Care of dying adults in the last days of life

Improving care at the very end of life.
Foreword

We will all experience death, whether it is our own or that of a loved one. The bereaved person’s perception that they have witnessed a “good” death can significantly improve their ability to adjust and move forward, while a “bad” death can have a long-lasting negative impact on their well-being. Therefore the care given must be of the highest standard and must recognise and strive to accommodate the wishes of the dying person and their loved-ones, if it is to provide not just the comfort that the dying person deserves but also the solace the bereaved need.

The document ‘One Chance to get It Right’ (2014) highlighted the need to help staff recognise, assess, communicate and provide individualised care and support for dying people (Leadership Alliance for the care of Dying People 2014). The Alliance’s five Priorities for Care puts people and those important to them at the centre of decisions about their treatment and care, and follows the recommendation made by the independent Neuberger (2014) review of the LCP.

More recently the National Institute for Health and Care Excellence (NICE) guideline ‘Care of the Dying Adult’ (2015) gives professionals a comprehensive, humane and evidence-based framework for giving dying people, their families and others important to them, the best possible care based on each individual’s needs and wishes.

This guideline will help support doctors, nurses and other healthcare professionals in the Isle of Man in giving consistent, compassionate and high quality clinical care for every person at the end of their life. The approach should be applied irrespective of the place in which someone is dying: hospital, hospice, community and during transfers between different settings.

Please note that there are several other documents (Rapid Discharge Plan, Just In Case Box Policy And End of Life Form) which are used to support these guidelines. They have not been included as the whole document would be too onerous.

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Priorities of Care for the Dying Person

Published June 2014 by the Leadership Alliance for the Care of Dying People

The Leadership Alliance for the Care of Dying People have set out five priorities for care of a person when it is thought that they may die within the next few days or hours.

1. **Recognise**
   The possibility that a person may die within the next few days or hours is recognised and communicated clearly. All decisions and actions taken should be in accordance with the person’s needs and wishes. Individuals are regularly reviewed and decisions revised accordingly. Always consider reversible causes, e.g. infection, dehydration, hypercalcaemia, etc.

2. **Communicate**
   Sensitive communication takes place between staff and the dying person, and those identified as important to them.

3. **Involve**
   The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

4. **Support**
   The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

5. **Plan & Do**
   An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.
Recognising Dying

If it is thought that a person may be entering the last few days of life

1. Gather and document information on:
   - the person’s physiological, psychological, social and spiritual needs.
   - current clinical signs and symptoms.
   - medical history and the clinical context, including underlying diagnoses.
   - the person’s goals and wishes.
   - the views of those important to the person about future care.

2. Assess for changes in signs and symptoms and review any available investigation results that may suggest a person is entering the last days of life.
   - signs such as agitation, Cheyne–Stokes breathing, deterioration in level of consciousness, mottled skin, noisy respiratory secretions.
   - symptoms such as increasing fatigue and loss of appetite.

3. Functional observations such as changes in communication, deteriorating mobility or performance status, or social withdrawal. Be aware that improvement in signs and symptoms or functional observations could indicate that the person may be stabilising or recovering. Avoid undertaking investigations that are unlikely to affect care in the last few days of life unless there is a clinical need to do so.

4. Use the knowledge gained from the assessments and other information gathered from the multi-professional team, the person and those important to them, to help determine whether the person is nearing death, deteriorating, stable or improving.

5. Monitor the person at least every 24 hours and update the individualised care plan.

6. Seek specialist palliative care advice when there is a high level of uncertainty (for example, ambiguous or conflicting clinical signs or symptoms) about whether a person is entering the last days of life, may be stabilising or if there is potential for even temporary recovery.
Communication

1. Establish the communication needs and expectations of people who may be entering their last days of life, taking into account:
   - if they would like a person important to them to be present when making decisions about their care
   - their current level of understanding that they may be nearing death
   - their cognitive status and if they have any specific speech, language or other communication needs
   - how much information they would like to have about their prognosis
   - any cultural, religious, social or spiritual needs or preferences.

2. Identify the most appropriate available multi-professional team member to explain the dying person's prognosis. Base this decision on the professional's:
   - competence and confidence
   - rapport with the person.

3. Discuss the dying person's prognosis with them (unless they do not wish to be informed) as soon as it is recognised that they may be entering the last days of life and include those important to them in the discussion if the dying person wishes.

4. Provide the dying person, and those important to them, with:
   - accurate information about their prognosis (unless they do not wish to be informed), explaining any uncertainty and how this will be managed, but avoiding false optimism
   - an opportunity to talk about any fears and anxieties, and to ask questions about their care in the last days of life
   - information about how to contact members of their care team
   - opportunities for further discussion with a member of their care team
5. Explore with the dying person and those important to them
   • whether the dying person has an advance statement or has stated preferences about their care in the last days of life (including any anticipatory prescribing decisions or an advance decision to refuse treatment or details of any legal lasting power of attorney for health and welfare)
   • whether the dying person has understood and can retain the information given about their prognosis.

6. Discuss the dying person's prognosis with other members of the multi-professional care team, and ensure that this is documented in the dying person's record of care.
Involve

Please also refer to the recommendations on shared decision making in NICE's guideline on patient experience in adult NHS services.

1. Establish the level of involvement that the dying person wishes to have and is able to have in shared decision making, and ensure that honesty and transparency are used when discussing the development and implementation of their care plan.

