section 2.8: care of the imminently dying person and following death

"Palliative care respects the dignity of the dying person and aims to achieve the best possible quality of life for them." [1]

recognition of transition to the terminal phase

Diagnosing dying is essential so that the most appropriate interventions for the patient and family can be implemented. This usually follows a discussion involving the primary treating medical team and confirmation of treatment goals, which is then followed by a meeting with the patient and family.

At this time the most significant areas of concern for patients include:

- receiving adequate management of pain and other symptoms
- avoiding inappropriate prolongation of dying
- retaining control over their end of life decisions
- relieving burdens that their dying would impose on loved ones
- strengthening relationships with their loved ones[2]

Characteristics of this phase include:

- death is likely in a matter of days and no acute intervention is planned or required
- the typical features in this phase include
  - profound weakness
  - essentially bed bound
  - drowsy for extended periods
  - disorientated for time and has a severely limited attention span
  - increasingly disinterested in food and drink
  - difficulty swallowing medications[3]
- frequent, usually daily interventions aimed at physical, emotional and spiritual issues are required
- the family/caregivers recognise that death is imminent and care is focused on emotional and spiritual issues as a prelude to bereavement.

Other physical signs frequently include [4]:

changes to circulation

- hands and arms, feet and then legs may be increasingly cool to touch
- cyanosis, duskiness or mottling may be noted

changes to breathing

- breathing may become noisy or "rattly" as pharyngeal and respiratory secretions accumulate when the patient is unconscious or semi-conscious and too weak to be able to cough

- breathing patterns may become shallow or erratic with long periods of apnoea

changes to consciousness

- loss of interest in surroundings
- increasing amount of time sleeping, appearing uncommunicative or unresponsive and slow to arouse with stimulation, brief periods of wakefulness only
- confusion about the time, place, and identity of people surrounding them, often including those close and familiar people
- restlessness or repetitive motions such as pulling at bed linen or clothing
- excessive sleeping may occur several days before death and then a semi-comatose state prior to death

continence

- loss of control of bladder or bowel function as muscles begin to relax
- decreased urinary output which becomes darker and concentrated

goals of care at this time

- signs and symptoms of impending death should be recognized and communicated
- care appropriate for this phase of illness is provided to patient and family
- the patient's transition to the actively dying phase is recognised, when possible, and is documented and communicated appropriately to patient and their family
- the family is educated regarding the signs and symptoms of approaching death
- end-of-life concerns, hopes, fears, and expectations are addressed openly and honestly in the context of social and cultural customs
- symptoms at the end of life are assessed and documented with appropriate frequency and are treated based on patient and family preferences
- the care plan is revised to meet the unique needs of the patient and family at this phase of the illness
- patient and family wishes regarding care setting for the death are documented[5]

guidelines for management

- clarify and confirm treatment goals with patient and/or family – ensure that there is clear documentation in the case notes of the treatment goals and decision trail that can be easily followed by other staff members
- check for an End of Life Pathway or guidelines in your hospital
- setting of care:
    - create a calm and receptive environment
    - allow the family time, and a quiet and private space with the patient both during the dying phase and after death
    - provide a single side room if possible or let the family know that this is a priority
- close monitoring of the patient's level of comfort
    - adjust schedules for vital signs and nursing and medical interventions; include only those that relate directly to patient comfort

  - check for pressure areas – use pressure relieving equipment including overlay mattresses or foam
  - maintain vigilant, gentle mouth care – including mouth toilets and lip balm or lanolin
  - check for fever, use cool sponging and consider regular Paracetamol administration if required (by rectal route if patient is not able to swallow)
- observe for, report, document and treat symptoms as and when they arise:
  - check for any signs of pain, nausea, dyspnoea or other discomfort, particularly prior to position changes, sponging or other nursing interventions
  - provide analgesia prior to interventions if pain is present and regular and "as necessary" pain relief – use available pain charts to aid assessment and documentation
  - report and manage restlessness or agitation
  - monitor bowel care, manage constipation gently and with consideration for the patient's nearness to death
  - continue to talk to the patient during review or in providing care, even if they appear to be unconscious – assume they can still hear you
  - discuss management of symptoms as a team – what management is most appropriate given this patient's particular illness, stage and personal wishes?
- review medications:
  - establish which medications are essential for controlling symptoms – consider rationalising other medications, communicate this management strategy to family
  - anticipate difficulties with swallowing and adjust medication schedule accordingly, with provision of parenteral medications that may be required rapidly or urgently
- identify the patient and family's specific needs:
  - talk with the family to identify what would be important for the patient at this time, may include music choices or being read to, particular friends and relatives visiting, family staying by the bedside at night
  - utilise information already known about cultural and religious backgrounds, rituals, family dynamics and prior experiences with death
  - actively explore what patients and family need to do in terms of unfinished business
- actively offer the family information, interpretation and support:
  - be aware that most people are totally unfamiliar with the functional process of dying
  - provide information about the physical signs of dying to help in adjustment to changes (information can be given gently and in advance)
  - interpreting these changes and explaining their significance to family is essential, eg "the kinds of changes that I am seeing tell me that there is little time remaining" and "are there other significant people in your family who would want to visit or be here at this time?"

