Leeds Community Healthcare NHS Trust

Symptom Management Guidance in the Last Days of Life	
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Executive Summary

This guidance has been produced to support Leeds Community Healthcare (LCH) staff delivering care to patients at the end of their life and provides guidance on patient comfort and managing symptoms in the last days of life. It is relevant for independent prescribers and non-prescribing health care professionals and includes recommendations for prescribing medicines to manage common symptoms.

LCH works closely with specialist palliative care colleagues in Leeds Palliative Care Network in developing symptom management guidance to reflect local and national best practice. Key factors in effective symptom management at end of life are staff knowledge, skills and confidence, 7 day access to medicines and palliative care advice in and out of hours and shared electronic patient records (Hospice UK, 2017). These factors and relevant National Institute for Clinical Excellence (NICE) Guidelines and quality standards underpin this guidance and its implementation in practice.

Currently Leeds guidance within acute and community settings has slight variations. Leeds Palliative Care Network is undertaking an audit of anticipatory medicines use that may inform future guidance. This audit has been paused during the pandemic and will resume in the coming months. The changes to this guidance in terms of prescribing and management of common symptoms are therefore minimal, pending the outcome of this audit and further review.

Equality Analysis

Leeds Community Healthcare NHS Trust's vision is to provide the best possible care to every community. In support of the vision, with due regard to the Equality Act 2010 General Duty aims, Equality Analysis has been undertaken on this policy and any outcomes have been considered in the development of this guideline.

Symptom management guidance in the last days of life

Contents

1 Introduction

1.1 Background

Patient comfort is widely recognised as a key measure of good palliative and end of life care, particularly in the last days of life when patients can experience several common symptoms (NICE, 2020). Maximising comfort and well being is one of the six national palliative care ambitions (National Palliative and End of Life Care Partnership, 2021) and a Leeds Palliative Care Network strategic outcome (Leeds Palliative Care Network, 2021) helping to drive improvements in this area.

A national review of care in the last days of life highlighted three main areas of concern that can impact directly on patient comfort and symptom management (The Leadership Alliance for Care of the Dying Person, 2014):

- recognising that a person was dying was not always supported by an experienced clinician and not reliably reviewed, even if the person may have had potential to improve
- the dying person may have been unduly sedated as a result of injudiciously prescribed symptom control medicines
- the perception that hydration and some essential medicines may have been withheld or withdrawn, resulting in a negative effect on the dying person.

These concerns have informed NICE Guideline (NG31) and Quality Standard (QS144) for the Care of Dying Adults in the Last Days of Life (NICE, 2020; NICE 2021a). NICE outline the use of medication and non- pharmacological measures within an individualised plan of care that includes symptom management, hydration, psychological, social and spiritual support and which is sensitively discussed with the person and those important to them. This discussion should include what medicines may be needed, taking into consideration the most appropriate route of administration if the person is unable to take or absorb medication orally, to ensure continuous symptom control where required.

NICE Quality Standard QS13 End of Life Care for Adults (NICE, 2021b) and NICE Guideline NG142 End of Life Care for Adults: Service Delivery (NICE, 2021c) outline the importance of early recognition and advance care planning to ensure effective coordination of care that reflects patients wishes and care preferences in the last months, weeks and days of life. The needs of carers are seen as integral to care and a new NICE quality standard (NICE, 2021b) requires health care professionals to consider carers' health and wellbeing and to provide accessible practical and emotional support at home. This includes the need for services to support carers in managing patients' symptoms in the home care setting.

1.2 Local improvements

LCH works both independently and within Leeds Palliative Care Network to deliver continuous improvements in end of life care across all care settings and at the point of

transfer of care. Local and national drivers are reflected in these improvements, many of which support effective and responsive symptom management at the end of life.

Local improvements include:

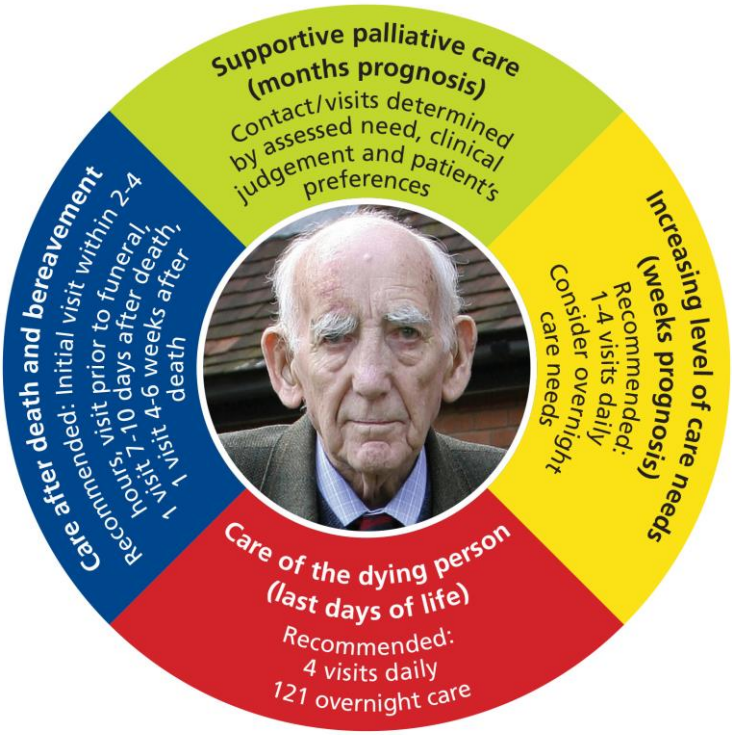
- The availability of 7 day palliative care advice and support from LCH Palliative Care Leads and Specialist Palliative Care Community Nurse Specialists
- Co-produced symptom management guidance for use across community settings
- An increase in Independent Prescribers available to prescribe common medicines at end of life
- An agreement with pharmacies through NHSE to stock common medicines used at end of life is in place
- Adaptation of LCH *Care in the Lasts Days of Life* information leaflet (appendix 1) to support conversations with patients and carers across all community settings
- An annual survey of bereaved carers experience of care in the last days that includes symptom management
- LCH standard operating procedure for remote prescribing to support symptom management for palliative care patients
- LCH standard operating procedure for transcribing medication that allows registered clinicians to transcribe anticipatory and syringe driver medicines to prevent any delay in symptom management at end of life
- LCH guidance for carers or patients requesting to administer subcutaneous medications in palliative care
- Leeds Palliative Care Network guidance for managing seizures and bleeds in at risk patients
- Palliative and end of life care education and training programmes, consolidated in practice with LCH palliative care leads
- The Planning Ahead SystmOne template to help coordinate care and share patients wishes and care preferences across LCH, Primary Care and the Leeds hospices and to provide access to symptom management guidance
- Implementation of ReSPECT (Recommended Summary or Emergency Care and Treatment) to support advance care planning.

1.3 LCH model of care

Recognition that a patient is in the last days of life is vital in meeting patients' needs as their condition deteriorates. In the last days of life patients' needs should be reviewed at least daily by an experienced registered clinician (NICE, 2021a) and regularly reviewed by a senior clinician, ideally the case manager, to ensure any changes or improvement in condition are promptly recognised. A night care assessment should be offered to ensure patients care needs overnight are identified and met.

To provide high quality, individualised care in a community setting, optimising the frequency of visits, ensuring the competence of staff in assessing and managing common symptoms at end of life are vital in maintaining patient comfort and enabling patients to be cared for in their preferred place of care and death.

LCH's Service Delivery Framework for Palliative and End of Life Care sets out service and care expectations, including the last days of life, when it is recommended a patient receives up to four visits daily and one to one (121) overnight care to ensure regular review of their comfort and plan of care.



