

## 1. Introduction

- 1.1.1 This guidance refers only to the care of adults (aged 18 years and upwards) who are recognised as dying and in the last days of life.
- 1.1.2 NICE published guidance on End of Life Care for infants, children and young people (Quality Standard QS160) in September 2017. This is available online at <https://www.nice.org.uk/guidance/qs160>
- 1.1.3 The Diana Service provide end of life care in the community for infants, children and young people up to the age of 18 years and can be contacted on 0116 2955080 if you require support in arranging this. Further information is available at: [http://www.leicspart.nhs.uk/Library/HOD0350LPTNHSamendsDianakidhometodieleaflet\\_V4.pdf](http://www.leicspart.nhs.uk/Library/HOD0350LPTNHSamendsDianakidhometodieleaflet_V4.pdf). Rainbows Hospice is the East Midlands Hospice providing in patient care for children and young people. Further information is available at <https://www.rainbows.co.uk/>.
- 1.2 This guidance aims to make sure that the care of the dying person is personalised, reflects their individual needs and preferences and that attention is paid to assessing and addressing physical, emotional, psychological, social and spiritual needs of that individual, as well as his/her personal care needs and dignity. It also sets out clear requirements for accountability and review of the clinical situation. It has been revised following recommendations made by NICE (*Care of Dying Adults in the Last Days of Life*, 2015 / 2017) and the National Leadership Alliance for Care of the Dying (*One Chance To Get It Right*, 2014) and Diabetes UK (End of Life Care, Diabetes Care, March 2018).
- 1.3 In order to use this guidance, the multi-disciplinary team (MDT) should have made a face-to-face assessment of the dying person and be in agreement that reversible causes for their current condition have been considered, treated if appropriate and that the patient is likely to die within the next few days.
- 1.4 This guidance is to be used in conjunction with UHL's Individualised End of Life Care Plan (see Appendix 1). It also contains a prompt sheet which should be inserted into the clinical notes (attached as Appendix 3) and a copy of an information leaflet available for those important to the patient which provides a written guide about what to expect when someone is dying. These documents are available for downloading and printing on InSite and can be ordered from the Print Rooms at each hospital site. Guidance on anticipatory prescribing is available on InSite and is included at the end of this document (Appendix 4).
- 1.6 When it is recognised that a person is dying, the Individualised End of Life Care Plan should be created following discussion with the dying person and those they identify as important to them. This should be used in conjunction with other care plans in use throughout UHL to support patient care.

## 2. Scope

- 2.1 This guidance applies to all healthcare professionals employed by UHL, including those on bank, agency and honorary contracts who care for patients who are dying.

## 2.2 Responsibility and Accountability

- 2.2.1 The dying person will have a clearly designated senior responsible clinician and registered nurse responsible for their care. These staff will be responsible for ensuring

that the dying person and their families/carers are involved in decisions about care wherever possible, and that decisions are made in a timely way.

- 2.2.2 Decisions that are needed to maintain the person's comfort and safety can, and should, be made by appropriately trained staff 'on the spot', including out-of-hours. However, those decisions that can wait for review by a senior responsible clinician – who has gathered the necessary information to inform his/her clinical judgment – should be deferred until the senior responsible clinician or their nominated deputy is available. Healthcare professionals should be aware of relevant out-of-hours services and how to contact these including the on call CNS in Palliative Care Service at weekends at UHL via switchboard and advice from the Consultant in Palliative Medicine via LOROS out-of-hours.
- 2.2.3 **In hospital**, the senior responsible clinician is the dying person's named consultant during their rostered hours. Outside of that period, this responsibility is taken on by the senior responsible clinician for that clinical area/ward. The dying person's named consultant has a duty to ensure that adequate information is available to the covering senior responsible clinician to support decision-making.
- 2.2.4 The dying person and his/her family and carers should know who is the **registered nurse responsible** for leading the nursing care of that individual at any one time. This nurse is responsible for communicating effectively with the family, checking their understanding and ensuring that any emerging concerns are addressed. They should 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.
- 2.2.5 In hospital, the **ward sister or charge nurse** will be given this overall responsibility. On each shift, the name of the nurse responsible for delivering care on each shift will be identified and communicated to the dying person (if able) and those important to them when present.
- 2.2.6 The person's senior responsible clinician and any doctor who deputises for him/her, as well as any nursing staff who need specific advice or support, have a duty to consult specialists in palliative care when the dying person's needs warrant it or if they need advice or support about the care.

### 3. Clinical Guidance

#### 3.1 ***Part 1: Multi-disciplinary assessment of a person who is thought to be dying and in their last days of life***

**The principles of the 2005 Mental Capacity Act should be applied throughout. Discussions and information should be tailored to individual's preferences. Refer to the UHL Mental Capacity Act Policy B23/2007 on InSite for further details.**

##### 3.1.1 Recognition that the patient is dying

Recognising that somebody is dying and likely to be in the last days of life can be difficult. This decision should be made by a senior responsible clinician in conjunction with other members of the team involved in the person's care (e.g. nursing staff) who have specific information to contribute.

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

This should be done in consultation with the person (where possible) and those who are important to the dying person, such as their families and/or carers (where present or contactable).

Documentation of this decision should be clear about:

- Who has been involved in the decision
- Relevant diagnoses and specific clinical factors relevant to the decision
- That reversible causes have been considered and acted upon if appropriate

Signs and symptoms that may suggest a person is entering the last days of life include:

- Symptoms such as increasing fatigue and loss of appetite
- Functional observations such as changes in communication, deteriorating mobility or performance status, or social withdrawal
- Cheyne–Stokes breathing, deterioration in level of consciousness, mottled skin, noisy respiratory secretions and progressive weight loss

Patients who have signs and symptoms that suggest they may be in the last days of life should be monitored at least every 24 hours for further changes to help determine if they are nearing death, stabilising or recovering.

Monitoring does not necessarily imply the use of equipment or invasive tests. Changes in signs and symptoms can be gathered from talking with, observing and examining the person and using 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.

Seek advice from colleagues with more experience of providing end of life care 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 (*See section on Responsibility for more detail*).

### **3.1.2 Sensitive communication with the dying person and those important to them**

Adults in the last days of life, and the people important to them, should be given opportunities to discuss, develop and review an individualised plan of care.

It should be clearly communicated to the dying person and their family/carers the senior responsible clinician and registered nurse responsible for their care are, and the names of these people should be clearly documented on the care plan.

Communication at this time should include:

- What is happening and why you think the person is dying
- Likely prognosis (this may be hours - days) and the clinical uncertainties in the current situation
- Elicit any concerns they have and how these will be addressed (if it is not possible to do so, explain why)
- Preferences and priorities for care, including review of advance care plans which may have been made previously (*see Section 3*). What is most important for the patient and family at this time?
- Preferred place of death (Home, hospice, hospital, or other place of care)

- Reasons for any planned intervention or treatment changes, including the use of syringe drivers and prescribing of anticipatory medication.

Remember that open, honest and sensitive communication is important at a pace that is right for the patient and those they identify as important to them. To support shared decision making, use clear, understandable and plain language in all forms of communication. If needed, provide additional support to help the dying person understand information, communicate their wishes or make decisions. If you are unable to meet the dying person's wishes, explain the reasons why to them and those important to them.

If the dying person or family do not want to discuss their deterioration and that they may die, their wishes should be respected, but they should be offered the opportunity to discuss this further at another time.

Provide information about how to contact those involved in caring for the dying person if this is needed.

### **Contact details of individuals important to the dying person should be clearly established as early as possible.**

This should include:

- Who is the 1<sup>st</sup> contact? Is there a 2<sup>nd</sup> contact?
- What to do if they cannot be contacted
- Does each contact want to be contacted at all times or only at certain times?
- Who would the dying person want the hospital to liaise with after their death (e.g. for bereavement support or to collect the death certificate)? If this is different to the next of kin or other contacts, ensure this is clearly documented.

When the dying person lacks capacity, decisions should be made in their best interests, taking into account any known prior wishes, and in consultation with person's family and carers and other members of the team. All decisions should be made in line with GMC Guidance: <http://www.gmc-uk.org/guidance/ethicalguidance/endoflifecare.asp>

If a person does not have any friends or family and lacks capacity to be involved in discussions and decisions about their care in the last days of life, an Independent Mental Capacity Advocate (IMCA) should be involved.

### **Differences in opinions**

If there are differences in opinion about what is in the best interests of the dying person and/or the way in which care will be delivered, these should be discussed openly. Alternatives should be explored in a proactive way, including seeking a second opinion or consulting those with particular expertise (such as requesting a specialist palliative care review).

### **Deprivation of Liberty Safeguards (DoLS)**

If the dying person's care is being supported by a DoLS, sensitively explain to those important to them that this will remain in place. As of 3<sup>rd</sup> April 2017, these no longer routinely require referral to the coroner.