2. As part of any shared decision making process take into account:
   - whether the dying person has an advance statement or an advance decision to refuse treatment in place, or has provided details of any legal lasting power of attorney for health and welfare
   - the person's current goals and wishes
   - whether the dying person has any cultural, religious, social or spiritual

3. Identify a named lead healthcare professional, who is responsible for encouraging shared decision making in the person's last days of life. The named healthcare professional should:
   - give information about how they can be contacted and contact details for relevant out of hours services to the dying person and those important to them.
   - ensure that any agreed changes to the care plan are understood by the dying person, those important to them, and those involved in the dying person's care.
Support

1. Health and care staff must regularly assess and address (if possible) the needs of those important to the dying person, and offer information about getting access to other sources of help and support.

2. Health and care staff in in-patient facilities must ensure those important to the person are welcome and enabled to spend time with the dying person.

3. Those who wish to participate in caring for the dying person must be supported by staff to do so, e.g. by showing them simple practical techniques.

4. Health and care staff must acknowledge that the needs of the dying person, and those important to them may differ. Differences must be acknowledged and addressed in a sensitive way.

5. Respect those who do not wish to talk openly about death and dying. However staff must find a sensitive way to remain clear in their communication, and to avoid euphemisms.

6. Health and care staff must offer information and explanations to those important to them to prepare them for what happens when a person is close to death, whether the death is occurring at home or in an institution.

7. When a person is imminently dying, the responsible nurse or other healthcare professional must check with the dying person’s family and those important to them about how they would best wish to be supported. Some prefer to be left alone; others prefer a staff member to briefly check in with them every now and then; others may need more support. Importantly, they need to know where staff are if they are needed.

8. Those important to the dying person, including carers, may have their own spiritual and religious needs which may, or may not, be similar to that of the dying person. Staff must involve chaplains or relevant religious leaders if the family and those important to the person want this.
9. When a person has died, the wellbeing of the bereaved must be considered, and health and care staff must ensure adequate support is available for their immediate needs. They must be allowed time with the deceased person, if they wish, without being put under pressure.

10. Those important to the dying person will require additional support if the death has been unexpected or if it occurs after a very short deterioration, for example help to understand post mortem, coroners’ and death certification procedures, and to have their questions answered.
Plan & Do

1. Establish as early as possible the resources needed for the dying person (for example, the delivery of meals, equipment, care at night, volunteer support or assistance from an organisation) and their availability.

2. In discussion with the dying person, those important to them and the multiprofessional team, create an individualised care plan. The plan should include the dying person's:
   - personal goals and wishes
   - preferred care setting
   - current and anticipated care needs
   - preferences for symptom management
   - needs for care after death, if any are specified
   - resource needs.

3. Record individualised care plan discussions and decisions in the dying person's record of care and share the care plan with the dying person, those important to them and all members of the multi-professional care team.

4. Continue to explore the understanding and wishes of the dying person and those important to them, and update the care plan as needed. Recognise that the dying person's ability and desire to be involved in making decisions about their care may change as their condition deteriorates or as they accept their prognosis.

5. While it is normally possible and desirable to meet the wishes of a dying person, when this is not possible explain the reason why to the dying person and those important to them.

6. Ensure that shared decision making can be supported by experienced staff at all times. Seek further specialist advice if additional support is needed.
Maintaining hydration

1. Support the dying person to drink if they wish to and are able to. Check for any difficulties, such as swallowing problems or risk of aspiration. Discuss the risks and benefits of continuing to drink, with the dying person, and those involved in the dying person’s care.

2. Offer frequent care of the mouth and lips to the dying person, and include the management of dry mouth in their care plan, if needed. Offer the person the following, as needed:
   - help with cleaning their teeth or dentures, if they would like.
   - frequent sips of fluid.

3. Encourage people important to the dying person to help with mouth and lip care or giving drinks, if they wish to. Provide any necessary aids and give them advice on giving drinks safely.

4. Assess, preferably daily, the dying person’s hydration status, and review the possible need for starting clinically assisted hydration, respecting the person’s wishes and preferences.

5. Discuss the risks and benefits of clinically assisted hydration with the dying person and those important to them. Advise them that, for someone who is in the last days of life:
   - clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, but may cause other problems.
   - it is uncertain if giving clinically assisted hydration will prolong life or extend the dying process.
   - it is uncertain if not giving clinically assisted hydration will hasten death.

6. Ensure that any concerns raised by the dying person or those important to them are addressed before starting clinically assisted hydration.

7. When considering clinically assisted hydration for a dying person, use an individualised approach and take into account:
• whether they have expressed a preference for or against clinically assisted hydration, or have any cultural, spiritual or religious beliefs that might affect this documented in an advance statement or an advance decision to refuse treatment.
• their level of consciousness.
• any swallowing difficulties.
• their level of thirst.
• the risk of pulmonary oedema.
• whether even temporary recovery is possible.

8. Consider a therapeutic trial of clinically assisted hydration if the person has distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium, and oral hydration is inadequate.

9. For people being started on clinically assisted hydration:
   • Monitor at least every 12 hours for changes in the symptoms or signs of dehydration, and for any evidence of benefit or harm.
   • Continue with clinically assisted hydration if there are signs of clinical benefit.
   • Reduce or stop clinically assisted hydration if there are signs of possible harm to the dying person, such as fluid overload, or if they no longer want it.

10. For people already dependent on clinically assisted hydration (enteral or parenteral) before the last days of life:
   • Review the risks and benefits of continuing clinically assisted hydration with the person and those important to them.
   • Consider whether to continue, reduce or stop clinically assisted hydration as the person nears death.
Pharmacological management of common symptoms

This section focuses on the pharmacological management of common symptoms at the end of life and includes general recommendations for non-specialists prescribing medicines to manage these symptoms.

