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Symptom Management Guidance in the Last Days of Life	
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Symptom management guidance in the last days of life

Contents

1 Introduction

Patient comfort is widely recognised as a key measure of good palliative and end of life care (EoLC), particularly in the last days of life when patients can experience a number of common symptoms (National Palliative and End of Life Care Partnership, 2015). Potential improvements in symptom management have been documented in a series of local and national reports and their recommendations underpin continuous improvements within Leeds Community Healthcare NHS Trust (LCH) and across the Leeds Palliative and End of Life Care Managed Clinical Network. Areas highlighted include staff training, access to and availability of medicines, and provision of advice and support (Ingold and Hicks, 2013; Leadership Alliance for Care of the Dying Person, 2014; Parliamentary and Health Service Ombudsmen, 2015; NICE, 2015; Hospice UK, 2017). Implementation within LCH neighbourhood teams of a Neighbourhood Palliative Care Lead role has strengthened clinical leadership and helped embed improvements in staff skills and knowledge in relation to symptom management and enhanced the role of Independent Nurse Prescribers.

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):

- Lack of involvement of an experienced clinician in recognising and regularly reviewing a person's needs in the last days of life
- The dying person being unduly sedated, as a result of injudiciously prescribed and administered medication
- The perception that hydration and some medications may have been intentionally withheld or withdrawn

Subsequent NICE guidance for care in the last days of life (2015) outlines the use of medication within an individualised plan of care that includes symptom management, hydration, psychological, social and spiritual support. NICE quality standard for the care of dying adults in the last days of life (2017) recognises the importance of non-pharmacological measures in relation to symptom management.. It also emphasizes the need to sensitively discuss with the person and those important to them 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. These principles are reflected throughout this guidance.

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 and providing support at night are vital in maintaining patient comfort and enabling patients to be cared for in their preferred place of care and death. Service and care expectations are outlined in LCH's Service Delivery Framework for Palliative and End of Life Care (2016) and in the last days of life it is recommended a patient receives four visits daily, ideally all from the neighbourhood team responsible for their care, to ensure regular review of their comfort and plan of care. Patients' needs must be reviewed daily by a registered nurse 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 provided to ensure patients care needs overnight are met. Specialist palliative care advice is available at all times and should be sought in a timely manner.

Rationale for first line choices in this guidance:
The unique home care setting has influenced this guidance; as health care professionals are not always immediately accessible and there may be a short delay following a request to visit. This is reflected in the suggested first line symptom management medications. Compatibility and both local and national palliative care symptom management guidance have also been considered.

Medication compatibility
The medications in this guidance are generally physically and chemically compatible. It is however important to consider compatibility and seek advice as necessary when using high doses, three or more medications in one syringe driver, or medications not included in this guidance.

Patients with heart or renal failure, dementia or frailty and the elderly
The medications and doses recommended within this guidance are generally suitable for the initial management of symptoms in these groups of patients in the last days of life, however further guidance is available on Leeds Health Pathways and EPaCCS. It is important to seek advice from an Independent Prescriber or Specialist Palliative Care Teams when using medications not included in this guidance, or if there are particular individual patient concerns or adverse reactions.

2 Aims and Objectives

The following pages provide a guiding framework for symptom management in the last days of life to promote patient comfort reflecting the NICE (2015) 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, preferably before it is used
- 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

Client Inclusion
This guideline refers to adults receiving palliative care, who are thought to be in the last days of life and whose death is expected. Typically they will have recognised palliative care needs and an Electronic Palliative Care Coordination System (EPaCCS) record with details of their care wishes and preferences.

An experienced clinician must have assessed the patient as being in the last days of life and communicated this to the multidisciplinary team.

Client Exclusion
This guidance does not apply to infants, children and young people under 18 years of age, and adults who die suddenly.

3 Definitions

The **last days of life** generally refers to the last two to three days (NICE, 2015), however this can vary between hours and on occasion 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 (NICE, 2017).

EPaCCS

EPaCCS (Electronic Palliative Care Coordination System) supports coordination of care by enabling the recording and sharing of people's care preferences and key details about their care.

4 Responsibilities

This guideline applies to independent prescribers and all nurses with a valid NMC registration working with adults in community settings and working within the Standards of Proficiency for Nurse and Midwife Prescribers (NMC, 2015), Royal Pharmaceutical Society Competency Framework (2016) and NMC Code (2015) and Standards for Medicines Management (NMC 2010).