### 3.1.3 Patient preferences and decisions made in advance

If the dying person retains capacity, check their current preferences for care and treatment, and what is most important to them at this time as part of shared decision making. Document these in the dying person's medical records and on the Individualised Plan of Care for the Dying Patient. Find out, and respect, the extent to which individuals wish their families and those important to them to be involved in decision-making.

Adults in the last days of life with dementia, cognitive impairment, learning disabilities or language barriers may have difficulties communicating their preferences for care. Healthcare professionals should establish the dying person's cognitive status, and if they have any speech, language or other communication needs; their current level of understanding and if they would like a person important to them to be present when discussing preferences about their care. All information provided should be accessible, as far as possible, to people with cognitive problems, and people receiving information should have access to an interpreter or advocate if needed.

#### Check whether the dying person has:

- Any 'Advance Care Plan', Emergency Health Care Plan or ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) form
- An Advance Decision to Refuse Treatment (ADRT)
- A Lasting Power of Attorney for health and welfare decisions
- Preferences for care at time of, or after death (e.g. religious or cultural needs - patients may assume we know, so it is important to ask and record on the Individualised Plan of Care of the Dying Patient)
- Any current spiritual or religious needs (e.g. would they want to see a member of the Chaplaincy Team? Is there something else which could provide comfort?)
- A preferred place of death
- A recorded resuscitation decision and complete if this is not available

If the dying person identifies home as their preferred place of death, discuss with them and those important to them whether they can be supported to die at home. Establish as early as possible the resources needed (for example, the delivery of meals, equipment, care at night, volunteer support, or assistance from an organisation such as 'hospice at home') and their availability. Contact the Discharge Team urgently for support. The Discharge Team are available 08.00 – 17.00 Monday – Friday, out of hours contact the duty/flow manager.

**If the person lacks capacity** to make a particular decision, that decision or action taken on their behalf must be in their best interests. Involve them as far as is possible. It is appropriate to elicit the views of those close to the dying person and use these as part of a best interest's assessment.

### 3.1.4 Review of treatments and investigations

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, should be agreed with the dying person and those important to them. Ensure all discussions are documented in the medical notes and the agreed plan of care is recorded on the end of life care plan.

Recognise that the dying person's ability and desire to be involved in making decisions about their care may change as their condition deteriorates.

**Symptom needs** must be assessed at least daily - ideally by a doctor and a nurse. It is important to regularly reassess symptoms and the aims of management as previous symptoms may improve or worsen, and new symptoms may arise. If symptoms are identified, appropriate action should be taken to address these. If the dying person's symptoms do not respond to medication or other

interventions, or persist after 24hours, then contact the Specialist Palliative Care Team for clinical advice or to request review.

Any interventions, including the route, role and side-effects of different medications should be explained to the dying person (if able) and those important to them. Consider whether there is a reversible cause of the dying person's symptoms. Treatments that are in a dying person's best interests to promote comfort and dignity should not be delayed if reasonable steps to contact the family or carers have been unsuccessful.

Seek advice from colleagues with more experience of providing end of life care 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.

See Appendix 4 for specific guidance for symptoms in the last days of life.

**Anticipatory prescribing** should be carried out for common symptoms at the end of life so that if non-drug measures are not sufficient to help any symptoms that develop, appropriate treatments are available. This would usually include medication for pain, nausea, respiratory secretions, breathlessness and agitation ('common symptoms at the end of life').

Anticipatory medications should be prescribed with individualised indications for use, dosage and administration. Any medication given should be targeted for specific symptoms, used in the smallest doses that work and their use regularly reviewed and adjusted if needed. Further guidance on prescribing is available in Appendix 4.

As with all treatments, explanations about the purpose and intended benefits of anticipatory prescribing should be provided to the dying person (if able) and those important to them.

**Observations:** Review whether routine observations are still appropriate. If a decision is made to continue certain observations, their purpose and what action should be taken if these are abnormal should be clear. Avoid undertaking observations if they would not change how you would care for the dying person.

If there is an unexpected change in the dying person's condition (e.g. new breathlessness), clinical observations (e.g. oxygen saturations) may still be of value to guide a change in the individualised plan of care.

Blood glucose monitoring may need to continue to prevent symptomatic hypo or hyperglycaemia but strict glycaemic control will be less important - see Appendix 4 for guidance about managing diabetes in the last days and hours of life.

**Risks and benefits of current treatments** should be reviewed and discussed:

- 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
- Continue treatments promoting comfort and dignity; check the route of administration is appropriate. Medications, such as regular analgesia, anticonvulsants and anti-emetics may need to be given by an alternative route (e.g. subcutaneous infusion) to ensure these symptoms remain controlled even when the dying person is unable to swallow.
- Any treatments which are not helping to relieve symptoms should be reviewed. If there are treatments that are unlikely to be promoting comfort and dignity, or are causing side effects, they should be reviewed and stopped if appropriate following discussion with the dying person (if able) and those important to them (as in usual practice).

- See Appendix 3 for guidance about managing diabetes in the last days and hours of life. It is important that insulin continues when a patient has Type 1 diabetes to avoid keto-acidosis.

### **Pressure-relieving equipment**

- Patients should be reassessed for pressure-relieving equipment and any necessary equipment must be provided in a timely way.
- Please refer to guidance on the Care of Pressure Areas in the Last Days of Life. This can be found on InSite for further guidance (*Prevention and Management of Pressure Ulcers in Adults & Children Policy and Guidance* section 6.3. Ref B23/2014).

**Resuscitation status** should be reviewed. Relevant discussions and the decision about cardiopulmonary resuscitation should be clearly documented - including the separate completion of the East Midlands DNACPR form when a DNACPR decision is made. See UHL Policy Decisions about Cardiopulmonary Resuscitation B25/2014 for further information.

Discussions about CPR should be held in a sensitive and appropriate manner and the dying person and family preferences for discussions and treatments should be taken into consideration. In keeping with GMC guidance, a second opinion should be sought if there is disagreement between the clinical team and the dying person/family.

Please note, when somebody is dying from a progressive condition and is in the last few days of life, cardiopulmonary resuscitation is unlikely to be successful or appropriate.

### **Implantable Cardiac Defibrillator (ICD)**

When a person is likely to die very soon and has an ICD in place, concerns often arise that they may receive shocks in the dying phase. These can be painful and distressing, and timely discussions about deactivating the ICD should be had with the dying person and those important to them. Wherever possible it is best to plan to deactivate the ICD within normal working hours, working with the cardiac technicians to do this.

In an emergency and 'out of hours' an ICD can be deactivated using a circular biotronic magnet. This is available from acute units in UHL (e.g. ED, CDU, CCU). Further advice can be obtained from the on call cardiologist.

Discussions about deactivation of the ICD and any action to be taken should be recorded in the dying person's medical notes and on Individualised End of Life Care plan.

### **3.1.5 Food and fluids**

An individualised approach to patients need for food and drink should be taken. Patients who are able to eat and drink should be offered and helped to take fluids and/or food if they wish. Daily assessment enables changes in hydration status and associated symptoms to be identified, along with problems with oral hydration and any need for clinically assisted hydration.

Staff must be proactive about discussing food and hydration with the dying person and those important to them. As part of discussing food and hydration, staff should encourage the dying person and those important to them to voice any concerns or questions they may have, and help make a plan to address these.

Dying people may not have a desire to drink, and mouth care to wet the mouth and promote comfort should be offered to them. 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.

Patients who are dying should not routinely be made nil by mouth (NBM). If the dying person is at risk of aspiration, the risks and benefits of eating and drinking should be discussed. The dying person should be allowed to accept these risks if they wish, and it should be documented in their notes that it is agreed they can be “fed at risk”. If they lack capacity, this should be discussed with the family and taken into account when making an assessment of best interests.

The normal route of hydration is oral, but some people who want to drink may not be able to do so. If a patient is unable to swallow, or there is another reason (such as delirium or symptomatic thirst not relieved by mouth care), the potential benefits and burdens of artificial hydration and nutrition should be considered. If the person has capacity, this should be discussed with the patient. Clinically assisted hydration may relieve distressing symptoms, such as thirst or delirium, but may cause other problems. If a patient is receiving artificial nutrition or hydration, the clinical team should review this regularly, preferably daily ensuring that benefits outweigh any burdens for the patient.

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:

- 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
- Clinically assisted hydration may relieve distressing symptoms or signs related to dehydration, such as thirst or delirium, but may cause other problems such as fluid accumulation or excessive secretions

Hydration status must be assessed by staff at least daily. This should include a review to look for signs of dehydration (e.g. dry mouth, thirst, confusion and/or agitation) or fluid overload (e.g. pulmonary or peripheral oedema). All discussions and decisions about food and fluid should be clearly documented, including the risks and benefits of hydration options. 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.