1. When it is recognised that a person may be entering the last days of life, review their current medicines and, after discussion and agreement with the dying person and those important to them (as appropriate), stop any previously prescribed medicines that are not providing symptomatic benefit or that may cause harm.

2. When involving the dying person and those important to them in making decisions about symptom control in the last days of life:
   - Use the dying person’s individualised care plan to help decide which medicines are clinically appropriate.
   - Discuss the benefits and harms of any medicines offered.

3. When considering medicines for symptom control, take into account:
   - the likely cause of the symptom.
   - the dying person’s preferences alongside the benefits and harms of the medicine.
   - any individual or cultural views that might affect their choice.
   - any other medicines being taken to manage symptoms.
   - any risks of the medicine that could affect prescribing decisions, for example prescribing cyclizine to manage nausea and vomiting may exacerbate heart failure.

4. Decide on the most effective route for administering medicines in the last days of life tailored to the dying person’s condition, their ability to swallow safely and their preferences.

5. Consider prescribing different routes of administering medicine if the dying person is unable to take or tolerate oral medicines. Avoid giving intramuscular injections and give either subcutaneous or intravenous injections.
6. Consider using a syringe pump to deliver medicines for continuous symptom control if more than 2 or 3 doses of any ‘as required’ medicines have been given within 24 hours.

7. For people starting treatment who have not previously been given medicines for symptom management, start with the lowest effective dose and titrate as clinically indicated.

8. Regularly reassess, at least daily, the dying person’s symptoms during treatment to inform appropriate titration of medicine.

9. Seek specialist palliative care advice if the dying person’s symptoms do not improve promptly with treatment or if there are undesirable side effects, such as unwanted sedation.
Anticipatory prescribing

1. Use an individualised approach to prescribing anticipatory medicines for people who are likely to need symptom control in the last days of life. Specify the indications for use and the dosage of any medicines prescribed.

2. Assess what medicines the person might need to manage symptoms likely to occur during their last days of life (such as agitation, anxiety, breathlessness, nausea and vomiting, noisy respiratory secretions and pain). Discuss any prescribing needs with the dying person, those important to them and the multi-professional team.

3. Ensure that suitable anticipatory medicines and routes are prescribed as early as possible. Review these medicines as the dying person’s needs change.

4. When deciding which anticipatory medicines to offer take into account:
   - the likelihood of specific symptoms occurring.
   - the benefits and harms of prescribing or administering medicines.
   - the benefits and harms of not prescribing or administering medicines.
   - the possible risk of the person suddenly deteriorating (for example, catastrophic haemorrhage or seizures) for which urgent symptom control may be needed.
   - the place of care and the time it would take to obtain medicines.

5. Before anticipatory medicines are administered, review the dying person’s individual symptoms and adjust the individualised care plan and prescriptions as necessary.

6. If anticipatory medicines are administered:
   - Monitor for benefits and any side effects at least daily, and give feedback to the lead healthcare professional.
   - Adjust the individualised care plan and prescription as necessary.
Deterioration in the patient’s condition

Recognise when people are entering the last few days of life

Could this patient be in the dying phase?

Is there a potentially reversible cause for the patient’s condition?
Exclude: opioid toxicity, renal failure, hypercalcaemia, infection

Is referral to Palliative Care Team required?

or
Second opinion?

Ensure sensitive communication between staff and the dying person and those important to them.

Involve the dying person in decision-making

Support the needs of the family and those identified as important to them

Plan & Do

- Create an Individualised Care Plan
- Ensure Anticipatory Medication is prescribed to ensure good symptom control.
- Assess hydration status, and review the possible need for starting clinically assisted hydration, respecting the person’s wishes and preferences.
- End of Life Form is completed by G.P. and faxed to MEDS (community)
- Daily assessments are carried out.

Any changes in the plan of care are discussed with the patient, relative/carer.
Pain

Managing pain
1. Consider non-pharmacological management of pain in a person in the last days of life.
2. Be aware that not all people in the last days of life experience pain. If pain is identified, manage it promptly and effectively, and treat any reversible causes of pain, such as urinary retention.
3. Assess the dying person’s level of pain and assess for all possible causes when making prescribing decisions for managing pain.
4. Follow the general principles of pain management, taking into account the person’s wishes.
5. Use a validated behavioural pain assessment if the person is unable to communicate effectively.

Breakthrough Pain
This medication should be given at the first sign of an unwanted symptom, before it has a chance to build up, remembering that medications can take up to 20 minutes to take effect.

- PRN dosage will be calculated as a sixth of the total 24 hour syringe pump infusion.

Analgesic Route
- The oral route is the preferred if the person is able to swallow.
- Transdermal Fentanyl is appropriate in the setting of severe continuous pain in individuals who cannot use the oral route; however, it is not suitable for unstable pain.
- The subcutaneous route is preferred when a parenteral route is needed. The intramuscular route should be avoided as it is generally more painful, and has variable absorption, compared to other routes.
- If the syringe pump is being used to administer opiate analgesia such as Diamorphine, then extra breakthrough analgesia must be prescribed and administered as a subcutaneous injection.
The commonly used drugs listed below must **NOT** be given by the SC route as they may cause tissue necrosis:

- Antibiotics
- Diazepam
- Chlorpromazine
- Prochlorperazine (Stemetil®)

**Opioid Equianalgesic Table**

This chart should be only used as a guide. The titration to optimum pain control should always be individualised.

