Care of dying adults in the last days of life (Guidance)

University Hospitals of Leicester NHS
NHS Trust

Trust ref: B1/2014

1. Introduction

1.1 This guidance refers only to the care of adults (aged 18 years and upwards) who are recognised as dying i.e.in their last days of life. It is not mandatory to apply the recommendations and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers.

1.1.1 NICE published guidance on Care of Dying Adults in the last days of life (NG31) in December 2015 and updated in October 2021. NICE Quality Standard (QS144) was published in 2017. These are available on line athttps://www.nice.org.uk/guidance/ng31 and https://www.nice.org.uk/guidance/qs144/chapter/Quality-statements

1.1.2 For guidance on care of infants, children and young people, NICE published guidance on End of Life Care for infants, children and young people (NG61 and QS160) in September 2017. These are available online at https://www.nice.org.uk/guidance/ng61 and https:// www.nice.org.uk/guidance/qs160 and are not covered in the scope of this document.

1.1.3 The Diana Children's Community 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. 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/.

1.1.4 For the purposes of this guideline the word 'patient' will be used in relation to the dying adult and the word 'family' will be used in relation to the NOK, family, relatives, carers or those important to the dying patient.

1.2 This guidance aims to ensure that the care of the patient 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 to include updated guidelines for prescribing in diabetes and renal failure.

1.3 In order to use this guidance, a face to face assessment of the patient must have been made by a minimum of a senior responsible clinician and registered nurse, or their nominated deputies. Reversible causes for the current condition must have been considered, treated if appropriate and the patient should meet the criteria for being in their last week of life.

1.4 When it is recognised that a patient is likely to be in their last week of life, an Individualised Care Plan for the Last Days of Life should be created following discussion with the patient where possible, and with those they identify as important to them. This should be used in conjunction with any other appropriate care plans in use throughout UHL to provide ongoing support to patient care.

1.5 Creation of an Individualised Care Plan for the Last Days of Life must be approved by the consultant responsible for the care of the patient and this must be documented on the care plan. Approval of creating an Individualised Care Plan indicates agreement of the consultant to take responsibility for the decision to change the focus of care and the communication of this decision to the MDT and the patient's family. The patient should be assessed on a regular basis by the medical team thereafter, to ensure that any change in condition including further deterioration, improvement or stability is detected and that daily care plans are adjusted accordingly and communicated to the patient and

their family.

1.6 This guidance is to be used in conjunction with UHL's Individualised Care Plan and a copy of an information leaflet available for the family, 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 management of common symptoms in the last days of life is available on InSite and is included at the end of this document (Appendix 1).

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 adult patients who are dying.

2.2 Responsibility and Accountability

2.2.1 The patient will have a clearly designated senior responsible clinician and registered nurse responsible for their care. These staff will be responsible for ensuring that the patient and their family are involved in decisions about care wherever possible, and that decisions are made in a timely way.

2.2.2 **Doctor.** In hospital, the senior responsible clinician is the patient's named consultant. Outside of the consultant's normal rostered hours, this responsibility is taken on by a nominated deputy; usually the senior responsible clinician (consultant or senior registrar) for that clinical area/ward. It is the duty of the named consultant to ensure that adequate information is available to the nominated deputy in order to support decision-making out of hours.

2.2.3 **Registered nurse.** In hospital, the ward sister or charge nurse has overall responsibility which can be delegated to a nominated registered nurse. The patient and the family should know the name of 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 patient, the family and those involved in the patient's care.

2.2.4 **Specialist Palliative Care team.** The patient's senior responsible clinician/ deputy, have a duty to consult specialists in palliative care when the patient's needs warrant it or if they need advice or support about the care. Ward doctors and nurses should be aware of relevant out-of-hours Palliative Care CNS weekend services, accessed via telephone and ICE referrals and Palliative Medicine Consultant out-of-hours advisory service accessed via UHL switchboard, medirota or LOROS.

2.2.5 **Timing of decision making.** Out of hours decisions that are needed to maintain the patient's comfort and safety can, and should, be made by appropriately trained staff 'on the spot'. 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. This includes decisions on significant changes in treatment focus, such as initiating or discontinuing individualised care plans for last days of life, unless there is an unavoidable need to make this decision out of hours.

2.2.6

3. Clinical Guidance – Initial assessment and creating an individualised care plan

3.1 Multi-disciplinary assessment of a patient who is thought to be dying and in their last week 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 the senior responsible doctor, or their nominated deputy, in conjunction with the responsible registered nurse and other members of the team involved in the patient's care who have specific information to contribute.