### **3.1.6 Consider the needs of those important to the dying person (e.g. family and carers)**

The needs of the family and carer at this stage should be assessed:-

- Remember that families and those important to the dying person, including carers, have their own needs which can be overlooked at this time.
- Recognise that they may be physically and emotionally tired, anxious or tearful.
- Ask about their needs for support or information, and meet these as far as possible.
- Listen to, and acknowledge their needs and wishes, even when it is not possible to meet them.

They should be offered support and signposted to other relevant services (such as their GP) if appropriate. Document on the Individualised care plan the family and carer’s support needs.

## **3.2 Part 2 : Ongoing review of the dying person**

### **3.2.1 At every patient encounter**

The comfort and emotional wellbeing of the patient should be assessed. If those important to the dying person are present, their needs should also be assessed.

If there are any concerns or symptoms, document what is being done to address these, and whether the measures taken were helpful.

When considering medications for symptom relief, take into account:

- The likely cause of the person's symptoms. Consider whether non-pharmacological interventions are possible, and treat any reversible causes of symptoms such as urinary retention
- If 'prn' medications have been given, whether these have been helpful
- The dying person's preferences and wishes for their care
- The most effective route for administering medications (ie. the subcutaneous route will be more effective than oral for patients who are unable to swallow, or vomiting)

In an inpatient setting it is expected that an assessment of the dying person will take place at least every four hours.

**The assessments should check for the following needs and a plan put in place if any issues are identified:-**

- Pain or discomfort (including non-pharmacological management)
- Agitation or restlessness
- Respiratory secretions
- Nausea or vomiting
- Breathlessness
- Mouthcare
- Food and fluids
- Urinary problems
- Bowel problems
- Skin integrity
- Personal hygiene needs
- The patient's emotional, psychological spiritual and religious needs
- Wellbeing of the relatives/those close to the patient
- Other symptoms

**If symptoms do not respond to medication or other interventions, or persist after 24 hours, refer to the Specialist Palliative Care Team for advice or to request review.**

### 3.2.2 At least daily

- There should be a clinical review of overall wellbeing. This should include a discussion with the medical and nursing teams and a review of symptoms and treatments over last 24 hours. Adjustments should be made if required, and a syringe driver considered if more than 2 'prn' doses of medication to control any symptom has been required.
- If a syringe driver is required, continue to ensure that 'prn' medication is given for symptom control if required and the dose of medication in the syringe driver and prn dose is reviewed at least daily to manage symptoms.
- The individual's needs for food and fluids are assessed. Support the dying person to eat and drink as long as they are able to.

- The relatives/those close to the patient are contacted to update them and elicit and address their needs.
- Any indications of improvement are noted and appropriate actions taken. If the person is no longer thought to be dying, this should be explained to the dying person and those important to them, and the plan of care should be altered.
- Ensure that any changes to the care plan are understood by the dying person, those important to them, and those involved in the dying person's care.
- If the dying person is unable to verbally communicate pain, consider using behavioural assessment tools.
- Refer to Specialist Palliative Care if the person and/or situation require this, and ring for advice if unsure about anything.

### 3.3 **Education and Training**

The Palliative and End of Life Care Team will continue to deliver education and training about end of life care. This guidance aims to raise awareness and help structure normal clinical activity rather than develop new skills. Further advice on this guidance, or the use of an Individualised Care Plan is available from the Specialist Palliative Care Team on ext. 5414 (LRI), 3540 (GH) and 4680 (LGH).

E-learning is available through e-ELCA <https://www.e-lfh.org.uk/programmes/end-of-life-care>

### 3.4 **Monitoring and Audit Criteria**

All guidelines should include key performance indicators or audit criteria for auditing compliance. If this template is being used for associated documents (such as procedures or processes) that support a policy then this section is not required as all audit and monitoring arrangements will be documented in section 8 of the policy.

<i>What key element(s) need(s) monitoring as per local approved policy or guidance? (e.g. Policy standards or objectives)</i>	<i>Who will lead on this? Name of lead and what is the role of other professional groups</i>	<i>What method will be used to gather evidence?</i>	<i>How often is the need to monitor each element? How often is the need to complete a report? How often is the need to share the report?</i>	<i>Who or what committee will the completed report go to. How will each report be interrogated to identify the required actions and how thoroughly should this be documented in eg. meeting minutes</i>
<b>Element to be Monitored</b>	<b>Lead</b>	<b>Method</b>	<b>Frequency</b>	<b>Reporting arrangements</b>
Documentation of end of life care in accordance with policy recommendations	Dr Julia Grant supported by Rebecca Proctor (Medical and Nursing End of Life Care Leads)	Audit	Annually	To End of Life Care Committee and to UHL Quality Assurance Committee

### 3.5 **Legal Liability Guideline Statement**

Guidelines or Procedures issued and approved by the Trust are considered to represent best practice. Staff may only exceptionally depart from any relevant Trust guidelines or Procedures and always only providing that such departure is confined to the specific needs of individual circumstances. In healthcare delivery such departure shall only be undertaken where, in the judgement of the responsible healthcare professional it is fully appropriate and justifiable - such decision to be fully recorded in the patient's notes.

### 3.6 **Supporting Documents and Key References**

This document has been produced in accordance with the recommendations from the July 2013 'More Care Less Pathway' report, the proposed response to this from the June 2014 'One Chance to Get it Right' report and the 'Care of dying adults in the last days of life', December 2015. It has been updated following<sub>10</sub> publication of NICE Quality Standard

(QS144) 'Care of dying adults in the last days of life' (March 2017).

3.7 **Key Words:** *End of life care, dying, palliative, care of the dying, last days of life, adult, symptom control, syringe driver*

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*This table is used to track the development and approval and dissemination of the document and any changes made on revised / reviewed versions*

<b>DEVELOPMENT AND APPROVAL RECORD FOR THIS DOCUMENT</b>	
<b>Author / Lead Officer:</b> Dr Laura Clipsham	<b>Job Title:</b> Palliative Medicine Consultant
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<b>Latest Approval Date:</b> February 2019 (PGC Chair's minor amendments process)	<b>Next Review Date:</b> December 2021
<b>Version Number:</b> V2	<b>Details of Changes made during review:</b> References to responsibility for care in community settings removed, guidance reviewed in line with NICE guidance NG31: <i>care of dying adults</i> , EOLC plan layout adjusted, symptom control flow chart added
<b>Version Number:</b> V3	<b>Details of Changes made during review:</b> Title of guidance changed. Statement added that this guidance refers to adults aged 18 years and above (1.1); guidance reviewed in line with NICE Quality Standard (2017): <i>Care of dying adults in the last days of life (QS144)</i> ; DOLS statement updated; EOLC plan layout adjusted. Care plans not in pre-existing care plans have been taken from <i>The Royal Marsden Manual of Clinical Nursing Procedures (9<sup>th</sup> Ed.)</i> (2015).
<b>Version Number:</b> V4	<p><b>Details of Changes made during review:</b></p> <p>1.2, 3.1.4 Additional of reference to Diabetes UK Guidance for management of patients with diabetes who may be in the last days or hours of life including the addition of a flowchart within the symptom management guidance in Appendix 3.</p> <p>Minor wording changes:</p> <p>2.2.1 Additional reference to SPCT support outside the working week</p> <p>3.1.2 and 3.1.3 addition of prompt: what is most important to the patient at this time?</p> <p>3.1.3 Addition of reference and hyperlink to the national ReSPECT document and additional information prompting reader to consider cultural and religious needs</p> <p>3.1.4 Prompt added to discuss potential side effects of sc medications as per NICE QS144</p> <p>3.1.5 Importance of daily review if artificial hydration or nutrition is in place</p> <p>End of Life Care Plan: "The multidisciplinary team have agreed that this patient is dying and patient and family have been offered an opportunity to talk about this" added to top of paperwork</p> <p>What is most important to the patient and family at this time?</p> <p>Would input from chaplaincy team be helpful?</p> <p>Doctor has reviewed the need for observation and blood tests and recorded a plan in the medical notes</p> <p>Doctor has reviewed regular medications, stopping those which are causing harm/are of limited benefit and adjusting the route of essential medications (for example converting oral analgesia to a subcutaneous infusion)</p> <p>Doctor has discussed changes with patient and family</p> <p>"and spiritual" added to assessment of needs of family</p> <p>If in place, have benefits/burdens of artificial nutrition or hydration been reviewed <b>Yes</b> <input type="checkbox"/> <b>No</b> <input type="checkbox"/> added as a daily prompt</p> <p>"If symptoms have not responded to medication or other interventions, and persist after 24hours, refer to the Specialist Palliative Care Team for advice or to request review" added as footer to care plan</p> <p>Symptom management: "Starting with the lowest dose" added where a range is suggested for morphine, midazolam and levomepromazine in line with QS144</p> <p>Algorithm added in line with Diabetes UK guidance for managing diabetes in the last days or hours of life</p>

*Patient ID Sticker*

## INDIVIDUALISED END OF LIFE CARE PLAN FOR CARE IN THE LAST DAYS OF LIFE

**The multidisciplinary team have agreed that this patient is dying and patient and family have been offered an opportunity to talk about this. Please complete this care plan with the dying person and those who have been identified as important to them.**

If unable to do so, please document the reason why in the medical notes

**Consultant:** ..... **Date:**..... **Time:**.....

**CONTACT DETAILS OF THOSE IMPORTANT TO THE DYING PERSON**

1<sup>st</sup> Contact Name: ..... Relationship:.....

