

Care Management Guidelines
Clinical Decision Making at
End of Life

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Introduction

- This guideline is intended to help health practitioners plan a patient's care in a way that is consistent with the realities of their situation and, as far as possible, meet their needs and wishes.
- Where cure is no longer realistic, the aim is to achieve the best death and dying process possible in the circumstances.
- Care should be based on viewing the patient's needs in the context of the whole person rather than a series of (medically defined) parts. Due acknowledgement of the patient's key relationships (family and friends) and social context is also important.
- Clarity around goals of care is essential to assist medical decision making, to inform multidisciplinary care planning, and for patients and families to be able to set their priorities. These are some of the attributes of a 'good death' from a qualitative study in the United States (Steinhauser et al. 2000).
- Patients and families:
 - Fear a bad death more than death itself.
 - Value:
 - pain and symptom management;
 - clear decision-making;
 - preparation for death;
 - completion; and
 - affirmation of the whole person.
 - Place a high priority on:
 - making contributions such as gifts, time and money (meaning/role/usefulness); and
 - decreasing family burden, planning ahead, arranging affairs, and saying good bye.
- Despite widespread anxiety about doing 'death-talk' with people, if done appropriately, it is usually helpful for the patient (Clayton et al. 2007). There is now evidence to suggest that it also assists in the grieving process (Maciejewski et al. 2007).
- The purpose of assessing the goals of care is to enable these priorities to be addressed. If treatment aimed at cure is being deployed there is little or no chance of this being achieved.

Key Ethical Messages

- Dying is a natural part of living, and death is an inevitable consequence of having life. No amount of medical progress can change this fact.
- Treatment abatement in the setting of a terminal illness is appropriate and necessary. Nothing in the law of ethics requires practitioners to treat dying people as if they are curable.
- By working in harmony with the realities of the situation medicine can improve the journey considerably, but failure to recognise the dying process can make it worse, and prevent the timely deployment of appropriate palliative care.
- Dementia is considered to be a progressively fatal process and requires a palliative approach to care, especially in its advanced stages.
- The best possible pain and symptom relief in the clinical circumstances is both a patient's right and a clinician's duty.
- Appropriately negotiated treatment abatement and symptom relief do not constitute causing death.

- Medical provision of hydration and nutrition is medical treatment like any other and is not required by law if it is not medically indicated. It does require patient consent.
- Cardiopulmonary resuscitation is usually not indicated in a terminal illness.
- Sedation in the terminal phase is used to treat agitation and distress, especially signs of an agitated delirium in the context of the dying process, otherwise known as 'terminal restlessness'.
- The Ontario coroner (Dr James Young, 1997) has set out four conditions which need to be satisfied for palliative care interventions to be legal in his jurisdiction, and summarise well the ethical and legal basis of palliative care:
 - the care must be intended solely to relieve suffering;
 - it must be administered in response to suffering or signs of suffering;
 - it must [be] commensurate with that suffering; and
 - it cannot be a deliberate infliction of death. Documentation is required, and the doses must increase progressively.

Assessment

Key questions to be addressed by health practitioners when establishing goals of care or when there is to be a transition in the goals of care (Ashby et al 2005):

- Are the clinical facts of the case well established? Is the diagnosis correct?
- Has sufficient time elapsed to be reasonably confident that there is no reasonable prospect of substantial improvement or recovery?
- Is there consensus amongst the clinicians about the diagnosis, prognosis and most appropriate course of medical action? Is a case conference necessary?
- Has the patient, or (if lacks capacity) the patient's family, carer(s) or legally appointed agent been advised of the above? Have they had a chance to express their opinions?
- Has the patient's general practitioner been involved?

Patient Autonomy and Consent

Patient consent is required before treatment may be started or stopped.

- Where a patient lacks the capacity to make their own decisions about a medical treatment, a person responsible will need to act on their behalf. The Guardianship and Administration board in Tasmania sets out a hierarchy of persons who can perform this role:
 - For a child (under 18 years) the person responsible will be the child's parent or, if they are married, their spouse.
 - A person responsible for an adult (18 years or over) will be a guardian; this includes an Enduring Guardian who has the power to make decisions about health care.
 - If there is no guardian, his or her spouse (this includes de facto spouses and same sex spouses); or
 - If there is no spouse an unpaid carer who is now providing support to the person or provided this support before the person entered residential care; or
 - If there is no carer a close relative or friend of the person, who has a close personal relationship with the other person through frequent personal contact and who has a personal interest in the other person's welfare.
- Neither patients nor persons responsible can insist on treatment that is futile and therefore medically contraindicated in the circumstances, nor can they insist on actions that are illegal or contrary to professional ethics.