Signs and symptoms that may suggest a patient 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

3.1.2 Collecting information

If it is thought that a patient may be entering the last week of their life, where possible and practicable, the following information should be gathered and documented:

- Medical history and the clinical context, including underlying diagnoses
- The patient's physiological, psychological, social and spiritual needs
- Current clinical signs and symptoms
- The patient's goals and wishes
- The views of those important to the patient about future care

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

3.1.3 Documentation of decision-making

There should be clear documentation regarding:

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

3.1.4 Monitoring

Patients who have signs and symptoms that suggest they may be in the last week of life should be monitored at least every 4 hours by a nurse and daily by a doctor.

If there are any changes identified such as uncontrolled or worsening symptoms requiring a change in prescribing or treatment plan, or conversely an improvement in signs and symptoms or functional observations suggesting that the patient may be stabilising or recovering, a medical review should take place and a new treatment plan formulated. If a patient is receiving clinically assisted nutrition or hydration or other active treatments e.g antibiotics, this should be reviewed by a doctor on a daily basis. Medical review should also take place if any concerns regarding the current treatment plan are raised by the family. Any change in focus of care or treatment plans should be sensitively communicated to the patient (if able) and their family.

Monitoring does not necessarily imply the use of equipment or invasive tests or a medical face to face review. Changes in signs and symptoms can be gathered from variously talking with, observing and examining the patient, using the knowledge gained from the 4 hourly nursing assessments, reviewing the drug charts in particular PRN medication usage and any other information gathered from the multi- professional team, the patient and family, to help determine whether the patient is nearing death, deteriorating, stable or improving.

When there is a high level of uncertainty about whether a patient is entering the last week of life, may be stabilising or if there is potential for even temporary recovery for example, ambiguous or conflicting clinical signs or symptoms, a face to face medical review should take place and advice should be sought from colleagues with more experience of providing end of life care.

3.1.5 Investigations or treatments

Investigations or treatments that are unlikely to affect care in the last few days of life should be avoided unless there is a clinical need to do so. For example, if a blood count could guide the use of platelet transfusion to avoid catastrophic bleeding, **and** it is acceptable to the patient to undertake this treatment.

3.2 Sensitive communication with the patient and their family

3.2.1 Dying patients and their family, should be given opportunities to discuss, develop and review an individualised plan of care.

This plan of care should be agreed by the senior responsible doctor and registered nurse and their names should be clearly documented on the care plan and communicated to the patient and their family.

3.2.2 Communication at this time should include:

- What is happening and why you think the patient 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.

3.2.3 Open, honest and sensitive communication is important at a pace that is right for the patient and their family. To support shared decision making, clear, understandable and plain language should be used in all forms of communication. If needed, additional support should be provided to help the patient understand information, communicate their wishes or make decisions. If the patient's wishes cannot be met, the reasons for this should be explained to them and their family.

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

Information should be provided about how to contact those involved in caring for the patient if this is needed.

3.2.4 Contact details of the family should be clearly established as early as possible. This should include:

- Who is the 1st contact? Is there a 2nd contact?
- What to do if they cannot be contacted
- Does each contact want to be contacted at all times or only at certain times?

When the patient lacks capacity, decisions should be made in their best interests, taking into account any known prior wishes, and in consultation with their family and other members of the team. All decisions should be made in line with GMC Guidance:

Treatment and care towards the end of life - ethical guidance summary - GMC (gmc-uk.org)

If a patient 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.

3.2.5 If there are differences in opinion about what is in the best interests of the patient 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).

3.2.6 Deprivation of Liberty Safeguards (DoLS) If the patient's care is being supported by a DoLS, it should be sensitively explained to the family that this will remain in place. As of 3rd April 2017, deaths that occur when a DOLS is in place, no longer routinely require referral to the coroner.

3.2.7 Patient preferences and decisions made in advance. If the patient retains capacity, they must be offered the opportunity to express their current preferences for care and treatment, and what is most important to them at this time as part of shared decision making. These should be documented in the patient's medical records and on the Individualised Care Plan. The extent to which patients wish their family to be involved in decision-making should be determined, documented and respected.

3.2.8 Patients who are dying and have a diagnosis of dementia, cognitive impairment, learning disabilities or language barriers may have difficulties communicating their preferences for care. Healthcare professionals should establish the patient'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 family member 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.