Tel No: ..... Mobile ..... Other: .....

When to contact: Any time  Not at night  Other .....

2<sup>nd</sup> Contact Name: ..... Relationship:.....

Tel No: ..... Mobile ..... Other: .....

When to contact: Any time  Not at night  Other .....

**PREFERENCE OR WISHES FOR CARE AT THE END OF LIFE OR AFTER DEATH (INCLUDING SPIRITUAL WISHES), AND ADVANCE DECISIONS REGARDING END OF LIFE CARE. WHAT IS MOST IMPORTANT TO THE PATIENT?**

Please document if the dying person has an Advance Decision to Refuse Treatment (ADRT), Lasting Power of Attorney for health (Health LPA), Advance Care Plan or any expressed preference or wishes about their care (and who is involved) now, at the time of death and after death.

What is most important to the patient and family at this time?.....  
.....  
.....

**Where is the patient's preferred place of death (PPD)?** Home  Hospital  Hospice  Other .....

**Would input from the chaplaincy team be helpful?** Yes  No

**Is the dying person able to communicate their needs to people around them?** Yes  No

*If applicable, please indicate what is affecting the dying person's ability to communicate, and how this is being addressed.*

- Sensory difficulties (eg. hearing or visual impairment) : .....
- Cognitive impairment (eg. Decreased consciousness, dementia or acute delirium): .....
- Learning disabilities: .....
- Language barriers: .....
- Other: .....

**DNACPR form completed and valid?** Yes  No

*Ensure this is valid and completed if not*

**Doctor has reviewed need for observations and blood tests and recorded a plan in the medical notes** Yes  No

**Doctor has reviewed medications, stopping those which are causing harm/are of limited benefit and adjusting the route of essential medications (e.g. converting oral analgesia to a subcutaneous infusion)** Yes  No

**Doctor has discussed changes with patient and family** Yes  No

**'Last Days of Life' booklet or leaflet given?** Yes  No  *If not, why not?* .....

Who was it given to?: ..... **Opportunity given to discuss?** Yes  No  *If not, why not?* .....

**What support do those identified as important to the dying person require and how are you meeting their needs?**

Physical (eg. meals, any mobility problems): .....

Social (eg. do they wish to stay?, children under 18yrs): .....

Emotional and spiritual (eg. how are they coping?).....

Any specific requests? (*for support now, at the time of death, or when bereaved?*) .....

**Who was involved in completing this care plan?**

Patient  (*If not, why not?*) .....

Person(s) important to the patient  Name(s): .....

Name of Healthcare Professional (doctor).....(PRINT).....(SIGN)  
(nurse).....(PRINT).....(SIGN)

Patient ID Sticker

## INDIVIDUALISED END of LIFE CARE PLAN – INITIAL ASSESSMENT

**This care plan should be used in conjunction with other care plans in use throughout UHL to support patient care.**

**Date Care Plan Started:** ...../...../.....      **Time of assessment:**.....

IS ..... <small>(patient name)</small>	DISPLAYING SIGNS OF:-		YES	NO	SIGNATURE
If answering "Yes" to any of the below, please complete or review a care plan using existing UHL plans when available (eg. for skin care) or the attached Individualised End of Life Care Plan for other issues					
1) Pain or Discomfort?	<input type="checkbox"/>	<input type="checkbox"/>			
2) Agitation or Restlessness?	<input type="checkbox"/>	<input type="checkbox"/>			
3) Respiratory Secretions?	<input type="checkbox"/>	<input type="checkbox"/>			
4) Nausea or Vomiting?	<input type="checkbox"/>	<input type="checkbox"/>			
5) Shortness of Breath?	<input type="checkbox"/>	<input type="checkbox"/>			
6) Dry or Dirty Mouth?	<input type="checkbox"/>	<input type="checkbox"/>			
7) Urinary Problems? <i>How are these being addressed?</i> .....	<input type="checkbox"/>	<input type="checkbox"/>			
8) Bowel Problems? <i>Bowels Last Opened</i> ...../...../.....	<input type="checkbox"/>	<input type="checkbox"/>			
9) Skin Breakdown or Pressure Sores?	<input type="checkbox"/>	<input type="checkbox"/>			
10) Emotional / Psychological or Spiritual Distress?	<input type="checkbox"/>	<input type="checkbox"/>			
11) Other Symptoms ( <i>Specify</i> ).....	<input type="checkbox"/>	<input type="checkbox"/>			
Have medications been prescribed 'prn' for the following symptoms:			<input type="checkbox"/>	<input type="checkbox"/>	
Pain			<input type="checkbox"/>	<input type="checkbox"/>	
Shortness of Breath			<input type="checkbox"/>	<input type="checkbox"/>	
Agitation			<input type="checkbox"/>	<input type="checkbox"/>	
Nausea & Vomiting			<input type="checkbox"/>	<input type="checkbox"/>	
Secretions			<input type="checkbox"/>	<input type="checkbox"/>	
Have the patient's hygiene needs been met?	<input type="checkbox"/>	<input type="checkbox"/>			
<b>Is the dying person able to communicate their needs to people around them?</b> Yes <input type="checkbox"/> No <input type="checkbox"/> <i>If applicable, please indicate what is affecting the dying person's ability to communicate, and how this is being addressed.</i> <input type="checkbox"/> Sensory difficulties (eg. hearing or visual impairment) : ..... <input type="checkbox"/> Cognitive impairment (eg. Decreased consciousness, dementia or acute delirium): ..... <input type="checkbox"/> Learning disabilities: ..... <input type="checkbox"/> Language barriers: ..... <input type="checkbox"/> Other: .....					
<b>How is the wellbeing of relatives / those important to the dying person being maintained?</b> ..... .....					
<b>Food and Drink</b>					
<b>Assess patient's ability to eat and drink and hydration status- are there signs of dehydration/fluid overload?</b> Yes <input type="checkbox"/> No <input type="checkbox"/> <b>If able to eat and drink, the dying person should be offered and helped to take fluids and/or food if they wish.</b> <b>Discuss food and hydration with the dying person and those important to them. Encourage them to voice any concerns or questions they may have, and help make a plan to address these.</b>  Eating and / or drinking independently <input type="checkbox"/> Needs assistance to eat and / or drink <input type="checkbox"/> 'Feed at risk' <input type="checkbox"/> Unable to eat and / or drink <input type="checkbox"/> Reason for being unable to eat and/or drink .....  <b>If a decision is made to 'feed at risk', ensure this is documented in the medical notes and follow UHL guidance</b> If unable to eat and drink assess the need for clinically assisted hydration or nutrition Is artificial hydration/nutrition in place? Yes <input type="checkbox"/> No <input type="checkbox"/> Route: NG <input type="checkbox"/> IV <input type="checkbox"/> Subcutaneous <input type="checkbox"/> Other <input type="checkbox"/> ..... Have benefits/burdens of artificial nutrition or hydration been reviewed today? Yes <input type="checkbox"/> No <input type="checkbox"/>					

# INDIVIDUALISED END of LIFE CARE PLAN

DATE: .....

*Patient Sticker*

**DAILY REVIEW:** REASSESS A MINIMUM OF 4 HOURLY

Ensure 'prn' medications have been prescribed for common symptoms:  
Pain / Breathlessness / Agitation / Nausea & Vomiting / Secretions

Is ..... (patient name) DISPLAYING SIGNS OF:-

If answering "Yes" to any of the below, please complete a care plan using existing UHL plans when available (eg. for skin care) or the attached Individualised End of Life Care Plan for other issues

ANSWER Y (YES) OR N (NO) FOR EACH SYMPTOM

TIME						
1) Pain or Discomfort?						
2) Agitation or Restlessness?						
3) Respiratory Secretions?						
4) Nausea or Vomiting?						
5) Shortness of Breath?						
6) Dry or Dirty Mouth?						
7) Urinary Problems? <i>How are these being addressed? .....</i>						
8) Bowel Problems? <i>Bowels Last Opened ..... / ..... / .....</i>						
9) Skin Breakdown or Pressure Sores?						
10) Emotional / Psychological or Spiritual Distress?						
11) Other Symptoms ( <i>Specify</i> ).....						
Have the patient's hygiene needs been met?						
<b>SIGNATURE</b>						

**Is the dying person able to communicate their needs to people around them?** Yes  No   
*If applicable, please indicate what is affecting the dying person's ability to communicate, and how this is being addressed.*  
 Sensory difficulties (eg. hearing or visual impairment) : .....  
 Cognitive impairment (eg. Decreased consciousness, dementia or acute delirium): .....  
 Learning disabilities: .....  
 Language barriers: .....  
 Other: .....