(Initial dose conversions should be conservative; it is preferable to under-dose the individual and use rescue medication for any shortfalls).

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<th>MST or Zomorph</th>
<th>MXL daily</th>
<th>Oral Oxynorm (Oxycodone IR) 4hrly</th>
<th>Oxycontin (Oxycodone MR) 12hrly</th>
<th>Transtec Patch (Buprenorphine patch) 72hrly</th>
<th>Durogesic and Durogesic D-trans (Fentanyl Patch) 72hrly</th>
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Opioid Equianalgesic Table

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For further guidance especially with renal failure – refer to Palliative Care Resource File

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<td>50-60mg</td>
<td>330mg</td>
<td>75-90mg</td>
</tr>
<tr>
<td>540mg</td>
<td>1080mg</td>
<td>300mcg/hr</td>
<td></td>
<td>60mg</td>
<td>360mg</td>
<td>90mg</td>
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</table>

<table>
<thead>
<tr>
<th>Oxycontin 12hryl</th>
<th>5 mg</th>
<th>10 mg</th>
<th>20 mg</th>
<th>40 mg</th>
<th>60 mg</th>
<th>80 mg</th>
<th>100 mg</th>
<th>120 mg</th>
<th>130 mg</th>
<th>160 mg</th>
<th>170 mg</th>
<th>200 mg</th>
<th>220 mg</th>
<th>240 mg</th>
</tr>
</thead>
<tbody>
<tr>
<td>5-10 mg</td>
<td>15 mg</td>
<td>25-30 mg</td>
<td>50-55 mg</td>
<td>80 mg</td>
<td>110 mg</td>
<td>135 mg</td>
<td>160 mg</td>
<td>175 mg</td>
<td>215 mg</td>
<td>230 mg</td>
<td>270 mg</td>
<td>300 mg</td>
<td>320 mg</td>
<td></td>
</tr>
</tbody>
</table>

These tables have been generated using values that **may** differ from manufacturers’ recommendations, but are based on expert opinion

*Taken from Merseyside and Cheshire Palliative Care Guidelines 2010*

Author: Cheryl Young, Practice Development Lead / NCGC member - NICE guideline (NG31)
Date of issue: 01/06/2016
Date of review: 01/06/2018
**Transdermal Fentanyl Patches**

- Transdermal fentanyl is for use in individuals with **stable** pain. It should **NOT** be used for titration against rapidly escalating pain.
- Never use transdermal fentanyl patches in opioid naïve individuals, as this may lead to dangerous respiratory depression.
- The starting dose of transdermal fentanyl is calculated on the basis of the oral Morphine sulphate equivalent dose as listed in the conversion chart below.

<table>
<thead>
<tr>
<th>Total 24 hour oral morphine mg</th>
<th>Fentanyl patch mcg/hour</th>
</tr>
</thead>
<tbody>
<tr>
<td>60-134</td>
<td>25</td>
</tr>
<tr>
<td>135-224</td>
<td>50</td>
</tr>
<tr>
<td>225-314</td>
<td>75</td>
</tr>
<tr>
<td>315-404</td>
<td>100</td>
</tr>
</tbody>
</table>

- Continue to administer oral Morphine Sulphate for 12 hours after applying the first patch, i.e.:
  - Immediate release Morphine Sulphate 4 hourly for 12 hours, or the final dose of modified release Morphine Sulphate, taken at the same time as applying the first patch.
  - For breakthrough pain, prescribe immediate release Morphine Sulphate equivalent to the 4 hourly dose. This may be required for the first 24-48 hours of transdermal Fentanyl use.

**In the terminal Phase**

When considering the use of transdermal Fentanyl it may be appropriate to discuss the individual’s requirements with the Palliative Care Team.

- **Do not remove** the patch when the person can no longer tolerate oral medication
- Continue with the current dosage and change every 72hrs as previously
- Use subcutaneous injections to deliver breakthrough medication and a syringe pump to deliver the increasing analgesia requirements
• If a new, opioid responsive pain develops, use subcutaneous morphine/diamorphine as required for breakthrough pain. Use the conversion chart to calculate the dose.
• The diamorphine via the syringe pump should be used in addition to the fentanyl patch.

4 hourly dose of Diamorphine = Fentanyl patch strength (micrograms /hour)
Subcutaneously (mg)  5

Fentanyl is approximately 4 times more potent than oral Morphine; this table provides a guide to dose conversions, but if in doubt seek advice.

<table>
<thead>
<tr>
<th>FENTANYL patch strength (micrograms / hour)</th>
<th>4 hourly dose of DIAMORPHINE subcutaneously (mg)</th>
<th>4 hourly dose of MORPHINE subcutaneously (mg)</th>
</tr>
</thead>
<tbody>
<tr>
<td>25</td>
<td>5</td>
<td>5-10</td>
</tr>
<tr>
<td>50</td>
<td>10</td>
<td>15</td>
</tr>
<tr>
<td>75</td>
<td>15</td>
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<td>150</td>
<td>30</td>
<td>45</td>
</tr>
<tr>
<td>200</td>
<td>40</td>
<td>60</td>
</tr>
</tbody>
</table>

Discontinuation of transdermal Fentanyl
• Discontinuation of transdermal Fentanyl is not straightforward, primarily because of the intradermal reservoir of drug which remains following removal of the patch.
• Caution must be exercised, since the addition of alternative opioids may result in significant respiratory depression.
• For advice on discontinuing fentanyl and using another opioid, always contact the Palliative Care Team, or hospice out-of-hours.
Example

**PAIN**

Has the person been taking any strong opioids for pain

**Yes**

If patient is already taking oral opioids(s) convert from oral to SC syringe pump.