3.2.9 Check whether the patient has:

- Any 'Advance Care Plan', Emergency Health Care Plan or ReSPECT form (Recommended Summary Plan for Emergency Care and Treatment) including a recorded resuscitation recommendation
- An Advance Decision to Refuse Treatment (ADRT)
- A Lasting Power of Attorney (LPA) for health and welfare decisions
- Preferences for their 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 Care Plan.
- 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, or alternative if their first choice cannot be met

3.2.10 If the patient identifies home as their preferred place of death, this must be discussed with them and their family to establish if this can be supported. The Discharge team are available 08.00 – 17.00 Monday – Friday to arrange rapid home support for last days of life. Out of hours the duty/flow manager can be contacted.

3.2.11 Best Interest Decision making

If the patient lacks capacity to make a particular decision and does not have an ADRT, LPA or other prior decision pertaining to the current situation, a best interests decision involving the family must be made. The lack of capacity and the best interests assessment must be clearly documented.

3.3 Review of treatments and investigations

3.3.1 An Individualised Care Plan, which includes food and drink, symptom control and psychological, social and spiritual support, should be agreed with the patient and family. All discussions and plans should be documented in the Individualised Care Plan.

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

3.3.3 Symptom needs should be assessed at least 4 hourly by a nurse and daily by a doctor. 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 patient's symptoms do not respond to medication or other interventions, or persist after 24hours, then the Specialist Palliative Care team should be contacted for clinical advice or to request review.

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

3.3.5 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 patient is entering the last days of life, may be stabilising or if there is potential for even temporary recovery.

See Appendix 1 for specific guidance for symptoms in the last days of life.

3.3.6 **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. These drugs are sometimes known to relatives as 'just in case' medications.

3.3.7 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 1.

3.3.8 As with all treatments, explanations about the purpose and intended benefits of anticipatory prescribing should be provided to the patient (if able) and their family.

3.3.9 **Observations:** Consideration to continue or stop routine observations is needed. If a decision is made to continue certain observations, their purpose and what action should be taken if these are abnormal should be clear. Observations are not necessary if results would not change management of the patient.

3.3.10 Oxygen saturations. If there is an unexpected change in the patient'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.

3.3.11 Capillary blood glucose monitoring may need to continue to prevent symptomatic hypo or hyperglycaemia but strict glycaemic control will be less important - see Appendix 2 for guidance about managing diabetes in the last days and hours of life. Urine dip for glucose may reduce the need to check capillary blood glucose levels.

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

3.3.13 Investigations that are unlikely to affect care in the last few days of life should be avoided unless there is a clinical need to do so

3.3.14 Treatments promoting comfort and dignity should be continued; 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 patient is unable to swallow.

3.3.15 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 patient (if able) and those important to them (as in usual practice).

3.3.16 See Appendix 2 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.

3.3.17 Pressure-relieving equipment. Patients should be reassessed for pressure-relieving equipment and any necessary equipment should be provided in a timely way. 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).

3.4 Resuscitation status

3.4.1 Relevant discussions and the decision about cardio- pulmonary resuscitation should be reviewed and clearly documented on a ReSPECT form and updated on Nervecentre. See UHL Policy Decisions about Cardiopulmonary Resuscitation B25/2014 for further information.

3.4.2 Discussions about CPR should be held in a sensitive and appropriate manner, and the preferences of the patient and their family 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 patient/ family. The Individualised care plan for the last days of life can be used when a patient remains for cardio-pulmonary resuscitation attempts, but this decision should be proactively reviewed on a daily basis or until the clinical situation changes.

3.4.3 It should be noted that when a patient is dying from a progressive condition and is in the last few days of life, cardiopulmonary resuscitation is unlikely to be successful or appropriate.

3.4.4 Implantable Cardiac Defibrillator (ICD) or Cardiac resynchronisation device (CRT-D)

When a patient is likely to die very soon and has an ICD / CRT-D 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 / CRT-D should be had with the dying patient and their family. Wherever possible it is best to plan to deactivate the ICD / CRT-D within normal working hours, working with the cardiac technicians to do this. They can contacted via ext 12905.

3.4.5 In an emergency and 'out of hours' an ICD / CRT-D 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.

3.4.6 Discussions about deactivation of the ICD / CRT-D and any action to be taken should be recorded in the dying patient's medical notes and on the Individualised care plan for the last days of life.