Staff must seek advice and support from an Independent Prescriber and Specialist Palliative Care Team where appropriate. Advice and support is available from both hospices seven days per week. 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.

5 Resources & Equipment

Equipment required for administration of medication subcutaneously should be readily accessible to ensure prompt and effective symptom management.

An LCH information leaflet *Care in the Last Days of life* is available from stores.

6 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 anyone lacking capacity should, or may require an Independent Mental Capacity Advocate, where treatment or residence decisions have a significant impact on an 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 ask ELSIE (LCH Intranet) and refer to EPaCCS (Electronic Palliative Care Coordination System).

7 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.

8 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 in relation to assessment and management of common symptoms in the last days of life and conversations about care is available to staff delivering palliative and end of life care as a regular part of their role. 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.

9 Management of common symptoms in the last days of life

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).

Good mouth care is essential for patients in the last days of life (appendix 1). The plan of care should be sensitively discussed and the LCH patient information leaflet *Care in the Last Days of life* offered to patients and carers.

Prescribing guidance

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 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 EPaCCS and includes the local guidance listed below.

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
Syringe driver prescribing guidance
http://nww.lhp.leedsth.nhs.uk/common/guidelines/other_versions/3320.pdf
Prescribing at end of life - Renal Failure
http://nww.lhp.leedsth.nhs.uk/common/guidelines/detail.aspx?id=5025
Prescribing at end of life - Impaired Liver Function
http://nww.lhp.leedsth.nhs.uk/common/guidelines/detail.aspx?id=5029

9.1 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 **Oxycodone 10mg/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

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 EPaCCS					

9.2 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 every 12 hours +30mg Morphine Sulphate Solution (Oramorph®) as required = 90mg oral morphine
- 90mg ÷ 3 = 30mg diamorphine subcut infusion over 24hr

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

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 according to 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/or doses 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

9.3 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 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

- 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 - seek advice 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 those prescribed for the management of nausea and vomiting as an alternative, or in combination with midazolam - seek advice from an Independent Prescriber regarding dose
- 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.

9.4 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

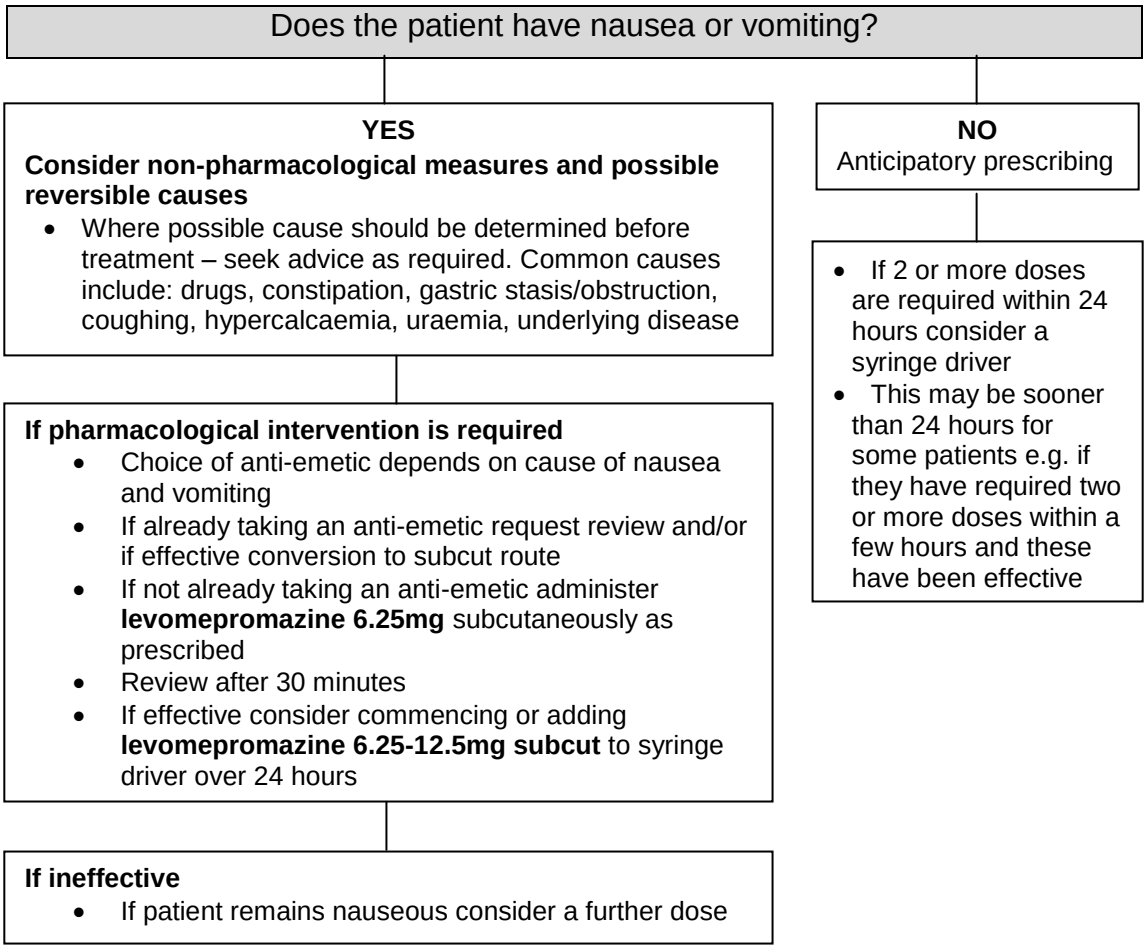
Respiratory secretions remain problematic and distressing