To convert from oral MORPHINE to 24hr SC infusion of DIAMORPHINE
Divide the total daily dose of MORPHINE by 3
e.g. MXL 90mg + ORAMORPH 30mg- (120MG) ÷ 3 = 40mg DIAMORPHINE

To convert from oral OXCONTIN MR to 24hr SC infusion of OXCODONE
Divide the total daily dose of OXCONTIN by 2
e.g. OXCONTIN 60mg bd + OXYNORM 40mg = 160mg ÷ 2 = 80mg OXCODONE HYDROCHLORIDE

To convert from oral OXCONTIN to 24hr SC infusion of DIAMORPHINE
Multiply the total daily dose of OXCODONE by 2 and then divide by 3 (2/3)
e.g. OXCODONE 60mg bd = 120mg x 2 = 240mg/3 = 80mg DIAMORPHINE

*Breakthrough dose should be 1/6 of the total daily dose of strong opioids.*

e.g. DIAMORPHINE 60mg/24hrs SC via syringe pump
DIAMORPHINE 10mg SC 2hrly prn

OXCODONE HYDROCHLORIDE 60mg/24hrs via syringe pump SC
OXCODONE HYDROCHLORIDE 10mg 2hrly prn SC

Review every 24hrs and titrate the opioid dose in the syringe pump:

- e.g. Add the total dose of SC DIAMORPHINE/ OXCODONE given prn in the previous 24hrs to the amount in the syringe pump.

Contact Specialist Palliative Care Team for further advice.

Please refer to the British National Formulary BNF for current guidance on medications and dosages.

**No**

In anticipation of future symptoms
Prescribe DIAMORPHINE 2.5mg-5mg 2hrly prn SC

Has the person any pain?

**Yes**

Assess for cause, consider:
- Full bladder or rectum
- Pathological fracture

Prescribe and administer DIAMORPHINE 2.5mg-5mg 2hrly prn SC
Continue to give prn dosage accordingly.
Review this every 24hrs.

If 3 or more prn doses required in 24hrs
set up syringe pump

Doses via syringe pump should be titrated according to total 24hr prn doses

Author: Cheryl Young, Practice Development Lead / NCGC member - NICE guideline (NG31)
Date of issue: 01/06/2016
Date of review: 01/06/2018
Anxiety delirium and agitation

- Explore the possible causes of anxiety or delirium, with or without agitation, with the dying person and those important to them.

- Be aware that agitation in isolation is sometimes associated with other unrelieved symptoms or bodily needs for example, unrelieved pain or a full bladder or rectum.

- Consider non-pharmacological management of agitation, anxiety and delirium in a person in the last days of life.

- Treat any reversible causes of agitation, anxiety or delirium, for example, psychological causes or certain metabolic disorders (for example renal failure or hyponatraemia).

- Consider a trial of a benzodiazepine to manage anxiety, agitation or delirium.

- Consider a trial of an antipsychotic medicine to manage delirium or agitation.

- Seek specialist advice if the diagnosis of agitation or delirium is uncertain, if the agitation or delirium does not respond to antipsychotic treatment or if treatment causes unwanted sedation.
Example

Anxiety delirium and agitation

### Present
Assess and treat reversible causes:
- severe pain; full bladder, full rectum; nicotine withdrawal; opioid toxicity.

### Absent
In anticipation of future agitation prescribe MIDAZOLAM 2.5mg-5mg prn SC
Review this at least every 24hrs

Consider if Anxiety or Delirium

#### DELIRIUM
Prescribe and administer
- HALOPERIDAL 0.5mg 2hrly prn SC
  
  Alternatively
  - LEVOMEPROMAZINE 6.25mg-12.5mg 4-6hrly prn SC
  - Review at least every 24hrs

If three or more doses required in 24hrs – commence a syringe pump.
- HALOPERIDOL 5mg -15mg /24hrs SC
  
  Alternatively
  - LEVOMEPROMAZINE 25mg /24hrs SC
  - Continue with PRN medication
  - Doses in syringe pump should be titrated according to total 24hr PRN doses

#### ANXIETY
Prescribe and administer
- MIDAZOLAM 2.5mg-5mg 2hrly prn SC
  
  Give MIDAZOLAM 5mg 2hrly prn SC if previously on benzodiazepines
  - Review at least every 24hrs

If three or more doses required in 24hrs – commence a syringe pump.
- Doses via syringe pump should be titrated according to total 24hr PRN doses
  - MIDAZOLAM (total PRN dose / 24hrs SC)
  
  Alternatively
  - LEVOMEPROMAZINE 12.5mg /24hrs SC
  - Continue with PRN medication
  - Doses in syringe pump should be titrated according to total 24hr PRN doses

**SEVERE AGITATION IS OFTEN RESISTANT TO THE EFFECTS OF SEDATIVES AND MAY NEED REPEATED DOSES OR A COMBINATION OF BOTH ANTIPSYCHOTIC AND BENZODIAZEPINE MEDICATION**

Contact Specialist Palliative Care Team for further advice.
Please refer to the British National Formulary BNF for current guidance on medications and dosages.
Respiratory tract secretions

Managing noisy respiratory secretions

1. Assess for the likely causes of noisy respiratory secretions in people in the last days of life. Establish whether the noise has an impact on the dying person or those important to them. Be prepared to talk about any fears or concerns either may have. Reassure those important to the dying person that, although the noise can be distressing, it is unlikely to cause discomfort.