3.5 Nutrition and Hydration

3.5.1 An individualised approach to the patient's 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.

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

3.5.3 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 patient 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.

3.5.4 Patients who are dying should not routinely be made nil by mouth (NBM). If the dying patient is at risk of aspiration, the risks and benefits of eating and drinking should be discussed. The dying patient 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.

3.5.5 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 patient has capacity, this should be discussed with the patient

3.5.6 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.

3.5.7 Discuss the risks and benefits of clinically assisted hydration with the dying patient 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 contribute to secretions

3.5.8 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 patient (such as fluid overload) or if they no longer want it.

3.6 Consider the needs of those important to the dying patient eg family and carers

- The needs of the family at this stage should be assessed to ensure that their own needs are not 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.
- Offer support and signpost to other relevant services (such as their GP) if appropriate.

Document on the Individualised Care Plan what the needs of the family are.

4 Clinical Guidance – Ongoing review of the dying patient

4.1 At every patient encounter the comfort and emotional wellbeing of the patient should be assessed. If those important to the dying patient are present, their needs should also be assessed. If there are any concerns or symptoms, these must be addressed and the interventions documented and evaluated.

4.2 When considering medications for symptom relief, take into account the likely cause of the patient's symptoms, consider whether non-pharmacological interventions are possible, and treat any reversible causes of symptoms such as urinary retention. Consider 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)

4.3 Assessments should take place at least every 4 hours (nurses) checking 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
- Nutrition and hydration
- 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

4.4 If symptoms do not respond to medication or other interventions, or persist after 24 hours, referral to the Specialist Palliative Care Team for advice or to review is recommended.

4.5 Daily medical review should include:

- Discussion between 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.
- The patient's need for food and fluids. The patient should be supported to eat and drink as long as they are able to and desire to do so.
- The family are contacted to update them and elicit and address their needs
- Any indications of improvement are noted and appropriate actions taken. If the patient is no longer thought to be dying, this should be explained to the patient and their family and the plan of care should be altered.
- Ensure that any changes to the care plan are understood by the patient, their family and the clinical team.
- If the patient is unable to verbally communicate pain, use assessment tools e.g. PAINAD or CVE which can be printed from insite or are part of the Nerve Centre 4 hourly nursing assessment.
- Involvement of the Specialist Palliative Care Team does not replace the responsibility of the ward teams to undertake these daily reviews.

5 Education and Training

The Specialist Palliative 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. 15414 (LRI), 13540 (GH) and 14680 (LGH).

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

Additional courses and training can be booked through HELM

6 Monitoring and Audit Criteria

What key element(s) need(s) monitoring as per local approved policy or guidance? (e.g. Policy standards or objectives)	*Who will lead on this?* *Name of lead and what is the role of other professional groups*	*What method will be used to gather evidence?*	*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?*	*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*
Element to be Monitored	**Lead**	**Method**	**Frequency**	**Reporting arrangements**
Documentation of end of life care in accordance with policy recommendations, NICE guidelines, NACEL recommendations and CQC requirements	Dr Sarah Bell & Gayle Hemstock (Medical and Nursing End of Life Care Leads)	Audit	Annually	To Specialist Palliative Care Governance Group, End of Life Steering Group and to UHL Quality Assurance Committee

6.1 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, 'Care of dying adults in the last days of life', December 2015 and publication of NICE Quality Standard (QS144) 'Care of dying adults in the last days of life' (March 2017).

6.2 **Key Words:** *End of life, dying, palliative, last days of life, adult, symptom control, syringe driver, pathway, individualised care plan, SWAN, anticipatory medications, dignity, pain, nausea, breathlessness, secretions, agitation, terminal*

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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

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Author / Lead Officer: Dr Sarah Bell	**Job Title:** Palliative Medicine Consultant
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Version Number: V2	**Details of Changes made during review:** References to responsibility for care in community settings removed, guidance reviewed in line with NICE guidance NG31: *care of dying adults*, EOLC plan layout adjusted, symptom control flow chart added