SIGNATURE:

**How is the wellbeing of those important to the dying person being maintained?** (*Daily assessment*)  
 .....  
 .....  
 What information has been given to relatives and those important to the dying person today?  
 .....

SIGNATURE:

## Food and Drink

**Assess the patient's ability to eat and drink and hydration status- are there signs of dehydration/fluid overload?** Yes  No   
**If able to eat and drink, the dying person should be offered and helped to take fluids and/or food if they wish.**  
**Discuss food and hydration with the dying person and those important to them. Encourage them to voice any concerns or questions they may have, and help make a plan to address these.**  
 Eating and / or drinking independently  Needs assistance to eat and / or drink  'Feed at risk'  Unable to eat and / or drink   
 Reason for being unable to eat and/or drink .....

**If a decision is made to 'feed at risk', ensure this is documented in the medical notes and follow UHL guidance**  
 If unable to eat and drink assess the need for clinically assisted hydration or nutrition

Is artificial hydration/nutrition in place? Yes  No  Route: NG  IV  Subcutaneous  Other  .....

Have benefits/burdens of artificial nutrition or hydration been reviewed today? Yes  No

# INDIVIDUALISED END OF LIFE CARE PLAN

DATE: .....

**DAILY REVIEW:** REASSESS A MINIMUM OF 4 HOURLY

Ensure 'prn' medications have been prescribed for common symptoms:  
Pain / Breathlessness / Agitation / Nausea & Vomiting / Secretions



Patient Sticker

Is ..... (patient name) DISPLAYING SIGNS OF:-

If answering "Yes" to any of the below, please complete a care plan using existing UHL plans when available (eg. for skin care) or the attached Individualised End of Life Care Plan for other issues

ANSWER Y (YES) OR N (NO) FOR EACH SYMPTOM

TIME						
1) Pain or Discomfort?						
2) Agitation or Restlessness?						
3) Respiratory Secretions?						
4) Nausea or Vomiting?						
5) Shortness of Breath?						
6) Dry or Dirty Mouth?						
7) Urinary Problems? <i>How are these being addressed? .....</i>						
8) Bowel Problems? <i>Bowels Last Opened ..... / ..... / .....</i>						
9) Skin Breakdown or Pressure Sores?						
10) Emotional / Psychological or Spiritual Distress?						
11) Other Symptoms ( <i>Specify</i> ).....						
Have the patient's hygiene needs been met?						
<b>SIGNATURE</b>						

**Is the dying person able to communicate their needs to people around them?** Yes  No   
*If applicable, please indicate what is affecting the dying person's ability to communicate, and how this is being addressed.*  
 Sensory difficulties (eg. hearing or visual impairment) : .....  
 Cognitive impairment (eg. Decreased consciousness, dementia or acute delirium): .....  
 Learning disabilities: .....  
 Language barriers: .....  
 Other: .....

SIGNATURE:

**How is the wellbeing of those important to the dying person being maintained?** (*Daily assessment*)  
 .....  
 .....  
 What information has been given to relatives and those important to the dying person today?  
 .....

SIGNATURE:

## Food and Drink

**Assess the patient's ability to eat and drink and hydration status- are there signs of dehydration/ fluid overload?** Yes  No   
**If able to eat and drink, the dying person should be offered and helped to take fluids and/or food if they wish.**  
**Discuss food and hydration with the dying person and those important to them. Encourage them to voice any concerns or questions they may have, and help make a plan to address these.**  
 Eating and / or drinking independently  Needs assistance to eat and / or drink  'Feed at risk'  Unable to eat and / or drink   
 Reason for being unable to eat and/or drink .....

**If a decision is made to 'feed at risk', ensure this is documented in the medical notes and follow UHL guidance**  
 If unable to eat and drink assess the need for clinically assisted hydration or nutrition

Is artificial hydration/nutrition in place? Yes  No  *Route: NG*  *IV*  *Subcutaneous*  *Other*  .....

Have benefits/burdens of artificial nutrition or hydration been reviewed today? Yes  No

**Care Plan (Appendix 2): Use this page to document a plan of care for symptoms not addressed in pre-existing Nursing CORE care plans.**

DATE CARE PLAN STARTED	SYMPTOM	GOAL	ACTIONS / CARE NEEDS	NAME & SIGNATURE
	<b>Agitation / restlessness</b>	<b>The dying person is calm and not demonstrating, or reporting a feeling of agitation or restlessness</b>	<ol style="list-style-type: none"> <li>1. Involve the dying person and family members in recognising signs of agitation, restlessness and distress.</li> <li>2. Careful assessment should include consideration of any precipitating factors including medications, reversible metabolic causes, constipation, urinary retention, hypoxia, withdrawal from drugs or alcohol, uncontrolled symptoms or existential distress.</li> <li>3. Clear, concise communication, continuity of carers if possible, the presence of familiar objects and people and a safe immediate environment can all be helpful interventions</li> <li>4. If the patient's symptoms are not relieved, consider administering PRN medication. Discuss the role of this with patients and those identified as important to them, and offer reassurance throughout. If requiring 2 or more PRN doses in 24hours, consider the need for a syringe driver.</li> <li>5. If symptoms are not controlled after 24 hours, refer to Specialist Palliative Care.</li> </ol>	
	<b>Respiratory Tract Secretions</b>	<b>The dying person is free of respiratory tract secretions</b>	<ol style="list-style-type: none"> <li>1. Consider whether respiratory tract secretions are causing distress to the patient</li> <li>2. Consider whether respiratory tract secretions are causing distress to relatives / people important to the dying person</li> <li>3. Offer reassurance (to patient and those important to them).</li> <li>4. Changing the position of the patient in the bed may reduce the noisiness of breathing. It is important to reassure family that the patient is not drowning or choking, and is unlikely to be distressed by the symptom themselves</li> <li>5. Prompt medical staff to review the role of artificial hydration if this is in situ (this may contribute to secretions)</li> <li>6. If the patient's symptoms are not relieved, consider administering PRN medication. If requiring 2 or more PRN doses in 24hours, consider the need for a syringe driver.</li> <li>7. If symptoms are not controlled after 24 hours, refer to Specialist Palliative Care.</li> </ol>	
	<b>Nausea and Vomiting</b>	<b>The dying person is not vomiting and is satisfied with the current nausea control</b>	<ol style="list-style-type: none"> <li>1. Involve the dying person and family members in assessing nausea and vomiting. Comprehensive assessment is paramount. Identify potentially reversible causes. Consider the complications of the disease process as well as side-effects of drugs.</li> <li>2. Anti-emetics may need to be rationalised and/or administered via a different route (e.g. subcutaneous syringe pump) as the patient may no longer be able to swallow or tolerate oral medication.</li> <li>3. Because the insertion of a nasogastric tube is considered a fairly invasive and uncomfortable procedure, it is unlikely to be appropriate for the management of nausea and vomiting in the last days of life. Those nasogastric tubes already in situ should remain unless causing distress to the patient.</li> <li>4. Offer reassurance (to patient and family). If the patient's symptoms are not relieved, consider administering PRN medication.</li> <li>5. If requiring 2 or more PRN doses in 24hours, consider the need for a syringe driver. If symptoms are not controlled after 24 hours, refer to Specialist Palliative Care. Patients with mechanical vomiting secondary to bowel obstruction may require medications to reduce the volume of gastric secretions.</li> </ol>	

PLEASE REFER TO SYMPTOM GUIDANCE FOR ADULT PATIENTS AS NEEDED (THESE ARE AVAILABLE ON INSITE)

**Care Plan (Appendix 2): Use this page to document a plan of care for symptoms not addressed in pre-existing Nursing CORE care plans.**

