Information for Service Providers

SA Community Care

End of Life Care Services

Introduction

The purpose of this document is to provide information about the SA Health delivery of end of life care (EoLC) services for individuals with a life-limiting illness, and their families and carers under the SA Community Care (SACC) Program.

EoLC community services aim to:

- support people to be cared for, and die, in their place of residence (home or residential aged care facility), if this is their wish, and enable their family/carer(s) to participate as they are able;
- prevent avoidable hospital admissions; and
- enable early supported discharge where clinically safe to do so.

EoLC services provided under the Community Nursing 'palliative care' and the Hospital and Health Care @ Home (HHC@H) EoLC contracts expired on 30 June 2018, and have been combined in the SACC Program.

End of Life Care (EoLC)

EoLC is recognised as the care of people, and their families and carers, who are 'approaching the end of life' and are likely to die within the next 12 months. It includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and other support staff.

Palliative care, is a term often used interchangeably with EoLC and is an approach to treatment that supports people at the end of life to improve their quality of life through the prevention and relief of suffering. Conditions requiring a palliative approach include, but are not limited to:

> advanced, progressive or incurable diseases;

> general frailty; or

> chronic diseases.

EoLC is commonly provided across three settings including:

> community (home and residential aged care facilities);

> designated palliative care beds in hospices; and

> acute hospitals.

Throughout the course of their illness, some people will receive EoLC care in all three settings, whilst others may be seen in only one setting. The focus under the SACC Program is on providing community based EoLC services within a person's home or residential aged care facility (when part of a hospital avoidance strategy).

During the last year of life a person may be in a stable, unstable, deteriorating or terminal phase of their illness. The palliative care phase is one of the clinical assessment tools utilised by the National Palliative Care Outcomes Collaboration (PCOC) to measure and benchmark patient outcomes in palliative care. The phase a person is in determines the intensity, complexity, speed of response, skills and expertise required to provide care. As an example:

- A person in stable phase may initially require only simple community care services (**Community Care**).
- A person in the unstable phase may require a rapid response, but only a short term increase in level of care (**EoLC**).
- A person in the deteriorating phase may require steadily increasing services over time, and there is skill required of health professionals to anticipate needs and plan care accordingly (**EoLC or End of Life Care Terminal (EoLCT)**).
- A person in the terminal phase (last few days of life) may require higher level of services and supports, and the skill level of health professionals and the responsiveness of services are likely needed to increase (**EoLC or EoLCT**).

Further to the *Service Provider Obligations* detailed in the panel agreement, the following principles apply to the provision of EoLC:

- Service providers deliver EoLC and support on a 24 hour, 7 day a week basis.
- People who wish to die at home are able to access support from the SACC Program including EoLC and Terminal EoLC services, where there is no other suitable service immediately available to provide the required level and type of care.
- An individual's wishes expressed in an Advance Care Directives and/or Resuscitation Plan – 7 Step Pathway will be upheld by service providers.
- The development and review of a care plan (that then informs service delivery) is the responsibility of the Identified Care Coordinator (ICC).
- ICCs work collaboratively with SA Health staff, service providers, and general practitioners to ensure a person's care needs are met.
- Every effort is made to provide seamless care and services, for example:
    - minimal delays in resuming services after an ED presentation or admission
    - minimal changes to service provider staff where possible, and
    - minimal number of agencies involved.
- If the person is in stable phase or deteriorating phase and there are delays to care provision (e.g. My Aged Care), interim solutions through the SACC Program can be accessed until other supports can commence.

Overview of Services

EoLC services delivered under the SACC Program are described under two service types - **EoLC** and **EoLCT**. Refer to further information under `Service Types' for more detail on page 5 and 6.

EoLC and EoLCT service types are commonly commenced when a person's life limiting condition or illness has progressed to the point where their care requirements cannot be met entirely by other state or Commonwealth services. For example, a person may have been well supported in the community through Commonwealth aged care funded services during the stable phase, but now require additional or alternative care types to be delivered for a period of time by staff with EoLC qualifications or experience in the palliative approach.

