

Palliative Care Services

Module overview

Please note: This module must be read in conjunction with the Fundamentals of the Framework (including the glossary and acronym list).

Palliative care is the care of people who are expected to die in the near future due to a progressive, life-limiting illness. Palliative care also includes the support of the dying person's family and/or carers. Through a network of specialist and primary care providers and community partnerships, palliative care services aim to support terminally ill people to live as they choose until death. Palliative care services play an important role in helping families and carers cope during the patient's illness and with subsequent bereavement.

Palliative care is multidisciplinary care delivered by coordinated medical, nursing, allied health, pastoral care and social services. Palliative care integrates the physical, psychological, social, spiritual and cultural aspects of care. The right of each patient to make informed choices in their own time about the care they receive, and the environment in which they receive that care, is integral to effective palliative care services. Consequently, patients with highly complex symptom management issues may choose to return home for end-of-life care with the understanding that they have direct access to only the lower level palliative care services in their chosen place of care.

Palliative care service delivery should be based on quality management principles that comply with the Standards for Providing Quality Palliative Care for all Australians.¹ These standards incorporate key principles considered essential for all palliative care services, including:

- comprehensive assessment and management of symptoms
- consultation and coordination
- patient access to support
- continuity and coordination of care
- public health initiatives
- comprehensive discharge planning
- bereavement support
- education
- family and carer access to support
- staff and volunteer support
- research
- respite care.

Pastoral carers provide spiritual care as one aspect of the holistic approach to palliative care services for patients and families. While pastoral carers are not generally part of the palliative care workforce, they are integral members of the multidisciplinary team. Access to pastoral/spiritual care is essential for all levels of palliative care services, as are processes to assist referrals to appropriate pastoral or spiritual care services.

Historically, patients with advanced cancer (and their families and/or carers) have been the most common recipients of palliative care. However, terminally ill people suffering from other progressive diseases also benefit from palliative care services. Terminal progressive diseases include, but are not limited to, end-stage organ failure, progressive neurological conditions, acquired immunodeficiency syndrome, frailty, dementia and the end-stage of inherited metabolic disorders.

Palliative care services need to be responsive to the individual needs of patients and their families and/or carers. In particular, services should be sensitive to the palliative care requirements of special needs groups and their families including:

- Aboriginal and Torres Strait Islander peoples²
- people from culturally and linguistically diverse backgrounds
- children and young people
- people who live in residential care and/or other institutions (including prisons)
- people who are homeless or financially disadvantaged
- adults with impaired decision-making capacity (including those with an intellectual disability)
- people with mental illness
- people living in rural and remote communities.³

Although the general principles and basic approach of palliative care apply to children, adolescents and adults, there are important differences between these age groups, which must be addressed when providing paediatric palliative care.⁴ Please refer to the relevant children's services module/s.

The differences associated with paediatric palliative care include:

- variations in patient diagnoses
- the developmental, psychological and social needs of children
- the unique place of children as dependent members of families
- the particular ethical issues involved where minors are concerned
- the physiological factors that relate specifically to children and their illnesses.

Paediatric palliative care recognises that children have complex clinical and support needs, while their family and/or carers have an increased emotional burden and the risk of complicated grief.^{5,6,7}

Consultative or outreach palliative care services are generally provided from higher level palliative care services (Levels 4, 5 and 6) to lower level services (Levels 1, 2 and 3).

Service networks

In addition to the requirements outlined in the Fundamentals of the Framework, specific service network requirements include:

- evidence of clinical networks at all levels of palliative care services to ensure evidence-based care is provided by multidisciplinary teams in both ambulatory and/or inpatient acute settings
- multidisciplinary teams work in an interdisciplinary manner (i.e. work collaboratively, holding regular meetings to discuss the patient status and the evolving plan of care) and increase their capability as patients require greater complexity of care
- documented processes between higher level service networks and oncology services, including haematology services, radiation oncology services, diagnostic services (including high-quality imaging and pathology services), interventional pain management services, surgical and medical subspecialties, medication services and allied health services
- documented processes for referral to services at other levels.

