

GUIDELINES FOR CARE OF THE DYING PATIENT

Staff this document applies to:

All Clinical Staff of Austin Health

State any related Austin Health policies, procedures or guidelines:

[Family Meeting Guidelines – Cancer Services](#)

[Palliative Care Consultancy Service: Referral Guidelines](#)

[Palliative Care Unit: Admission Guidelines for Health Professionals](#)

[Medical Oncology Manual](#)

[Syringe Driver NIKI T34: Subcutaneous Medication Administration](#)

[Life Prolonging Treatment: A Guide to Life Prolonging Treatment and Limitation of Treatment](#)

[Advance Care Planning Policy](#)

[Management of Nausea and Vomiting in Palliative Care Patients](#)

Management of Terminal Delirium (Restlessness)

[Management of Terminal Respiratory Secretions in Palliative Care Patients](#)

[Catastrophic Terminal Events](#)

[Pressure Injury Prevention and Management](#)

[Mouth Care for Oncology/Haematology Patients](#)

[Care of the Deceased](#)

[Religious Guidelines for the Care of the Dying](#)

Purpose:

This guideline is to assist clinical staff to provide optimal end of life care to patients within Austin Health.

Diagnosing Dying:

(Decisions regarding life-prolonging treatment would, ideally, be in place prior to implementing end of life care. This however may not always be possible. [The Life Prolonging Treatment guide](#) should be consulted in conjunction with these guidelines.)

Making a diagnosis that the patient is dying can be a complex process. In the hospital setting where the treatment emphasis is generally “cure” orientated, potentially futile investigations and treatments may continue at the expense of patient comfort if the diagnosis of dying is not made.

In cancer patients, in addition to objective measures of disease progression such as investigations/imaging, the following criteria generally support the diagnosis of dying:

- A progressive deterioration in the responsiveness of the patient (e.g. their ability to respond to surroundings, decreased energy levels, becoming semi-comatose)
- Reduced ability to swallow (e.g. able to only take sips of fluid, unable to take oral medication)

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- Deteriorating physical function (e.g. the patient has become bed-bound).

In other chronic incurable diseases predictability of the dying phase is not always as clear. A range of factors will need to be considered including:

- Diagnosis of a life-threatening illness.
- No further curative treatment options.
- Cause of deterioration (infection, hypercalcaemia etc.), although in some circumstances investigating for and/or intervening in these factors will not be consistent or appropriate with the patient's wishes, prognosis or goals of care.

An important factor is that the members of the multi-professional team caring for the patient identify and agree that the patient is dying. Disagreement within the multi-disciplinary team leads to anxiety, confused goals of care and subsequent poor patient management and confused communication with the family.

The advantages of diagnosing dying are also important. As well as directing the emphasis of care to become comfort based and ceasing unnecessary interventions, improving the awareness of dying can enhance communication for the patient and family, enable discussion about place of care and assist the patient with their final wishes.

Communication with patient and family:

Frequent discussions with the patient and family are essential at this time. This should include:

- Discussions with the patient (if possible) and/or family to determine the patient's wishes, and nomination of a spokesperson (Medical Enduring Power of Attorney if in place).
- Establishing if an advance directive or advanced care plan has been completed.
- Completing the hospital Resuscitation Plan (LR0.5 or "green form")
- Discussing the rationale for change from acute to palliative management.
- Explanation of the palliative approach to care and defining the goals of care.
- Review of current treatment/medications – what shall be ceased, continued, commenced.
- Description of types of active symptom control that may be needed, in addition to medication changes.
- Describing, if appropriate (and possible), how the dying process is likely to progress
- Exploration of the patient and family's cultural and psychological needs. There are often cultural barriers to discussing death, which should be sensitively acknowledged and addressed. It should be remembered that patients' interests are of primary consideration in these discussions.
- Consideration for appropriate referral to the Palliative Care Consultancy Service, Social Work and Pastoral Care.

A family meeting may be the best way to approach this delivery of complex information.

Please refer to [Family Meeting Guidelines – Cancer Services](#) for further information and guidance.

Review of Care Plans and Treatments:

When the patient is regarded to be in the last days or hours of life a change in the focus of treatment is usually required. The emphasis will change from that of patient survival to focusing on patient comfort. The provision of adequate analgesia and effective symptom management is imperative.