Management

Palliative Phase: See Symptom Management Guidelines

Terminal Phase: See [Terminal Care Guidelines](#)

Setting Goals of Care

- It is difficult to predict accurately when a person will die. Medical prognostication studies show wide discrepancies between what doctors predict and actual survival of patients (Glare and Sinclair 2008).
- Murray has suggested that medicine suffers from ‘prognostic paralysis’ and, particularly in the primary care setting, needs to ask questions like “would I be surprised if the patient were to die in the next year?”, and reframe its responses accordingly (Murray et al. 2005).
- Although hard and fast objective clinical criteria for the onset of the terminal phase are not available, the recognition of a natural dying process is central to the ethics and practice of palliative care. It is about ‘making a call’, that is weighing up all the available observations and coming up with a plan of action.
- Impending death, when a person is said to be ‘dying’ or ‘actively dying’, is recognised by a combination of clinical and behavioural features, although they may all go unnoticed or be denied.
- The objective clinical evidence consists of declining appetite, weight loss, recumbency, lassitude, physiological systems failure, disease progression, vital organ failure. There is also an associated decrease in oral intake that usually ceases altogether as the patient’s conscious state lapses.
- In cancer, tumour-related factors are more predictive in early disease. In later stages performance status, nutritional status, key symptoms like dyspnoea and confusion, and certain biological parameters such as serum albumen, white cell count may be more significant (Glare and Sinclair 2008).
- Although very variable and personal, the overt or covert psychological evidence may consist of anticipatory grief, emotional withdrawal, and future planning which acknowledges the impending death, e.g. funeral planning, by either the patient who is dying and/or family members.

Curative or Restorative Care Phase (‘beating it’)

- *Aim:* In the curative/restorative phase all efforts are directed towards cure or prolonged remission with restoration of health status and function.
- *Prognosis:* Indefinite, normal life expectancy possible.
- *Level of adverse effects:* A high level of adverse effects and even a significant chance of treatment-related mortality may be accepted for curative treatment (e.g.: brain aneurysm surgery, bone marrow transplant). Whilst pain and symptom control should always be addressed, comfort may be a secondary consideration if it conflicts with curative treatment.
- *Life-sustaining treatments:* All given as needed.
- *Medical provision of hydration and alimentation:* Yes
- *Cardio-pulmonary resuscitation:* Yes.

Palliative Care Phase (‘living with disease, anticipating death’)

- *Aim:* In the palliative phase the disease is deemed to be incurable and progressive, and the goals of care are modified in favour of comfort, quality of life and dignity. Length of survival is no longer the sole determinant of treatment choice and life-prolongation is advised to be a secondary objective of medical treatment.

Note: There is a subset of patients who survive long term with metastatic disease, and whilst their disease is responding to treatment, their needs are better described as SUPPORTIVE rather than palliative care.

- *Prognosis:* Months, sometimes years.
- *Level of adverse effects:* Active treatment of the underlying disease may be undertaken for specific symptoms (e.g. radiotherapy or chemotherapy for palliative endpoint). All treatment-related adverse effects should be proportionate to the goals.
- *Life-sustaining treatments:* For other chronic medical conditions are usually continued (e.g. insulin, anticonvulsants) where cessation would result in premature death, unrelated to the main disease that is anticipated to result in death, or where quality of life would be adversely affected (Abernethy & Currow).
- *Medical provision of hydration and alimentation:* Given if indicated and desired. (e.g.: PEG feeding for head and neck cancer patients with obstructed swallowing).
- *Cardio-pulmonary resuscitation (CPR):* Is usually not recommended, but this should be discussed with the patient, if competent. If death and dying have already been explicitly discussed with the patient or person responsible, it may be concluded in some situations, that specific discussion of CPR is not warranted.

Terminal Care Phase ('dying very soon')

- *Aim:* In the terminal phase, death is believed to be imminent. Comfort, quality of life and dignity are now the only considerations.
- *Prognosis:* Hours or days.
- *Level of adverse effects:* Active treatment of the underlying disease stopped. No treatment-related toxicity is acceptable, this applies to all medical, nursing and allied health interventions.
- *Life-sustaining treatments:* For other chronic medical conditions are usually stopped (e.g. steroids, insulin, anticonvulsants), unless doing so would cause suffering.
- *Medical provision of hydration and alimentation:* Usually ceased and replaced with nourishment on request and rigorous mouth care.
- *Cardio-pulmonary resuscitation:* Is not recommended and a not for resuscitation order is negotiated.
- *Consider:* Implementation of the [Inpatient Integrated End of Life Care Pathway](#) if the patient is in hospital or residential aged care facility.