- 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.

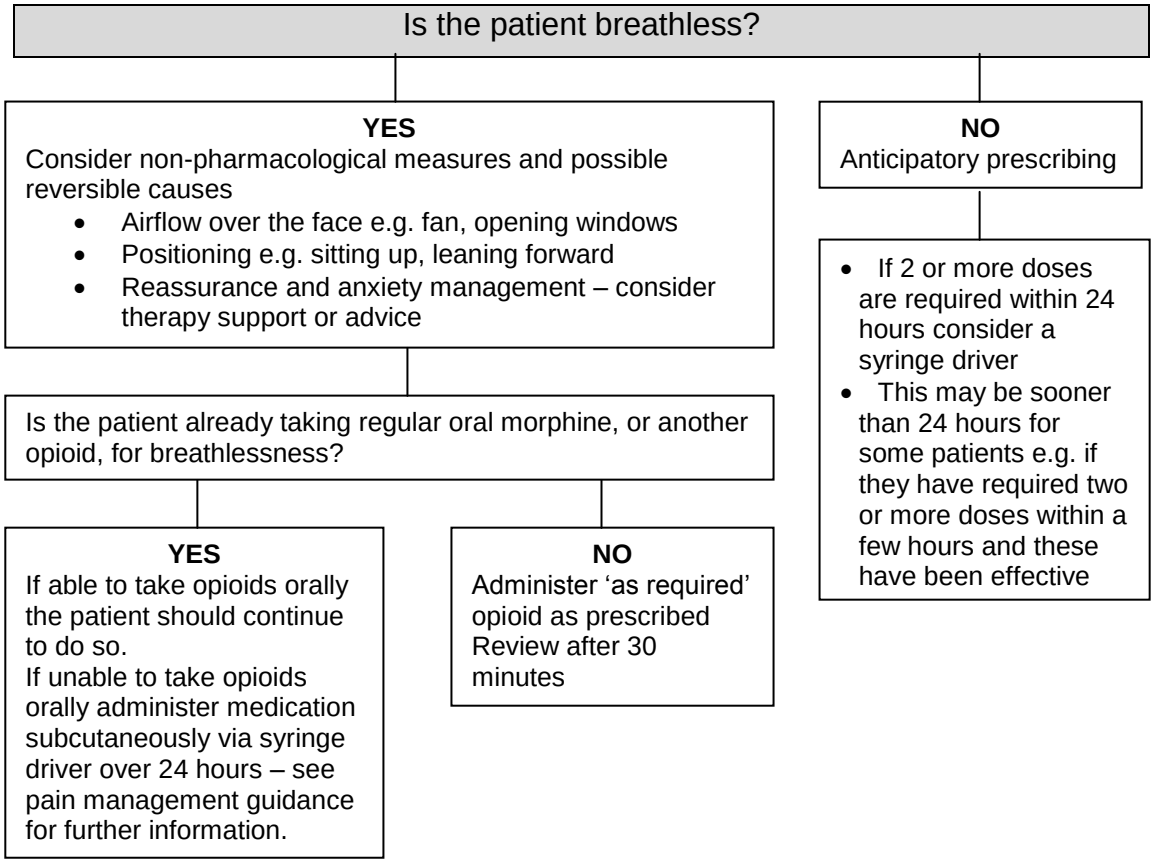
9.5 Management of Nausea and Vomiting



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.