Patients approaching the last days of life or with high complexity of palliative care are prioritised in **Neighbourhood Team Essential Visit Guidance** in terms of planned and unplanned care to ensure that care is responsive and the needs of patients at end of life are prioritised.

Palliative care support and advice is available 7 days a week from LCH palliative care leads and specialist palliative care community teams and should be sought in a timely manner. Hospice specialist palliative care services can be contacted for advice in and out of hours, including for patients not known to them.

2 Scope

This guideline applies to independent prescribers, all nurses with a valid NMC registration and registered therapists delivering end of life care to adults in community settings.

This guideline connects with:

- LCH Medicines Code (PL324)
- LCH Controlled Drug Policy (PL359),
    - appendix: guidance on patient and carer administration of subcutaneous medication in palliative care
- LCH Policy for the Safe use of the Saf-T Intima cannula and T34 Syringe Driver in Symptom Management for Adults (PL 838)
- LCH Guideline for Clinically Assisted Hydration for Adults (GL028)
- LCH SOP Record keeping of controlled drugs in a community setting

- LCH Standard Operating Procedure (SOP) Remote Prescribing for Palliative Care patients
- LCH SOP Transcription of medication records in the community

3 Purpose

This guidance provides a guiding framework for promoting comfort and symptom management in the last days of life. It ensures medication is prescribed and administered in line with best practice and highlights the importance of communication with patients and carers about its use in line with NICE guidance that:

- All medications, including anticipatory medicines, must be targeted at specific symptoms, have a clinical rationale for the starting dose, be regularly reviewed and adjusted as needed for effect
- The reason for any intervention, including use of a syringe driver must be explained to the patient and those important to them
- The likely side effects of specific interventions, especially those that may make the person sleepy, must be discussed with the patient where possible so they can make informed decisions and explained to those important to them if the patient wishes.

4 Definitions

Palliative care is described by NICE (2021c) as aiming to provide relief from pain and other distressing symptoms, integrating the psychological, social and spiritual aspects of the person's care, and continuing to offer a support system to help people to live as actively as possible until their death.

End of Life is described by NICE (2021c) as care that is provided in the 'last year of life'. It includes the care and support given in the final weeks and months of life and the planning and preparation for this. It includes people with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

The **last days of life** generally refers to the last two to three days of life (NICE, 2020), however this can vary between hours and on occasion be a week or more depending on the speed of deterioration and underlying condition of the person.

Anticipatory medication is required to ensure there is no delay in responding to a symptom if it occurs in the last days of life and should have individualised indications for use, dosage and route of administration (NICE, 2021a).

Planning Ahead SystmOne template is shared across LCH, Primary Care and Leeds hospices. It supports advance care planning and coordination of care by recording and

sharing of people's care preferences and key details about their care. It also includes links to recommended symptom management guidance and comprises:

- What Matters to Me tool to support personalised care
- ReSPECT (Recommended Summary Plan for Emergency Care and Treatment)
- EPaCCS (Electronic Palliative Care Coordination System).

EPR- Electronic Patient Record

Subcutaneous injection refers to the bolus administration of medication into the tissue layer between the skin and the muscle.

Syringe driver is an ambulatory, portable, battery operated, medical device used to administer a continuous infusion of medication, in this instance subcutaneously.

5 Responsibilities

Chief Executive

The Chief Executive has overall responsibility for this guideline. In practice this responsibility is generally delegated to Heads of Service.

Executive Directors, Business Unit Clinical Leads and General Managers

Have delegated responsibility for ensuring the organisation can fulfil the requirements of the guideline, in terms of provision of training, conditions and resources as appropriate.

Clinical Leaders, Service Managers and Heads of Service

Are responsible for ensuring that:

- The guideline is disseminated, implemented and monitored within their services
- Staff within their areas are aware of the guideline and their duty to follow it.

Responsibility of Staff

This guideline applies to independent prescribers working within the Royal Pharmaceutical Society Competency Framework for all Prescribers (2021) and all Registered Nurses and Therapists delivering care at the end of life.

Staff must seek advice and support from an Independent Prescriber and Specialist Palliative Care Team where appropriate. Out of hours there is a Palliative Medicine Consultant available on call via SJUH switchboard for advice.

All staff employed by LCH must work in concordance with the Leeds Safeguarding Multi-agency Policies and Procedures and local guidelines in relation to any safeguarding concerns they have for service users and the public with whom they are in contact.

6 Resources and Equipment

Equipment required for administration of medication subcutaneously should be readily accessible to ensure prompt and effective symptom management. The Saf-T Intima subcutaneous cannula is used if a patient requires subcutaneous medication to reduce the need for injections, as per LCH policy.

Independent Prescribers and registered clinicians delivering end of life care can access recommended symptom management resources via the Planning Ahead SystmOne template, Leeds Palliative Care Network website and/or Leeds Health Pathways.

LCH registered clinicians are provided with a copy of the *Yorkshire and Humber guide to symptom management in palliative care* (Yorkshire and Humber End of Life Care Group, 2019) booklet at training.

LCH information leaflet *Care in the Last Days of life* (appendix 1) is available from stores and in bases.

7 Management of common symptoms in the last days of life

A personalised plan of care should include comfort and symptom management and reflect patients' wishes and care preferences for symptom management.

The medications suggested are not exhaustive and it is important to use clinical judgment and consider individual patient factors when using this guidance. Patients' medicines should be regularly reviewed including the use of 'when required' medicines (Care Quality Commission, 2017).

7.1 Promoting patient comfort – hydration and mouth care

Eating and drinking needs must be considered as part of the plan of care and patients should be supported to take food and fluids orally for as long as possible. Hydration status should be assessed daily in the last days of life and the risk of aspiration considered if a patient develops swallowing difficulties.

Mouth care is essential to promote comfort for patients unable to take fluids orally at end of life, to keep their mouth moist, clean and comfortable (Royal College of Nursing, 2021). Local guidance on mouth care and management of common problems such as dryness, coating, soreness, ulceration and thrush is available to support practice (appendix 2). A soft toothbrush is generally recommended for cleaning the mouth. Single use foam sponge swabs and lemon and glycerine swabs are not recommended as there is a serious risk of choking from the head of foam sponge swabs detaching, they are not effective at removing plaque and long term use of lemon and glycerine swabs can dry the mouth (Royal College of Nursing, 2021).

In some circumstances, after consideration of the risks and benefits, it may be appropriate to initiate clinically assisted hydration, for example if a patient is experiencing symptoms of dehydration. Further guidance is available to support this decision making in **LCH Guideline for Clinically Assisted Hydration for Adults**.

The plan of care should be sensitively discussed and time given for patients and carers to explore any queries or concerns.

7.2 Carer and patient administration of subcutaneous medication in palliative care

Guidance to support **carer and patient administration of subcutaneous medication in palliative care** has been developed for those requesting to administer medication independently. This framework contains inclusion and exclusion criteria and a practice guide and requires a risk assessment, training and assessment of practice. A practice assessment and consent form must be completed if implemented in practice. Further information and guidance can be found in **LCH Controlled Drug Policy appendices** https://lch.oak.com/Content/File/Index/a1c69dd4-5a1f-4f16-a5ba-37347af32c67

7.3 Prescribing guidance

Prescribing guidance is accessible via Leeds Health Pathways, Leeds Palliative Care Network and on the Leeds Planning Ahead (ReSPECT/EPACCS) template.