Service requirements

In addition to the requirements outlined in the Fundamentals of the Framework, specific service requirements include:

- providing patient and carer information about the service and other support services
- collecting activity data
- assisting patients to achieve their achievable goals
- addressing the needs of family (including bereavement support)
- supplying appropriate support in the case of complicated bereavement
- providing support mechanisms for staff and volunteers
- having evidence of home visiting protocols, if applicable.

Workforce requirements

In addition to the requirements outlined in the Fundamentals of the Framework, specific workforce requirements include:

- access to a multidisciplinary mix of staff with competency-based skill levels and defined roles in order to deliver safe and effective care, including, but not limited to, bereavement counsellors, dieticians, occupational therapists, pharmacists, physiotherapists, psychological and emotional support services, social workers and speech pathologists, as required
- all health professionals involved in the care of palliative patients are educated about the psychosocial impact of life-limiting illness for the patient and family, and in the management of issues associated with dying, death and bereavement
- where paediatric palliative care is provided, a range of professional healthcare providers have experience in paediatrics and have undertaken, or are working towards, a paediatric palliative care qualification.

Specific risk considerations

In addition to risk management outlined in the Fundamentals of the Framework, specific risk considerations for palliative care services include:

- lack of patient/family preparedness for death
- suboptimal symptom management and support, particularly for patients choosing to return home for end-of-life care
- lower level services may have reduced access to pathology services able to deal with urgent requests, with the potential for delays in the diagnosis and treatment of conditions such as hypercalcaemia
- inability to provide cover for planned leave of key staff or volunteers
- local conditions can affect staffing levels of specialist and non-specialist palliative care clinicians, with the potential to affect the support and supervision structures for patients and their families and/or carers.

Level 1 Palliative Care Service

Service description

A Level 1 service provides support for the palliative care of clients/patients living in the community. The care provided is generally low-complexity care; however, palliative care clients/patients with complex needs may choose to live where they have access only to a Level 1 service. Services are provided during business hours and may be provided in the home, the community or in ambulatory settings.

Level 1 palliative care services are provided primarily by registered nurses with generalist qualifications or other non-medical health professionals. Local medical services may be accessed through a registered medical practitioner (general practitioner).

Where providers have relevant knowledge and skills in paediatric health care, the Level 1 service may care for children.

If patients require transfer, this should occur within 24 hours or as determined by geographical constraints.

Service requirements

As per module overview, plus:

- healthcare providers involved in assessing the care and support needs of patients/clients and their families/carers have relevant knowledge of palliative care principles and practices, and, when necessary, seek advice from or refer to specialist palliative care services
- access—24 hours—to specialist palliative care service/consultancy
- communication and collaboration with health facilities and/or specialist palliative care teams (may be via telehealth)
- access to bereavement support services
- access to subcutaneous infusion devices for symptom management
- access to an equipment hire service for items such as hospital beds
- may have access to non-government organisation support services (e.g. domiciliary nursing services).

Workforce requirements

As per module overview, plus:

Medical

- access to a registered medical practitioner
- may have access to a visiting registered medical specialist with credentials in palliative medicine

Nursing

- at least one registered nurse is available

Allied health

- access to allied health professionals, as required (may be via telehealth)

Other

- access to Aboriginal and Torres Strait Islander liaison officer for services with Aboriginal and Torres Strait Islander patients.

Support service requirements

A Level 1 service requires:

Service	On-site	Accessible
medical imaging		1
medication		1
pathology		1

Level 2 Palliative Care Service

Service description

A Level 2 service provides community-based ambulatory services and, in the event that palliative patients require 24-hour nursing care, access to inpatient beds (not necessarily palliative care beds). There may be advice and guidance provided from higher level services via mechanisms such as telehealth consultations or remote ward visits.

Service requirements

As per Level 1, plus:

- access—24 hours—to a Level 4, 5 or 6 palliative care service for advice and guidance
- access—24 hours—to telehealth services and equipment
- access to non-government organisation support services (e.g. domiciliary nursing services).

Workforce requirements

As per Level 1, plus:

Medical

- access to a registered medical specialist with credentials in palliative medicine
- access to a registered medical practitioner for review of patients

Nursing

- a registered nurse who has completed professional development activities in palliative care

Allied health

- as per Level 1 service

Other

- as per Level 1 service.