9.6 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

10 Monitoring Compliance and Effectiveness

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 on ESR	Neighbourhood Palliative Care Leads Palliative Care Service Lead LCH workforce	Quarterly	ABU Clinical Lead Palliative Care Service Lead	Palliative Care Service Lead	ABU Clinical Lead Palliative Care Service Lead
Incidents	Reported via Datix	ABU Clinical Lead Palliative Care Service Lead	Quarterly	ABU Clinical Lead	ABU Clinical Lead Palliative Care Service Lead	ABU Clinical Lead Palliative Care Service Lead
Patients achieving their preferred place of death	Reported via EPaCCS	Palliative Care Service Lead	Monthly	Palliative Care Service Lead	ABU Clinical Lead Palliative Care Service Lead	ABU Clinical Lead Palliative Care Service Lead

11 Ratification and approval process

Following the consultation process this guideline was ratified and approved by the Executive Director of Nursing, Adult Business Unit Clinical Lead and Medicines Management.

12 Dissemination and Implementation

This guideline will be made available to staff via the intranet and disseminated to Neighbourhood Teams and other adult services through Senior Leadership Teams and the LCH Palliative Care Leads using newsletters and local forums, training and updates. Implementation in practice will be supported by the Neighbourhood Palliative Care Leads.

13 Review arrangements

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

14 References

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

Ingold, K and Hicks, F (2013) Health Needs Assessment End of Life Care Services for Adults in Leeds, NHS Leeds South and East CCG and Office of the Director of Public Health.

Leadership Alliance for the Care of Dying People (2014) Once Chance to Get it Right

National Palliative and End of Life Care Partnership (2015) *Ambitions for palliative and end of life care*

Nice (2015) Care of Dying Adults in the last days of life

NICE (2017) quality standards for the care of dying adults in the last days of life

NMC (2015) Code

NMC (2015) Standards for Medicines Management

NMC (2015) Standards of Proficiency for Nurse and Midwife Prescribers

Parliamentary and Health Service Ombudsmen (2015) Investigations into complaints about end of life care

Royal Pharmaceutical Society October (2016) A Competency Framework for all prescribers

15 Associated documents

LCH Guidelines for the administration of subcutaneous fluids (hypodermoclysis) to adult patients in community settings

LCH SOP for EPaCCS (Electronic Palliative Care Coordination System)

LCH SOP Remote prescribing for palliative care patients

LCH SOP Record keeping of controlled drugs in a community setting

LCH SOP Transcription of medication records in the community

LCH Service deliver framework for palliative and end of life care

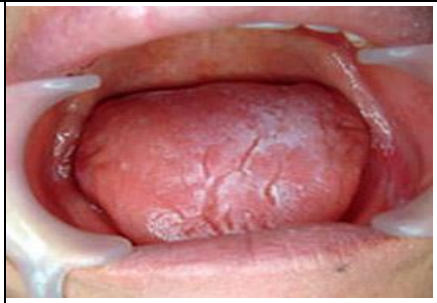
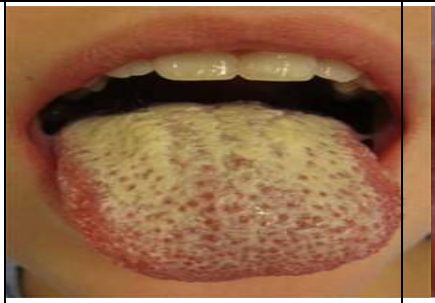
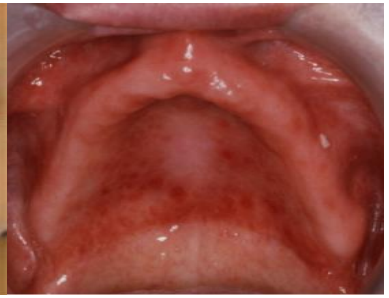
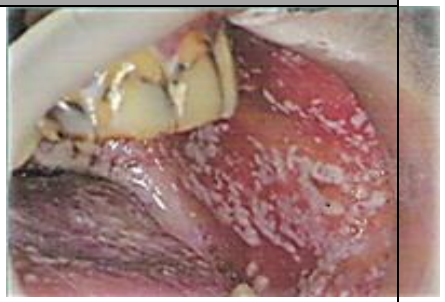
Leeds Opioid Conversion Guide, Leeds Palliative and End of Life Care Managed Clinical Network

Impaired liver function – prescribing at end of life, Leeds Palliative and End of Life Care Managed Clinical Network

Renal failure – prescribing at end of life, Leeds Palliative and End of Life Care Managed Clinical Network

