



End-of-life care

Standardised care process

Objective

To promote an evidence-based approach to the care for older people living in a residential care setting during the actively dying stage.

Why the response to the actively dying stage is important

The last days and hours of a resident's life require an individualised approach so that a 'good death' is experienced. The care team must be able to recognise when the resident has entered the active period of dying (RNAO 2011).

The goals of end-of-life care are to:

- minimise distress and suffering for the dying resident, their family and carers
- provide comfort through the best pain and symptom control possible
- provide spiritual and emotional support
- provide culturally appropriate care
- provide information and support
- preserve dignity
- support choice and respect the resident's wishes.

Definitions

Note: Varied definitions of 'end of life' are used. In Victoria, Australia, the following definitions apply, with this standardised care process relating to the 'actively dying' phase of end of life.

Altered breathing patterns: as the person approaches death their pattern of breathing will often change; alterations in the breathing pattern may range from slow to rapid to irregular (eTG 2016).

Delirium: also known as agitation or terminal restlessness. A mental disturbance characterised by confusion disordered speech and hallucinations (RNAO 2011). The person may exhibit restlessness and seem unable to find a comfortable position. They may try to get out of bed, pluck at the sheets or the air, groan, or speak incoherently (eTG 2016). This is very common with a prevalence of up to 80% at the end of life in palliative care (CareSearch 2020).

Dying, actively dying or terminal phase: where death is imminent and likely to occur within hours or days or, occasionally, weeks (ACSQHC 2015; CareSearch 2020; eTG 2016).

Dyspnoea: a subjective symptom characterised by difficulty or laboured breathing, air hunger or shortness of breath (RNAO 2011). Up to 70% of people referred to palliative care experience dyspnoea (CareSearch 2020).

End of life: when death is expected to occur within the next 12 months. This includes people whose death is imminent and expected within hours or days (Australian Government 2018; Department of Health and Human Services Victoria 2016; RNAO 2020; Sax Institute 2017).

End-of-life care: the care delivered to people with progressive, incurable illness to live as well as possible until they die. It allows the supportive and palliative care needs of both the resident and their family/carer to be identified and met using the palliative approach to care for approximately the last 12 months of life (Australian Government 2018; Department of Health and Human Services Victoria 2016).



Palliative approach: an approach to treatment that improves the quality of life of residents facing life-limiting illness by preventing and relieving suffering. It involves early identification, and impeccable assessment and treatment of, pain and other problems including physical, psychosocial and spiritual problems (ASQHC 2015; Australian Government 2018; Department of Health and Human Services Victoria 2016).

Respiratory tract secretions: pooling of secretions in the throat which results in repetitive noisy breathing. Caused by the person's inability to cough effectively or to swallow in order to clear secretions from the oropharynx or trachea (eTG 2016).

Terminal restlessness: an agitated delirium that occurs in some people during the last few days of life (WA Cancer & Palliative Care Network 2011).

Team

Manager, registered nurses (RNs), enrolled nurses (ENs), personal care attendants (PCAs), leisure and lifestyle staff, general practitioner (GP), allied health professionals, residents and/or family/carers.

Acknowledgement

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Brief standardised care process

Recognition and assessment

- Recognise the common signs of the active phase of dying.
- Rule out deterioration due to reversible causes.
- Where there is an affirmative answer to the key prognostic question: *Would it be surprising if the resident were to die within the next few hours or days?*
- Conduct a comprehensive assessment to establish the resident's end-of-life plan of care.
- Document the assessment and its outcomes and communicate them to the care team.

Interventions

- Review and address the resident's advance care plan and/or the resident's goals of care.
- Maintain effective communication strategies with the resident, family/carer and care team.
- Cease unnecessary interventions.
- Review and rationalise medicines to promote optimal symptom control, and review routes of administration.
- Organise advance prescribing for common end-of-life phase symptoms.
- Manage common end-of-life symptoms.
- Address comfort care measures.
- Address emotional, spiritual, religious, cultural and self-care support needs.

Referral

- Specialist palliative care services
- Residential in-reach teams
- Pharmacist
- Pastoral care
- Religious ministers
- Bereavement counselling

Evaluation and reassessment

- Reassess the resident and their family/carers regularly to establish goals/outcomes of care and changes in care needs.
- Regularly monitor all medicines for efficacy and side effects.

Resident involvement

- Respect the advance care plan and/or goals of care as described by the resident and their family/carers.
- Invite the family/carers to be involved in practical care if they wish.

