

Palliative Care

Care Management Guidelines
Terminal Care

Terminal Care

Introduction

- The term 'terminal phase' or 'mode' refers to the hours or days immediately preceding death.
- Terminal care is active care with a focus on symptom management and dignity.

Key Principles

- The first step in the delivery of appropriate and timely terminal care is to recognise dying.
- Terminal care is based on an understanding that death is imminent and unavoidable, and that efforts to prolong life are no longer indicated.
- All patient care at this time relates directly to the patient's level of comfort.
- Whilst good care can nearly always make a favourable contribution to the patient's comfort and dignity, there are few perfect deaths, just as there are few perfect births. Death cannot be 'tamed' or defeated; it certainly cannot be 'controlled'.
- Where possible, the transition to terminal care should be pre-empted and done gradually so that all concerned can adapt. Planning for anticipated changes and possible emergencies is necessary. However, rapid changes in condition, or a reluctance to confront the realities of the situation, may not permit this.
- For family and friends this will be the last memory of the dying person, and their experience of this time may have a profound impact on their grief and bereavement.

Assessment

- Terminal care is deployed for patients who are assessed as having reached the terminal phase of their illness. A person may perceive themselves as being close to the end of their life, and clinicians should be open to such patient-initiated 'death talk', even if it does not quite fit with the clinical data.
- This clinical component of the assessment is sometimes referred to medically as 'diagnosing' dying. Diagnosing dying is a process. It does not usually require any new investigations.
- The process is not always clear-cut, as a patient's condition can oscillate, and prognostication is inherently problematic.
- It is therefore a matter of 'making a call', on the basis of objective and subjective evidence, intuition and experience.
- Good knowledge of the patient from family, carers, nursing staff and others may be just as reliable as a medical opinion when it comes to survival estimates.
- Sharing the uncertainties of the situation is important: dying is an unstable and deteriorating process.
- Despite every effort to get it right, a 'wrong' call, where a patient's prognosis may be longer than anticipated, and communicated, is rarely a problem if there is good communication, and such 'grief work' is rarely wasted for patients and families.
- The 'diagnosis' of dying is usually based on clinical evidence:
 - disease progression;

- body systems failure; and
- overt and covert patient behaviour, emotional and physical: e.g. withdrawal from the world, increasing drowsiness, and increasing weakness, more time in bed, eating and drinking decreasing, difficulty swallowing medications, talking about death and dying.

Key Prognostic Questions

- Is this deterioration likely to be due to a reversible condition whose investigation and treatment would not be excessively burdensome?
- Would it be surprising if the patient were to die within the few hours or days; or if in hospital, during or shortly after this admission?

(based on the approach of Murray et al [3])

Goals

- Clarify and confirm the patient's end of life wishes with the patient/family/caregivers.
- Provide the best possible pain and symptom control in the circumstances.
- Anticipate and prepare for eventualities - 'hope for the best but plan for the worst'. This may include anticipatory medication orders, crisis orders, etc.
- Appropriate social, spiritual, and emotional accompaniment of the dying patient and their family and/or friends.
- Provide timely information and support.

Management

- The role of the DHHS Palliative Care Services is to provide consultation, shared care or direct care depending on patient and family need, wishes and location of care.
- For inpatients it is strongly suggested that the inpatient **end of life care pathway** be activated (see [End of Life Care Pathway](#)).
- Observations, investigations, and interventions that are a routine part of life-maintaining care are no longer appropriate.
- Ongoing assessment of signs and symptoms of impending death.
- A syringe driver is a useful tool in medication delivery, but is not an automatic necessity. It is used to infuse specific drugs for specific symptoms, usually when using the oral route is no longer possible.
- Morphine and other opioids are indicated for the specific indications of relief of pain or shortness of breath only.
- Whether an inpatient or at home, good general nursing care is at the core of patient comfort and dignity at the end of life. Essential elements are:
 - regular attention to mouth care and general hygiene;
 - use of pressure relieving cushions and mattresses to prevent skin breakdown, regular, regimented change in position may not be appropriate in the last hours or days if the patient is comfortable; and
 - managing bowel and bladder care to prevent constipation and urinary retention.

Provision of Nutrition and Hydration

- Decrease and eventual cessation of oral intake is a normal part of the dying process.

- The medical provision of hydration and nutrition (via PEG, naso-gastric or IV routes) is not indicated during the final phases of the dying process.
- Food and drink are always made available to conscious patients if they would like it.
- Very occasionally the provision of subcutaneous fluids (hypodermoclysis) may be tried for severe symptomatic thirst in conscious patients.
- Oral comfort is maintained by regular mouth care. Families and carers can assist with this.

Principles of Medication Management in Terminal Care

- Review medications with a view to rationalisation: assess which medications need to be continued for symptomatic relief, and which have the primary function of preventing long term complications of disease and can be ceased e.g. antihypertensives, hypoglycaemias, or anticoagulants.
- Ensure the patient and/or family understand the reasoning behind the changes.
- Anticipate the need to change the delivery route of medications as the patient develops difficulties with swallowing.
- Anticipate parenteral medications that may be needed rapidly or urgently. Ensure that written orders for these are in place and the medication is available.
- Opioid dose escalation when pain is not an issue is not indicated in dying patients. Opioids and their metabolites may cause agitation and promote pain, hyperalgesia and allodynia.
- Where renal function is deteriorating, reduce the dose of renally eliminated medications or find alternatives.