Points for consideration include:

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- Resuscitation Plan (L0.5) should be completed and management plan clearly outlined.
- Review and rationalise medications. Only those with a symptomatic benefit should be continued.
- Review the need for other interventions which do not directly benefit the patient and discontinue as appropriate, i.e.
 - Blood tests
 - Blood glucose monitoring
 - IV fluids and antibiotics
 - Artificial feeds
 - Blood and blood product transfusions
 - Implantable cardioverter (deactivation of defibrillator)
 - Weaning of mechanical ventilation and/or extubation

Symptom Management:

It is important to regularly assess patients to achieve good symptom control, and alert staff and family members to the fluctuating nature of the dying process. Symptoms associated with dying may fluctuate through the day, hour or even within minutes. The most common symptoms in the terminal phase include:

- Pain
- Nausea/vomiting
- Agitation
- Respiratory tract secretions
- Dyspnoea
- Dry mouth

The cause of symptoms should be considered, and investigated as appropriate given the goals of care. For example, urinary retention should always be considered as a cause of agitation even when very close to death, but performing a chest x-ray for dyspnoea is unlikely to be appropriate in the terminal phase.

Suggested PRN Medications

It is important to ensure there are adequate and appropriate PRN medications for symptom control during the terminal phase. As terminal symptoms can be variable and unpredictable it is usually inappropriate to restrict use to a specific time frame; instead, limitations should be based on pharmacological onset of action, with review if ineffective. The Care of the dying meds Careset on Cerner may be used in assisting prescription.

The following table outlines recommended PRN medications for the management of potential symptoms associated with dying in an opioid and benzodiazepine naïve patient. These choices may vary depending on previous usage, age and renal function, and should be **titrated to effect**. For further advice contact the Palliative Care Consultancy Service, ext 9947. Also, individual policies regarding symptoms provide further guidance.

Symptom	Medication	Starting dose	Route	Frequency	Max dose/24hrs
Pain	Morphine	2.5-5mg	Subcut	1 hourly prn	Seek help if high doses
Nausea	Metoclopramide	10mg	Subcut	qid prn	80mg
	OR Haloperidol	0.5-1mg	Subcut	tds prn	10mg
Agitation	Haloperidol	0.5-1mg	Subcut	qid prn	10mg
	AND/OR Midazolam	2.5mg (consider 1mg if elderly)	Subcut	1 hourly prn	Seek help if high doses
Secretions	Hyoscine butylbromide	20mg	Subcut	4 hourly prn	2.4mg
	OR Glycopyrrolate	0.2-0.4mg	Subcut	4 hourly prn	1.2mg
Dyspnoea	Morphine	2.5mg	Subcut	1 hourly prn	Seek help if high doses
	AND/OR Midazolam	1mg	Subcut	1 hourly prn	Seek help if high doses

Subcut = subcutaneous

Use of syringe driver

Not every dying patient requires a syringe driver (a continuous subcutaneous infusion or CSCI) to achieve optimal comfort. A syringe driver may be indicated if a patient is unable to swallow oral medications and has symptoms that require frequent or continuous treatment, or if there is a problem with the absorption of oral medications.

Regular oral opioid analgesia will require appropriate conversion to a parenteral form. The [Eastern Metropolitan Palliative Care Consortium: Guide to Practice](#) is invaluable in assisting with this process.

In brief, a patient's background opioid dose should be converted into a parenteral form and dose, with an adequate PRN dose also prescribed. As a general guide, a PRN dose should be kept in proportion to the background, usually between a tenth and a sixth, e.g. if a patient is receiving 60mg of morphine subcutaneously over 24 hours then you would expect them to need about 10mg as a PRN dose. This should be prescribed hourly, given the pharmacokinetics of morphine.

Syringe driver doses should be titrated daily to take into account previous PRN dose requirements and thus ensure continuous comfort.

Hydration and Nutrition:

Loss of interest in food and drink is part of the normal dying process, as is difficulty swallowing. A dry mouth should be managed with frequent mouth care, including ice chips, mouth swabs, lip balm and oral gels such as Biotene or Oral Balance. Relatives who are concerned that a patient is suffering from dehydration or starvation should be reassured that food, drink and assistance with eating and drinking will be available for as long as a patient desires, but that artificial provision may be more burden than benefit. It has been shown that parenteral hydration at a rate of 1L per 24 hours does not impact on symptoms or mortality when compared with placebo. Higher rates than this may be associated with detrimental effects such as symptomatic pulmonary or peripheral oedema.