Special attention must be given when prescribing medication at end of life to ensure symptom management can be provided when needed. Time is critical when prognosis is hours to days; and ensuring correct medication is available and prescribed at correct doses enables nursing staff to respond quickly as symptoms arise. All staff should be aware of the need to proactively contact an appropriate prescriber with a view to reviewing the dose and/or dose interval to prevent any potential breakdown in symptom control. For example, a dose interval of 4-6 hourly could delay responding to a symptom if it occurs. This is of particular importance when access to prescribers is limited out of hours.

Anticipatory subcutaneous medication should be prescribed for common symptoms that can develop in the last days of life.

- Drug choice and dose depends on patient individual characteristics e.g. reduced renal or liver function, age, frailty, co-morbidities
- The following guidance from The Renal Association is helpful when defining reduced renal function http://www.renal.org/information-resources/the-uk-eckd-guide/ckd-stages#sthash.7TIbvfXO.dpbs
- An indication for anticipatory medications should be documented on the prescription
- The purpose and possible side effects of medications (e.g. sedation with midazolam) should be discussed with patients and carers where possible
- For a patient already receiving background opioid medication, as required doses should be proportionate to the background opioid regime. Further guidance on prescribing at end of life is available on Leeds Health Pathways and the Planning Ahead SystmOne template and includes the local guidance listed below.

The following **prescribing guidance** to support end of life care is available on Leeds Health Pathways and Leeds Palliative Care Network website

- Leeds Palliative Care Network (2019) Leeds Opioid Conversion Wheel for guidance on switching between opioids or switching opioid route http://nww.lhp.leedsth.nhs.uk/common/guidelines/detail.aspx?ID=4687

- Leeds Palliative Care Network (2020) Prescribing at end of life - Renal Failure http://nww.lhp.leedsth.nhs.uk/common/guidelines/detail.aspx?id=5025
- Leeds Palliative Care Network (2020) Prescribing at end of life - Impaired Liver Function http://nww.lhp.leedsth.nhs.uk/common/guidelines/detail.aspx?id=5029
- Yorkshire and Humber guide to symptom management in palliative care (Yorkshire and the Humber End of Life Care Group, 2019) https://leedspalliativecare.org.uk/wp-content/uploads/2019/09/A-Guide-to-Symptom-Management-in-Palliative-Care-Yorkshire-and-Humber-End-of-Life-Care-Group.pdf

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Symptom management guidance in the last days of life

Prescribing Guidance

Guidance for prescribing anticipatory subcutaneous (SC) medication in the last days of life					
Symptom / indication	**Drug name / strength**	**Route**	**Dose**	**Frequency**	**Quantity**
Pain and/or breathlessness	***Diamorphine**	SC	Opioid naive and no known renal failure 2.5mg – 5mg	As required Do not repeat within 30 minutes Max FOUR doses in24 hours	10 (ten) x 5 mg ampoules Also prescribe water for injection if required
	or **Morphine sulphate 10mg / 1ml**	SC	Opioid naive and no known renal failure 2.5mg-5mg	As required Do not repeat within 30 minutes Max FOUR doses in24 hours	10 (ten) x 10mg/ml ampoules
	or **Oxycodone10 mg/ 1mL**	SC	Opioid naive 1mg-2mg IF recent GFR available and <50 oxycodone may be used. Refer to guidance and/or seek specialist advice if required.	As required Do not repeat within 30 minutes Max FOUR doses in24 hours	10 (ten) x 10 mg/mL ampoules

Symptom management guidance in the last days of life

Agitation If agitation is likely to be due to <u>delirium</u> seek advice from Specialist Palliative Care	***Midazolam 10mg/ 2mL**	SC	2.5mg-5mg If known renal or liver failure refer to guidance and/or seek specialist advice if required	As required Do not repeat within 30 minutes Max FOUR doses in 24 hours	10 (ten) x 10mg/2mL ampoules Do not prescribe 5mg/5ml ampoules
Nausea and/or vomiting	***Levomepromazine 25mg/ 1mL**	SC	6.25mg	As required Do not repeat within 30 minutes Max FOUR doses in 24 hours	10 (ten) x 25mg/mL ampoules
Respiratory secretions	***Hyoscine butylbromide (Buscopan®) 20mg/ 1mL**	SC	20mg	As required Do not repeat within 30 minutes Max FOUR doses in 24 hours	10 (ten) x 20mg / mL ampoules
SC – subcutaneous *First line choice in community settings and available to prescribe on Planning Ahead (ReSPECT/EPaCCS template)					

Symptom management guidance in the last days of life

The information below provides guidance on managing common symptoms in the last days of life.

7.4 Management of pain

Consider non-pharmacological measures and possible reversible causes. Remember the importance of offering information and explanation and addressing patients and carers' concerns.

Is the patient already taking oral morphine for pain?

YES
If able to take opioids orally patient continues to do so

If unable to take opioids orally administer medication subcutaneously via syringe driver.
All opioid medications taken in the previous 24 hours must be taken into consideration.
Converting a patient from oral morphine to a 24 hour syringe driver of subcutaneous diamorphine:

- Divide the TOTAL dose of oral morphine in the previous 24 hours by 3

Eg. Morphine Sulphate (MST®,Zomorph®) 30mg every12 hours +30mg Morphine Sulphate Solution (Oramorph®) as required = 90mg oral morphine
90mg ÷ 3 = 30mg diamorphine subcut infusion over 24hr

NO
Anticipatory prescribing

2 or more dose are required within 24 hours consider a syringe driver

This may be sooner than 24 hours for some patients e.g. if they have required two or more doses within a few hours and these have been effective

Breakthrough pain

- Ensure a subcutaneous opioid is available as required = 1/6 of the 24 hour dose
- If pain is present at the same time as commencing a syringe driver administer an as required dose and review after 30 minutes
- Repeat if required and has been effective
- If the analgesic dose delivered via the syringe driver is increased, then the subcut opioid 'as required' dose must be reviewed with a view to increasing in line with this i.e. 1/6 of the 24 hour dose

Patient's pain remains uncontrolled

- Reassess cause of the symptom and effectiveness of as required doses administered within the previous 24 hours
- Consider increasing the total 24 hour dose of analgesia in syringe driver by up to 30%-50%; level of increase will depend on a range of factors e.g. number of as required doses given, the indication for the doses and their effectiveness
- This may be sooner than 24 hours for some patients e.g. if they have required two or more doses within a few hours
- Seek advice from Independent Prescriber/Specialist Palliative Care as required

IMPORTANT

When converting analgesia, equivalences are approximate only and should be adjusted accordingto response
Contact an Independent Prescriber and/or Specialist Palliative Care Team for advice as required:

- To convert from one strong opioid to another, opioid patch is in situ, or pain escalating rapidly
- If the patient experiences distressing opioid side effects e.g. hallucinations or muscle spasm
- For patients with known renal or liver failure and e-GFR is known alternative opioids and/ordoses may be used. Further prescribing guidance is available on Leeds Health Pathways/ EPaCCS.

For guidance on switching between opioids or switching opioid route see Leeds Opioid Conversion Wheel http://nww.lhp.leedsth.nhs.uk/common/guidelines/detail.aspx?ID=4687

7.5 Management of terminal restlessness

Is the patient restless or agitated?

YES

Consider non-pharmacological measures and possible reversible causes

- Reassurance by family /staff
- Is the patient's bladder full / are they constipated or in pain/ is opioid toxicity a possibility (observe for plucking, twitching, jerking)?
- Promote a calm environment and consider any known wishes and preferences

If ineffective

- Administer midazolam 2.5mg - 5mg s/c as required
- Review after 30 mins

If patient remains agitated administer midazolam 5mg s/c as required

Patient's agitation remains uncontrolled

- Reassess cause of symptom
- If 2 or more as required doses are required within 24 hours and have been effective a syringe driver of 10-30mg midazolam s/c in 24 hours may be prescribed
- This may be sooner than 24 hours for some patients e.g. if they have required two or more doses within a few hours
- Seek advice from an independent prescriber/Specialist Palliative Care as required e.g. for advice on managing delirium.