EoLC services are provided through service allocations that meet the individual needs of the individual, their family and carer. A person may be in the unstable, deteriorating or terminal phase of their illness. Services are delivered by provider staff who have qualifications or expertise in the palliative approach to care.

Care and treatment options available include symptom management, medication support, patient/carer education and some minor procedures such as pleural drainage, wound management, equipment prescription and pressure injury management. More general services such as personal care may also be necessary on a short-term basis.

Eligibility

An individual is eligible for EoLC and EoLCT services if they:

- Are experiencing, or are likely to have imminent, functional decline associated with a diagnosed life limiting illness or condition, such that there is a risk of admission.
- Require a rapid service response (nursing, equipment, allied health) due to either:
    - the rapid deteriorating nature of their life limiting illness or condition (for example in unstable or deteriorating phase); and/or
    - to support timely discharge from hospital or hospice.
- Require services from staff who have qualifications or expertise in the palliative approach to care.

Specific clinical indicators include:

- Individual is in the unstable, deteriorating or terminal phase, and they are reasonably expected to be in the last year of their life.
- Individual has (or imminently will have) an Australia-modified Karnofsky Performance Scale (AKPS) score of 60 or less.
- Rug-ADL score of 16 or more.

The individual is also required to:

- Have a current care plan that has been developed by a health professional based on an assessment of the person, and their family and carer where applicable.
- Have an ICC (or the Metropolitan Referral Unit agrees to take on the ICC role on a temporary basis until one is identified).

Services under the SACC Program (including EoLC and EoLCT) are not intended to replace or duplicate services immediately available under other funding arrangements, eg, Commonwealth Home Support Program or Residential Aged Care. However, SACC services (including EoLC and EoLCT) can be accessed if eligibility for a Commonwealth service is yet to be determined, or there is a delay in commencement, or it is not able to meet the individual's care needs.

Access for individuals with Private Health Cover or Department of Veteran Affairs (DVA) Entitlements

Services under the SACC Program (including EoLC and EoLCT) are not intended to replace or duplicate services immediately available through the individual's health insurance or DVA entitlements.

Individuals with private health cover or DVA entitlements, who want to transition to public care services, must be registered with an SA Health Specialist Palliative Care (SPC) service. The SPC service state-wide referral form is available on the SA Health Palliative Care Services page.

If an individual is admitted to a private hospital, and are likely to need EoLC and EoLCT services in the community to enable early supported discharge, private providers should initiate the referral to SPC services as soon as possible to prevent delays in service commencement.

Referral

EoLC and EoLCT services are accessed by a health professional, on behalf of the person, by making a referral to the Metropolitan Referral Unit (MRU).

The referral should include:

- the care plan that has been developed by a health professional, based on an assessment of the person, and their family and carer;
- reference to how the person meets the eligibility criteria (as above)
- information on clinical indicators (as above); and
- the service requirements to meet person's individual care needs, and known preferences and wishes.

The MRU is open between 8.00am and 8.00pm, seven days a week including public holidays. A copy of the referral form is available on the SA Health Hospital Avoidance and Discharge Support Services webpage and should be faxed to the MRU.

Telephone: 1300 110 600

Fax: 1300 546 104

Email: Health.MetropolitanReferralUnit@health.sa.gov.au

Allocation of Services

The MRU is responsible for arranging the provision of services that best meets the needs of the individual, and their family and carer, after:

- Reviewing referrals, including the persons care plan.
- Identifying the services people may already be receiving via Commonwealth program or other supports.
- Considering what other services may meet the person's needs which could be accessed either by their ICC or the MRU.

The specific service supply instructions are issued by the MRU to the service provider(s) under a 'Referral Management Plan'. The service provider then actions these instructions in-line with the contractual arrangements, and SA Health policy and other requirements.

SA Health EoLC and EoLCT Services

EoLC and EoLCT services under the SACC Program are provided 7 days a week including public holidays, with the option for 24 hour support for individuals.