Version Number: V3	**Details of Changes made during review:** 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): *Care of dying adults in the last days of life (QS144)*; DOLS statement updated; EOLC plan layout adjusted. Care plans not in pre-existing care plans have been taken from *The Royal Marsden Manual of Clinical Nursing Procedures (9th Ed.)* (2015).
Version Number: V4	**Details of Changes made during review:** 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 guidanc in Appendix 3. Minor wording changes: 2.2.1 Additional reference to SPCT support outside the working week 3.1.2 and 3.1.3 addition of prompt: what is most important to the patient at thistime? 3.1.3 Addition of reference and hyperlink to the national ReSPECT document and additional information prompting reader to consider cultural and religiousneeds 3.1.4 Prompt added to discuss potential side effects of sc medications as per NICE QS144 3.1.5 Importance of daily review if artificial hydration or nutrition is in place 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 What is most important to the patient and family at this time? Would input from chaplaincy team be helpful? Doctor has reviewed the need for observation and blood tests and recorded a plan in the medical notes 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) Doctor has discussed changes with patient and family "and spiritual" added to assessment of needs of family If in place, have benefits/burdens of artificial nutrition or hydration been reviewed **Yes** □ **No** □ added as a daily prompt **"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 Symptom management: "Starting with the lowest dose" added where a range is suggested for morphine, midazolam and levomepromazine in line with QS144 Algorithm added in line with Diabetes UK guidance for managing diabetes in the last days or hours of life
Version Number: V5	**Details of Changes made during review:** 1.1.1 Addition of section to reference NICE guidelines and standards foradults 1.1.2 Updated contact details for Diana service 2.2 Reformatting to improve clarify of responsibilities related to differentroles
Version Number: V6	**Details of Changes made during review:** 1.1.3: "Diana service" changed to "Diana Children's community service". Telephone number confirmed with websidte 4.4.23 1.1.4 Definition of patient and family for purposes of document and standardisation of language throughout 1.4: Relevant timespan for care plan increased from last 2-3 days of life, to last week of life – correction continued throughout document Addition of requirement for named consultant responsibility to initiate care plan with MDT involvement Correction of typos throughout document 1.5 Rewording 'anticipatory prescribing' to 'symptom management of common symptoms' 3.1 Rephrasing through section to provide consistency of tense and tone 3.1.3: monitoring requirements changed to "every 4 hours by nurses, every 24 hours by doctor" 3.2.2 Removed: Who would the patient 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 Significant rephrasing of paragraphs for clarity and for consistency of tense and tone throughout document including renumbering of sections due to re formatting (sections merged for ease of editing) Appendix 1 – Individualised care plan removed. To be replaced with new version once formally signed off Appendix 2 – nursing care plans removed. To be replaced with new version once signed off Appendix 4: Symptom management flow charts removed and merged with Guidance Symptom Management for Patients with Renal Failure at the End of Life UHL Renal Guideline Trust Ref: C241/2016. Renumbered Appendix 1 Appendix 4: Recommendation to contact specialist level palliative care team for advice on antipsychotics at the end of life – addition Appendix 5: Renumbered appendix 2 Insuman Basal removed from blue box as treatment option as due to be discontinued by manufacturer in June 2023.. CBG aim added

Appendix 1

Symptom management in the last days of life.

If symptoms persist for more than 24 hours or for further advice, contact the Specialist Level Palliative Care Team. OOH advice can be sought from the Palliative Medicine Consultant on-call