DATE CARE PLAN STARTED	SYMPTOM	GOAL	ACTIONS / CARE NEEDS	NAME & SIGNATURE
	<b>Mouthcare</b>	<b>The dying person's mouth is clean</b>	<ol style="list-style-type: none"> <li>1. When possible, encourage patients to carry out their own oral care.</li> <li>2. Carry out an oral assessment using an oral assessment tool.</li> <li>3. Inspect the patient's mouth, including teeth, with the aid of a torch, spatula and gauze, paying special attention to the lips, buccal mucosa, lateral and ventral surfaces of the tongue, floor of the mouth and the soft palate.</li> <li>4. Using a soft, small toothbrush and toothpaste (or foam stick if the gingiva is damaged or susceptible to bleeding), brush the patient's natural teeth, gums and tongue</li> <li>5. Give a beaker of water to the patient. Encourage the patient to rinse the mouth vigorously then spit the contents into a receiver. Paper tissues should be on hand to dry any spillage of water or dribbling.</li> <li>6. If the patient is unable to rinse and spit, use a rinsed toothbrush to clean the teeth and moistened foam sticks to wipe the gums and oral mucosa. Foam sticks should be used with a rotating action so that most of the surface is used.</li> <li>7. Ensure the patient is comfortable. Offer reassurance (to patient and family)</li> <li>8. If symptoms are not controlled after 24 hours, refer to Specialist Palliative Care</li> </ol>	
	<b>Breathlessness</b>	<b>The dying person is satisfied with management of their breathlessness</b>	<ol style="list-style-type: none"> <li>1. Involve the dying person and family members in recognising signs of breathlessness.</li> <li>2. Offer reassurance to the patient and family. Reposition the patient, for example sit them in a more upright position. Open a window or use a hand held fan to keep air moving across the face. Distraction techniques and relaxation therapy and involving the MDT including OT, physiotherapist and palliative care team may be needed.</li> <li>3. If the patient's symptoms are not resolved, consider administering prn medication to manage breathlessness and/or anxiety, using the lowest effective dose to control the symptom. If two or more doses are given in 24h, consider the need for a syringe driver.</li> <li>4. If symptoms are not controlled after 24 hours, refer to Specialist Palliative Care</li> </ol>	
	<b>Other</b> <i>(Please specify)</i>			
	<b>Communication with those important to the dying person</b>	<b>Those that are identified as important to the dying person are supported and involved in decisions about the dying persons care</b>	<ol style="list-style-type: none"> <li>1. Protect the time for psychosocial focus of conversation. This involves telling other staff that you don't wish to be disturbed for a prescribed period. Set a realistic time boundary for your conversation at the beginning</li> <li>2. Introduce yourself and your role, and develop rapport with those important to the dying person</li> <li>3. Identify any concerns that those important to the dying person may have, and if there is anything they would like to discuss. Respond to verbal and non-verbal cues e.g. acknowledging emotions and behaviours</li> <li>4. Explore whether they have any specific needs – e.g. Accommodation, meals, children, and emotional support needs.</li> <li>5. If they do not want to talk, respect this but continue to offer opportunities to talk to nursing or medical staff</li> <li>6. Be empathic. Acknowledge you may not have been able to cover all concerns and summarise what has been discussed to check understanding.</li> <li>7. Agree any action points and follow up as necessary.</li> <li>8. Document your conversation as part of the 'last days of life' care plan.</li> </ol>	

PLEASE REFER TO SYMPTOM GUIDANCE FOR ADULT PATIENTS AS NEEDED (THESE ARE AVAILABLE ON INSITE)

## PROMPT SHEET: Guidance for Care of Patients Who Are Dying and Likely to be in the Last Days of Life. *(Appendix 3)*

**The principles of the 2005 Mental Capacity Act should be applied throughout. Discussions and information should be tailored to individuals' preferences**

It is expected that **as a minimum**, the documentation to support the decision that a patient is likely to be in the last few days of life, and the plan for their ongoing care covers the areas set out in this prompt sheet. Detailed guidance on providing care in the last days of life is available on InSite.

### A. Initial Multidisciplinary Assessment of a Patient who is thought to be Dying and in Their Last Days of Life.

#### 1. Recognition That the Patient is Dying

**Consider:**

- Who has been involved in the recognition of dying?
- Relevant diagnoses and specific clinical factors relevant to the recognition of dying.
- That reversible causes have been considered and acted upon if appropriate.
- Why the person is considered to be dying?
- Names of responsible doctor and nurse communicated.
- Gather information on the person's goals and wishes for care.

#### 2. Sensitive Communication With the Dying Person and those Important to them.

This should include what is happening and why you think the person is dying, preferences and priorities for care, their likely prognosis and the clinical uncertainties and how you will try to address any concerns which are identified.

- Wishes not to discuss what is happening should be respected but further opportunities to discuss again offered.

Consult an Independent Mental Capacity Advocate (IMCA) if patient lacks capacity and no friend/family or carers.

Differences in opinions should be openly discussed and actively addressed eg. by seeking a second opinion.

Contact details of family and people important to the dying person should be clearly established and documented (including their preferences for when to be contacted).

#### 3. Patient Preferences and Decisions Made in Advance

**Check whether the patient has:-**

- Any 'advance care plan' or Emergency Health Care Plan
- An Advance Decision to Refuse Treatment (ADRT)
- A Lasting Power of Attorney for health and welfare decisions
- Preferences for care at time of or after death
- Any spiritual or religious needs
- A preferred place of death
- A recorded resuscitation decision
- What is most important to the patient and family at this time?

**If the person has capacity**, discuss their current preferences for care and involve in making a plan with this in mind.

**If the person lacks capacity**, it is appropriate to elicit the views of those close to the patient and use these as part of a best interest's assessment.

**Adults in the last days of life with dementia, cognitive impairment, learning disabilities or language barriers may have difficulties communicating their preferences for care. Healthcare professionals should establish the person's cognitive status, and if they have any speech, language or other communication needs; their current level of understanding and if they would like a person important to them to be present when discussing preferences about their care.**

#### 4. Review of Treatments and Investigations

**Current symptom needs** should be assessed

**Anticipatory prescribing** for common symptoms at the end of life should occur. Local guidance for specific drugs and doses is available on the Trust Intranet

**Palliative care advice and input** must be sought if difficult symptoms or input is needed for other aspects of the patient's care

**CPR status** should be reviewed. When somebody is in the last days of life, CPR is unlikely to be successful or appropriate. Please note, for DNACPR decisions, the form must be completed.

**Observations:** Review whether routine observations are still appropriate and record plan in medical notes

**Risks and benefits of current treatments** should be reviewed and discussed

**Pressure relieving equipment:** Reassess and provide any necessary pressure-relieving equipment

**Implantable Cardiac Defibrillator (ICD):** If in situ, these should usually be deactivated to prevent potentially painful and distressing shocks in the dying phase

#### 5. Food and Fluids

Patients who are able should be offered and helped to take fluids and/or food if they wish.

If a patient is at risk of aspiration, the risks and benefits should be discussed and documented.

The potential benefits and burdens of artificial hydration and nutrition should be considered. It should be offered if it is thought to be in the best interests and clinically appropriate.

#### 6. Needs of Family/Carer

The needs of the family and carer should be assessed. Remember that families and those important to the person may be physically and emotionally tired, anxious or tearful.

### B. Ongoing Assessment of a Person who is thought to be in the Last Days of Life

#### At Every Patient Encounter

The comfort and emotional wellbeing of the dying person should be assessed daily.

If family are present, their needs should also be assessed. Document any concerns or symptoms, what is being done to address these, and whether the measures taken were helpful. Ask for advice from a senior team member or the palliative care team if it is difficult to consistently maintain comfort, dignity or other aspect of wellbeing.

It is expected that an assessment of the patient's wellbeing will take place at least every four hours - this will usually be conducted by nursing staff.