Advance Care Planning

Advance Directives

- End-of-life decision-making in Tasmania is assisted by the Department of Health and Human Services guidelines, released in 1998¹, and Guardianship Legislation passed in 1995².
- The guidelines include a section on Advance Care Directives (ACD's) (section e, page 4).
- The Guardianship and Administration Act 1995 makes provision for competent adult persons to appoint guardian(s) to act for them when they lack the capacity to do so for themselves, and this guardian is empowered to make medical decisions.³
- Common Law and professional ethics codes also apply.
- As part of a national program of research and evaluation under the auspices of the National Palliative Care Program⁴, the [Respecting Patient Choices](#) (RPC)⁵ pilot project at the Royal

¹ Dying with Dignity: Guidelines on the Care and Management of People who are Dying, 1998. DC&HS, Tasmania.

² Guardianship and Administration Act 1995.

³ http://www.publicguardian.tas.gov.au/enduring_guardianship, accessed 24/2/08.

Hobart Hospital (RHH) has been successfully undertaken⁶. There is an amended official guardianship form that includes the RPC 'Statement of Wishes'.

- A legal avenue for ACD's therefore exists, and is in use, both within the context of the RPC project, and outside it.

Note: Advance care directives have been embraced by general practice and information is available on the Tasmanian Divisions website via GP South.

'Goal of care' is a clinical term that categorises the aims of treatment in terms of what a realistic outcome might be for a particular patient at this stage of their illness trajectory.

The approach to decision-making at the end of life recommended here is to assign the patient's situation to one of three care phases. These phases are: curative/restorative, palliative or terminal (Ashby and Stoffell 1991). Patients move from one category to another during their illness trajectory. For some patients cure is never an option, and others only present in the terminal phase of care.

Consultation and Advice

Seek advice:

- Where there is difficulty in determining the goals of care;
- Where there is family disagreement about treatment issues when the patient lacks capacity; or
- Professional concerns about ethical or legal aspects of treatment abatement decisions.

Revision history and planned frequency

Endorsed September 2009

Next review September 2010

⁴ <http://www.health.gov.au/palliativecare>, accessed 24/2/08.

⁵ <http://www.respectingpatientchoices.org.au/>, accessed 24/2/08.

⁶ Royal Hobart Hospital Respecting Patient Choices Pilot Project. Final Report, March 2007. Prepared by Jenny Mason-Cox.

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Goals of Care			
	Curative/Restorative 'beating it'	Palliative 'living with disease, anticipating death, but not now'	Terminal 'dying very soon'
Situation	Cure or a durable remission realistic.	Disease incurable and progressive.	Acceleration of disease processes; body systems failing; death imminent.
Evidence	Reasonable chance of cure on clinical assessment and in the literature.	Disease progression and resistance to treatment.	Disease progression; Body systems failure; Overt and covert patient behaviour, emotional and physical; and Withdrawing from the world, more time in bed, eating and drinking less, talking about death and dying.
Key Prognostic Question	Does this patient have a reasonable chance of cure or durable remission?	Would we be surprised if the patient were to die within the next year?	Would we be surprised if the patient were to die within the next week?
Prognosis	Years	Weeks, months (but can be years).	Hours or Days.
Therapeutic Ratio	High level of adverse effects, both a chance of mortality and significant morbidity may be accepted by the patient if cure is the aim.	Any treatment must be favourable in terms of: a) improving comfort or quality of life; and b) minimal adverse effects, at a level compatible with a)	No adverse effects from treatment: medical, nursing and allied health inputs strictly limited to comfort and dignity.
CPR	Yes	Usually no, but maybe for patients deemed to have a long prognosis e.g. Ca breast with bone secondaries.	No
Medical Provision of Nutrition and Hydration	Yes, when indicated.	Maybe – justifiable if it provides relief from suffering; more likely fluid than food.	No – unless suffering.
Role of DHHS Palliative Care (PC)	Rare Consultative one off or short series of consultations for symptom management or patient/family support. <i>DHHS PC level 2</i>	Episodic Consultation, shared care or direct care depending on patient and family need. <i>DHHS PC levels 2, 3 or 4</i>	Consultation, shared care or direct care depending on patient and family need. <i>DHHS PC levels 2, 3 or 4.</i>