Palliative Care

Module Overview

This module should be read in conjunction with the SA Health Palliative Care Services Plan 2009-2016.

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 heath, 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 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 complying 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 peoples[2]
- 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 children's palliative care.[4] Please refer to the relevant children's services module/s.

The differences associated with children's palliative care include:

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

Children's palliative care recognises 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]

Outreach palliative care services are generally provided from higher level palliative care services (Levels 4 and 6) to lower level services (Levels 1 and 2).

Service Networks

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

- multidisciplinary teams work in an interdisciplinary manner (i.e. work collaboratively, holding regular meetings to discuss patient status and the evolving plan of care) and increase their capability as patients require greater complexity of care. For service levels which do not have multidisciplinary teams they should demonstrate partnership arrangements with level 4-6 services.
- 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

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
- assisting patients to achieve their achievable goals
- addressing the needs of family (including bereavement support, carer burden during the active client phase, grief and loss support services)
- identification and referral for appropriate support in the case of complicated bereavement
- providing support mechanisms for staff and volunteers
- providing relevant clinical indicator data to satisfy accreditation and other statutory reporting obligations
- compliance with SA Health policy directives and guidelines that are referenced at:
  - SA Health Policy Directives
  - SA Health Policy Guidelines
  - SA Health Clinical Directives and Guidelines

Workforce Requirements

The CSCF does not prescribe staffing ratios, absolute skill mix, or clerical and/or administration workforce requirements for a team providing a service, as these are best determined locally and in accordance with relevant industrial instruments. Where minimum standards, guidelines or benchmarks are available, the requirements outlined in this module should be considered as a guide only. All staffing requirements should be read in conjunction with the Health Care Act 2008, Awards and relevant Enterprise Agreements including, but not limited to:

- SA Health Salaried Medical Officers Enterprise Agreement 2013
- SA Health Visiting Medical Specialists Enterprise Agreement 2012
- SA Health Clinical Academics Enterprise Agreement 2014
- Nursing/Midwifery (South Australian Public Sector) Enterprise Agreement 2013
- SA Ambulance Service Enterprise Agreement 2011
- SA Public Sector Wages Parity Enterprise Agreement Salaried 2014

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, medical staff, nurses, 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 children's palliative care is provided, a range of professional healthcare providers have experience in paediatrics and have undertaken, or are working towards, a children's palliative care qualification.
- nursing and allied health roles with an advanced scope of practice should be working towards post graduate qualifications.

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.
- complexities around consent, sharing of information with families and significant others, and working with families with broken relationships and difficult dynamics.

Palliative Care	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6
Service description	> Provides care up to the level where specialist support or input is required to ensure quality end of life care (applies to non-specialist palliative care providers) > Provides quality end of life care including assessment, triage, care coordination & clinical management, bereavement risk assessment and bereavement care for patients with uncomplicated needs associated with end of life care. > Services provided during business hours and may be provided in the home, community, hospital or residential aged care facility > Provided primarily by primary and acute care teams > Has formal links with a palliative care services for purposes of referral, consultation and access to specialist care as necessary	> Provides palliative care for patients, primary caregivers and families whose needs exceed the capability of primary care providers. > Services provided 24 hours a day, 7 days a week via a mobile service to site of care either by direct or via telephone consultation > Provides assessment, & community & clinical education > Provides care consistent with needs and provides consultative support, information and advice to primary care providers > Has formal links with primary care providers and a formal partnering relationship with a Level 6 service as well as with a local Level 4 service (through clustering arrangements if present) to meet the needs of patients, caregivers and families with complex problems. > Has quality and audit programs	> N/A.	> As for Level 2, able to support higher resource level (due to population base or the presence of a Country General Hospital that brings with it additional responsibility to a cluster of smaller services), or the presence of a hospice associated with an adjacent Level 6 service. > Provides inpatient care within satellite hospice unit beds (in periurban centres) or a small cluster of (non-dedicated) palliative care beds. > Has formal links to primary care providers and a formal partnering relationship with a Level 6 service as well as with Level 2 services (within a cluster if present) to meet the needs of patients, caregivers and families with complex problems.	> N/A.	> Provides comprehensive care for the needs of patients with complex need, and support for their caregivers and families. > Provides inpatient care, mostly in hospice units with some capacity within acute care beds of metropolitan hospitals based on need. > Has formal links with primary care providers and formal partnering agreements with a number of Level 4 and Level 2 services across the state to meet the needs of patients, caregivers and families with complex problems. > Contributes to high quality specialist research, advanced clinical training and graduate education programs and has integrated links to relevant academic units including professorial chairs where available.

