Key priorities and guidance for care in the last few days and hours of life.

3rd Edition

Produced in partnership with Countess of Chester NHS Foundation Trust, Cheshire and Wirral Partnership, the Hospice of the Good Shepherd and West Cheshire Clinical Commissioning Group

Review Nov 2016
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Introduction

The purpose of this document is to provide guidance to facilitate the delivery of good quality holistic end of life care for those people who are identified as being in the last days and hours of their life.

There may be uncertainty in identifying when someone is dying. Illness can be unpredictable and changes may occur suddenly.

This document does not provide detailed instruction or a list of steps to be taken. Each person is an individual with their own particular priorities, concerns and preferences. This document should inform the reasoning which is necessary to provide individualised person-centred care.

This document aims to guide health and other care professionals supporting people who are recognised as being in the last days and hours of their life and their families. It highlights key priorities which are applicable in all care settings and should be used in conjunction with other local policies, the 5 key priorities advocated in `One chance to get it right` (2014) and NICE guidance `Care of dying adults in the last days of life` (2015).

Staff can be confident that they are providing good individualised care for people who are in the last days and hours of life by:

- Applying the key priorities
- Ensuring their care takes into account the uncertainty involved in recognising that someone is dying
- Understanding the importance of sensitive and clear communication with people who are recognised as possibly being in the last days and hours of life, their families and those who are important to them.
- Understanding the role of food and drink in the dying phase
- Following locally recognised good practice guidance about end of life care
- Directing people, families and those identified as being important to them to relevant information according to their assessed needs.

The document is also available to members of the public.
5 Key Priorities

The key priorities highlight essential aspects of care for teams to address when caring for people in the last days and hours of life. Applying these principles will support staff in caring for dying people and those close to them.

When it is thought possible that a person may die within the next few days or hours, the priorities for care are:

1. **Recognise**
   
The possibility that a person may be dying is recognised and communicated, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.

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 and do**
   
An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support is agreed, coordinated and delivered with compassion.

The priorities of care reinforce that the focus for care in the last few days and hours of life must be the person who is dying. The priorities are set out in sequential order but are all equally important to achieving good care in the last days and hours of life and there is significant overlap between them. Each supports the primary principle that individual care must be provided according to the needs and wishes of the dying person.
Priorities for care of the dying person

1. Recognise

This possibility that a person may die is recognised and communicated, decisions made and actions taken in accordance with the person’s needs and wishes and these are regularly reviewed and decisions revised accordingly.

Recognising dying can be highly complex

- Agreement that a person’s death is expected within days or hours must be based on a multi-disciplinary discussion about the person’s condition which acknowledges that recognising dying involves an element of uncertainty.
- Use knowledge from assessments and other information gathered from the multi-professional team, the person and those important to them to determine whether the person is nearing death, deteriorating, stable or improving. ²
- Regular ongoing monitoring of a person’s changing condition should continue.

Rationale

If it is recognised that a person is clinically unstable and may not recover despite medical treatment, it enables decisions about future care to be made which should involve that person, if possible, their family and those identified as important to them.

Examples of considerations to be made and documented

- When a person’s condition deteriorates and it is thought they may die i.e. within the next few days or hours, they should be assessed by a doctor who is competent to judge whether the change is potentially reversible or the person is likely to die. ¹
- If the doctor judges the person is likely to die, taking into account the views of others caring for the person, this must be clearly and sensitively explained to the person (if conscious and they have not indicated that they would not wish to know) their family and others identified as important to them, in a way that is appropriate to their circumstances
• Doctors and nurses must acknowledge, accept and communicate uncertainty that exists about the prognosis
• The content and outcome of all discussions must be documented and accessible to all those involved in a person’s care, taking into account the person’s wishes about sharing confidential information. This includes conversations about prognosis, treatment goals and care plans at each point in time, and particular goals, wishes and concerns that the person, their family and those identified as important to them, have expressed.
• A individualised holistic plan of care must be developed, documented, and the person be regularly reviewed to check that the plan of care remains appropriate and to respond to changes in the person’s condition, needs and preferences
• The dying person must be reviewed by a senior clinician within the person’s care team at least daily- or sooner if there is unanticipated change in the person’s condition- to assess whether they are still likely to be dying (given the uncertainties of prognosis) and if the plan of care remains appropriate. The senior clinician may delegate this responsibility to another clinician who has appropriate training and competence but will remain accountable for overall care of the dying person.

