Care in the Last Days of Life

Introduction
This guideline is an aid to clinical decision making and good practice in person-centred care for patients who are deteriorating and at risk of dying. The patient may have a new life-limiting condition, one or more advanced illnesses, or both. A decision will have been made that hospital admission or transfer to a high-dependency unit or intensive treatment unit is not appropriate. While this guideline focuses on physical symptoms, psychosocial and spiritual issues will also need to be addressed to give holistic care.

Assessment
- Identify any potentially reversible causes for the patient’s deterioration. These may include:
  - dehydration
  - infection
  - opioid toxicity
  - steroid withdrawal
  - acute kidney injury
  - delirium
  - hypercalcaemia
  - hypo or hyperglycaemia

Start treatment, if appropriate for the individual patient and care setting; plan review. Discussion at this time may include appropriate levels of intervention (known in some boards as ceilings of treatment).

- Discuss prognosis (the patient is deteriorating and at risk of dying), agree goals of care and preferred place of care with the patient or a welfare attorney, and the family.
- Take account of any advance/anticipatory care planning or documented patient wishes.
- An individual care plan will be agreed with the patient if possible or any welfare attorney, discussed with the family, and documented in the patient record.
  - This includes a decision about cardio pulmonary resuscitation
  - Explain to the patient and their family that all support, care and treatment that are of benefit will continue to be given and reviewed.
- Prompt and careful planning is needed for a safe discharge home or to a hospice or care home.
- If patient or family needs are complex, consider contacting the palliative care team for advice.
Management

Care planning and regular review
Regular, planned **review** and **documentation** of the care plan will make sure the best care is given as the patient’s condition deteriorates, stabilises or improves.

- **Food and drinks:** support the patient to take these as long as they are able and want to.
- **Comfort care:** usually includes an alternating pressure mattress to minimise avoidable skin breakdown due to overall deterioration of condition, repositioning for comfort, eye care, mouth care, bladder and bowel care.
- **Medicines:** review and stop any treatments not consistent with the agreed goals of care.
  - Choose an appropriate route: if patient is able to swallow continue with usual oral medication. If they are having difficulty swallowing consider changing to liquid formulations or change to the subcutaneous (SC) route if preferred (or unable to swallow).
  - Consider the need for a SC infusion of medication via a syringe pump.
  - Make sure **anticipatory medications** for common symptoms are available and prescribed for as required use, by the oral and SC routes (see below).
- **Investigations or clinical interventions:** consider, and regularly review, appropriateness, benefit and burdens (e.g., blood tests, radiology, vital signs and regular blood sugar monitoring). Make a clear record of any interventions that are not appropriate.
- **Assisted hydration or nutrition:** consider the benefits and risks; review plan regularly.
  - Over-hydration can contribute to distressing respiratory secretions. However, where indicated, a slow SC fluid infusion may be considered on an individual basis (see **Subcutaneous fluids** guideline).
- Consider **emotional, spiritual, religious, cultural, legal and family needs**, including those of children and people with cognitive impairment or learning disability.
- **Bereavement:** identify those at increased risk; seek additional support.

Communication

- **Discuss the care plan with the patient, if possible, and the family, and explain what changes to expect in the patient’s condition.** Sensitively explore wishes regarding **organ and tissue donation** where appropriate.
- Make sure family members are aware of the care plan. Record a plan of how and when to contact the family if the patient deteriorates or dies.
- Hand over care plan to other team members: hospital at night team, general practitioner, community nurses; out-of-hours community services.
Symptom control in the last days of life\(^1\)

**Anticipatory prescribing**
All patients should have as required medication for symptom control available (see [Anticipatory prescribing guideline](#)).

- Opioid analgesic SC, hourly. Dose depends on the patient, clinical problem and previous opioid use.
  - one tenth to one sixth of 24-hour dose of any regular opioid.
  - If not on a regular opioid, morphine SC 2mg or diamorphine SC 2mg.
- Anxiolytic sedative: midazolam SC 2 to 5mg, hourly.
- Antisecretory medication: hyoscine butylbromide SC 20mg, hourly.
- Anti-emetic: QT levomepromazine SC 2.5 to 5mg, 8 hourly.

**Pain**
- Paracetamol or diclofenac (as liquid, dispersible or rectally).
- The benefits of non-steroidal anti-inflammatory drugs (NSAIDs) may outweigh the risks in a dying patient; can help bone, joint, pressure sore, inflammatory pain.
- Convert the total 24-hour oral morphine or oxycodone dose to a 24-hour SC infusion, for example:

<table>
<thead>
<tr>
<th>Oral Morphine 30mg</th>
<th>SC Morphine 15mg</th>
<th>SC Diamorphine 10mg</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral Oxycodone 15mg</td>
<td>SC Morphine 15mg</td>
<td>SC Oxycodone 7 to 8 mg</td>
</tr>
</tbody>
</table>

- For opioid dose conversions, see [Choosing and changing opioids](#) guideline or seek advice.
- Fentanyl patches should be continued in dying patients (see [Fentanyl patches](#) guideline).
- For a patient with stage 4–5 chronic kidney disease, see [Last days of life (renal)](#) guideline.
- Breakthrough analgesia, should be prescribed hourly as required:
  - one tenth to one sixth of 24-hour dose of any regular opioid orally and SC.
  - If not on any regular opioid, use morphine SC 2mg or diamorphine SC 2mg.