NO
Anticipatory prescribing

If 2 or more doses are required within 24hours consider a syringe driver

This may be sooner than 24 hours for some patients e.g. if they have required twoor more doses within afew hours and these have been effective

IMPORTANT

- Ensure injectable midazolam is prescribed as 10mg/2ml and not 5mg/5ml
- Signs of agitation can include pulling/removing sheets or clothes, trying to get out of bed, vocalisation e.g. moaning & calling out and emotional changes such as anxiety,anger, irritability
- Patients with known renal and liver failure may be more sensitive to sedatives - seekadvice from an Independent Prescriber as required.
- Higher (10mg) doses of midazolam may be used for management of the following:
  - Haemorrhage
  - Seizures –if anti-epileptic medication already prescribed
- If midazolam is ineffective levomepromazine may be used at higher doses than thoseprescribed for the management of nausea and vomiting as an alternative, or in combination with midazolam - seek advice from an Independent Prescriber regardingdose
- Consider delirium if patient has sepsis or major organ failure, is unable to focus/maintain attention, or is experiencing confusion, disorientation and hallucinations – refer to Specialist Palliative Care Team if agitation persists
- Haloperidol can be useful if delirium/confusion present and is generally less sedating.

7.6 Management of Respiratory Tract Secretions

Does the patient have respiratory tract secretions?

YES

Assess cause and if the patient or family are distressed by the symptom

- Consider the source of the secretions (e.g. salivary, bronchial, gastric reflux or fluid overload) as this can affect management e.g. bronchial secretions are less likely to respond to anti-secretory drugs
- Explain the likely cause and that pharmacological management may be limited in its effectiveness
- Provide information and if the patient has reduced consciousness reassure the family that the patient is likely to be unaware of the secretions

NO

Anticipatory Prescribing

If a dose is required consider a syringe driver if effective – see opposite

Consider non-pharmacological measures and possible reversible causes

- Simple measures e.g. re-positioning to a tilt or on to side may be effective
- Consider seeking advice from physiotherapist e.g. regarding postural drainage
- Review effectiveness of non-pharmacological measures

If ineffective

- Administer **hyoscine butylbromide 20mg s/c prn**
- Review after 30 minutes
- If hyoscine butylbromide effective consider commencing syringe driver
- NB Medication will only prevent further secretions developing

Respiratory secretions remain problematic and distressing

- Seek specialist palliative care advice

IMPORTANT

- This symptom should be treated early to help prevent further secretions developing
- Good mouth care is essential
- If using hyoscine butylbromide, metoclopramide may be less effective as they have opposite effects on the GI tract
- Consider midazolam, if the patient is distressed by retained secretions
- Hyoscine butylbromide is incompatible with cyclizine in certain mixes
- Hyoscine hydrobromide can be used as an alternative to hyoscine butylbromide, but can be more sedating and occasionally causes paradoxical agitation
- Therapist support and/or oral suctioning may be appropriate in some circumstances and if tolerated.

7.7 Management of Nausea and Vomiting

Does the patient have nausea or vomiting?

YES

Consider non-pharmacological measures and possible reversible causes

- Where possible cause should be determined before treatment – seek advice as required. Common causes include: drugs, constipation, gastric stasis/obstruction, coughing, hypercalcaemia, uraemia, underlying disease

If pharmacological intervention is required

- Choice of anti-emetic depends on cause of nausea and vomiting
- If already taking an anti-emetic request review and/or if effective conversion to subcut route
- If not already taking an anti-emetic administer **levomepromazine 6.25mg** subcutaneously as prescribed
- Review after 30 minutes
- If effective consider commencing or adding **levomepromazine 6.25-12.5mg subcut** to syringe driver over 24 hours

If ineffective

- If patient remains nauseous consider a further dose

NO

Anticipatory prescribing

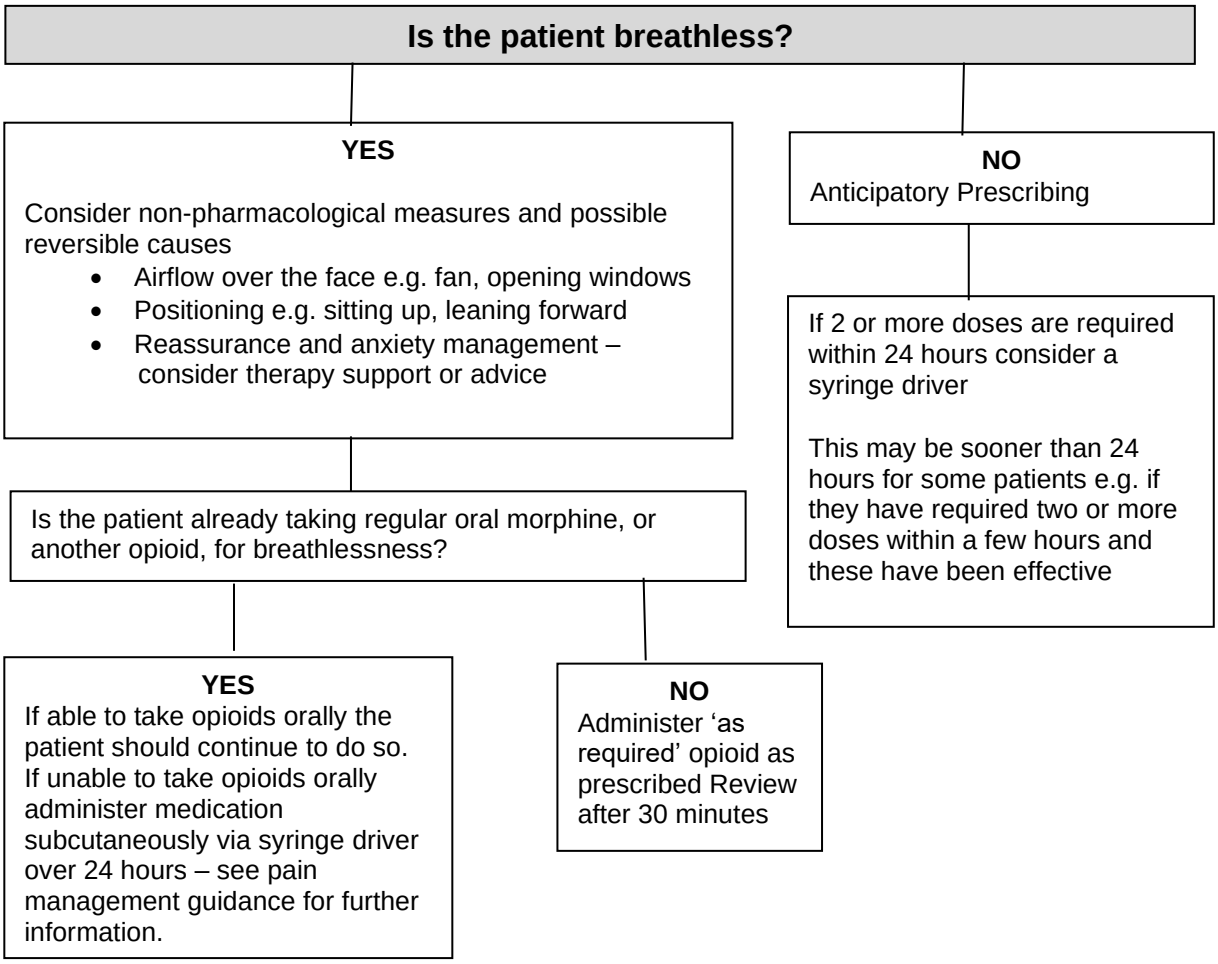
If 2 or more doses are required within 24 hours consider a syringe driver