Palliative Care	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6
Service requirements	As per module overview, plus: > Healthcare providers involved in assessing 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 equipment hire service for items such as hospital beds. > May have access to non-government organisation support services (e.g. domiciliary nursing services).	As per Level 1, plus: > Access—24 hours—to Level 4 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).	> N/A.	As per Level 2, plus: > care coordination of palliative services managed through central point. > regular patient reviews conducted by specialist palliative care staff, either in person or via telehealth. > may have access to regular on-site palliative care clinic. > may have access to specialist palliative care service in the community or inpatient setting > close liaison with Department of Emergency Medicine, where service is available. > access to relevant mental health services.	> N/A.	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. > regular multidisciplinary team meetings with other Level 6 services. > after-hours service provision accessible for other services regarding highly complex symptom management issues. > on-site interventional pain management readily accessible or available for review within 48–72 hours. > access to invasive procedures for high-risk patients.

Palliative Care	Level 1	Level 2	Level 3	Level 4	Level 5	Level 6
Workforce requirements	As per module overview, plus: **Medical** > access to registered medical practitioner. > may have access to visiting registered medical specialist with credentials in palliative medicine. **Nursing** > staffing levels in accordance with the relevant industrial instruments. > access to at least one registered nurse or generalist community nurse. **Allied Health** > access to allied health professionals, as required (may be via telehealth).	As per Level 1, plus: **Medical** > access to registered medical specialist with credentials in palliative medicine. > access to registered medical practitioner for review of patients. **Nursing** > staffing levels in accordance with the relevant industrial instruments. > may have access to a palliative care nurse with local support from general medical practitioner, allied health staff, pastoral care and volunteers **Other** > may have access to a coordinated volunteer service.	> N/A.	As per Level 2, plus: **Medical** > on-site access—24 hours—to medical practitioners. > access—24 hours—to registered medical specialist with credentials in palliative medicine. **Nursing** > staffing levels in accordance with the relevant industrial instruments. > may have access to a palliative care nurse with local support from general medical practitioner, allied health staff, pastoral care and volunteers **Allied Health** > access to allied health and pastoral care staff, as required	> N/A.	As per Level 4, plus: > Interdisciplinary team including a service director, palliative medicine specialists, a clinical nurse leader, and an expanded range of clinical and allied health staff with specialist qualifications. **Other** > access to 24 hours to out of hospital treatment/ support to support ongoing treatment plans.
Specific risk considerations	> Nil	> Nil	> Nil	> Nil	> Nil	> Nil

Support services requirements for Palliative Care services	Level 1		Level 2		Level 3		Level 4		Level 5		Level 6	
	On-site	Accessible	On-site	Accessible	On-site	Accessible	On-site	Accessible	On-site	Accessible	On-site	Accessible
Anaesthetic								4			4	
Haematological malignancy								3				4
Medical				2				3				4
Medical imaging		1		2				5			5	
Medical oncology								4				5
Nuclear medicine								4				5
Pathology		1		2				2				3
Perioperative (acute pain services)								5			5	
Pharmacy		1	3				4				5	
Radiation oncology								5				5
Surgical								4				4

Legislation, regulations and legislative standards	Non-mandatory standards, guidelines, benchmarks, policies and frameworks (not exhaustive & hyperlinks current at date of release of CSCF)
Refer to the Fundamentals of the Framework for details.	In addition to what is outlined in the Fundamentals of the Framework, the following are relevant to palliative care services: > 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/ > South Australian Government. Palliative Care Services Plan 2009-2016. www.sahealth.sa.gov.au > Royal Australasian College of Surgeons. Trauma Verification: Model Resource Criteria for Level I, II, III & IV Trauma Services in Australasia. RACS; 2009. www.surgeons.org/media/309212/2009-08-04_MRC_for_website.pdf

Reference List:

1. Palliative Care Australia. Standards for providing quality palliative care for all Australians, 4th ed. Canberra: PCA; 2005.
2. Australian Government Department of Health and Ageing. Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples: Resource Kit. Canberra: Australian Government; 2004. 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/
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/
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. Australian Family Physician 2006;35(10):776–9.

For more information

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Interpreter

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