2. Communicate

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

Communication is an essential component of each individual person’s care

Communication should be sensitive, informative and timely and may include such aspects as:

• The person’s condition
• How much information they would like to be given, including about prognosis
• The understanding of the person, their family and those identified as important to them of the current situation
• Their cognitive status and if they have any speech, language or other communication needs
• Uncertainty around the current situation
• Expectation around the person’s condition and care
• Shared decision making around the individualised plan of care
• Reassurance of ongoing regular review

__________________________________
- Any cultural, religious, social or spiritual needs or preferences.
- Information about how to contact members of their care team

It is essential that good communication takes place between health and other care professionals to ensure continuity of care.

Rationale

Good communication facilitates the preparation for what is likely to happen.

Examples of considerations to be made and documented

- Regular daily assessment of the understanding of the person (where possible) and their family and those important to them.
- Sensitive communication relating to this understanding which may include explanations about:
  - The person’s condition
  - Uncertainty
  - The individual person’s needs relating to clinically assisted nutrition and fluids (by drip or feeding tube) as they approach the end of their life and how these will be addressed. This is distinct from food and drinks which the person will be supported to take as able and wanted.
- The name of the senior clinician responsible for the person’s care.
- The named nurse responsible for leading the nursing care.
- How to contact key professionals involved in care.

   (This does not represent an exhaustive list of examples)

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.

Significant decisions about a person’s care, including recognising dying, should be made on a shared decision-making basis
Responsibility for decisions made is carried by the senior clinician responsible for the care of the person and incorporates the wishes of the person, family and those important to them.

Rationale

- Recognising dying can be highly complex and the perspectives of all those involved in the person’s care are essential to ensure that a person is identified as likely to be in the last days or hours of their life, allowing for inherent uncertainty.
- Team discussion allows all those involved in the person’s care to understand the reasons for the change in focus of care and to sensitively and informatively communicate this to the person (where possible) and their family and those identified as important to them.
- The focus of care will shift towards interventions to keep the person comfortable.
- Identifying that a person may be in the last days or hours of life allows the team to focus on their priorities, including their preferred place of death, and begin rapid plans to achieve this aim if appropriate and possible.

Examples of considerations to be made and documented

- A plan for managing the person’s condition should be made. This should include a record of decisions made by the multi-disciplinary team including:
  - Explanation of reasons for recognising that the person is dying.
  - Decisions to stop or not begin medical interventions which are considered to be of no benefit to that person.
- The circumstances, care needs, goals and wishes of each individual person should be considered in deciding which interventions are appropriate.
- Consideration should include the balance of burden and benefit to the person of each intervention and the contribution of each intervention.
- The person’s preferred place of care should be identified and achieved if possible.
- It is essential that all members of the team acknowledge that recognising dying involves elements of uncertainty, therefore, regular ongoing monitoring of a person’s changing condition should continue.
- The 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.
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.

The needs of relatives and those identified as being important are recognised and addressed

It is important to recognise that the last days and hours of a person’s life may be a distressing time for family members and others who are close to them. Staff should recognise and respect this both before and after the person has died and support them accordingly.

