD 8.6

Provide leadership to support others in skill and knowledge development, enhance service delivery and drive best practice.

Indicators:

- a. Utilises expertise in palliative and end of life care in the provision and support of education, supervision, research, communication and collaboration.
- b. Demonstrate leadership through modelling the social work role, managing crises, implementing conflict resolution and stress management strategies, providing constructive feedback, facilitating peer support for staff and encourage professional supervision for all team members.
- c. Provide leadership in the ongoing team building process and demonstrate the ability to foster effective communication among members of the interdisciplinary team, fostering and promoting self-reflective practice.
- d. Provide a leadership role and build capacity in research, education, development, delivery and evaluation of holistic palliative services at all levels of the health, social and primary care and community sectors.
- e. Develop leadership in research regarding the integration of palliative and end of life care into other areas of social work activity, for example: aged care, mental health, disability, family and domestic violence, working with refugees and migrants, in drug and alcohol settings and working with prison populations.
- f. Undertake a leadership role in program development, strategic planning, quality improvement, research and education activities, providing guiding expertise to established and new clinicians in this area, enhancing their critical thinking and clinical skills.
- g. Provide leadership, support and education and offer expertise to support schools of social work to include programs on palliative and end of life care and support individuals, groups and organisations with an aim to build resource capacity in the community.

Glossary

Advance Care Directive

Also known as Advance Health Directive. An Advance Care Directive is a legal document that is prepared at a time when a person has capacity and allows a person to make their future healthcare preferences known if they were to lose their capacity to make decisions. Individuals may require extra assistance to participate in their own decision making to the full extent that they are able (Assisted Decision Making). An Advance Care Directive will only operate when a person no longer has decision making capacity. The law and forms for Advance Care Directives are different in each state and territory and the terminology used may vary as well (e.g. Advance Directives, Advance Health Directives).^{16,17,36}

Advance Care Plan

A person's preferences for 'health and personal care, and preferred health outcomes' can be expressed through discussions with the health care team and can be formalised through a documented advance care plan. Where indicated, such as in the case of people with an Intellectual Disability, a person can still be supported in exploring and articulating their wishes through a process of assisted decision making. In circumstances where Assisted Decision Making has not been successful, the process to appoint a substitute decision maker may be required. Plans should be made on the person's behalf and prepared from the person's perspective to guide decisions about care.¹⁷⁽³²⁾

Advance Care Planning

The process of preparing for likely scenarios as a person's disease progresses and usually includes assessment of, and discussion about, a person's understanding of their medical condition and prognosis, values, preferences and personal and family resources. Advance care planning supports a person, or in the case of a minor, their parent or guardian, in communicating their wishes about their end of life care, and can guide decision making when a person can no longer communicate their wishes.¹⁷

Assisted decision making

The process by which the person is assisted to make their own decision, rather than relying upon someone else to make it for them. Methods of assistance can be as simple as breaking down complex concepts into simple ones, relying upon people who are familiar to the person with a disability to explain how best to engage with the person through to using different assistive technologies or devices to enable participation. Since the United Nations Convention on the Rights of People with a Disability in 2006, it has been expected that we assist all people to participate in their own decision making to the full extent that they are able. However, changes to State legislation and reports by the Australian Law Reform Commission has driven this move further to the extent that service providers should now start with the expectation that the person has capacity to make their own decisions, assist them to make their own decisions and record these wishes and preferences for future care planning and only if this fails, involve substitute decision making.^{37,38}

Care plan

A plan that outlines a person's care needs, the types of services they will receive to meet those needs, who will provide the services and when. It is developed by the person's service providers in consultation with them as part of the care planning process. The care plan is holistic and based on the assessment of their care team. The care plan includes information about a person's physical, cultural, psychological, social and spiritual needs.²³

Carer

A carer is a person who provides personal care, support and assistance to another individual. They might be a spouse, defacto partner, child, parent, other relative, guardian or friend. Some people may be a carer for a person with a disability, medical condition (including a terminal or chronic illness) or mental illness, or they are frail and aged. A person is not considered a carer if they are paid, a volunteer for an organisation or caring as part of a training or education program.¹⁶

Generalist Palliative Care Provider

All health professionals provide 'end of life care' which is integral to standard clinical practice of most health professionals who do not work in specialist palliative care teams. The principles of palliative care are embedded in the care that they provide.^{13,14}

Gillick Competency

Gillick competency refers to when a minor has the capacity to consent to health care. The definition of a minor varies between jurisdictions (often a young person aged less than 16 – 18 years). To be Gillick competent, the minor must have sufficient understanding, intelligence and maturity to appreciate the nature of the health care, the consequences and risks of the health care that is proposed and the alternatives, including the consequences of not receiving the health care. This will vary according to the significance of the decision and factors within the child such as their maturity.^{37,38,39}

Interprofessional team

Interprofessional team has been used throughout this document and aims to reflect both multidisciplinary and interdisciplinary teams. An interprofessional team comprises "professionals from a range of disciplines who work together to deliver comprehensive care that addresses as many of the individuals' health and other needs as possible. The professionals in the team may function under one organisational umbrella or may be from a range of organisations brought together as a unique team. As an individuals' condition changes, the composition of the team may change to reflect the changing clinical and psychosocial needs of the individual."⁴⁰⁽⁵⁶³⁾