2. Consider non-pharmacological measures to manage noisy respiratory or pharyngeal secretions, to reduce any distress in people at the end of life.

3. Consider a trial of medicine to treat noisy respiratory secretions if they are causing distress to the dying person. Tailor treatment to the dying person’s individual needs or circumstances, using one of the following drugs:
   - ATROPINE or
   - GLYCOPYRRONIUM or
   - HYOSCINE BUTYLBROMIDE or
   - HYOSCINE HYDROBROMIDE.

4. When giving medicine for noisy respiratory secretions:
   - Monitor for improvements, preferably every 4 hours, but at least every 12 hours.
   - Monitor regularly for side effects, particularly delirium, agitation or excessive sedation when using atropine³ or hyoscine hydrobromide³.
   - Treat side effects, such as dry mouth, delirium or sedation

5. Consider changing or stopping medicines if noisy respiratory secretions continue and are still causing distress after 12 hours (medicines may take up to 12 hours to become effective).

6. Consider changing or stopping medicines if unacceptable side effects, such as dry mouth, urinary retention, delirium, agitation and unwanted levels of sedation, persist.
Example

Respiratory tract secretions

Present

Explanation and reassurance to those important to the dying person

Consider non-pharmacological interventions
- Repositioning the person
- Discontinuing artificial hydration
- Suction may help

Prescribe and administer:
HYOSCINE HYDROBROMIDE 0.4mg 4-6hrly PRN SC
or
GLYCOPHYLLIN 0.2mg 4-6hrly PRN SC
or
HYOSCINE BUTYLBROMIDE 20mg 4-6hrly SC
or
ATROPINE 0.4mg 4-6hrly PRN SC
Continue to give prn dosage accordingly.

Symptoms persisting

Absent

In anticipation of future symptoms
Prescribe:
HYOSCINE HYDROBROMIDE 0.4mg 4-6 hrly prn SC
or
GLYCOPHYLLIN 0.2mg 4-6 hrly prn SC
or
HYOSCINE BUTYLBROMIDE 20mg 4-6 hrly SC
or
ATROPINE 0.4mg 4-6 hrly PRN SC

Symptoms and concerns resolved

If 2 or more prn doses required in 24hrs, consider syringe pump
HYOSCINE HYDROBROMIDE 1.2mg-2.4mg / 24hrs SC (total 2.4mg in 24hrs)
Or
GLYCOPHYLLIN 1.2mg / 24hrs SC
or
HYOSCINE BUTYLBROMIDE 60mg-120mg / 24hrs SC
or
ATROPINE 1.2mg-2.4mg / 24hrs SC
Liaise with Specialist Palliative Care Team for further advice

Contact Specialist Palliative Care Team Refer to the Palliative Care Team for further advice.
Please refer to the British National Formulary BNF for current guidance on medications and dosages.
Nausea and vomiting

Assess for likely causes of nausea or vomiting in the dying person. These may include:
- certain medicines that can cause or contribute to nausea and vomiting
  recent chemotherapy or radiotherapy
- psychological causes
- biochemical causes, for example hypercalcaemia
- raised intracranial pressure
- gastrointestinal motility disorder
- ileus or bowel obstruction

Discuss the options for treating nausea and vomiting with the dying person and those important to them
- consider non pharmacological methods for treating nausea and vomiting in a person in the last days of life

When choosing medicines, take into account:
- the likely cause and if it is reversible
- the side effects, including sedative effects, of the medicine
- other symptoms the person has
- the desired balancing of effects when managing other symptoms
- compatibility and drug interactions with other medicines the person is taking

For people in the last days of life with obstructive bowel disorders consider:
- HYOSCINE BUTYLBROMIDE as the first line pharmacological treatment
- OCTREOTIDE if the symptoms do not improve within 24 hours of starting treatment with HYOSCINE BUTYLBROMIDE
- CYCLIZINE is not recommended in people with heart failure.
**Example**

### Nausea and Vomiting

**Present**

- Assess for cause.
- Could the person have a bowel obstruction?
  - **IF YES**
    1. Avoid pro-kinetic antiemetic i.e metoclopramide
    2. Stop stimulant laxatives
    3. Liaise with Palliative Care Team.
    4. Prescribe and administer CYCLIZINE 50mg SC 8hrly prn
    5. Review this every 24hrs.
- If 3 doses required in 24hrs, set up syringe pump with CYCLIZINE 150mg/24hrs SC (total 150mg in 24hrs)

**Absent**

- Assess for cause.
- Are symptoms persisting with no specific cause identified?
  - **IF YES**
    1. Prescribe and administer CYCLIZINE 50mg 8hrly prn SC injection.
    2. Continue to give prn dosage accordingly.
    3. Review this every 24hrs.
    4. If 3 doses required in 24hrs, set up syringe pump with CYCLIZINE 150mg / 24hrs SC (total 150mg in 24hrs)

**Consider an alternative antiemetic if previous one is not effective.**

**PRN**

- HALOPERIDOL 2.5mg – 5mg prn SC
  - or
- LEVOMEPROMAZINE 6.25mg prn SC

**Syringe Pump over 24hrs**

- HALOPERIDOL 5mg – 10mg 24 hours SC
  - or
- LEVOMEPROMAZINE 12.5mg – 25mg/24hrs SC

**Contact Specialist Palliative Care Team for further advice.**

Please refer to the British National Formulary BNF for current guidance on medications and dosages.