Staff knowledge and education

- Palliative approach
- Managing a family conference and meeting family/carer needs
- Common signs and symptoms at end of life
- Knowledge and skills in managing the common symptoms experienced at end of life
- Knowledge and skills in meeting emotional, spiritual/religious and cultural needs and managing existential distress
- Bereavement options for family/carer



Full standardised care process

Recognition

Recognise the common signs of the active phase of dying:

- rapid and irreversible day-to-day deterioration
- restlessness and agitation
- delirium that is not related to any other underlying cause
- progressive weakness
- changed or noisy breathing
- excessive secretions in the upper airway
- peripheral shutdown and cyanosis
- decreased level of consciousness or reduced cognition
- little interest in food and fluid
- difficulty swallowing
- progressive and irreversible weight loss
- decreased urinary output that is dark in colour
- difficulty waking the resident
- reduced function in communication, mobility, activities of daily living and social activity.

Assessment

Rule out deterioration due to reversible causes such as:

- dehydration
- infection
- delirium
- hypercalcaemia
- drug toxicity or withdrawal.

Ask the key prognostic question: *Would it be surprising if the resident were to die within the next few hours or days?*

Where the answer is 'no', contact the resident's GP and begin a comprehensive assessment to determine whether the resident is entering the last days of life as well as meeting the resident's and family/carer's end-of-life care needs.

Work in partnership with the resident, their family/carer and the care team to establish:

- required disease management
- the resident's physical, social and psychological needs
- cultural, faith and spiritual practices

- the resident's ability and wish to participate in shared decision making regarding their end-of-life care
 - comprehension of what is happening at the end of life
 - education, information and support needs
 - loss and grief support
- need for specialist palliative service input.

Assess the resident for signs of distress or discomfort. Where preferred, use validated symptom assessment and screening tools. These should include but not be limited to:

- Australian modified Karnofsky Performance Status scale
- Pain scales (for example, Abbey)
- Confusion Assessment Method (CAM).

Document the assessment and its outcomes.

Communicate the prognosis to the resident and their family/carer.

Communicate the assessment findings to the care team.

Interventions

All interventions should aim to provide comfort, symptom control and support for the resident and their family/carer.

- Check for an existing advance care plan.
- Reaffirm the existing goals of care.
- In the absence of an advance care plan or goals of care, give the resident and/or their family/carer an opportunity to establish preferences for care in the last days of life.
- Communication:
 - Clarify the resident's resuscitation status.
 - Hold a family/carer conference.
 - Hand over the care plan to the care team.
 - Ensure the end-of-life care plan and advance care plan or goals of care are accessible to the care team and other health professionals involved in the resident's care.
 - Reassure the dying resident and their family/carer and explain what to expect as the resident's condition deteriorates.



- Cease unnecessary observations and communicate this to the team. These may include:
 - blood glucose monitoring and blood tests
 - vital signs including blood pressure monitoring.
- Manage the resident's continence and pressure area needs in a manner that minimises distress or discomfort (this may result in reducing the frequency of interventions or the introduction of continence aids).

Review medicines to provide optimal symptom control.

- Review and rationalise medicines that have no therapeutic value in the dying stage or are not consistent with the goals of care.
- Review routes of administration:
 - Oral medicines may no longer be viable due to dysphagia, nausea or decreased level of consciousness.
 - Alternatives include transdermal, sublingual, rectal or parenteral routes.
 - The subcutaneous route is the preferred parenteral route because it is less invasive and has fewer risks of infection.
 - The use of a syringe driver will be determined by the need for 24-hour administration of a medication, the availability of appropriately qualified staff and access to specialist palliative care services.
- Prescribing in advance for common end-of-life phase symptoms that can develop quickly (pain, nausea and vomiting, terminal restlessness, dyspnoea and respiratory tract secretions) should be planned in partnership with the residential home, the GP, pharmacist, resident and family/carer.
 - Relevant medicines should be prescribed and readily available.
 - Ensure medicines are prescribed for the appropriate route.
 - Sufficient ranges of dose should be prescribed and made available to deal with a worsening of symptoms.
 - Review prescriptions as the resident's needs change.

Management of common end-of-life symptoms

Pain and discomfort (Note: pain or discomfort may be expressed as agitation)

- Pharmacological interventions:
 - Ensure a pre-emptive prescription of opioid analgesia is available.
 - Regularly assess for signs (verbal or non-verbal) of pain using a pain assessment tool.
 - Where required, provide continuous and breakthrough analgesia until the resident is comfortable.
 - Seek urgent specialist advice if the resident's pain is not controlled.
- Non-pharmacological interventions:
 - Reposition or provide an alternative mattress to minimise the resident's distress or discomfort.
 - Manage continence and address underlying causes such as urinary retention or constipation.