Symptom to be managed	Reversible causes that may need specific interventions	Non-pharmacological measures to consider	Anticipatory prescribing (PRN medication) *Patients in last days of life must ALWAYS have PRN medication prescribed even if already using regular medications for these symptoms. Use lowest dose that has effect.*		Regular prescribing using a continuous subcutaneous infusion (CSCI) via T34 syringe driver ONLY *If new symptom with no reversible causes identified and patient is requiring 2+ PRN doses / 24 hrs with some effect* *Or patient is on regular oral medication that needs converting to CSCI delivery*		
			eGFR > 60	**eGFR <60**	**eGFR > 60**	**eGFR <60**	**eGFR <30**
Pain	Muscle spasm Intestinal colic e.g. from constipation/ total bowel obstruction Urine retention Ascites	Repositioning Bowel and bladder management to reduce pain from visceral stretch Consider if draining ascites is appropriate	**Opioid naiive**		**No regular opioids but has received 2+ PRN doses in past 24 hrs**		
			Morphine 2.5mg – 5mg SC PRN Min interval 1 hour	Oxycodone 1mg-2mg SC PRN Min interval 6 hours** ***If pain returns within 6 hours, min interval can be cautiously reduced to 4 hourly. Discuss with Specialist Palliative Care team if unsure.*	Add up the PRN doses of SC morphine in past 24 hrs and prescribe this dose as a CSCI via T34 syringe driver over 24 hrs e.g. 4 doses of morphine 2.5mg SC have been given in past 24 hrs = start syringe driver with 10mg SC morphine over 24 hrs	Add up the PRN doses of SC oxycodone in past 24 hrs and prescribe this dose as a CSCI via T34 syringe driver over 24 hrs e.g. 4 doses of oxycodone 1mg SC have been given in past 24 hrs = start syringe driver with 5mg SC oxycodone over 24 hrs (May need to round up or down depending on vial size)	Add up the PRN doses of SC oxycodone in past 24 hrs and convert to alfentanil by dividing by 10. Prescribe as a CSCI via T34 syringe driver over 24 hrs e.g. 4 doses of oxycodone 1mg SC have been given in past 24 hrs. 4mg / 10 = 400micrograms. Start syringe driver with 400micrograms SC alfentanil over 24 hrs
	In case of nausea, prescribe either levomepromazine 2.5mg – 5mg SC PRN (Max 25mg/ 24 hrs) or Haloperidol 0.5mg – 1mg SC PRN (Max 5mg/ 24 hrs)		**On regular opioids**		**Pain currently controlled on regular oral opioids and need to use SC route**		
	These conversions are only a guide and may need adjusting based on the patient's individual situation. *Discuss with the specialist level palliative care team if help is needed, or the patient has hepatorenal failure.*		Calculate morphine SC PRN dose by dividing the 24 hr morphine dose by 6 e.g. syringe driver of 15mg SC morphine over 24 hrs = PRN 2.5mg SC morphine Min interval 1 hour	Calculate oxycodone SC PRN dose by dividing the 24 hr oxycodone dose by 6 e.g. syringe driver of 15mg SC oxycodone over 24 hrs = PRN 2.5mg SC oxycodone or multiplying the 24 hr alfentanil dose by 10/6 e.g. syringe driver of 2mg SC alfentanil over 24 hrs = syringe driver of 20mg SC oxycodone over 24 hrs = PRN 3mg SC oxycodone Min interval 6 hours**	To convert PO morphine to SC morphine, divide the total 24 hr PO morphine dose by 2. Prescribe as a CSCI via T34 syringe driver over 24 hrs. e.g. 20mg bd PO Morphine MR = start syringe driver with 20mg SC morphine over 24 hrs	To convert PO oxycodone to SC oxycodone, divide the total 24 hr PO oxycodone dose by 2. Prescribe as a CSCI via T34 syringe driver over 24 hrs. e.g. 10mg bd PO Oxycodone MR 10mg = start syringe driver with 10mg SC oxycodone over 24 hrs	To convert to SC alfentanil CSCI via T34 syringe driver over 24 hrs: PO morphine – add up 24hr dose and divide by 30 e.g. 30mg bd PO Morphine MR = 2mg SC alfentanil over 24 hrs PO oxycodone – add up 24hr dose and divide by 20 e.g. 30mg bd PO Oxycodone MR = 3mg SCalfentanil over 24 hrs
					Pain NOT currently controlled on regular oral opioids and need to use SC route		
					Calculate equivalent CSCI doses for T34 syringe driver/ 24 hrs as above and increase dose by 30-50% e.g. if calculate a syringe driver with 30mg SC morphine over 24 hrs is equivalent dose to current analgesia, increase prescription to syringe driver 40mg SC morphine over 24 hrs		