This may be sooner than 24 hours for some patients e.g. if they have required two or more doses within a few hours and these have been effective

IMPORTANT

- Monitor for unacceptable side effects of medication
- Common causes of nausea and vomiting include constipation, gastric stasis/obstruction, coughing, hypercalcaemia, medication and uraemia
- Levomepromazine is particularly useful for multifactoral or indeterminate nausea and vomiting and can be sedating
- Levomepromazine 2.5mg may be prescribed if there are concerns over drowsiness and/or higher dose is contraindicated e.g. reduced renal or hepatic function
- If already on cyclizine, haloperidol or metoclopramide and symptoms are controlled convert to subcut. The subcut dose is equivalent to the oral dose and these antiemetics can all be safely given subcutaneously
- Some anti-emetics may reduce seizure threshold; for people with unstable epilepsy seek specialist advice
- Avoid metoclopramide if patient has colic
- Where possible avoid haloperidol, levomepromazine and metoclopramide in patients with Parkinson's Disease – seek advice from Palliative Care Team / consider use of cyclizine
- S/c cyclizine:
  - Should be diluted with water for injection
  - Check compatibility with other syringe driver medications and contact Specialist Palliative Care if advice required.

7.8 Management of Dyspnoea



IMPORTANT

- Oxygen therapy
  - Consider if hypoxic and tolerating cannula/mask
  - If no benefit discontinue
- If already taking an opioid for pain the as required dose is generally appropriate for breathlessness
- If the patient is anxious consider midazolam s/c as required
- In renal and liver impairment the patient may be on an alternative opioid for pain/breathlessness
- If the patient is already taking an oral opioid for pain a different opioid for breathlessness should not be prescribed – seek advice as required

7.9 Medication administered by syringe driver

Management of the common symptoms above may require medication to be administered continuously by a syringe driver. Further guidance is available in **Guidance on prescribing and administering drugs for syringe drivers in the last days of life in the community** (Leeds Palliative Care Network, 2022; appendix 3) and **LCH Policy for the Safe use of the Saf-T Intima cannula and T34 Syringe Driver in Symptom Management for Adults**.

7.10 Management of bleeds and seizures in at risk patients

Some patients may be at risk of seizures and bleeds in the last months, weeks or days of life. Specialist palliative care advice should be sought and the management plan discussed and agreed with patients and carers. Leeds Palliative Care Network (2020) has developed information to support the management of and discussions about these potentially distressing symptoms:

- **Palliative care patients at risk of bleeding: information for families and carers** (appendix 4)
- **Community palliative seizure management plan: information for families, carers and staff** (appendix 5)

8 Mental Capacity Act (MCA 2005 Code of Practice)

This Act applies to all persons over the age of 16 who are assessed to lack capacity to consent or withhold consent to treatment or care. Under the MCA there are occasions when an individual lacking capacity may require the provision of an Independent Mental Capacity Advocate, specifically when treatment or residence decisions have a significant impact on that individual's life and rights.

In the last days of life many patients will lose capacity and staff should refer to the outcomes of advance care planning discussions and any known wishes or preferences previously expressed. Staff also need to be clear about their role and responsibilities in assessing capacity and best interest decision making.

For further information see LCH intranet.

9 Risk Assessments

Refer to comprehensive assessments, including risk assessment, and reporting incidents as relevant. Refer to equipment, resources and training needs, advice and support for patients and carers relating to risks involved
All incidents will be reported via Datix® and investigated in line with the Incident and Serious Incident Management Policy.

10 Training Needs

Refer to the Statutory and Mandatory Training Policy Training Needs Analysis. Up to date information is available on the Intranet for course details.

Palliative care training is provided for staff delivering end of life care that includes assessment and management of comfort and common symptoms in the last days of life. Core skills are included in the Adult Business Unit Skills Matrix.

During the pandemic training was adapted to combine face to face training with smaller groups of staff, consolidated in practice with LCH Palliative Care Leads. On going support and development is provided in practice by LCH Palliative Care Leads. A senior clinician development programme for 2022 is in development with specialist palliative care colleagues and will include aspects of symptom management.

Bespoke communication skills training to support sensitive end of life care conversations, including advanced level for senior clinicians, is provided through Leeds hospices.

It is the responsibility of each practitioner to access training and demonstrate his/her knowledge and competency. It is the responsibility of managers to ensure that practitioners can attend training as detailed above.

11 Monitoring Compliance

Minimum requirement to be monitored/ audited	Process for monitoring/ audit	Lead for the monitoring/audit process	Frequency of monitoring/ auditing	Lead for reviewing results	Lead for developing/ reviewing action plan	Lead for monitoring action plan
Staff training	Staff attendance recorded locally – in future via ESR Staff skills recorded on skills matrix locally	Palliative Care Leads Neighbourhood Clinical Quality Leads	Quarterly	Palliative Care Clinical Quality Leads Clinical Pathway Leads	Clinical and Operational Heads of Service Palliative CareClinical Service Manager	ABU Clinical Lead
Incidents	Reported via Datix	Palliative Care Leads Neighbourhood Clinical Quality Leads	Quarterly	Clinical Pathway Lead	Clinical Heads of Service Palliative Care Clinical Service Manager	ABU Clinical Lead ABU Quality Lead
Patients achieving their preferred place of death	Reported via EPaCCS	Palliative Care Leads Neighbourhood Clinical Quality Leads	Monthly	Palliative Care Clinical Quality Leads Clinical Pathway Leads	Clinical and Operational Heads of Service Palliative Care Clinical Service Manager	ABU Clinical Lead ABU General Manager

12 Ratification and approval process

This guideline has been consulted on as part of the review process and has been quality assured by Clinical Governance Team (QPD)

13 Dissemination and Implementation

This is a reviewed guideline and will be disseminated via existing cascade systems within LCH Adult Services and the LCH palliative care leads using newsletters and local

forums, training and updates. Implementation in practice is supported by the LCH palliative care leads.

14 Review arrangements

This guideline will be reviewed in three years by the author or sooner if there is a local or national requirement.

15 References and Further Reading

Care Quality Commission (2017) Key lines of enquiry, prompts and ratings characteristics for healthcare services

Hospice UK (2017) No painful compromise: A guide for commissioners and providers to improve pain management for dying people at home

Leeds Community Healthcare NHS Trust (2021) Care in the last days of life. Information for carers

Leeds Palliative Care Network (2019) The Leeds opioid conversion guide for adult palliative care patients

Leeds Palliative Care Network (2020) Prescribing at end of life - Renal Failure

Leeds Palliative Care Network (2020) Prescribing at end of life - Impaired Liver Function

Leeds Palliative Care Network (2022) Guidance on prescribing and administering drugs for syringe drivers in the last days of life in the community

Leeds Palliative Care Network (2020) Palliative Care patients at risk of bleeding. Information for families and carers 2nd ed.

Leeds Palliative Care Network (2020) Community palliative seizure management plan. Information for families, carers and staff 2nd ed.