**Rationale**

- Lasting memories of what happened around the time of death can stay with those who have been bereaved for many years and can support or hinder them in their adjustment to the death

**Examples of considerations to be made and documented**

- Assess the needs of family and those identified as important and address these as far as possible
- Give opportunity for family and those identified as important to ask any questions and express any concerns
- Flexible visiting should be made available to the family and those identified as important
- Provide information on facilities available to family and those recognised as being important to them
- Sensitive communication with family and those identified important before and after the death of a person should take place.
- When a person dies the care does not end and a continuing duty of care should be recognised.
• What is written on the medical certificate of cause of death should be sensitively explained when it is given to the family, answering any questions and checking understanding.
• If it is recognize that the death will need to be referred to the Coroner this should be explained at a suitable time together with the rationale

5. Plan and Do

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support is agreed, coordinated and delivered with compassion.

Each individual person’s physical, psychological, social and spiritual needs are recognised and addressed as far as is possible

The holistic needs of a person must always be the prime consideration when planning and providing care, and this applies equally to the last days and hours of life as to other times.

Rationale

People who are dying must be cared for with respect and dignity with their needs anticipated and managed by competent staff.

Examples of considerations to be made and documented

• Assessment of holistic needs relating to the four domains: physical, psychological, social and spiritual should be undertaken
• Assessment of nursing care and interventions should be undertaken and a plan developed according to need
• An agreed individualised plan of care should be documented and reviewed at least daily
• Any discussions and outcomes resulting from these discussions should be documented
• Key physical symptoms such as: pain, breathlessness, respiratory tract secretions agitation, nausea and vomiting should be assessed and any interventions to address these documented in the case record
• Any outstanding psychological and social issues causing distress for the person, their family and those identified as important to them should be identified and addressed where possible.

• The person’s religious and/or spiritual needs must be identified and contact made with relevant individuals who may be in a position to support the person, their family and those identified as important to them, if they wish.

• When needed the person’s current care team should seek advice from the appropriate Specialist Palliative Care Team.

• Individual assessment regarding food and drink should be clearly documented.

• The resuscitation status of the person should be reviewed in accordance with local policy and communicated to the person, family and those identified as important, unless the clinician believes that involving the person in the process will cause physical or psychological harm.¹

• Last offices should be undertaken with respect and dignity according to local policy and in accordance with the person’s wishes.
Clinical Guidelines

These guidelines aim to facilitate clinical decision-making and good practice in person-centred care for people who are deteriorating and likely to be in the last few days or hours of life. It is recognised that there can be uncertainty in identifying when a person is dying and reversible causes for the person’s deterioration should be excluded or treated where appropriate.

For example:

- Dehydration
- Hypercalcaemia
- Opioid toxicity
- Sepsis
- Withdrawal of steroids
- Delirium
- Acute kidney injury

Changes that may indicate that a person is entering the last few weeks or days of life may include:

- Signs such as agitation, Cheyne-Stokes breathing, deterioration in level of consciousness, mottled skin, noisy respiratory secretions and progressive weight loss
- Symptoms such as increasing fatigue and loss of appetite
- 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 a person may be stabilizing or recovering.²

The clinical team must fully assess the physical, psychological, spiritual and social needs of the person.

Where the doctor (senior clinician with overall responsibility) has identified that a person is in the last few days or hours of life they must discuss and agree a plan of care with the person (where possible) their family and those identified as important. Ideally this should be done in-hours and by the team who know the person best.

The agreed plan of care should clarify and document the following:

- Significant decisions about a person’s care, including recognising dying, which should be made on a shared decision-making basis.
- Recognition of dying and the rationale for this
- The person’s understanding and holistic care preferences
• The understanding of the family and those identified as being important, of the current situation
• Proposed plan of care including discussion about:
  o Do not attempt cardio pulmonary resuscitation (DNA-CPR) status
  o Deactivation of implantable cardioverter-defibrillator (ICD) according to local policy, if the person has one in place.
  o The risks and benefits of food and drink.
  o Discontinuation of routine nursing observations and interventions not thought to be clinically appropriate.
  o Planned nursing interventions should include:
    - Supporting the person to take food and drink as long as they are able and want to.
    - Comfort care including:
      ➢ Pressure area care and repositioning for comfort
      ➢ Eye care
      ➢ Mouth care
      ➢ Bowel and bladder care
      ➢ Assessment of symptoms
• All medication should be reviewed and non-essential medication(s) should be discontinued with essential medication(s) being continued by the appropriate parenteral route.
• 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 medicine prescribed.
• 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 multiprofessional team.²
• 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 may take to obtain medicines³
• Seek specialist palliative care advice if needed eg for advice on anticonvulsants, steroids, insulin and other complex symptom management.
Decision-Making and Capacity

The focus of care in the last few days and hours of life must be the person who is dying and their needs and wishes.