EoLC and EoLCT services are delivered by service provider staff who have qualifications and expertise in the palliative approach, including skills in assessing the persons, and their families and carers, current and anticipatory care needs. Wherever possible, these services will be delivered by the same staff to reduce the number of people entering a person's home, and promote continuity of care. In addition to these services, individuals can also access once off single nursing visits under the service type **Registered Nurse Palliative (RNP) – Single** for times where a person's condition or illness deteriorates rapidly, or they need further care as a top-up to their allocated EoLC service.

Service provider staff work in partnership with the persons ICC, Local Health Network Specialist Palliative Care team, general practitioners and other relevant health care professionals to ensure everyone is working from a care plan.

Service providers are responsible for matching the skills and experience of the visiting health professional (nurse or allied health) to the needs of the person, and their family and carers, outlined in the Referral Management Plan. It is expected that in the majority of cases a Registered Nurse or Allied Health professional will provide the care, however, some care may be provided under their supervision by delegates, for example, an enrolled nurse or care worker with the appropriate qualifications and/or training in the palliative approach to care.

Service Types

Allied health assessment and equipment prescription is in-line with arrangements under the general SACC Program.

End of Life Care (EoLC)

EoLC services allow for the provision of nursing care to an individual with a life-limiting illness or condition, and their family and carer, to assist them to remain at home. People accessing this service are commonly in the unstable or deteriorating phase of their illness or condition.

This service type offers tailored services that meet the needs of the individual, and their family and carer.

Care and treatment is provided as a visiting service into the person's home (including a residential aged care facility where part of an early discharge or a hospital avoidance strategy) over a 4 week period, up to a maximum of 16 hours. During this time, the service provider is required to regularly review the care plan and provide feedback to the ICC so that the care plan continues to meet the needs of the of the individual, and their family and carer.

The MRU will arrange additional services, as advised by the ICC, and in response to the person's ongoing care needs.

Care and treatment options available in this service type include:

- Assessment and management of symptoms related to illness
- Narcotic infusion pump
- Breakthrough pain medication including patient and family education
- Continence management and education
- Post-procedure monitoring e.g. ascites/pleural taps and pleural drains
- Care of Percutaneous Endoscopic Gastronomy (PEG)
- Delirium/terminal restlessness
- Advanced Care Planning discussions to inform ACD documentation
- ADL, hygiene and pressure area care.

Other community services such as personal care may also be necessary on a short-term basis if this is not being managed by a Commonwealth or other more appropriate service.

Service providers will be provided with a visit schedule from the MRU, however, there is some flexibility in the allocation of visits across the 4 week period (referred to as an EoL bundle of care) if the needs of the individual, and their family and carer(s) changes. For example, within the first week the person may only require 2 home visits, and in the next 3 weeks require 3 or 4 visits per week.

If an individual receiving EoLC services is admitted to hospital the MRU must be notified as soon as possible by the service provider, and the current episode of care is placed on hold. When the person is discharged from hospital and returns to their place of residence:

- the EoLC service allocation is re-activated by the MRU/service provider; and any unused hours of allocated care are to apply until the full 16 hours of service are utilised;
- the ICC is responsible for reviewing the care plan to ensure services still meet the current and anticipatory needs of the individual, and their family and carer and informing the MRU of any required changes to the care plan.

End of Life Care Terminal (EoLCT)

EoLCT services allow for the provision of more intensive nursing care to an individual in the terminal phase of their illness (last few days of life), to assist them to remain, and die, at home. People accessing this service are likely to already be receiving services via the EoLC service type, or other community based services.

Nursing care and treatment is provided as a visiting service into the person's home (including a residential aged care facility where part of an early discharge or a hospital avoidance strategy) for the last 7 days of life, and can include overnight or weekend care if required.

Care and treatment options available in this service type include:

> Narcotic infusion pump
> Breakthrough end of life medication management/pain medication
> Bowel care including management of obstructions
> Post-procedure monitoring e.g. ascites/pleural taps and pleural drains
> Care of Percutaneous Endoscopic Gastronomy (PEG)
> Delirium/terminal restlessness
> ADL hygiene and pressure area care
> Overnight RN/care worker

Registered Nurse Palliative (RNP) – Single

RNP - Single service type provides responsive care at times when a person's condition or illness deteriorates rapidly, or they need further care as a 'top-up' to their allocated EoLC service allocation in order to avoid a hospital admission, or during an unstable phase.