Yorkshire and Humber Guide to Symptom Management in palliative Care, Health Education England

Oral hygiene management in adults – LCH symptom management guidance in the last days of life (appendix 1)

Healthy Mouth	Dry Mouth	Coated Mouth	Sore or Ulcerated Mouth	Oral thrush
				
Description	**Description**	**Description**	**Description**	**Description**
Patient able to eat without discomfort. Lips, mucous membranes, tongue smooth, pink and moist. Healthy gums are usually pink and firm. Teeth are free from bacteria. Dentures fit comfortably.	Dryness of lips. Dryness of mucus membranes. Impaired taste. Difficulty chewing and swallowing. Furrowed tongue with deep grooves.	'Coating' may be on any part of the tongue, be yellow, brown or black in colour and cause discomfort and taste changes. The person may be reluctant to eat and drink.	Redness of mucus membranes. Ulcerated areas on gums, tongue or lips. Pain and inability to take food or drink into mouth. Difficulty chewing and swallowing.	White spots or redness and soreness of the tongue and mucus membranes. Cheilitis (soreness, redness and fissures at the angles/corners of the mouth). Pain with difficulty eating and drinking.
Management	**Management**	**Management**	**Management**	**Management**

Essential mouth care management
• Use of a soft, small toothbrush is preferable for any mouth care. Where this is not available foam mouth swabs can be used
• If foam mouth swabs are used
  • check foam head is firmly attached before use
  • do not leave mouth swabs soaking in liquid prior to use as this may affect the strength of the foam head attachment
  • dispose of after single use
• If the person has dentures remove them at night, clean using denture brush and soak them in water overnight
• If the person is conscious, support them to use a soft small toothbrush and a pea sized amount of toothpaste 2 times daily.
• If the person is unconscious, hourly care is recommended using water to clean the teeth, gums and oral cavities.
• Support family members or carers to provide mouth care if they wish to be involved
	Essential mouth care management plus:
	• Continue mouth care and look for reversible causes. Review medication, patients are often on multiple medicines which can cause dry mouth
	• Encourage frequent sips of cold unsweetened drink, if the person is able to swallow.
	• Sugar-free chewing gum/low sugar pastilles/boiled sweets.
	• If oxygen is in use humidification is helpful
	• Consider the use of ice cubes, ice lollies
	• Topical artificial saliva substitues: Biotene oral-balance 2-4 hourly when required to lips,tongue and oral cavities. AS Saliva Orthana (contains pork)
	• If the above measures are not effective, salivary stimulants may be an option. Seek specialist advice
		Essential mouth care management plus:
		• Continue mouth care and address dry mouth
		• Brush tongue gently with a soft small tooth brush
		• Pineapple is sometimes suggested, but caution is suggested with the use of acidic substances, as they can increase risk of dental caries/infections. The importance of this depends on the person's prognosis and whether they still have teeth.
			Essential mouth care management plus:
			• Identify the cause and treat where possible Continue essential mouth care management.
			• If person is conscious and able to spit out, consider use of Gelclair®, alcohol free mouthwash or normal saline
			• Topical analgesia options: paracetamol mouth rinse, Benzydamine Hydrochloride (Diflam®), Choline salicylate (Bonjela®)
			• If not responsive to above measures, consider use of topical anaesthetics and apply directly to painful area e.g. Lidocaine (Xylocaine®) 10% spray applied using cotton bud prn. Avoid anaesthesia to pharynx before meals/drinks
			• For severe oral pain, consider the combined use of topical and systemic preparations. Seek specialist advice.
				Essential mouth care management plus:
				• Continue mouth care.
				• Look for and treat reversible causes
				• Consult local guidelines for use of antifungals/check for drug interactions. Options include fluconazole (capsules or suspension) 50mg daily for 7 days . or nystatin oral suspension 100,000 units/ml, 1ml q.d.s. for 7 days; hold in mouth for 1 minute, then swallow (avoid concomitant use of chlorhexidine(May need higher doses/longer courses for immunosuppressed patients)
				• Remove and clean dentures (cleansing agent depends on the dentures)

Appendix 2
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 home to 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

Guideline dissemination and implementation plan

Name of author who is leading with disseminating the document **Sarah McDermott, Palliative Care Service Lead**	**Title of Document** **Symptom management guidance in the last days of life**

