End of life care at home

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Palliative care – a reminder

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual
Palliative care

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
o offers a support system to help the family cope during the patient’s illness and in their own bereavement

o uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness,
- in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications
Patients with cancer and depression experience more physical symptoms, have poorer quality of life, and are more likely to have suicidal thoughts or a desire for hastened death than are cancer patients who are not depressed.

Signs of dying

- increasingly weak, sleepy, disinterested in getting out of bed, seeing anyone other than close family, less interested in surroundings, confused or agitated

- physical changes suggesting the body closing down
  - skin colour changes, skin temperature changes, slowing of respiration or Cheyne-Stokes respiration, involuntary twitching or moaning
Management

- Planning for the death is important.

- If in an institution, ensure that advance care plans indicate that the person is not for resuscitation.

- Ensure cultural or religious wishes are known and followed.

- Ensure that the patient and family are aware of the progression of disease and let them know what you expect to happen.
Management

- much anxiety near the end of life is engendered by a fear of the unknown so provide information about those things that are known to mitigate feelings of uncertainty

- anticipate what might happen rather than wait for a crisis

- anticipatory prescribing is considered to be best practice - analgesics, antiemetics, anxiolytics and antisecretory drugs should all be considered remembering that the oral route will probably be lost so use the s/c route
Pain

- opioids are the predominant analgesics used

- if the oral route is not feasible then consider
  - fentanyl patches - not suitable for unstable pain but may be useful as an alternative to oral analgesic
  - s/c boluses prn or continuous infusion
  - conversion from oral to sc is 2:1 for morphine and oxycodone i.e. 10mg oral = 5mg sc
Nausea/vomiting

- not usually a great problem unless there is intestinal obstruction or it has previously not been controlled
Agitation/distress/anxiety

**Non pharmacological management**
- if are there fears/worries/tensions/spiritual issues consider what has helped in past
- consider and address constipation/urinary retention/pain

**Oral drugs**
- lorazepam tablets: 0.5 mg to 1 mg bd
- clonazepam drops (2.5 mg/mL - 0.1 mg per drop)
- midazolam sublingually or buccally (between gum and cheek)

**Subcutaneous drugs**
- midazolam 10 mg over 24 hrs is a usual starting dose if not on benzodiazepine previously
- clonazepam boluses may also be useful
Confusion

Non pharmacological management
- look for reversible causes
- aim for minimal disruption and have familiar people in the room

Oral drugs
- haloperidol drops (2mg/mL - 0.05mg per drop - 20 drops = 1mg), initiate at 1-2 mg prn and titrate to response (much higher doses may be required - see haloperidol page)
- in frail or elderly patients an initial dose of 0.5 - 1mg prn may be sufficient

Subcutaneous drugs
- haloperidol by continuous infusion 1-10mg over 24 hours
- boluses of 1-2mg may also be used
Retained/excess secretions

Non pharmacological management
- consider position change
- it may be distressing to the family/carers rather than the patient

Drugs
- hyoscine (Scopaderm) patch may be applied behind the ear although confusion and other anticholinergic side effects may occur
- hyoscine butylbromide may be useful - 20 mg sc followed by 30-60mg by continuous subcutaneous infusion over 24 hours
- secretions may become thickened and plugs may form
After death review

It can be helpful for teams to review what happened in order to learn from each patient and family

- What things went well?
- Did the patient and family resolve all unfinished business?
- Were all opportunities to say goodbye taken?
- Was death peaceful and dignified?
- Was everything possible done to care for the family and friends?
- How could care have been improved?
- How does each of the team of professional carers feel?
- What lessons have we learned that we can carry to the next?
Palliative Care Bridge
MacLeod RD, Vella-Brincat J, Macleod AD 2014
The Palliative Care Handbook
*Hammond Press*

palliativecarebridge.com