    - offer reassurance that noisy breathing is not causing added suffering to the patient
    - try to anticipate spoken and unspoken concerns or anxieties
    - encourage the family to say those important things that they would want to share with the patient
    - let the family know that it is likely that the patient can still hear their voices, even if they appear unconscious
    - offer to include the family in providing personal care for the patient such as mouth care, assisting with position changes, sponging
    - assist the family to manage multiple visitors if this becomes burdensome – use a visitors book outside the door of the patient room for visitors to record their messages and a sign on the door stating "please speak with staff before visiting"
- allow opportunities for farewells and completing unfinished business
    - issues may be functional, financial, spiritual, or psychosocial and will vary, depending upon the culture and family system – use open-ended questions and sensitively encouraging exploration and articulating concerns and identifying goals or tasks that can still be met

There are particular circumstances in which dealing with death is made more difficult – these include sudden deaths, which may occur even in the setting of a life limiting illness. This may take place in the emergency department where creating privacy and a quiet environment is made more problematic.

A recent exploration of the needs of bereaved relatives in this particular setting revealed that they require:[6]

- prompt attention from staff on arrival and frequent updates on their loved one's condition
- to be with the patient before death, including during resuscitation attempts, to know that the patient received prompt and appropriate treatment from pre-hospital and hospital staff
- to be informed of the death in a compassionate and unhurried manner
- assurance that the patient's belongings will be properly handled
- to be told what to do next (eg, how to contact an undertaker; when to go home)
- to have the opportunity for follow-up with the hospital to answer unresolved questions.

This information would also be valuable for staff working in coronary care and intensive care units.[7]

The palliative care team have specific skills in facilitating the refocusing of care in the last days or hours of life, and in supporting clinical decision making by acute care staff at these challenging times.[8]
Referral to a specialist palliative care team should be considered if:

- patient symptoms are difficult to manage
- there is significant family, caregivers or staff distress

Specialist medical and nursing staff can also provide telephone advice or arrange assessment as needed – contact them via the switchboard in large metropolitan public hospitals or through the local specialist palliative care service (see section 5 - *Accessing resources for care*).

care of the patient and family after death

The deceased patient receives last offices in preparation for the mortuary or coroner – practical interventions categorised according to hygienic, aesthetic and legal requirements. Legal requirements include the need to declare life extinct, and an appropriate certification of death must be completed by the treating medical officer. Some deaths must be reported to the coroner – see the website at www.courts.sa.gov.au.

Key aspects include the following:

- care of the deceased person and their family is undertaken in a sensitive and respectful manner and recognizes the need for quiet time and privacy
- utilise known information about the patient's culture and relevant religious rites and practice – offer to contact an appropriate priest, minister of religion or spiritual advisor
- acknowledgement that family and friends will have individual and varied reactions to the death and will require support, information which is paced to their needs and ready access to staff. – see Section 7 – *Bereavement, grief and loss* for information about grief following a death and risk factors for complicated grief
- if the death does not involve the coroner, allowing family or loved ones to participate in washing or dressing the deceased person may reduce the feeling of helplessness and facilitate the grieving process – remove intravenous or subcutaneous lines, oxygen therapy and other equipment so that family can feel free to touch or hold the person
- clarify whether there are significant friends or family who would like to visit prior to transfer of the body to the morgue.

Refer to your hospital's policy or procedure regarding the care of the deceased person's body.[9]

Other considerations

- contact with General Practitioner and any community nursing agencies involved in care is required to advise them of the death
- should the family or caregivers voice significant distress or mention previous or current concerns for themselves or for another about self harm, it is essential that the primary treating medical team are made aware of this immediately, contact is made with the distressed person's General Practitioner and that contact numbers for telephone support agencies are provided – the National Suicide Prevention Project has a website with information for individuals, families and staff – see www.livingisforeveryone.com.au.

related resources and information

CareSearch

Communication and end of life decision making – links to on-line tutorials and education modules for medical, nursing, allied health and geriatric staff. See www.caresearch.com

EPERC - Advancing care at the end of life – fast facts about palliative care, see http://www.eperc.mcw.edu/

Improving services to bereaved relatives in the emergency department: making healthcare more human. Williams A, O'Brien D, Laughton J, Jelin G (2000) *MJA* 173:480-484.

A guide to talking to patients about death and dying[10] is available from Palliative Care Council of South Australia Inc – phone 08 8291 4137

See Section 7- *Bereavement, grief and loss*

references

[1] A Snapshot of Palliative Care in Australia (2003) Summary of the National Palliative Care Plan Initiative. Australian Government Department of Health and Ageing, ACT.

[2] Singer P, Martin D, Kelner M (1999) Quality end-of-life care: Patients perspectives. *JAMA* 281:163-168

[3] Eagar K., Cranny C & Fildes D. (2004) Evaluation and palliative care: a guide to the evaluation of palliative care services and programs. Wollongong: Centre for Health Service Development, University of Wollongong.

[4] From Table 5: Signs and Symptoms of Approaching Death (Adapted from Hospice of Central Florida) www.hospicecares.org

[5] Standards for Providing Quality Palliative Care for all Australians (2005) Palliative Care Australia, ACT.

[6] Williams A, O'Brien D, Laughton J, Jelin G (2000) Improving services to bereaved relatives in the emergency department: making healthcare more human. *MJA* 173:480-484.

[7] Kissane D (2000) Neglect of bereavement care in general hospitals. *MJA* 173:4.

[8] Ellershaw J, Ward C (2003) Care of the dying patient: the last hours or days of life. *BMJ* 326:30-34.

[9] Joanna Briggs Institute Acute Care Manual (2005) Last offices.

[10] Burgess T, Beilby J, Brooksbank M (2001) Talking to patients about death and dying. Department of General Practice at Adelaide University and the Palliative Care Unit, Royal Adelaide Hospital.