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**Author:** Cheryl Young, Practice Development Lead / NCGC member  - NICE guideline (NG31)
**Date of issue:** 01/06/2016
**Date of review:** 01/06/2018
Dyspnoea

Managing breathlessness

1. Identify and treat reversible causes of breathlessness in the dying person, for example pulmonary oedema or pleural effusion.

2. Consider non-pharmacological management of breathlessness in a person in the last days of life. Do not routinely start oxygen to manage breathlessness. Only offer oxygen therapy to people known or clinically suspected to have symptomatic hypoxaemia.

3. Consider managing breathlessness with:
   - an opioid
   - a benzodiazepine or
   - a combination of an opioid and benzodiazepine.

¹At the time of publication (December 2015), this medication did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. See the General Medical Council’s Prescribing guidance: prescribing unlicensed medicines for further information.
EXAMPLE

**Dyspnoea**

**Present**

Consider non-pharmacological interventions:
- Position
- Fan therapy
- Music Therapy
- Reassurance

Manage respiratory secretions

**Absent**

In anticipation of future breathlessness
Prescribe DIAMORPHINE 2.5mg-5mg 2hrly prn SC or Normal PRN dose DIAMORPHINE SC if using it regularly for pain management and MIDAZOLAM 2.5mg-5mg 2hrly prn SC for anxiety/distress

Are they already taking oral morphine for breathlessness?

- No

**OPTION 1**
Prescribe and administer DIAMORPHINE 2.5mg 2hrly prn SC

Convert from oral opioids to a syringe pump.
Review this every 24hrs.
Doses via syringe pump should be titrated according to total 24hr PRN doses

**OPTION 2**
Prescribe and administer MIDAZOLAM 2.5mg 2hrly prn SC

Convert from oral opioids to a syringe pump.
Review this every 24hrs.
Doses via syringe pump should be titrated according to total 24hr PRN doses

**OPTION 3**
Prescribe and administer DIAMORPHINE 2.5mg + MIDAZOLAM 2.5mg 2hrly prn SC

Convert from oral opioids to a syringe pump.
Review this every 24hrs.
Doses via syringe pump should be titrated according to total 24hr PRN doses

**Contact Specialist Palliative Care Team**

Give normal PRN dose of DIAMORPHINE and/or MIDAZOLAM SC

**DEPENDING ON THE INDIVIDUAL’S NEED THE DOSES FOR PAIN AND DYSPNOEA MAY BE DIFFERENT**

**THE MEDICATION CHART NEEDS TO BE SPECIFIC (INDICATION FOR USE) SO THE APPROPRIATE DOSE AND FREQUENCY IS PRESCRIBED AND ADMINISTERED CORRECTLY**

Contact Specialist Palliative Care Team for further advice.
Please refer to the British National Formulary BNF for current guidance on medications and dosages.

Author: Cheryl Young, Practice Development Lead / NCGC member - NICE guideline (NG31)
Date of issue: 01/06/2016
Date of review: 01/06/2018
Community Anticipatory Prescribing for the Dying Person.

Use an individualised approach to prescribing anticipatory taking into account symptoms such as agitation, anxiety, breathlessness, nausea and vomiting, noisy respiratory secretions and pain.

When deciding which anticipatory medicines to offer take into account the place of care and the time it would take to obtain medicines especially out of hours.

Community Prescriptions can be written using the following wording:

Analgesic:
Diamorphine Hydrochloride injection (5mg ampoules)
Dose: 2.5mg-5mg, 2hourly prn SC for pain or breathlessness.
Supply 5 (five) 5mg ampoules.

Anxiolytic sedative:
Midazolam injection (10mg in 2ml ampoules)
Dose: 2.5mg-5mg, 2hourly prn SC for anxiety/distress/myoclonus.
Supply 10 (ten) 2ml ampoules.

Anti-secretory:
Hyoscine Hydrobromide injection (400mcg/ml ampoules)
Dose: 400mcg, 6hourly prn SC for respiratory secretions.
Maximum of 2400mcg (2.4mg) in 24 hours via syringe pump SC
Supply 5 ampoules.

Antiemetic:
Cyclizine injection (50mg/ml ampoules)
Dose: 50mg, 8 hourly prn SC for nausea.
Supply 5 ampoules.
or
Levomepromazine injection 25mg/ml
Dose: 6.25mg, 6 hourly prn SC for nausea.
Supply 5 ampoules.

Dilution
Water for injection 10mls
Supply 20 ampoules
**Syringe Pump**

The CME McKinley T34 syringe pump is a portable, battery operated device for delivering medication by continuous subcutaneous infusion (CSCI).

This syringe pump is the only 24 hour pump to be used (on the Isle of Man) for symptom management of palliative care individuals when the oral route cannot be used.

**ALL STAFF WHO USE THE McKinley T34 SYRINGE PUMP MUST HAVE TRAINING BEFORE THEY USE THE PUMP AS PART OF THEIR CARE.**

**Breakthrough Pain**

- If the syringe pump is being used to administer opiate analgesia such as Diamorphine, then extra breakthrough analgesia must be prescribed and administered as a subcutaneous injection
- Dosage will be calculated as a *sixth* of the *total 24 hour infusion*
- Separate subcutaneous injections should be prescribed as required

If a patient can no longer swallow oral meds and is in pain consider initially managing them with SC bolus injections, if they need 2 -3 or more injections in 24 hours set up a syringe pump.