Person-centred care

An approach to the planning, delivery and evaluation of health care that is founded in mutually beneficial partnerships among clinicians and people receiving care. Person-centred care is respectful of, and responsive to, the preferences, needs and values of the person and guides all clinical decisions, including the type of health services and care they access and how and when it is delivered. Key dimensions of person-centred care include respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers, and access to care.^{36,41,42}

Specialist Palliative Care Provider

A specialist palliative care provider is a medical, nursing or allied health professional recognised as a palliative care specialist by an accrediting body or who substantively works in a specialist palliative care service if an accrediting body is not available. A palliative care specialist has specialist knowledge, skills and expertise in the care of people living with an eventually fatal condition and their families and carers, including in the management of complex symptoms, loss, grief, and bereavement.¹³

Specialist Palliative Care Service

Specialist palliative care services are provided by an interdisciplinary team of specialist palliative care professionals whose substantive work involves consultative and ongoing care and support for people with a life-limiting illness, their carers and family. Specialist palliative care services are provided in care settings including community, home, hospitals, aged care homes, and hospices and palliative care units.

Specialist palliative care professionals would be expected to have recognised qualifications or accreditation in palliative care.^{13,36}

Substitute decision maker

A person appointed or identified by law to make decisions on a range of matters (may include health, personal or financial, depending upon the legislation within each State) on behalf of a person who is unable to make the particular decision required at the time needed due to a lack of decision making capacity. A substitute decision maker may be appointed by the person receiving care, appointed for (on behalf of) the person, or identified as the default decision maker by legislation, which varies by jurisdiction.^{36,37}

Voluntary Assisted Dying

Voluntary assisted dying means a person in the late stages of advanced disease can take a medication prescribed by a doctor that will bring about their death at a time they choose. Individuals who meet the legal requirements and complete all requirements under relevant State legislation can access Voluntary Assisted Dying. The process must be voluntary and is subject to a number of safeguards. The legislation varies across States within Australia and voluntary assisted dying is not legal in all states and territories. This process is also commonly referred to as euthanasia or medically assisted suicide.⁴³

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Appendix

PCA Palliative Care Service Development Guidelines, 2018

PCA Service Levels	
Level 1	Health professionals involved in providing Level 1: Palliative Care do not work full-time in palliative care but have other responsibilities. Can provide services to patients (and families) whose needs are straightforward and predictable
Level 2	Multidisciplinary team including medical practitioners, nurses and allied health professionals with skills and experience in palliative care; some team members will have specialist qualifications related to palliative care. Support people living with a life-limiting illness whose needs range from straightforward and predictable to intermediate and fluctuating; families and carers of these people
Level 3	Multidisciplinary team including medical practitioners, nurses and allied health professionals, most of whom will have specialist qualifications, extensive experience and skills in palliative care (and for whom this is their substantive role and area of practice). Support people living with a life-limiting illness whose needs include straightforward and predictable, intermediate and fluctuating, or complex and persistent; families and carers of these people

Clinical **Services** Capability Framework: Palliative Care: Examples from Queensland Health (similar to other states)

Service Level	
Level 1	Provides <i>low-risk</i> ambulatory care clinical services <i>only</i> Workforce Requirements: access to allied health professionals, as required (may be via telehealth).
Level 2	Provides <i>low-risk</i> inpatient and ambulatory care clinical services Workforce Requirements: access to allied health professionals, as required (may be via telehealth).
Level 3	Provides <i>low to moderate-risk</i> inpatient and ambulatory care clinical services with access to limited support services. Workforce Requirements: access to allied health professionals, as required (may be via telehealth).
Level 4	Provides <i>moderate-risk</i> inpatient and ambulatory care clinical services delivered by a variety of health professionals (medical, nursing, midwifery and allied health) including resident and visiting specialists. Workforce Requirements: access to on-site multidisciplinary team including, but not limited to, occupational therapist, pharmacist, physiotherapist, psychologist, social worker and speech pathologist.
Level 5	Manages <i>all but the most highly complex</i> patients and procedures. Acts as referral service for all but the most complex service needs which may mean highly complex, high-risk patients require transfer or referral to a level 6 service. Has strong university affiliations and major teaching with some research commitments in both local and multi-centre research. Workforce Requirements: designated multidisciplinary team including, but not limited to, occupational therapist, pharmacist, physiotherapist, psychologist, social worker and speech pathologist, or other health practitioners with relevant competencies.

Level 6	<p>Is the <i>ultimate high-level service</i> delivering complex care and acting as a referral service for all lower-level services. Can also be a state-wide super specialty service accepting referrals from across the state and interstate where applicable.</p> <p>Generally provided at a large metropolitan hospital.</p> <p>Has strong university affiliations and major teaching and research commitments in both local and multi-centre research.</p> <p>Workforce Requirements: postgraduate palliative care qualifications recommended or highly desirable for nursing and allied health professionals.</p>
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