**Agitation or Delirium**

<table>
<thead>
<tr>
<th>Anxiety or distress</th>
<th>Midazolam SC 2 to 5mg, hourly, as required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confusion or delirium</td>
<td>QT haloperidol SC 2mg, once or twice daily</td>
</tr>
<tr>
<td>Established terminal delirium or distress</td>
<td><strong>First line</strong> midazolam SC 20 to 30mg over 24 hours in a syringe pump + midazolam SC 5mg hourly, as required</td>
</tr>
</tbody>
</table>

---

1† Indicates this use is off licence
2QT Indicates this medication is associated with QT prolongation

---

Copyright © 2014 NHS Scotland
Issue Date: 31/05/2014
Rule Date: 31/05/2017
Page 3 of 5
Nausea and vomiting
(See Nausea and vomiting guideline)

If already controlled with an oral anti-emetic, use the same drug as a SC infusion.
Treat new nausea and vomiting with a long acting anti-emetic given by SC injection or give a suitable anti-emetic as a 24-hour SC infusion in a syringe pump.

Long acting anti-emetics:
- QT haloperidol SC 1mg 12 hourly, or 2mg once daily.
- QT levomepromazine SC 2.5mg 12 hourly, or 5mg once daily.

For doses of anti-emetics for use in a SC infusion see Subcutaneous medication guideline.

Persistent vomiting: a nasogastric tube, if tolerated, may be better than medication.

Breathlessness
(See Breathlessness guideline)

- Oxygen can improve breathlessness, but only if the patient is hypoxic. If oxygen is needed for symptom control, nasal prongs may be better tolerated than a mask.
- A fan (either on a table or handheld) should be tried, and a more upright position can help.

<table>
<thead>
<tr>
<th>Intermittent breathlessness or respiratory distress</th>
<th>Midazolam SC 2 to 5mg hourly, as required with or without lorazepam sublingual 500 micrograms, 4 to 6 hourly, as required. Opioid (2 hourly as required)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- regular opioid - use the same 4 hourly breakthrough dose for pain or breathlessness.</td>
</tr>
<tr>
<td></td>
<td>- no opioid - morphine SC 2mg or diamorphine SC 2mg</td>
</tr>
</tbody>
</table>

| Persistent breathlessness or respiratory distress | Midazolam SC 5 to 20mg + morphine SC 5 to 10mg or diamorphine 5 to 10mg (if no previous opioid use); given in a syringe pump over 24 hours. |

Respiratory tract secretions

- Reduce risk by avoiding fluid overload; review any assisted hydration or nutrition (intravenous [IV] or SC fluids, feeding) if symptoms develop. Suction may also exacerbate secretions.
- Changing the patient’s position, for example head down or lateral position may help.
- Intermittent SC injections often work well or medication can be given as a SC infusion (be aware that conscious patients may be troubled by dry mouth on these medications).
  - first line: hyoscine butylbromide SC 20mg, hourly as required (up to 120mg/24 hours)
  - second line: glycopyrronium bromide SC 200 micrograms, 6 to 8 hourly as required.
  - third line: hyoscine hydrobromide SC 400 micrograms, 2 hourly as required.
Acute terminal events
(See Emergencies in palliative care guidelines)

- Dying patients occasionally develop acute distress; this can be due to:
  - bleeding: haemorrhage from gastrointestinal or respiratory tract, or an external tumour
  - acute pain: bleeding into a solid tumour, fracture, or ruptured organ
  - acute respiratory distress: pulmonary embolism, retained secretions.
- Prescribe sedation in advance if the patient is at risk; warn the family. Agree an anticipatory care plan with the patient, if possible, family carers and key professionals.
- Give midazolam intramuscular (IM), 5 to 10mg, into the deltoid muscle or sedate using IV midazolam if IV access is available.
- If the patient is in pain or has continued respiratory distress despite midazolam, give morphine SC at double the usual breakthrough, as required, dose.

Practice Points

- Opioid analgesics should not be used to sedate dying patients.
- Sudden increase in pain or agitation; exclude urinary retention or other reversible causes.
- SC infusions of medication provide maintenance treatment only. Additional doses of medication by SC injection will be needed if the patient’s symptoms are not controlled, or when starting a SC infusion in an unsettled patient.
- Midazolam SC infusions are usually titrated in 5 to 10mg steps. Up to 5mg can be given in a single SC injection (1ml). Single SC doses can last 2 to 4 hours. Useful as an anticonvulsant.
- Terminal secretions can be controlled in about 60% of cases; fluid overload, recent aspiration and respiratory infection increase the incidence.
- Consider a nicotine replacement patch in heavy smokers with withdrawal symptoms.

Resources

Improving nutritional care www.dh.gov.uk
Nice guideline nutrition support in adults (feb2006) www.nice.org.uk
Scottish Government Interim Guidance - December 2013
HIS Best Practice Statement - Prevention and Management of Pressure Ulcers 2009

Organ donation
Patient leaflet:  What happens when someone is dying

Other relevant guidelines:
Subcutaneous medication (guidance on prescribing advice and drug compatibility tables)
Choosing and changing opioids
Subcutaneous fluids
Mouth care
Levomepromazine
End-of-life care in non-cancer illnesses