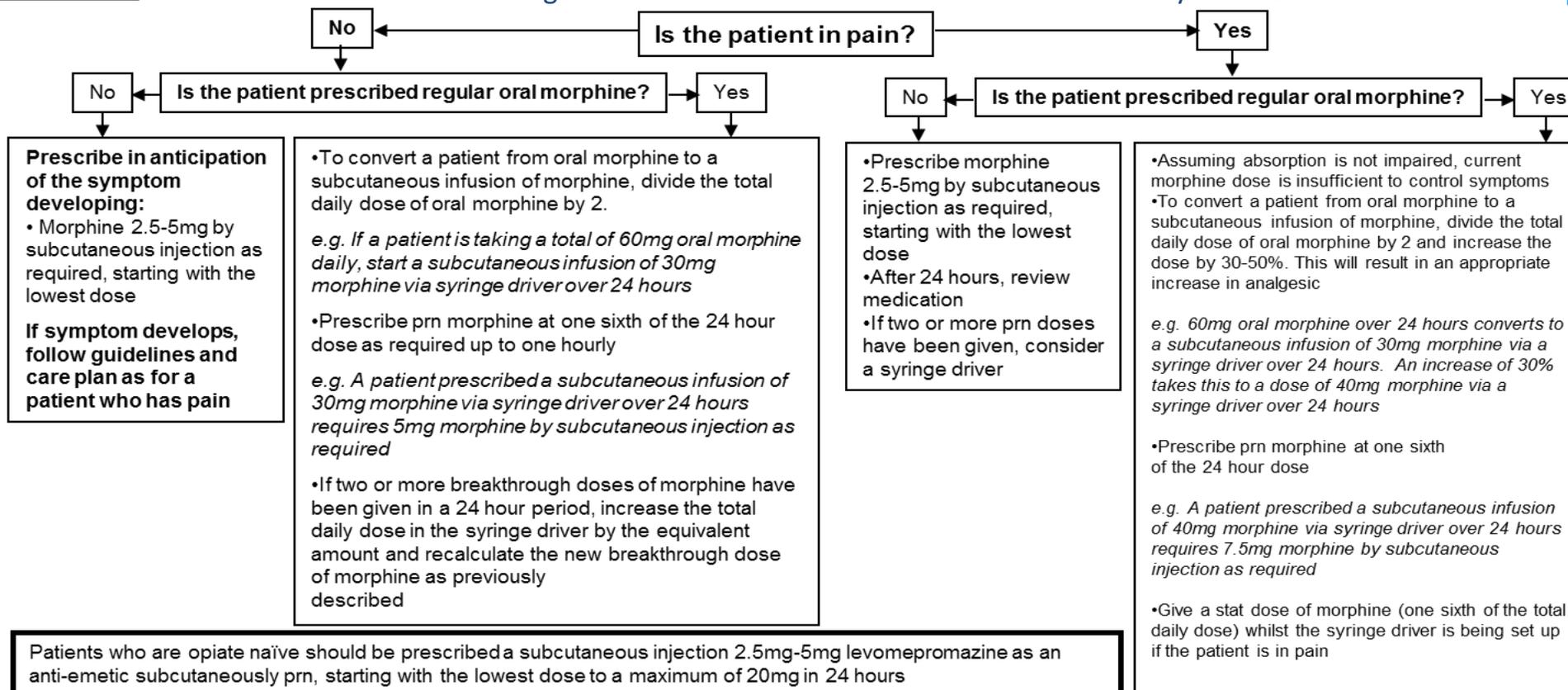
#### At Least Daily

There should be a review of overall wellbeing. This should include a discussion with the medical and nursing team about symptoms and treatments over last 24 hours. Adjustments should be made to the treatment plan if needed to try and maintain or improve comfort.

The individual's needs for food and fluids and the patient's hydration status are assessed.

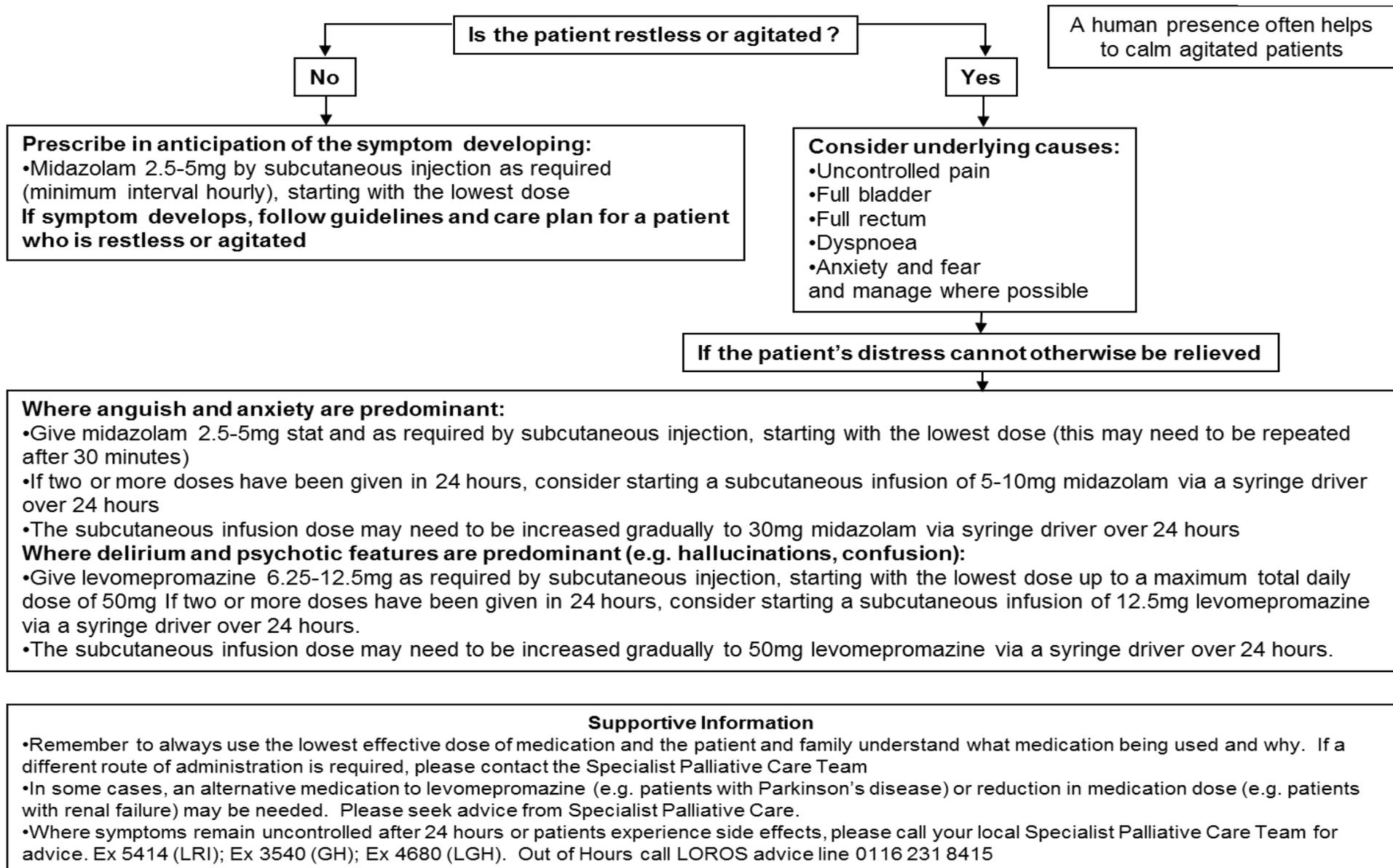
The relatives/ those close to the patient are contacted to update them and elicit and address their needs.

Signs and symptoms are assessed daily to review changes in patient condition and to help determine if they are nearing death, stabilising or recovering. Any indications of improvement are noted and appropriate actions taken



### Supportive Information

- Remember to always use the lowest effective dose of medication and the patient and family understand what medication being used and why. If a different route of administration is required, please contact the Specialist Palliative Care Team
- Some patients can benefit from rectal diclofenac (50mg or 100mg PR), particularly for muscle pain and stiffness
- Use lower doses morphine (1.25-2.5mg) in patients who are frail or cachectic
- Patients with renal failure should start on lower doses of morphine (1.25-2.5mg) with a minimum time interval of 6 hours between doses- see Symptom Management for Patients with Renal Failure at the End of Life available on InSite for more details.
- In some cases, an alternative anti-emetic (e.g. patients with Parkinson's disease) may be needed (See Management of Nausea and Vomiting in the Last Few Days of Life).
- Morphine is the opioid of choice for subcutaneous use although due to the volume of injection the maximum practical sc breakthrough dose is around 60mg.
- Where patients are taking alternative opioids regularly (for example fentanyl patches, methadone or oxycodone), where 24hour morphine doses are >400mg, eGFR <30 or where symptoms remain uncontrolled after 24 hours or patients experience side effects, please call your local Specialist Palliative Care Team for advice. Ex 5414 (LRI); Ex 3540 (GH); Ex 4680 (LGH). Out of Hours call LOROS advice line 0116 231 8415



## The Management of Respiratory Tract Secretions in the Last Few Days of Life

- Noisy respiratory tract secretions can be a normal part of dying
- Consider whether they are troublesome or need treating at all

Does the patient have troublesome respiratory tract secretions?