This service is purchased on an hourly basis in accordance with the needs of an individual, or their family and carer, and is provided as a visiting service in the person's home (including a residential aged care facility where part of a hospital avoidance strategy). It is expected that in the majority of cases this service will not need to be accessed if the individual is receiving an EoLC service.

Care and treatment options available in this service type include:

> Pain management and breakthrough end of life medication management/education
> Narcotic infusion and pumps
> Delirium/restlessness
> Symptom assessment and management
> Holistic palliative community nursing including ADL, pressure area support and education
> Wound management

- Continence bowel and bladder.

Service Provision

The provision of safe and quality EoLC within the community relies on a team based interdisciplinary approach and can include a range of different medical, nursing and allied health professionals depending on the care needs and wishes of the person, and their families and carers. Continuity and coordination between the team is promoted through effective communication, collaboration and teamwork, and is enhanced through the identification of a Care Coordinator. Quality EoLC also depends on regular assessment and review of the persons care plan by the ICC or other health professionals involved in the persons care to ensure it continues to meet the current and anticipatory care needs and wishes of the person.

When a person enters the terminal phase of their illness the care plan will generally focus on providing comfort and symptom control to the dying person and emotional and practical support to their family and carers. In line with National Palliative Care Standards, the care plan for a person's terminal care should include specific plans for managing physical, psychosocial, emotional, cultural or spiritual distress.

Advance Care Planning

To assist the ICC in developing a person's care plan, service providers with expertise and skills in advance care planning may also be required to facilitate advance care planning discussions with an individual, and their family and carer. A person may then choose to document their preferences and wishes in an Advance Care Directive, or Resuscitation Plan – 7 Step Pathway with their treating doctor.

If a person has refused specific care or treatment options in their Advance Care Directive, the service provider must follow the refusal(s) in the delivery of services.

Unlike Advance Care Directives, the Resuscitation Plan - 7 Step Pathway is not a legal document but an extension of the person's case notes. It can be used to document end-of-life clinical care plans, consistent with the persons preference and wishes contained in an Advance Care Directive/or expressed by the persons themselves in a conversation with their treating doctor.

The Service Provider is responsible for advising individuals, and their family and carers, to:

- keep a copy of their Resuscitation Plan – 7 Step Pathway and Advance Care Directive on the fridge, or where other important documents are stored, for access by SA Ambulance staff in case of an emergency; AND
- take a copy with them to hospital to support clinical decision making by SA Health clinical staff.

Changes to Care Plans

Service providers must deliver EoLC services in line with specific service supply instructions issued by the MRU under the Referral Management Plan, and with adherence to relevant policies and practices of SA Health.

If the service provider identifies that the Referral Management Plan needs to be altered (eg. the person requires additional support or a new piece of equipment), service provider staff should notify the ICC/MRU who is then responsible for reviewing the persons care needs, and if required, providing an amended care plan to the MRU.

Allied Health and Equipment

In home assessments can be provided to individuals who require EoLC and EoLCT services by allied health professionals to support the identification of current (and anticipatory) equipment and other home support needs, if the person is at risk of being admitted to hospital due to changes in their functional status or the level of carer support available, or to enable early supported discharge from hospital.

Any need for allied health assessment or equipment prescription should be identified in the Referral Management Plan by the individuals referring health professional, or through reviewing the persons care plan and notification to the Identified Care Coordinator.

The SACC Program 'Care Service List' sets out where Local Health Networks are responsible for consumables (e.g. medication consumables for Baxters Infusion Pump). Where this is not the case, service providers will provide a range of equipment as required.

Equipment prescribed for people accessing EoLC or EoLCT services will be available for the duration of the service, or as specified within the Referral Management Plan.

Every attempt should be made to avoid the need to swap like-for-like equipment, even if the funding source for the equipment changes.