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Symptom to be managed	Reversible causes that may need specific intervention	Non-pharmacological measures to consider	Anticipatory prescribing (PRN medication) *Patients in last days of life must ALWAYS have PRN medication prescribed even if already using regular medications for these symptoms. Use lowest dose that has effect.* *Discuss with specialist level palliative care team if need help with conversions or choice of drug*		Regular prescribing using a continuous subcutaneous infusion (CSCI) via T34 syringe driver ONLY *If new symptom with no reversible causes identified and patient is requiring 2+ PRN doses / 24 hrs with some effect* *Or patient is on regular oral medication that needs converting to CSCI delivery*		
Agitation and restlessness *Agitation is not an inevitable part of dying but can be a difficult symptom to treat in some patients*	Uncontrolled pain Full bladder Full rectum Hypoxia Hypoglycaemia Anxiety and fear Medication side effects or withdrawal Emotional or spiritual distress	Address reversible issues Reassurance and a human presence Quiet, calm environment (lighting, sound) Repositioning Support from chaplaincy / faith leader	**eGFR > 60**	**eGFR <60**	**eGFR > 60**	**eGFR <60**	**eGFR <30**
			Predominantly anguish, anxiety, fear				
			Midazolam 2.5 – 5mg SC PRN Min interval 1 hour	Midazolam 1.25mg - 2.5mg SC PRN Min interval 1 hour	Consider starting a CSCI via a T34 syringe driver of 5-10mg midazolam SC over 24 hrs		
			Predominantly delirium and psychotic features e.g hallucinations, confusion				
			Levomepromazine 6.25 mg - 12.5 mg SC PRN Or Haloperidol 0.5mg – 1mg SC PRN Minimum interval 1 hour		Consider starting a CSCI via a T34 syringe driver of 12.5mg levomepromazine SC over 24 hrs Or a CSCI via a T34 syringe driver of 1.5mg Haloperidol SC over 24 hrs In ESRF, starting doses may be halved.		
			If the cause of agitation is unclear, or if one of these medications is ineffective on its own, a combination of both midazolam and levomepromazine may be helpful both for PRN use and as a CSCI in a T34 syringe driver. *In some cases eg Parkinsons disease, alternatives to levomepromazine may be needed – discuss with Parkinson's team or specialist level palliative care team*				
			Patients who are prescribed long term medication for mood disorder (eg Olanzapine, Risperidone, Quetiapine) may require a syringe driver of levomepromazine when they can no longer take oral medication. Contact the specialist level palliative care team for advice on dose conversions				
Nausea and Vomiting	GI causes eg Reflux, Gastric stasis, Constipation, bowel obstruction Pain Medication - side effects or withdrawal Infection Raised ICP	Address reversible issues Consider stopping or reducing IV or SC fluids or enteral / parenteral feeds if GI cause Review medication	If effective PRN antiemetic not already prescribed use: Levomepromazine 2.5 – 5mg SC PRN Minimum interval 1 hour If the patient has Parkinson's disease, prescribe Ondansetron 4mg SC PRN, minimum interval 4 hours, up to a maximum of 16mg in 24 / hrs		**Nausea currently controlled on oral antiemetic** Convert regular antiemetic to a CSCI via T34 syringe driver over 24 hrs. Discuss with specialist palliative care team regarding drug compatibility **Nausea NOT currently controlled** Consider starting a CSCI via T34 syringe driver over 24 hrs of levomepromazine 6.25mg – 12.5 mg or haloperidol 0.5mg-1.5mg The dose may need to be increased gradually to a maximum in syringe driver of levomepromazine 25mg SC over 24 hrs OR haloperidol 5mg SC over 24 hours In ESRF, starting doses may be halved		