For some people who are entering the last days of life, mental capacity to understand and engage in shared decision-making may be limited. This may be temporary or fluctuating. This guidance should be used in conjunction with the Mental Capacity Act (2005)\(^3\).

If a person lacks capacity and there is a valid and applicable Advance Decision to Refuse Treatment (ADRT) then this must be abided by as it is legally binding. If the person has appointed a Lasting Power of Attorney (LPA) who has been registered for Health and Welfare, then the LPA can make decisions on the person’s behalf.

If it is established that a person lacks capacity at the relevant time to make the relevant decision then a decision must be taken in their best interests in accordance with the Mental Capacity Act (2005)\(^3\). The person making the decision must, if it is practicable and appropriate to do so, consult:

- Anybody named by the person as someone to be consulted on either the decision in question or similar issues;
- Anyone engaged in caring for the person, close relatives, friends or others who take an interest in the person’s welfare;
- Any holder of a lasting power of attorney or enduring power of attorney;
- Any deputy appointed by the court to make decisions for the person.

Also consider whether they have previously expressed preferences pertaining to their end of life care.

Further guidance on making a best interests decision is provided in the Mental Capacity Act Code of Practice\(^4\) and in local organisational policies. The Coroner considers the death of any person with an authorised Deprivation of Liberty Safeguard (DoLS) an inquest case due to the fact that a DoLS is essentially a state detention. Refer to local organisational policies regarding DoLS and referral to the Coroner.

For any dying person who is assessed to lack capacity and has no-one else to support them other than members of the healthcare team, consider consulting with the Independent Mental Capacity Advocate (IMCA) service.
Food and drink

It is normal for a person who is dying not to feel like eating and drinking and it is important that this is explained to the person, their family and those identified as important. It is essential to consider how the person currently receives food and fluids (oral, intravenous, subcutaneous, nasogastric, PEG) and ascertain if this is adequate and appropriate. People who are able to eat and/or drink should be helped and supported to do so if they wish, unless they choose not to. If a dying person makes an informed choice to eat or drink, even if they are deemed to be at risk of aspiration, this must be respected and they should be monitored for signs of aspiration/choking or distress.

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 advance decision to refuse treatment (ADRT)
- Their level of consciousness
- Any swallowing difficulties
- Their level of thirst
- The risk of pulmonary oedema
- Whether even temporary recovery is possible.

Giving clinically assisted hydration may relieve distressing symptoms or signs related to dehydration but it may also cause pain, discomfort or swelling at the infusion site. Health care professionals and people important to the dying person may believe that providing clinically assisted hydration will prolong dying or that “withholding” it will hasten death, but there is no evidence for this.

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.

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 of there are signs of possible harm to the dying person, such as fluid overload, or if they no longer want it.

Decisions about the use and/or discontinuation of clinically-assisted hydration and nutrition (i.e. intravenous, subcutaneous, nasogastric, PEG) must be based on consideration of the needs and circumstances of the particular individual person and must be in line with the General Medical Council (GMC) 2010 guidance Treatment and care towards the end of life: Good practice in decision making.7

The rationale for decisions and/or changes should be promptly communicated and carefully explained to family and those identified as important and the risk and benefits of clinically-assisted hydration and nutrition discussed with the person (where possible), family and those identified as important to the person.

Decisions surrounding use of clinically-assisted hydration and nutrition should be discussed with the multi professional team, the person, family and those identified as important in accordance with the Mental Capacity Act (2005).