In some cases, a person may no longer require nursing care under EoLC or EoLCT services, but still require the prescribed equipment to enable them remain at home. In this circumstance, the equipment should continue to be provided by the service provider and reviewed in-line with the persons care plan.

Medication Management

Pain and symptom management for people at the end of life is often managed by continuous subcutaneous medication, delivered via an infusion pump. When a patient is discharged home for EoLC there is often a requirement for a continuous subcutaneous infusion pump to be set up and managed. The preferred brand used by SA Health is the NIKI t34 Syringe Pump (NIKI Pump). The pumps provide a pre-programmed fixed continuous 24 hour delivery of medication.

Some SA Health hospitals send a pump home at discharge (if stock available), expecting change over that day and returned the next day by the service provider. Other hospitals require the service provider to drop off the pump at the hospital, and for it to be set up with the person prior to discharge.

Service providers providing EoLC and EoLCT under the SACC Program are expected to be able to provide NIKI Pumps to meet additional community care requests should a person's condition deteriorate at home, in order to avoid admission. These devices, and their management (including ongoing medical device cleaning, maintenance/compliance and consumables), are a requirement of service providers delivering EoLC and EoLCT services under the SACC Program.

Participation in Palliative Care Outcomes Collaboration (PCOC)

PCOC is a quality program utilising standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care. All service providers are required to participate in PCOC to improve practice and ensure they are meeting the National Palliative Care Standards.

More information about the program, including the standardised clinical assessment tools, is available on the PCOC website.

Service Role Delineation

Metropolitan Referral Unit (MRU)

The MRU provides a centralised single point of contact for referral to SACC Program services to support hospital avoidance and discharge support services for SA Health public hospitals.

The team of clinicians in the MRU review and assess referral information to coordinate the most appropriate service response. The delivery of services is then assigned to a service provider to deliver the in home care services to the individual.

Service Provider Staff

Service provider staff delivering EoLC and EoLCT services are responsible for delivering the services described in the individuals care plan and undertaking a clinical assessment using the Palliative Care Outcomes Collaboration assessment criteria at each visit to identify any changes in the persons current or anticipated care needs. These changes should be reported to the person's ICC who amends the care plan, and then informs the MRU.

Identified Care Coordinator (ICC)

In the context of the SACC Program, a care coordinator is someone who has been identified to undertake a coordination role on behalf of the person, family or carer, and facilitates the ongoing assessment and review of the care plan and communication with the MRU. Care coordination can be provided by a medical, nursing or allied health professional who is appropriately trained in the palliative approach, has knowledge of EoLC services and has regular contact with the patient, family and carer. The ICC may change, for example, in the early stages of a person's illness this may be a person's general practitioner, and then may transition to a SPC nurse in the terminal phase of care.

Specialist Palliative Care (SPC) Teams

Aligned to Local Health Networks, the SPC teams comprise specialist medical, nursing and allied health professionals who provide direct, but mainly consultative palliative care. EoLC services may be delivered under the guidance or direction of SPC team members (as part of the care plan). In this case, any changes in the person's clinical and/or functional status must be communicated back to the SPC team and ICC (if not part of the SPC team).

Paediatric Palliative Care

Under SACC, the provision of EoLC to children and adolescents is mostly delivered within **Community Care**. If a child or adolescent requires **EoLC** and/or **EoLCT**, the palliative care qualified nurse or allied health professional assigned to deliver the required service, must have paediatric experience.

It is acknowledged that any new providers may need lead-in time to upskill nursing and allied health staff in providing palliative care to children and adolescents. This education will be provided by the Women's and Children's Health Network.

SAAS extended care paramedics (ECPs)

SPC teams liaise with SAAS extended care paramedics in EoLC situations to provide care to people in their place of residence and reduce the need for hospital transfers.

SAAS ECPs have additional training that enables them to work collaboratively with other health care professionals to manage and treat people in their usual residence as much as possible. SAAS allocate an ECP to assess and treat a community member based on their clinical need as a result of having made a call to 000. It is particularly beneficial for people living independently or in residential aged care facilities.