No

**Prescribe in anticipation of the symptom developing:**

- Glycopyrronium 200-400 micrograms by subcutaneous injection as required, starting with the lowest dose, up to every four hours, maximum dose 1.2mg in 24 hours

**If symptoms develop, follow guidelines and care plan as for a patient who has respiratory tract secretions**

Yes

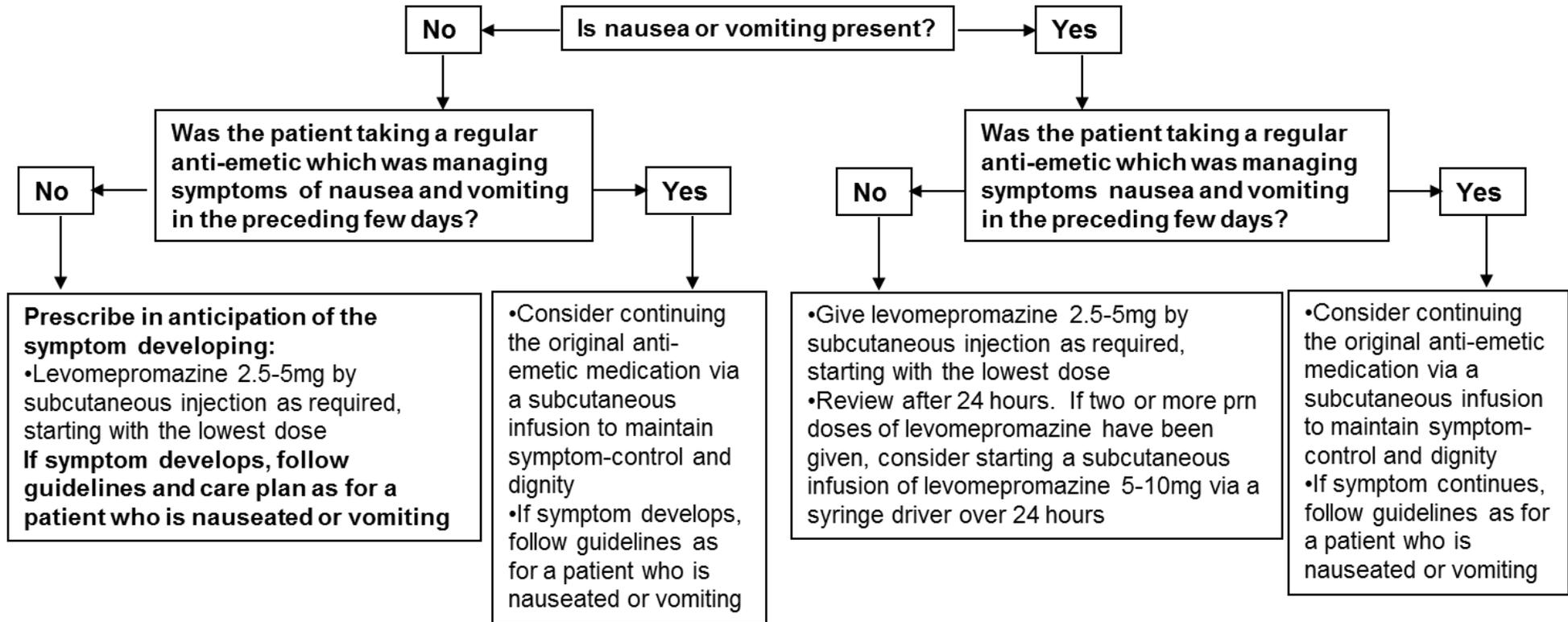
**Consider:**

- Patient positioning- consider tilting chin inwards and positioning the patient slightly on one side at a 30 degree angle
- Stopping artificial hydration and nutrition

- Give glycopyrronium 200 micrograms by subcutaneous injection as soon as symptom arises and as required, up to every four hours (maximum dose 1.2mg in 24 hours)
- If two or more doses of glycopyrronium have been given and are effective, consider starting a subcutaneous infusion of 600 micrograms glycopyrronium via syringe driver over 24 hours
- Give a stat dose of glycopyrronium 200micrograms while the syringe driver is being set up
- Review after 24 hours
- If symptoms persist, increase the total daily dose to a maximum of 1.2mg glycopyrronium via a syringe driver over 24 hours

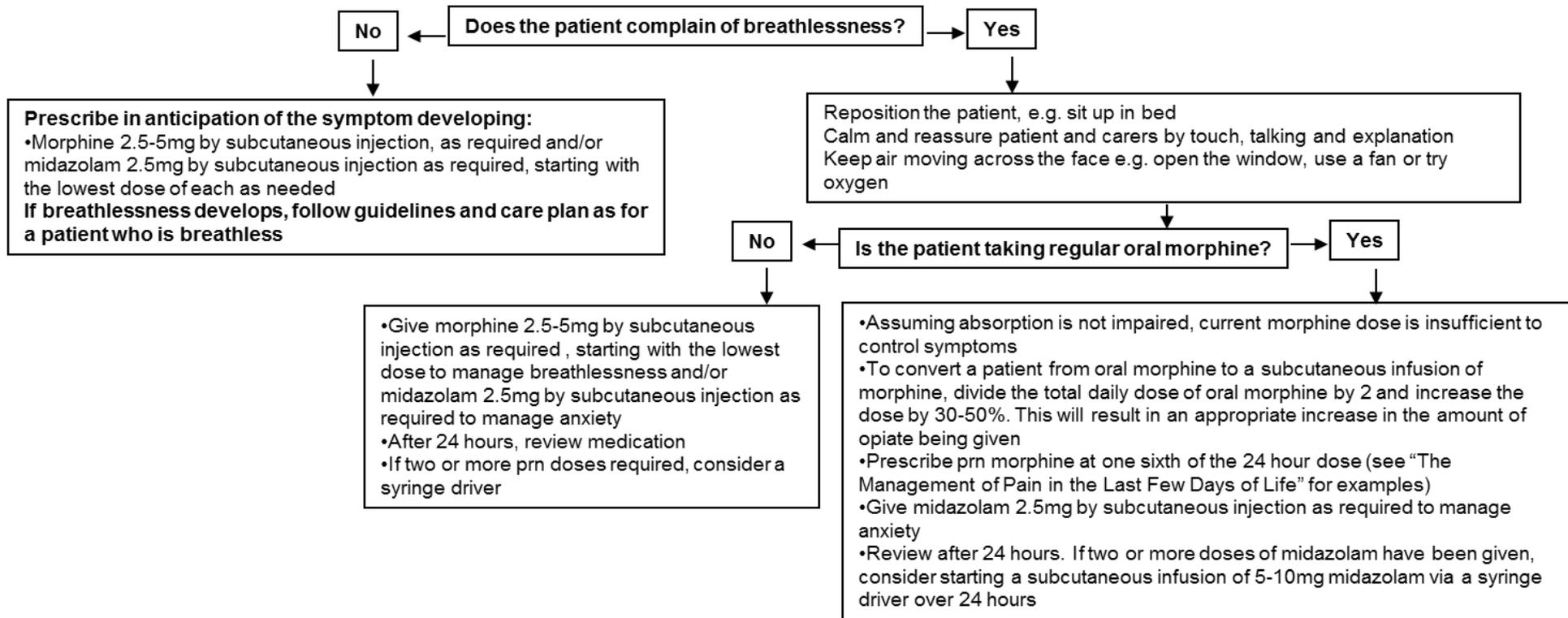
### Supportive Information

- Remember to always use the lowest effective dose of medication and the patient and family understand what medication being used and why. If a different route of administration is required, please contact the Specialist Palliative Care Team
- In a VERY SMALL number of patients, suction may be helpful
- This is a difficult symptom and glycopyrronium may not be effective. Glycopyrronium is unlikely to manage secretions which have already occurred.
- Remember to reassure relatives and friends. The patient is usually not distressed by the secretions.
- Where symptoms remain uncontrolled after 24 hours or patients experience side effects please call your local Specialist Palliative Care Team for advice. Ex 5414 (LRI); Ex 3540 (GH); Ex 4680 (LGH). Out of Hours call LOROS advice line 0116 231 8415



**Supportive Information**

- Remember to always use the lowest effective dose of medication and the patient and family understand what medication being used and why. If a different route of administration is required, please contact the Specialist Palliative Care Team
- In some cases, an alternative anti-emetic (e.g. patients with Parkinson's disease) may be needed. Prescribe ondansetron as first line antiemetic 4mg subcutaneously prn to a maximum of 16mg in 24hours.
- Where symptoms remain uncontrolled after 24 hours or patients experience side effects, please call your local Specialist Palliative Care Team for advice. Ex 5414 (LRI); Ex 3540 (GH); Ex 4680 (LGH). Out of Hours call LOROS advice line 0116 231 8415



Patients who have not taken an opiate before should be prescribed levomepromazine 2.5-5mg by subcutaneous injection prn as an antiemetic, starting with the lowest dose to a maximum of 20mg in 24 hours

**Supportive Information**

- Remember to always use the lowest effective dose of medication and the patient and family understand what medication being used and why. If a different route of administration is required, please contact the Specialist Palliative Care Team
- For patients taking alternative opioids regularly (for example fentanyl patches, methadone or oxycodone) or where symptoms remain difficult to manage, please call your local Specialist Palliative Care Team for advice. In some cases, an alternative anti-emetic (e.g. patients with Parkinson's disease) or reduction in medication dose (e.g. patients with renal failure) may be needed. Please seek advice from Specialist Palliative Care.
- Morphine is the most cost effective opioid to use subcutaneously and should usually be used first line although the maximum practical subcutaneous breakthrough dose is only 60mg. Use the same opioid for dyspnoea as for pain.
- Where symptoms remain uncontrolled after 24 hours or patients experience side effects, please call your local Specialist Palliative Care Team for advice. Ex 5414 (LRI); Ex 3540 (GH); Ex 4680 (LGH). Out of Hours call LOROS advice line 0116 231 8415

## Managing diabetes in the last few days of life