Support service requirements

A Level 2 service requires:

Service	On-site	Accessible
medical		2
medical imaging		2
medication	3	
pathology		2

Level 3 Palliative Care Service

Service description

A Level 3 service provides care for palliative patients in ambulatory and/or inpatient settings and is clearly identified as a dedicated palliative care service. This level service has established links with higher level palliative care services.

A Level 3 service provides a seamless continuum of care as patients move between the community and acute inpatient settings. This service may not have its own outreach into the community or provide inpatient care, but will work in collaboration with services that provide such care.

Service requirements

As per Level 2, plus:

- care coordination of palliative services is managed through a central point
- regular patient reviews are conducted by specialist palliative care staff, either in person or via telehealth
- may have access to a regular on-site palliative care clinic
- may have access to a specialist palliative care service in the community or inpatient setting.

Workforce requirements

As per Level 2, plus:

Medical

- access—24 hours—to a registered medical practitioner or visiting registered medical specialist with credentials in palliative medicine (may be off-site)

Nursing

- nurse manager (however titled) available to oversee the care of palliative patients
- registered nurse/s to support the nurse manager (however titled)

Allied health

- as per Level 1 service

Other

- access to pastoral/spiritual care staff
- access to a bereavement counsellor with high-level skills in bereavement risk assessment and counselling
- access to interpreters and/or cultural advocates for patients from Aboriginal and Torres Strait Islander or other culturally diverse backgrounds.

Support service requirements

A Level 3 service requires:

Service	On-site	Accessible
anaesthetic		3
medical		2
medical imaging		2
medical oncology		3
medication	3	
pathology		2
perioperative (Section 5, Acute Pain Services)		5

Level 4 Palliative Care Service

Service description

A Level 4 service provides ambulatory and/or inpatient care for palliative patients with moderately complex symptom management needs. This service may either provide the major care for a patient who is home- or community-based, or provide input and support to the primary providers of this care. Service provision may include off-site ambulatory services such as home visiting by nursing and/or allied health staff, for which a service agreement may be in place with a third-party provider. Inpatient services may include designated palliative care beds. A Level 4 service is coordinated by a health professional with experience, knowledge and skills in palliative care with access to a multidisciplinary team.

Service requirements

As per Level 3, plus:

- close liaison with a Department of Emergency Medicine, where such a service is available
- access to relevant mental health services.

Workforce requirements

As per Level 3, plus:

Medical

- on-site access—24 hours—to registered medical practitioners
- access—24 hours—to a registered medical specialist with credentials in palliative medicine

Nursing

- registered nurse in charge of each shift (however titled)

Allied health

- access to an on-site multidisciplinary team including, but not limited to, an occupational therapist, pharmacist, physiotherapist, psychologist, social worker and speech pathologist

Other

- as per Level 3 service.

Support service requirements

A Level 4 service requires:

Service	On-site	Accessible
anaesthetic		4
haematological malignancy		3
medical		3
medical imaging		5
medical oncology		4
medication	4	
nuclear medicine		4
pathology		2
perioperative (Section 5, Acute Pain Services)		5
radiation oncology		5
surgical		4

Level 5 Palliative Care Service

Service description

A Level 5 service has the capacity to manage a full range of clinically and/or psychosocially complex issues experienced by palliative care patients and/or their families/carers. This level service provides allocated palliative care inpatient beds, which may be located in a dedicated palliative care unit. A Level 5 service also provides, or is part of a service network that provides, off-site ambulatory services with 24-hour availability of medical staff.

The service is part of a service network with higher level services in palliative care or other specialties, ensuring access to the latest evidence-based care and treatment information.

Service requirements

As per Level 4, plus:

- provision of complex symptom management (including access to invasive procedures)
- provision of procedural medicine (e.g. ascites drainage, pleural taps)
- on-site bereavement service
- access to consultation-liaison psychiatry services
- access to interventional pain management.