There is evidence to suggest that clinically assisted hydration may aggravate oedema, ascites and pleural effusions in people with advanced cancer but may reduce myoclonus and sedation at the end of life.

There is no robust evidence to suggest that clinically assisted hydration causes or aggravates respiratory tract secretions in people who are dying.

Decisions to start or continue clinically-assisted hydration in the last days and hours of life must always be communicated with an acknowledgement that it will be reviewed and discontinued if it causes problems for the dying person.

Regular mouth care remains essential during the last days and hours of life and health and social care staff must pay attention to the dying person’s mouth care and other personal needs to maintain their comfort and dignity. Encourage those 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.

Spiritual care ²

It is important that spiritual and religious needs are regularly assessed and reviewed, as these are individual and may change. Support from the chaplaincy team should be offered.
Spiritual care is that care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires. When specialist spiritual/religious support is identified as required, health and care staff must ensure that the dying person, and those important to them, have ready access to information about the available chaplaincy and/or spiritual care provision.

Chaplains must have information about local faith leaders to enable, where requested by the person, referral to church or faith community leaders.

Staff must find out from the dying person, their family and those important to them, the details of any cultural or religious–specific requirements, including what constitutes respectful treatment of the body after death.

**Symptom control in the last days and hours of life**

**General principles**

All medications, including anticipatory medicines, must be targeted at specific symptoms, have a clinical rationale for the starting dose, be regularly reviewed and adjusted as needed for effect.

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 individualized care plan to help decide which medicines are clinically appropriate.
- Discuss the benefits and harms of any medicines offered.

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.
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.

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.

It is important to explain to the dying person, their family and those identified as important to them, the reason for any intervention, including the use of a continuous subcutaneous infusion (usually via a syringe driver). Other than in exceptional circumstances, this should be done before it is commenced.

It should be discussed with the dying person the likely side-effects of specific interventions, especially those that may make them sleepy. This will enable them to make informed decisions, and should also be explained to those important to the dying person if the person wishes.

Symptoms commonly experienced by people in the last hours and days of life are:-

- Pain
- Breathlessness
- Excessive respiratory tract secretions
- Restlessness / agitation
- Nausea and vomiting

It is important that medications to control the above symptoms are prescribed in anticipation of symptoms occurring.

‘As required’ doses should be prescribed with a clearly stated maximum dose and frequency where applicable. 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\(^2\).

It is important that established medications for currently controlled symptoms are converted to the appropriate parenteral equivalent as required.

The subcutaneous route is recommended for parenteral use in last days or hours of life and if two or more ‘as required’ doses are needed over 24 hours, a continuous subcutaneous infusion (CSCI) should be considered if not already in place or the dose adjusted in an established CSCI.

Local guidance contains recommendations for symptom control in the last days or hours of life.
Guidelines

Pain

Consider non-pharmacological management of pain in a person in the last days of life.

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.

People unable to take regular oral opioids should have their analgesia converted to an equivalent dose of opioid administered by continuous subcutaneous infusion (CSCI) this will usually be via a syringe driver.

Morphine sulphate is the parenteral opioid of choice in the last days or hours of life, unless the person is already established on an alternative opioid for a specific reason. Refer to algorithms *

If the person is opiate naïve morphine sulphate injection 2.5mg to 5mg subcutaneously 2 to 4 hourly is an appropriate starting dose.

Morphine sulphate should be used cautiously in people with renal failure. Contact the specialist palliative care team for advice.

Commencing morphine sulphate as a CSCI in people receiving oral morphine sulphate:

To calculate total 24 hour subcutaneous dose required:

\[
\frac{\text{Total 24 hour oral morphine sulphate}}{2} = \frac{24 \text{ hour morphine sulphate injection in syringe driver (CSCI)}}{2}
\]

Breakthrough (as required) dose:

\[
\frac{24 \text{ hour morphine sulphate injection (CSCI)}}{6} = \text{morphine sulphate injection subcutaneously 3 to 4 hourly as required}
\]

For people whose pain is controlled with transdermal opioids the patch should be continued and not removed in the last days or hours of life. If an increase in pain relief is needed additional analgesia can be given.