Leeds Palliative Care Network (2021) Leeds adult palliative and end of life care strategy 2021-26

National Institute for Health and Care Excellence (2020) Care of dying adults in the last days of life. NICE guideline [NG31]

National Institute for Health and Care Excellence (2021a) Care of dying adults in the last days of life. Quality standard [QS144]

National Institute for Health and Care Excellence (2021b) End of life care for adults. Quality standard [QS13]

National Institute for Health and Care Excellence (2021c) End of life care for adults: service delivery. NICE guideline [NG142]

National Palliative and End of Life Care Partnership (2021) Ambitions for palliative and end of life care: a national framework for local action

Royal College of Nursing (2019) Mouth Care Matters in End-of-Life Care

Royal Pharmaceutical Society (2021) A Competency Framework for all prescribers

The Leadership Alliance for Care of the Dying Person (2014) One chance to get it right

Yorkshire and the Humber End of Life Care Group (2019) A guide to symptom management in palliative care. Version 7

Useful website

The Renal Association - CKD stages

Appendix 1: Care in the Last Days of Life patient and carer information leaflet

https://www.carersleeds.org.uk/wp-content/uploads/2021/08/Care-in-last-days-of-life-lft-for-carers_July21_for-web_final.pdf

A doctor or other healthcare professional will assess your relative or friend's medication needs and decide on suitable drugs, the correct dose and when this should be taken. Medicine that is not helpful at this time may be stopped and new medication prescribed. Your relative or friend may not experience any discomfort, however if they do our priority is to control their symptoms. Having medication available will enable the nurses to respond promptly. We will offer to explain how we use the medication prescribed and the likely effect.

If your relative or friend is unable to swallow, a syringe pump may be needed to give medication to help keep them comfortable. If you have any queries or concerns about possible symptoms, medication or use of a syringe pump we can discuss these with you.

Sleeping and drowsiness

Your relative or friend may spend more time sleeping or be more drowsy when awake. As they become weaker they are likely to become unresponsive. This change is a gradual, natural process and simply being together can be a comfort. If they show any sign of distress or restlessness we can give medication to help with this. The medication used can be sedating, however only enough to control the symptom will be given and no more.

Changes in breathing and colour

In the last hours of life breathing patterns may change and sometimes there are long pauses between breaths. Breathing can also appear laboured. The skin can become pale, moist and slightly cool to touch. This is part of a gradual, natural process as the body becomes weaker and it is unlikely your relative or friend is aware of these changes.

You may hear a rattle when your relative or friend breathes. This can be caused when mucus or secretions build up in the airways. We may change their position or give medication to help with this. The noise itself is not a sign of distress, though we understand that some people may find it upsetting.

If you have any concerns or queries about any aspect of your relative or friend's care, please ask.

Contact us

If involved, your Neighbourhood Team will provide their contact details during the day 7am-5pm and out of hours 5-9.30pm.

Neighbourhood Night service: 9.30pm-7am, **0300 003 0045**

GP surgery: .....

Out of hours GP: **111**

Care home: .....

St Gemma's Hospice: **0113 218 5540**

Wheatfields Hospice: **0113 278 7249**

Other: .....

Further information

www.leedspalliativecare.org.uk

Help us get it right

If you have a complaint, concern, comment or compliment you can share your feedback using the contact details below:

Leeds Community Healthcare Trust
Tel: 0113 220 8585 Email: lch.pet@nhs.net

GP Practice
You can contact the Practice Manager or contact NHS England on:
Tel: 0300 3 11 22 33 Email: england.contactus@nhs.net

Care Home
You can contact the Care Home Manager or Leeds City Council if the care home is funded by them.
Tel: 0113 222 4405 Email: complaints@leeds.gov.uk

We can make this information available in Braille, large print, audio or other languages on request.

www.leedscommunityhealthcare.nhs.uk

Leeds Palliative Care Network

NHS Leeds Community Healthcare NHS Trust

Care in the last days of life

Information for carers

If your doctor or other healthcare professional believe your relative or friend is in the last hours or days of life they will have explained this to you. The information below describes the care we give to people in their own homes or care home in the last days of life. It details how you can be involved and some of the changes you may see in your relative or friend. Their condition will be reviewed regularly, every few hours or at each visit if they are at home, to make sure they are comfortable and have everything they need at this time. The staff caring for your relative or friend will also want to make sure you feel supported.

At this time our priorities are to:

- Be compassionate and sensitive at all times
- Let you know of any change in your relative or friend's condition
- Agree an individualised plan of care to meet your relative or friend's needs during the day and night. This will include:
  - Food and drink
  - Comfort and symptom control
  - Emotional, social and spiritual support
- Ensure care decisions reflect your relative or friend's wishes and are regularly reviewed
- Involve you and your relative or friend in decisions about care to the extent they and you want
- Work as a team, with you if you would like to be involved, to provide care and seek further advice whenever necessary
- Support you, and wherever possible respect your wishes, as well as those of your relative or friend.

This plan of care will be reviewed every day.

How you can help

If you are aware of any expressed wishes your relative or friend has shared that may help at this time or you would like to be involved in giving care please let us know. You may prefer not to discuss this or be involved in giving care. This will be respected.

Your relative or friend may have spoken to you about what mattered most to them at this time. These may include any religious, cultural or spiritual beliefs, or other wishes such as music, photographs and who they would like to be with them. If we need to be aware of these wishes please speak to one of us. If you would like support from a chaplain or other religious leader at this time and do not have any contact details we can offer information.

You can support your relative or friend in important ways such as spending time together, sharing memories and news of family and friends. If needed, the nurses will ask you for your contact details, so they can keep you updated about what is happening.

Please ask us if you are unsure about anything. We will be happy to answer any questions or concerns you may have and provide more information, or the Neighbourhood Team can also provide more information or contact other professionals if that would be helpful.

Who will be providing support?

The team providing care may vary depending on your relative or friend's needs and where they are being cared for, but typically includes:

- GP
- Neighbourhood Team (community nursing and therapy teams)
- Nurses and night sitters from the Neighbourhood Night Service
- Care home nurses and carers
- Specialist nurse or doctor
- Social Worker or Health Case Manager
- Home care providers

The team will work together to provide care during the day and night. Specialist advice or support is available from both Leeds hospices if needed, even if they have not been involved previously in providing care.

Changes in the last days of life

The care each person needs is unique, however there are some common signs or changes in the last days and hours of life. These are described below. If you have any queries or need more information please ask.

Food and drink

We will support your relative or friend to eat and drink for as long as possible. As they become weaker they may find swallowing and the effort of eating and drinking too difficult, or they may not want to eat and drink. When a person stops eating and drinking, good mouth care is very important to stop their mouth feeling dry. We will explain to you how mouth care is given and ask if you would like to help give this care.

If we are concerned that your relative or friend is uncomfortable because they cannot eat or drink we may consider giving artificial fluids. This is not common, however in these circumstances we would discuss this with you, the GP, other members of the care team and your relative or friend, where possible, before making a decision.

Comfort and symptom control

Every time your relative or friend's condition is reviewed, we will assess how comfortable they seem, provide personal care and change their position when needed. We will look for any changes in their eating and drinking, sleepiness or breathing and whether they seem in any discomfort, pain or distress.

Appendix 2: Mouth care guidance for adults

Being updated April 2022 – revised version and URL to be added

Appendix 3: Guidance on prescribing and administering drugs for syringe drivers in the last days of life in the community

https://leedspalliativecare.org.uk/wp-content/uploads/2022/04/Syringe-Driver-Medication-Ranges-final-Mar-2022.pdf

For advice on anything relating to this document please contact:

LCH Palliative Care Leads
Sue Ryder Wheatfields Hospice 0113 2787249
St Gemma's Hospice 0113 2185500

Key Points: Prescribers

All ranges are suggestions only and prescribers must take responsibility for their prescribing actions, taking into account possible reversible causes for deterioration and non-pharmacological approaches for symptom management. If necessary seek advice from LCH Palliative Care Leads or Specialist Palliative Care Teams, or an Independent Prescriber with experience in this area.

Drugs other than those listed in this document are not prescribed with ranges unless specifically advised to do so by a Specialist Palliative Care Team.
Discuss with the patient and/or carers the potential benefits and possible adverse effects of the medicines prescribed.