**Start the syringe pump immediately if the person has pain and:**

- is not currently on any opioid OR
- is receiving opioid on an ‘as required’ basis OR
- is receiving immediate release oral opioid preparation e.g. Oramorph; Oxynorm.
- persons on modified release oral opioid preparation e.g. MST®; MXL®

Ideally, start the syringe pump when the next dose of modified release preparation is due, but particularly in the community setting, this may not be a convenient or safe time. A decision on an appropriate time should be based on the clinical status of each individual person. All drugs should be mixed with water for injection unless contraindicated.

- **Octreotide, Ketorolac, Ketamine should be mixed with normal saline.**
- Please use conversation charts and flow diagrams for guidance when prescribing medication for a syringe pump.
Drug compatibility

It is common to see two drugs in a syringe pump, but if more drugs than this are required for symptom management it is advisable to contact the Palliative Specialist team for advice, as not all drugs are compatible or stable. Some drugs may be physically or chemically incompatible. Please check the BNF for drug compatibilities.

- Use a **20ml luer lock syringe** and draw up the prescribed medication and diluents to **17mls**.
- If a **30ml luer lock syringe** is recommended, draw up the medication and diluents to **23.5ml**.

Factors which may affect stability/compatibility are:
- drug concentration; brand/formulation; diluents; time interval; temperature of surroundings; exposure to light; order of mixing; delivery system material.

Oral treatment is to be re-started

If an oral modified release preparation is being commenced, the continuous subcutaneous infusion should be stopped when the first dose of modified release oral opioid is administered. The person may require breakthrough medication more frequently until therapeutic levels are reached.

Key references

Community / Care Home Guidance

Is the person dying?
BEFORE YOU CALL 999...

H

HAS! – the individual got DNA-CPR (do not attempt cardiopulmonary resuscitation) or an Advanced Directive to Refuse Treatment (ADRT)?

O

OPTIONS! – are the symptoms acute or longstanding? What medication / treatments have been trialled? Might symptoms be better managed with a different route of administration?

S

SYMPTOMS! - can any of the symptoms be reversed by any treatment that you can give? Have you liaised with the G.P./Palliative Care Team for advice?

P

PPC! Does the individual have an advance care plan e.g. Preferred Priorities for Care (PPC)? Consider, does the individual wish to be transferred to hospital or to be managed within the care home?

I

IS! the individual entering the dying phase of their life? Consider if the person is well enough to be moved.

T

TEAM! Has the multidisciplinary team (MDT) identified this individual as coming to the end of their life? If so, have the MDT been involved in the decision to transfer the individual to hospital.

A

AMBULANCE SERVICE! If the individual has a PPC, ADRT and/or DNA-CPR in place and needs to be transferred by ambulance to hospital, you need to inform the service and have copies of these documents available with the transfer form.

L

LISTEN TO THE INDIVIDUAL & FAMILY! Have you discussed with the individual/family their possible admission to hospital? Have you discussed with the individual/family that PPC may not be achieved if they are admitted to hospital.

N.B If the individual is not in the dying phase of life and symptoms are acute and potentially reversible then admission would be appropriate with a view to rapid discharge back home.

Author: Cheryl Young, Practice Development Lead / NCGC member - NICE guideline (NG31)
Date of issue: 01/06/2016
Date of review: 01/06/2018
Points to Remember

1. Recognise deterioration in a person – could this be a sign that they are dying?
2. Keep the person / family informed of any changes in care.
3. Stop unnecessary treatment and medication.
4. Prescribe anticipatory medication on an individual basis only - convert oral to SC medication if they are unable to swallow medication or if unlikely to be able to within the next few days.
5. Review the Do Not Attempt Cardiopulmonary Resuscitation Order. Documentation completed. Communication with the person (if conscious and willing) and those important to them.
6. Assess and monitor symptoms as they occur or at least every 24hrs.
7. Consider a syringe pump - discuss as far as possible the reasoning with the person and those important to them.
8. Support the person to take food and fluids by mouth for as long as tolerated. Communicate to them if appropriate, and those important to them the reduced need for food and fluids in the dying phase.
9. Assess the need for artificial hydration taking into account the person’s wishes and needs.
10. If the person has an Implantable Cardioverter Defibrillator (ICD), contact the person’s cardiologist. Refer to ECG technician and to local guidelines re deactivating it.
11. Prepare for any specific religious, spiritual or cultural need a person might have and support as necessary.
12. If the person is an Insulin Dependent Diabetic, contact Diabetes CNS for further guidance.
13. On rare occasions a person’s condition may improve. Seek a second opinion or specialist palliative care support as needed.
Hospice Isle of Man
Specialist palliative care services offer telephone advice, a single assessment visit or a period of specialist care according to need.

Referral
Can be made for an individual who has any life limiting illness, and is in or is entering the end of life phase of their illness, if they have;

- complex end of life care needs.
- uncontrolled pain or other symptoms.
- complex physical, psychological, spiritual or family needs that cannot be met by the staff

A referral should sent or faxed to Hospice Isle of Man. Referrals will be triaged at 9.30am each morning. Please be aware individuals may not be seen on the same day as referral sent. If visit is needed as a matter of urgency please contact the service to see if arrangements can be made.

Palliative Care Clinical Nurse Specialist Team (CNS)
Available Monday to Friday 9am-5pm

Hospice Isle of Man
Tel. 01624 647475 (team office with answerphone)
     01624 647400 (hospice reception)
Fax: 01624 647460

Palliative Care out of hours

- Contact Hospice Isle of Man Reception. A senior doctor and/or nurse is available to give telephone advice on complex symptom management.
- Contact Manx Emergency Doctors Service (MEDS) – may need to visit and review individual.