For people whose pain is managed with a transdermal patch, appropriate ‘as required’ doses of immediate release morphine sulphate should be prescribed as a subcutaneous injection.
If two or more of these doses are required over 24 hours a CSCI should be considered in addition to the patch.

Contact the specialist palliative care team for further advice on pain management for people whose pain is poorly controlled in the last days and hours of life or for advice on alternative opioids or if they are experiencing undesirable side effects.

**Breathlessness**

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

Non-pharmacological options should be considered these include:

- Reassurance and explanation
- Use of a fan or cool air across the face
- Adequate positioning of the patient to aid breathing.

Do not routinely start oxygen to manage breathlessness. Only offer oxygen therapy to people known or clinically suspected to have symptomatic hypoxaemia.

People who are breathless and already established on a long acting opioid eg modified release preparations may benefit from an ‘as required’ dose of immediate release opioids. This should be fully assessed according to the person’s preference and response to medication.

Benzodiazepines can be useful in the management of breathlessness. If the person is still able to take oral medication consider lorazepam 500 micrograms to 1mg sublingually. If not an alternative injection of midazolam 2.5mg subcutaneously could be considered. **Refer to algorithms** *

If the person finds the administration of oxygen helpful to relieve their breathlessness it can be continued. Nasal prongs may be better tolerated than a mask.

**Respiratory tract secretions**

It is important to talk to families and those identified as being important, giving explanation and reassurance, as this symptom may cause considerable distress to them.
Non-pharmacological measures are an important part of the management and may simply include a change of position.

Consider a trial of medicine to treat noisy respiratory secretions if they cause distress to the dying person. Refer to algorithms *

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 hyoscine hydrobromide.
- Treat side-effects, such as dry mouth, delirium or sedation.

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).

Suction should be avoided, as this maybe distressing to the person and only used as a last resort.

Fluid overload, recent aspiration and respiratory infection can increase the incidence of respiratory tract secretions.

Agitation, restlessness and delirium

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.²

Possible reversible causes of the agitation / restlessness should be sought and managed appropriately. Examples include:

- Urinary retention
- Opioid toxicity
- Nicotine withdrawal
- Constipation
- Noise

Midazolam 2.5mg 'as required' should be prescribed and administered subcutaneously for anxiety and agitation. See algorithms*

If a reversible cause for the agitation or restlessness is found this should be addressed if appropriate and the person assessed regularly for any further agitation/restlessness and 'as required' doses of midazolam administered as needed. It may be necessary to commence a syringe pump.

If terminal agitation is a problem alternative medication such as levomepromazine can be used and advice sought from the specialist palliative care team.

Haloperidol 2.5mg subcutaneously may be useful for people who are hallucinating.

Consider a nicotine replacement patch in heavy smokers.

Opioid analgesics should not be used to sedate people.

Acknowledge spiritual distress amongst the person, family and those identified as being important to them and access spiritual support appropriate to their need.

Nausea and vomiting

Assess for likely causes of nausea and vomiting in the dying person. These may include:

- Certain medicines that may cause or contribute to nausea and vomiting
- Recent chemotherapy or radiotherapy
- Psychological causes
- Biochemical causes such as hypercalcaemia
- Raised intracranial pressure
- Gastrointestinal motility disorder
- Ileus or bowel obstruction

Consider non-pharmacological methods for treating nausea and vomiting in a person in the last days of life.

For people whose nausea and vomiting is controlled with an oral anti-emetic, this can be converted to a CSCI.

For people who are opioid naïve consider the prescribing of an anti-emetic orally or subcutaneously according to their needs.
For those people who have had symptoms controlled with oral opioids but have not required regular anti-emetics there is no need to routinely prescribe regular anti-emetics, however, ‘as required’ prescribing should be considered for potential causes of nausea other than opioids.