For patients on analgesic patches (Fentanyl or Buprenorphine): leave the patch in place and seek specialist palliative care advice regarding syringe driver doses.
For patients on oral analgesics: an independent prescriber needs to review current medications as patients/relatives/carers may well need to stop oral and any other drugs as appropriate. MAR charts must be re-transcribed if medicines are altered.

There may be occasions when an anticipatory prescription of a syringe driver is required. This should NOT be standard practice and the reason for doing this must be documented in the patient's electronic record together with the indication for starting the syringe driver and medications that require stopping when the syringe driver is commenced.

Key points: Administration

Where a range is prescribed the first syringe driver is commenced at the lowest prescribed dose. If there is concern that this dose is too low then contact the LCH Palliative Care Leads or Specialist Palliative Care Teams for advice.

Prior to any decision to increase dose there must be an assessment of the benefit of the medications including PRN doses to determine if an increase is appropriate.

The ranges are suggestions and allow two dose increases of 30% to 50% if needed e.g. range is 20mg-45mg Initial dose 20mg/24hours 1st dose increase could be to 30mg/24 hours (50% increase) 2nd dose increase could be to 40mg/24hours (30% increase).

When increasing the dose of a drug within the prescribed range practitioners need to be mindful of the other drugs in the infusion. Care must be taken when increasing the dose of more than one drug in the syringe driver because of the potential additive effects e.g. increased drowsiness.

Opioid syringe pump drug prescribing

It is generally acceptable practice that when an increase in analgesia is required to increase the opioid dose by 30-50%. If a dose increase of greater than 50% appears to be indicated then contact the LCH Palliative Care Leads or Specialist Palliative Care Teams for advice and document rationale for dosage increase in clinical notes.

The recommended quantities allow for 72 hours of medication with two dose increases.

Current oral morphine dose in 24 hours	**Subcutaneous Diamorphine**			**Subcutaneous Morphine Sulphate**		
	Starting dose over 24 hours	**Dose range over 24 hours**	**Guide to number & concentration of ampoules**	**Starting dose over 24 hours**	**Dose range over 24 hours**	**Guide to number & concentration of ampoules**
Opioid naïve	5mg	5-10mg	5mg x 5	5mg	5-10mg	10mg/1ml x 5
10mg	5mg	5-15mg	10mg x 5	5mg	5-20mg	10mg/1ml x 5
20mg	7.5mg	7.5-20mg	10mg x 5	10mg	10-25mg	10mg/1ml x5
30mg	10mg	10-30mg	10mg x 10	15mg	15-40mg	30mg/1ml x 5
40mg	15mg	15-30mg	10mg x 10	20mg	20-45mg	30mg/1ml x 5
60mg	20mg	20-45mg	10mg x 10	30mg	30-60mg	30mg/1ml x 5
80mg	30mg	30-60mg	30mg x 5	40mg	40-80mg	30mg/1ml x 10
120mg	40mg	40-80mg	30mg x 10	60mg	60-100mg	30mg/1ml x 10
160mg	50mg	50-90mg	30mg x 10	80mg	80-130mg	30mg/1ml x 15

Current oral oxycodone dose in 24 hours	**Subcutaneous oxycodone**		
	Starting dose over 24 hours	**Dose range over 24 hours**	**Guide to number & concentration of ampoules**
Opioid naive	Seek specialist palliative care advice		
10mg	5mg	5-20mg	10mg/1ml x 5
20mg	10mg	10-25mg	20mg/2ml x5
30mg	15mg	15-40mg	20mg/2ml x 5
40mg	20mg	20-45mg	20mg/2ml x 10
60mg	30mg	30-60mg	20mg/2ml x 10
80mg	40mg	40-80mg	20mg/2ml x 10
120mg	60mg	60-100mg	20mg/2ml x 15
160mg	80mg	80-	20mg/2ml x 20

		130mg	

Non opioid syringe driver drug prescribing

Drug	Indication	Ampoule Size	Suggest dose range in 24 hours	Comments	Suggested number of ampoules
Midazolam	Agitation[1]	10mg/2mls	10-30mg	**Ensure reversible causes of agitation are addressed.** Start at 10mg unless the patient has required 10mg or more of midazolam PRN in the proceeding 24 hours or is extremely agitated or was previously on oral benzodiazepines	5-10
Midazolam	Seizures (patients who have had convulsions and/or are on an oral anticonvulsant for seizures)	10mg/2mls	20-60mg	Start at 20mg or 30mg and increase if necessary. Contact Specialist Palliative Care Teams if advice required on which starting dose to choose	10 -15
Hyoscine butylbromide	Secretions / death rattle or colic	20mg/ml	60-120mg	Start at 60mg and increase if secretions or colic remain problematic.	10
Levomepromazine	Nausea	25mg/ml	6.25-12.5mg	Start at 6.25mg unless the patient has required 2 or more SC PRN doses in the proceeding 24 hours or was on more than 12.5mg orally in 24 hours	5
Levomepromazine	Agitation[1]	25mg/ml	Seek specialist palliative care advice		
Haloperidol	Nausea	5mg/ml	1.5-5mg	Generally start at 1.5mg in 24 hours unless the patient was on a higher dose orally.	5
Haloperidol	Delirium	5mg/ml	Seek specialist palliative care advice		
Metoclopramide	Nausea and vomiting due to gastric stasis or bowel	10mg/2mls	30-60mg	Only use if nausea or vomiting has been controlled by metoclopramide prior to last days of life. If so convert the oral dose to SC (1:1 conversion)	10

	obstruction without colic				

[1] For agitation suggest start with midazolam and increase the dose. If patient not responding please seek specialist palliative care advice.

Ampoule size information for injectable medicines

Medication	Ampoule sizes available
Diamorphine hydrochloride	Dry powder: 5mg, 10mg, 30mg, 100mg, 500mg
Morphine sulphate Where possible minimize number of strengths available in each patient's hometo minimize risk of errors	10mg/1ml, 30mg/ml usual strengths 15mg/1ml, 20mg/1ml 20mg/2ml,30mg/2ml, 40mg/2ml, 60mg/2ml
Oxycodone hydrochloride	10mg/1ml, 20mg/2ml, 50mg/1ml
Midazolam Other preparations are available, however,their use should be restricted to minimise the risk of unintended overdose	10 mg/2ml
Hyoscine hydrobromide	400micrograms/1ml, 600micrograms/1ml
Hyoscine butylbromide	20mg/1ml
Levomepromazine hydrochloride	25mg/1ml
Cyclizine lactate	50mg/1ml
Haloperidol	5mg/1ml
Metoclopramide	10mg/2ml

Appendix 4
Palliative care patients at risk of bleeding: information for families and carers

https://leedspalliativecare.org.uk/wp-content/uploads/2020/03/Final-Palliative-Care-Patients-at-risk-of-Bleeding-Guidelines-Jan-20.pdf

Palliative Care patients at risk of bleeding

NHS

Information for families and carers

Date completed: ...../...../.....

Completed by: .....

Review date: ...../...../.....

Addressograph

Name: ..... **is at increased risk of bleeding due to:**

.....

This leaflet is intended to be used in face to face discussion with your medical and nursing care team, who will explain the information below. It is important that you feel able to ask if you have any concerns or unanswered questions.

This leaflet is being given to you because the doctors and nurses think your relative is at risk of bleeding. Living with the risk of bleeding, and caring for a family member or friend who is at risk of bleeding can be frightening.

This information is intended to help you know what to do in the event of a bleed and who you can contact for support.

If it happens there is a possibility that they might not survive the bleeding. If this is the case, our aim is to keep them comfortable.