Note: *It is never appropriate to simply sedate a patient with severe pain or dyspnoea as sedation does nothing to relieve the causal symptom(s).*

Family Needs

- Families require:
 - information about community supports available to them, including GP availability and 24 hour support;
 - information about, and interpretation of, the patients condition to enable them to understand the dying process;
 - instruction in carrying out the daily tasks of caregiving;
 - support to help them manage the physical and emotional demands they will experience;
 - validation of their contribution to the patient's comfort;
 - recognition of the need for respite, including overnight care;
 - clear instructions to follow for:
 - possible emergencies;
 - identifying when the patient has died; and
 - what to do when the patient dies.
 - opportunities for follow up to discuss the death and any unresolved questions.

Symptom Management

Restlessness

Some degree of agitation, moaning, jerking, or twitching are all common during the dying process, and this can be very variable. It is sometimes difficult to differentiate between a

potentially reversible or self limiting agitated delirium and the onset of terminal restlessness.

Consider potentially reversible causes:

- urinary retention and/or constipation;
- physical discomfort: too hot, too cold, uncomfortable position;
- environment: noisy, too bright, too dark;
- emotional or spiritual distress;
- accumulation of renally eliminated drugs e.g. morphine and metabolites;
- cumulative anticholinergic load:
 - anticholinergics;
 - tricyclic antidepressants; or
 - others – digoxin, alprazolam, ranitidine.
- withdrawal: drugs, nicotine.

Management – Non pharmacological

- Physical comfort;
- Quiet unchanging environment; low light to assist with orientation;
- Familiar company;
- Music/music therapy; and
- If the patient is a danger to themselves or others, sedating medication may be needed (see below).

Management - pharmacological

For conscious patients with disturbance of thought content try:

- Haloperidol 0.5 - 2.5mg orally, up to 6 hrly.
- Haloperidol 0.5 - 1mg SC three times a day, or 2.5 - 5mg / 24 hours by continuous subcutaneous infusion (CSCI).

Where sedation is a desired or necessary outcome (also where muscle relaxation is needed) try:

- Midazolam 2.5 - 5 mg sc prn, 15 - 30 mg/24hour by CSCI.
- or
- Clonazepam 0.2mg sublingually SL (drops) or S/C prn or 1 - 5mg / 24 hours by regular SL drops or S/C injection 8 – 12 hrly

In resistant cases:

- Phenobarbitone may be tried 200mg sc stat, and 600 - 1200 mg / 24 hr CSCI

Seek specialist advice ([Delirium Care Management Guidelines](#) and the [Adult Palliative Care Formulary](#)).

Secretions

- Noisy laboured breathing is common during the dying process. It is usually due to pooling of secretions in the pharynx and is similar to a snore.
- Pooled oral secretions are due to the loss of swallowing reflex, congestion due to weak respiratory muscles, and the loss of the cough reflex.
- Secretions are best managed with good mouth care, and by positioning the patient side to side with the head elevated a little to encourage drainage, maintain the airway and decrease the pooling of secretions. Pharyngeal suction is usually

contraindicated. Medication is not usually effective once noisy gurgling ('death rattle') is established.

- Explain to the family that:
 - the secretions are not usually bothersome to the patient;
 - the secretions are not usually accessible to suctioning;
 - deep suctioning is a physically distressing procedure;
 - medications to dry secretions may dry everything including the mouth and eyes, and contribute to patient discomfort; and
 - back ground music etc. will distract from the noise.
- Try anti-cholinergic:
 - Hyoscine hydrobromide 0.4mg 4/24 sc prn or 0.8 - 2.0mg/day CSCI (beware of potential anticholinergic CNS effects);
 - Atropine 0.6 - 1.2 mg 4 - 6/24 sc prn (beware of potential anticholinergic CNS effects); or
 - Glycopyrronium bromide (Glycopyrrolate) 0.4 - 0.8 mg sc prn or 0.8 - 2.0mg / 24hrs CSCI.

Note: not PBS funded; good choice for conscious patients where secretions are an issue. (see Consultation and Advice below)

- Hyoscine butylbromide 20mg 4/24 sc or 80 - 120mg / 24hrs CSCI

[Adult Palliative Care Formulary](#)

If the patient is distressed and struggling, sedation will usually be required. Refer to restlessness above.

Note: Noisy tachypnoea can only be managed by reducing the respiratory rate to normal through the titration of opioids and sedative medications.

Pain

- Physical discomfort should not be accepted as inevitable and part of the dying process. Weakness and inactivity bring their own discomfort, joints often become stiff and sore and skin is less resilient with pressure.
- If verbal pain reporting is still possible, be guided by the patient's reports.
- If the patient is not able to talk to you or is not coherent, observe 'antalgic' behaviour, especially on movement: signs of physical discomfort such as grimacing, frowning, vocalising and stiffening on movement.
- Base management on these observations, and on response to analgesic administration.
- Titrate opioid according to breakthrough requirements. Observe response.
- If no response, then try adding ketorolac or low dose ketamine [Pain Management – Care Management Guidelines](#).
- Avoid steroids due to central effects – sleep disturbance, agitation and psychiatric effects.
- Some oral drugs such as NSAID's and paracetamol may have to be stopped or given by another route.

Consultation and Advice

Seek advice when:

- There is unrelieved distress and terminal restlessness. If symptoms are not responsive to recognised management this should be considered a palliative emergency and specialist advice sought.
- For conscious patients where secretions are an issue and for access to glycopyrolate.
- When there is significant family, caregivers or staff distress.

Revision history and planned frequency

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