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Symptom to be managed	Reversible causes that may need specific intervention	Non-pharmacological measures to consider	Anticipatory prescribing (PRN medication) *Patients in last days of life must ALWAYS have PRN medication prescribed even if already using regular medications for these symptoms. Use lowest dose that has effect.* *Discuss with specialist level palliative care team if need help with conversions or choice of drug*		Regular prescribing using a continuous subcutaneous infusion (CSCI) via T34 syringe driver ONLY *If new symptom with no reversible causes identified and patient is requiring 2+ PRN doses / 24 hrs with some effect* *Or patient is on regular oral medication that needs converting to CSCI delivery*		
Breathless	Hypoxia DKA Pulmonary oedema	Sit patient as upright as is comfortable Fan therapy if tolerated Reassurance and a human presence Oxygen (if tolerated) is a treatment for hypoxia. It is not indicated if Oxygen saturations are in an appropriate range.	**eGFR > 60**	**eGFR <60**	**eGFR > 60**	**eGFR <60**	**eGFR <30**
			Morphine 2.5mg SC PRN Min interval 1 hour Max dose 15mg/ 24 hrs and Midazolam 2.5mg SC PRN Minimum interval 1 hour Max dose 30mg/ 24 hrs Morphine may relieve the sense of breathlessness, and midazolam can reduce the associated anxiety	Oxycodone 1mg – 2mg SC PRN Min interval 6 hours Max dose 10mg/ 24 hrs and Midazolam 1.25mg - 2.5mg SC PRN Minimum interval 1 hour Max dose 30mg/ 24 hrs Oxycodone may relieve the sense of breathlessness, and midazolam can reduce the associated anxiety	**OPIOIDS - Pt has received 2+ PRN doses in 24 hrs**		
					Add up the PRN doses of SC morphine in past 24 hrs and prescribe as a CSCI via T34 syringe driver over 24 hrs e.g. 4 doses of morphine 2.5mg SC have been given in past 24 hrs = start syringe driver with 10mg SC morphine over 24 hrs	Add up the PRN doses of SC oxycodone in past 24 hrs and prescribe as a CSCI via T34 syringe driver over 24 hrs e.g. 4 doses of oxycodone 1mg SC have been given in past 24 hrs = start syringe driver with 5mg SC oxycodone over 24 hrs (May need to round up or down depending on vial size)	Add up the PRN doses of SC oxycodone in past 24 hrs and convert to alfentanil by dividing by 10. Prescribe as a CSCI via T34 syringe driver over 24 hrs e.g. 4 doses of oxycodone 1mg SC have been given in past 24 hrs. 4mg / 10 = 400micrograms. Start syringe driver with 400micrograms alfentanil SC over 24 hrs
					MIDAZOLAM - Pt has received 2+ PRN doses in 24 hrs		
					If 2 or more doses of midazolam have been given or if breathlessness is causing anxiety/ fear/ panic, consider adding 5-10mg midazolam to the opioid syringe driver and gradually increasing to max dose 30mg over 24 hrs		
			Patients with severe, distressing breathlessness, should be referred to the specialist level palliative care team				
Respiratory tract secretions *Noisy respiratory secretions can be a normal part of the dying process- if not troublesome they many not need treating*	Bacterial chest infection Pulmonary oedema	Positioning - sitting up or lying in left lateral position can help Consider stopping or reducing IV or SC fluids or enteral feeds Suction – consider if large volume secretions which are distressing, not improving with other measures and is tolerated	**eGFR > 60**	**eGFR <60**	**eGFR > 60**	**eGFR <60**	**eGFR <30**
			Glycopyrronium 200 micrograms SC PRN Minimum interval 4 hours Max dose 1.2mg over 24 hours		**If pt has received 2+ PRN doses in 24 hrs** Consider prescribing a CSCI via T34 syringe driver of glycopyrronium 600 micrograms over 24 hrs If symptoms persist, gradually increase to max dose 1.2mg over 24 hrs		
			Some 'active' treatments may help with symptom control *e.g. Antibiotics may be considered if there is large volume, purulent sputum.* *e.g. Diuretics (furosemide) can help manage secretions associated with pulmonary oedema* *If secretions are not distressing the patient, offer reassurance to relatives*				

Appendix 2

Managing diabetes in the last few days of life

Discuss changing the approach to diabetes management with the patient and family (with consent).

The CBG target for this group is 6 – 15; aiming to avoid hypoglycaemia and symptomatic hyperglycaemia

If the patient has type 1 diabetes, is treated with insulin, or if there are particular requests or concerns (eg, recurrent hypo or hyperglycaemia), refer to the Diabetes Specialist Nurses (DSN) via ICE to support and agree a monitoring strategy

Type 2 diabetes
Diet controlled or Metformin treated

Stop Metformin
No glucose monitoring required

KEY POINTS

- 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 - with consent, check urine or CBG once daily at staggered times and record
- If symptoms are observed, it could be due to abnormal blood glucose levels
- Test urine or blood if the patient is symptomatic
- Observe for symptoms in a previously insulin treated diabetic where insulin has been discontinued

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

Stop tablets and GLP1 injections
Consider stopping insulin if the patient only requires a small dose

If insulin stopped:

- Urinalysis for glucose daily – if over 2+ check CBG
- If blood glucose over 20 mmol/L give 4-6 units rapid acting insulin
- Insulin to be given 4 hrly intervals only & **not** at bedtime
-
- Re-check CBG after 2 hours and again at 4 hours

If patient requires rapid acting insulin more than twice consider daily isophane insulin** or a long-acting analogue insulin e.g. Glargine (Lantus)

If insulin to continue:

- Prescribe once daily morning dose of isophane insulin ** or long-acting analogue insulin Glargine (Lantus) based on 25% less than total previous

Type 1 diabetes – do not stop insulin - **refer to DSN via ICE**

Continue once daily morning dose of either Insulin Glargine (Lantus), Insulin Degludec (Tresiba) with a reduction in dose

Check CBG once a day at teatime:

- If below 8 mmol/L, reduce insulin by 10-20%
-
- If above 20 mmol/L, increase insulin by10-20% to reduce riskof symptoms or ketosis

Key:

*Novorapid

**Humulin I / Insulatard