Workforce requirements

As per Level 4, plus:

Medical

- registered medical specialist with credentials in palliative medicine available 24 hours

Nursing

- palliative care nurse manager (however titled) coordinating care across a campus or multiple campuses
- registered nurse with palliative care qualifications and/or demonstrated competency in palliative care 24 hours
- palliative care nurse practitioner with relevant advanced training desirable

Allied health

- dedicated multidisciplinary team including, but not limited to, an occupational therapist, pharmacist, physiotherapist, psychologist, social worker and speech pathologist, or other health practitioners with relevant competencies

Other

As per Level 3, plus:

- designated bereavement counsellor with demonstrated competency in bereavement risk assessment and counselling and/or relevant postgraduate qualifications
- access to discharge coordinators.

Support service requirements

A Level 5 service requires:

Service	On-site	Accessible
anaesthetic		4
haematological malignancy		4
medical		4
medical imaging		5
medical oncology		4
medication	5	
nuclear medicine		5
pathology		3
perioperative (Section 5, Acute Pain Services)		5
radiation oncology		5
surgical		4

Level 6 Palliative Care Service

Service description

A Level 6 service provides a palliative care unit with the capacity to manage the highest level of patient risk and/or complexity and is able to provide highly complex symptom management. This service is intrinsically linked to Level 5 and/or Level 6 services from other disciplines. The service also provides an extensive range of interventional and diagnostic services.

Service requirements

As per Level 5, plus:

- regular multidisciplinary team meetings with other Level 6 services
- after-hours service provision available for other services regarding highly complex symptom management issues
- on-site interventional pain management readily available or available for review within 48–72 hours
- access to invasive procedures for high-risk patients.

Workforce requirements

As per Level 5, plus:

- where paediatric palliative care is provided, a range of professional healthcare providers who have undertaken a paediatric palliative care qualification
- postgraduate palliative care qualifications are recommended or highly desirable for nursing and allied health professionals

Medical

- the lead clinician responsible for clinical governance of the service is a registered medical specialist with credentials in palliative medicine

Nursing

- palliative care nurse practitioners with relevant advanced training

Allied health

- specialist palliative care pharmacist

Other

- designated bereavement counsellor with demonstrated competency in bereavement risk assessment and counselling, and relevant postgraduate qualifications.

Support service requirements

A Level 6 service requires:

Service	On-site	Accessible
anaesthetic	4	
haematological malignancy		4
medical		4
medical imaging	5	
medical oncology		5
medication	5	
nuclear medicine		5
pathology		3
perioperative (Section 5, Acute Pain Services)	5	
radiation oncology		5
surgical		4

Legislation, regulations and legislative standards

In addition to what is outlined in the Fundamentals of the Framework, palliative care services must comply with the following:

- *Criminal Code (Palliative Care) Amendment Act 2003*.
www.legislation.qld.gov.au/LEGISLTN/ACTS/2003/03AC015.pdf

Non-legislative standards, guidelines, benchmarks, policies and frameworks

In addition to what is outlined in the Fundamentals of the Framework, the following are relevant to palliative care services:

- Australian Council on Healthcare Standards. EQUIP 4 standards linkage to Standards for providing quality palliative care for all Australians. ACHS; 2009.
- Canning D, Yates P, Rosenberg J. Competency standards for specialist palliative care nursing practice. Brisbane: Queensland University of Technology; 2005.
www.pcna.org.au/
- Palliative Care Australia. Standards for providing quality palliative care for all Australians, 4th ed. Canberra: PCA; 2005. www.palliativecare.org.au/
- Queensland Government, Griffith University. Guidelines for the handling of medication in community based palliative care services in Queensland. Brisbane: Brisbane South Palliative Care Collaborative, Queensland Health; 2009.
www.health.qld.gov.au/cpcrc/medguidepccn.asp

Reference list

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www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm
3. Australian Government Department of Health and Ageing. The National Palliative Care Strategy: A National Framework for Palliative Care Service Development. Canberra: Australian Government; 2000.
www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-npcstrat.htm
4. Hynson J, Gillis J, Collins J, Irving H and Trethewie S. The dying child: how is care different? MJA 2003;179(6 Suppl):S20–2.
5. Australian Government Department of Health and Ageing. Community attitudes towards palliative care. Canberra: Australian Government; 2006.
www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-comm-att
6. Australian Government Department of Health and Ageing. Paediatric Palliative Care Service Model Review. Canberra: Australian Government; 2004.
7. Yates P. Palliative care for specific populations. Aust Fam Physician 2006;35(10):776–9.