How to prepare

Consider having the following readily available:

- A supply of absorbent dressings (if these have been provided) and dark coloured towels.
- Contact details for support - you could put these in your phone.
- A phone nearby.
- This leaflet.
- Buccal midazolam (if you have it).

What to do if bleeding starts

- The main priority is for someone to stay with your relative.
- To call for help, advice and support (see phone numbers on the back of this leaflet).
- Try to stay as calm as possible and reassure your relative or friend.

A small amount of blood can look very alarming. Use dark absorbent towels or dressings to slow down the bleeding by holding them firmly against a bleeding wound.

If there is a large amount of blood and your relative appears to be distressed then **midazolam** (which is a sedative drug) can be given to make them less aware of what is happening.

Information about midazolam

What is midazolam?

Midazolam is a sedative medication which means it makes people sleepy. In this case it is given to make your relative more relaxed, less distressed and less aware of what is happening.

- Midazolam can be given as an injection by nursing staff. An alternative, that is sometimes considered, is for family or friends to be shown how to use buccal midazolam into the mouth.
- The most important thing you can do, is to stay with the patient. Your presence will be reassuring. If you do not remember how to give this medication or do not feel that you can, please don't worry. We recognise that this situation may be frightening and things may happen quickly.

Information about buccal midazolam

How is the medication supplied?

- Buccal midazolam is usually supplied as a pre-filled syringe. The dose in the syringe is written on the side of the syringe.

How do I give the buccal midazolam?

- Place the tip of the syringe inside the mouth between the cheek and gum. Do not place the syringe or anything else between the person's teeth.
- Give half the dose over ***five seconds*** on one side of the mouth and the remaining half of the dose over ***five seconds*** on the opposite side of the mouth.

How quickly does buccal midazolam work?

- Buccal midazolam usually takes 5–10 minutes to work.

Are there any side-effects?

- Buccal midazolam can make people sleepy or restless. It may slow down breathing, but very rarely.

Preferences for hospital admission / place of care

(Please ensure this information is recorded on the person's RESPECT form and EDAN or on EPaCCS)

.....

.....

Useful contact numbers

GP/out of hours (OOH) GP:

.....

Community neighbourhood team:

.....

Hospice:

.....

Out of hours 111 primary care line:

0345 605 0621

If you cannot get through to anybody else and want urgent advice ring 999.

Produced in partnership with Leeds Community Healthcare NHS Trust,
The Leeds Teaching Hospitals NHS Trust, St Gemma's Hospice and Sue Ryder Wheatfields Hospice

Leeds Palliative Care Network

Developed by Suzie Gillon, Consultant in Palliative Care
Produced by: Medical Illustration Services MID code: 20190814_007/JG

LN004062
Publication date 01/2020
Review date 01/2022

Appendix 5
Community palliative seizure management plan: information for families, carers and staff
https://leedspalliativecare.org.uk/wp-content/uploads/2020/03/Final-Community-Palliative-Seizure-Plan-Jan-20.pdf

Community palliative seizure management plan

NHS

Information for families, carers and staff

Addressograph

Date completed: ...../...../.....
Completed by: .....
Review date: ...../...../.....

Name:
.....

is at increased risk of seizures due to:
.....

How to recognise a seizure:
.....
.....
.....
.....
Document type of seizure details here.

Regular medication for prevention of seizures:
.....
.....
.....

Emergency medication supplied to give for seizures:
.....
(if prescribed and appropriate see overleaf for guidance on giving buccal midazolam.)

What to do in the event of a seizure

Simple first aid advice:

- Protect the person from injury; removing harmful objects from nearby
- Cushion their head
- Do not restrain the person or put anything in their mouth
- Try to time the seizure
- Once the seizure has finished, roll them onto their side or place them in the recovery position
- Stay with them until recovery is complete
- **Consider emergency medication if supplied**

When to call for help:
.....

Who to call for help:
.....

Ward doctors to ensure this information is included in the EDAN & GP OOH handover form

Information about midazolam

What is midazolam?

Midazolam can be given to stop seizures and is also a sedative, which means it makes people sleepy. Midazolam can be given as an injection by nursing staff. An alternative is for friends or family to be shown how to use buccal midazolam into the mouth.

Information about buccal midazolam

How is the medication supplied?

- Buccal midazolam is usually supplied as a pre-filled syringe. The dose in the syringe is written on the side of the syringe.

How do I give the buccal midazolam?

- Place the tip of the syringe inside the mouth between the cheek and gum. Do not place the syringe or anything else between the person's teeth.
- Give half the dose over ***five seconds*** on one side of the mouth and the remaining half of the dose over ***five seconds*** on the opposite side of the mouth.

How quickly does buccal midazolam work?

- Buccal midazolam takes 5–10 minutes to work and most people will sleep after the seizure has finished. They should remain on their side during this time.

Are there any side-effects?

- Buccal midazolam can make people sleepy or restless. It may slow down breathing, but very rarely.

Can another dose be given if the first doesn't work? (and if so how long after the first dose)

.....

.....

Preferences regarding hospital admission/place of care

(Please ensure this information is recorded on the person's RESPECT form and EDAN or on EPaCCS).

.....

.....

.....

.....

Useful contact numbers:

GP/out of hours (OOH) GP:

.....

Community neighbourhood team:

.....

Other:

.....

.....

.....

If you can't get through to anyone else and want urgent advice ring 999

Please inform the GP if this person has a seizure so they can be reviewed and and if needed, their medication can be altered.

(If two or more seizures please contact GP/ OOH GP promptly)

Produced in partnership with Leeds Community Healthcare NHS Trust,
The Leeds Teaching Hospitals NHS Trust, St Gemma's Hospice and Sue Ryder Wheatfields Hospice

Leeds Palliative Care Network

Developed by Suzie Gillon, Consultant in Palliative Care
Produced by: Medical Illustration Services MID code: 20190814_007/JG

LN004062
Publication date 01/2020
Review date 01/2022

Guideline dissemination and implementation plan - Tick boxes that apply and add comments

Name of author who is leading with disseminating the document : Sarah McDermott	**Symptom Management in last days of life**

	Actions	**Dates**	**Comments**
1.	Induction Sessions required - provide dates:	n/a	Included in palliative care training. No update to training required.
2.	Launch Event required - provide dates:	Tbc	Will share through Quality Development Group, other ABU clinical forums and email.
3.	Raising at meetings, provide dates/which meetings:	Tbc	Will share through Quality Development Group, Clinical Pathway Lead Meeting and other ABU clinical forums
4.	Specific Instructions for disseminating the document		Share locally with teams and through training and forums. Highlight key changes.
5.	Lead for audit and monitoring		Sarah McDermott, Clinical Service Manager
6.	Do you require a link through to Leeds Health Pathways?		Yes
7.	Other actions		Add/update link to SystmOne Planning Ahead template last days of life tab

Guideline Consultation Process

Title of Document	**Symptom Management Guidance in the Last Days of Life**
Author (s)	Sarah McDermott clinical services manager Chris Toothill, Medicines Management Pharmacist (Governance and Risk) and Medication Safety Officer Moira Cookson, Advanced Clinical Pharmacist Palliative Care Dr Jason Ward – palliative medicine consultant
Revised Document	Version 3
Lists of persons involved in developing the guideline	Authors as above
List of persons involved in the consultation process	LCH Director and Deputy Director of Nursing LCH Deputy Medical Director ABU Quality Lead SBU / ABU Clinical Leads ABU Clinical and Operational Heads of Service LCH Library Services Manager ABU Clinical Pathway Leads and Clinical Service Managers LCH Palliative Care Leads Nurse Consultant St Gemma's Dr Gill Pottinger, CCG EoLC GP Lead