Burdens of Nutrition Support

As performance status reduces so do energy requirements, and people do not usually experience hunger in the dying phase. Evidence suggests that providing nutritional support can contribute to increased suffering in patients at the end of life, due to increased nausea, vomiting, bleeding, oedema, incontinence (bladder and bowel), or infections.

Management of Respiratory Distress:

Noisy breathing as a result of secretions moving with each breath can be of great concern for relatives. They should be reassured that in the terminal phase this is rarely distressing for the patient. See [Management of Terminal Respiratory Secretions in Palliative Care Patients](#) for more information and guidance.

Skin Care:

See the related guideline [Pressure Injury Prevention and Management](#).

Important points for consideration when performing wound management on a dying patient:

- Is the procedure uncomfortable or the wound painful? – ensure analgesia given prior, and minimise the frequency of dressing changes as much as possible.
- Is the wound odorous? – consider topical metronidazole gel, as well as environmental eg open window, bicarbonate soda in bowl.
- Is there a potential for bleeding at the wound site? – consider dressing products, topical tranexamic acid.

Psychosocial and Spiritual Consideration

A timely referral to social work and pastoral care should be considered for the dying patient, as the dying process is often accompanied by feelings such as helplessness and hopelessness, guilt and distress. It is important for social work and pastoral care to undertake a psychosocial and spiritual assessment to offer support and counselling, and identify any unmet needs. Additionally, appropriate support for family and friends has an important impact on the positive or negative experience of the death of a loved one.

It is also important to identify where the patient would like to die, and, should the patient wish to return home, to establish with the family whether this is feasible.

Music therapy and art therapy may also be very helpful at this time. Children especially may best express their emotions using art.

For some patients with religious beliefs it is important to facilitate plans for appropriate end of life rituals to be performed.

Bereavement support should be offered; this may be facilitated by the community palliative care service if the patient was known to them, or referral can be made to the [Australian Centre for Grief and Bereavement](#) (1300 664 786).

Place of Care:

Initial discussions with the patient and family should include considering the preferred place of care. Options include:

Waitlisting for Palliative Care Unit (PCU) – if patient has specialist palliative care needs, and transfer is appropriate.

Remaining on Ward – If there is no available PCU bed and death is anticipated in coming days, a single room should be arranged if possible.

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Return to Residential Care – Many High Level Care facilities provide end of life care. Contact the Residential Aged Care Liaison Nurse (pager 3043), Palliative Care CNC (pages 2150, 4355 or 6102), or facility directly, as well as GP to discuss. Discharge with clear end of life care plan and required medications.

Discharge home – Many people hope to die at home. If family wish to take a patient home for end of life care, the Palliative Care CNC should be contacted as soon as possible to assess whether this is feasible and to coordinate community supports.

Whilst patient remains on the ward the available facilities should be outlined to relatives and carers. These include toilet facilities, car parking, rest areas and the potential for staying overnight.

Care after Death:

Caring for the patient after death, and their family, is part of the overall continuum of care. Dignity and respect for the deceased should be maintained. Sensitivity to the cultural and religious beliefs (or lack thereof) is imperative. Personal preferences and cultural practices should be respected.

The [Religious Guidelines for Care of the Dying](#) is a resource to be used, in consultation with the family, to ensure that their particular cultural and /or religious beliefs are respected.

The [Guidelines for Care of the Deceased](#) may be referred to for individual practices prior to a body being transferred to Anatomical Pathology (Austin Campus), the Mortuary (Heidelberg Repatriation), or for a funeral director to collect from Royal Talbot.

Communication Strategy:

All Austin Health Staff - Forward emails to all of the below.

Medical Documents

Email to DL Medical Education All
Email to DL CSU Medical Directors

Nursing Documents

Email to DL CNE
Email to DL Nursing Group

Allied Health Documents

Email DL Allied Health Austin 5

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Legislation/References/Supporting Documents:

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The palliative care service at Austin Health participates in the Department of Human Services Primary Care Partnerships initiative.

Further references are available from the Palliative Care Service.

Authorised/Endorsed by:

Cancer Services Medical Group

Nursing Standards Committee

Drug and Therapeutics Committee

Clinical Policies and Procedures Committee

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