Nausea and vomiting

- Ensure a pre-emptive prescription of antiemetic is available.
- Regularly assess for signs and causes of nausea and vomiting.
- Where required, provide antiemetics until symptoms resolve.
- Seek urgent specialist advice if symptoms are not controlled.

Delirium/agitation

- Ensure pre-emptive prescriptions of a benzodiazepine and antipsychotic are available.
- Regularly assess for symptoms and possible underlying causes of agitation.
- Address reversible causes of agitation (for example, pain, delirium, emotional distress, urinary retention or faecal loading).
- Non-pharmacological interventions include:
 - a calm and quiet environment
 - familiar people in attendance
 - room lighting that is appropriate to the time of day
 - reassuring the resident's family/carer.



- If symptoms persist, initiate medication as prescribed.
- If there is no response to medication after 24 hours, add sedation.
- Seek urgent specialist advice if the resident's symptoms are not controlled.

Respiratory tract secretions

- Provide information and reassurance about the symptom.
- Pharmacological interventions:
 - Ensure a pre-emptive prescription of anticholinergic medication is available.
 - Initiate medication when the early signs of secretions appear. Continue until the symptoms resolve or review if there is no improvement within 12–24 hours.
- Regularly assess for signs of secretions.
- Determine the resident's and family's/carer's levels of distress resulting from the secretions.
- Non-pharmacological interventions include:
 - good mouth care
 - positioning the resident side to side with the head elevated a little to encourage drainage
 - maintaining the airway, decreasing the pooling of secretions and avoiding the use of suctioning
 - avoiding fluid overload
 - reassuring the family/carer
 - seeking urgent specialist advice if symptoms are not controlled.

Dyspnoea/altered breathing patterns

- Ensure pre-emptive prescriptions of opioid medication (for dyspnoea) and benzodiazepine (for anxiety) are available.
- Regularly assess for signs of changes in the resident's breathing.
- Determine the resident's and family's/carer's levels of distress resulting from the changed breathing. Provide information and reassurance about the symptom.
 - there is no evidence to support oxygen administration to the dying person.

- Non-pharmacological interventions include:
 - positioning
 - fan/airflow over the resident's face
 - ensuring a calm environment
 - reassurance.
- Pharmacological intervention:
 - Where required, provide opioid and/or benzodiazepine medication until symptoms resolve.

Acute end-of-life events (including haemorrhage, acute pain, unrelieved distress and acute respiratory distress)

- Ensure pre-emptive prescriptions of appropriate medicines are available.
- Regularly assess for signs of an acute event.
- Where required, provide medication until symptoms resolve.
- Seek specialist advice where required.

Comfort care measures and regular observations should include:

- general hygiene
- mouth and eye care
- skin and pressure area care
- comfortable positioning
- micturition
- bowel care
- nutrition and hydration as tolerated
- oral nutrition and hydration as tolerated – the benefits and risks of medically assisted (parenteral) nutrition and hydration should be considered before being commenced.

Address the emotional, spiritual, religious, cultural and self-care needs of the dying resident, their family/carer and staff.

Provide information on bereavement support for the family/carer and staff.



Referral

- Specialist palliative services
- Residential in-reach teams
- Pharmacist
- Pastoral care
- Religious ministers
- Bereavement counselling

Evaluation and reassessment

- Reassess the resident and their family/carer regularly to establish outcomes of care and changes in care needs.
- Regularly reassess all medicines for efficacy and side effects (at least daily).

Resident involvement

- Respect the resident's wishes as stated in the advance care plan where one exists and goals of care as described by the resident.
- Invite the family/carer to be involved in practical care if they wish.

Staff knowledge and education

- Palliative approach
- Managing a family/carer conference and meeting their needs
- Knowledge of and skills in recognising the common symptoms experienced at the end of life
- Knowledge and skills in meeting emotional, spiritual/religious and cultural needs and in managing existential distress
- Skills for communicating end-of-life issues
- Bereavement options for families/carers



Evidence base

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Important note: This standardised care process (SCP) is a general resource only and should not be relied upon as an exhaustive or determinative clinical decision-making tool. It is just one element of good clinical care decision making, which also takes into account resident/patient preferences and values. All decisions in relation to resident/patient care should be made by appropriately qualified personnel in each case. To the extent allowed by law, the Department of Health and the State of Victoria disclaim all liability for any loss or damage that arises from any use of this SCP.

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