Cyclizine may exacerbate symptoms of heart failure and should be avoided in these people.\textsuperscript{9} Consider the use of haloperidol or levomepromazine, but be aware that this may cause unpredictable sedation which should be discussed with the patient and those important to them.\textsuperscript{2,10}

Acute terminal events

Some dying people occasionally develop acute distress due to:

- Bleeding
- Acute pain
- Acute respiratory distress

People should be assessed for other causes of distress specific to their illness.

Prescribe anticipatory medication in advance if the person is at risk and discuss with family and those identified as being important to them. Agree an anticipatory care plan with the person, if possible, the family and those identified as being important to them.

Consider the anticipatory prescribing of intra-nasal midazolam.\textsuperscript{10}
Discuss changing the approach to diabetes management with patient and/or family if not already explored. If the patient remains on insulin ensure the Diabetes Specialist Nurses (DNSs) are involved and agree monitoring strategy.

Diabetes management in the last hours and days of life

Aim for Blood Glucose reading of 8 – 18mmol/L

Type 2 diabetes
Diet controlled or Metformin treated

Stop Metformin
Stop monitoring blood sugars

Type 2 diabetes or other tablets
and/or insulin/ or GLP1 Agonist

Stop tablets and GLP1 injections
Consider stopping insulin depending on dose (Contact DSN for advice)

Type 1 diabetes always on insulin

Continue once daily morning dose of insulin glargine (Lantus, Abasaglar or Toujeo) detemir (Levemir) or degludec (Tresiba) with reduction in dose (Contact DSN for advice)

If insulin stopped:
Urinalysis for glucose daily – if over 2+ check capillary blood glucose
If blood glucose over 20mmol/L give 6 units rapid acting insulin*
Recheck capillary blood glucose after 2 hours

If insulin to continue:
Prescribe once daily morning dose of isophane insulin^ or long acting glargine (Lantus, Abasaglar or Toujeo) based on 25% less than total previous daily insulin dose

Check blood glucose once a day at teatime:
If below 8 mmols/l reduce insulin by 10-20%
If above 18mmol/L or symptomatic (thirst, polyuria etc) increase insulin by 10-20% to reduce risk of symptoms or ketosis

If patient requires rapid acting insulin* more than twice consider daily isophane insulin^ or glargine (Lantus, Abasaglar or Toujeo)

Keep tests to a minimum. It may be necessary to perform some tests to ensure unpleasant symptoms do not occur due to low or high blood glucose.
It is difficult to identify symptoms due to “hypo” or hyperglycaemia in a dying patient.
- Sweating, fits and skin colour change in a drowsy or unconscious person may be due to hypoglycaemia
If symptoms are observed it could be due to abnormal blood glucose levels
Test urine or blood for glucose if the patient is symptomatic
Observe for symptoms in previously insulin treated patient when insulin has been discontinued
If PEG feeding is to continue, see specialist advice from DSNs/Palliative Care Team.
It is worth remembering that if steroids are continued in the dying phase they can affect blood glucose levels

Key
# Byetta (Exenatide)/Victoza, (Liraglutide), Lyxumia (Lixisenatide)
*Humalog/Novorapid/Apidra
^Humulin I/Insulatard/Insuman Basal

The Hospital Specialist Palliative Care Team are available Mon-Friday 9am-5pm on 01244 366086 or bleep 2689
The Diabetic Specialist Nurses are available Mon-Friday 9am – 5pm on ext 01244 363061 or bleep 2796
References


Resources

24/7 PALLIATIVE CARE ADVICE LINE FOR HEALTH PROFESSIONALS: 01244 852520
Palliative care team, Countess of Chester NHS Hospital 01244 366086 (9am to 5pm)
Palliative care team, CWP West 01244 340631 (9am to 5pm)
Hospice of the Good Shepherd, Chester 01244 851091


West Cheshire Palliative Care Guidelines in Dementia (2011)