	Actions	**Dates**	**Comments**
1	Awareness raising / updates	December 2017 – February 2018	Local dissemination within neighbourhood teams and review of formal training
2	Launch event	December 2017	Via Neighbourhood News and email cascade
3	Raising at meetings	December 2017 – February 2018	Palliative Care Group, Clinical forums, Cluster and NT meetings
4	Specific Instructions for disseminating the document	December 2017	To be led by Palliative Care Service Lead within LCH and via Leeds Palliative and End of Life Care Managed Clinical Network
5	Lead for audit and monitoring	2017-18	Citywide audit of anticipatory medication being considered by Leeds Palliative Care Managed Clinical Network
6	Do you require a link through to Leeds Health Pathways?	September 2017	Yes and updated on EPaCCS

The following will be actioned by the Quality and Professional Development Administrator:

- Email business units and departments requesting dissemination of document to applicable services
- Document uploaded on the LCH intranet
- Document forwarded to Leeds Health Pathways for uploading if applicable
- Superseded documents removed from the Intranet
- Article submitted to the next Community talk

Guideline Consultation Responses

Complete this template when receiving comments at various draft stages of the guideline.

Responder (including job titles and organisation)	Version, Comment and Date	Response from Author
Catherine Malia, Nurse Consultant, St Gemma's Hospice	15.6.17 version 2 draft 1.1 Re pain management - Should this say "patient can no longer manage oral medication?" If they are on oral opioids and can take them, they should continue. Re syringe driver increase of 30-50% - Need prompts to guide decision whether to go for lower or higher increase Re respiratory tract secretions My view would be to go with the NICE Guidance: • Assess • Explain cause and provide info/reassurance • Non-pharmacological • Review • Pharmacological • Review If antisecretories are to work they are best given promptly, however you will soon see if repositioning etc has an effect. Re breathlessness - Again, if they are able to they can continue oral route. If not, CSCI. Re MCA - Many EOL patients will lose capacity. Staff need to be clear about their role in best interests decision making/ACP etc.	Reviewed and amends/ additions made.
Marcia Perry, Executive Director of Nursing	Queried reference to the Liverpool Care Pathway	Reviewed and reference removed
Moira Cookson, Palliative Care Pharmacist, hospices.	Minor wording and formatting amendments suggested. Queried whether liver failure should be included. Suggested amend to 'If recent GFR <10 oxycodone may be used' Queried syringe driver of 10-30mg midazolam	Decision made by T&F group not to include liver failure as less common. Oxycodone prescribing guidance reviewed and revised to GFR <50.

	Queried use of glycopyronnium bromide as not mentioned in guidelines? If midazolam is ineffective levomepromazine may be used at higher doses than those prescribed for the management of nausea and vomiting as an alternative, or in combination with midazolam - seek advice from an Independent Prescriber regarding dose	Midazolam range is from current guidance Removed reference Included in 'important' box
Carolyn Nelson, Head of Medicines Management	As part of a change in the key lines of enquiry used by CQC, they are introducing a standard on 'when required' medication. This fits well with the symptom management guidance, and should be something that staff are able to evidence as part of the care provided at EoL. https://www.cqc.org.uk/sites/default/files/20170609_Healthcare-services-KLOEs-prompts-and-characteristics-FINAL.pdf	Reference included in section 9
Angela Gregson	Refer to stepped approach to symptom management. Move sections to before guidance/section 9	Amends made
Fiona Tandy, EoLC Facilitator (care homes)	Some repetition in the mouth care guidelines regarding continuing with essential mouth care. In the symptom guidance the writing is smaller in the important boxes.	Amended Text smaller as feedback from others is that each symptom should be on one page.
Hilary Briggs, Neighbourhood Palliative Care Lead	On the mouth care guidance I think the nystatin dose is wrong. It states 1000,000 units per ml, think it should be 100,000 units per ml	Checked and amended
Elly Charles Clinical Nurse Specialist, St Gemma's Hospice	Request to stress the importance of good communication with the relatives about symptom management, especially secretions. There is new evidence that repositioning is as effective as hyoscine and this needs to be added.	Additional reference made The evidence was considered by the task and finish group.
Lizzy Gascoigne, Clinical Nurse Specialist, St	Medication Boxes have a lot of information in them, but acknowledge that some HCP may require such information.	All info felt to be important by task and finish group

Gemma's Hospice		
Debbie Hargreaves, Clinical Nurse Specialist, St Gemma's Hospice	The statement 'regularly reviewed by a senior clinician ideally the case manager'. How often is this and who will it be? There is a lot of information in the important boxes which could be quite confusing	Outlined in Service Delivery Framework. All info felt to be important by task and finish group
Eileen Clark, Clinical Nurse Specialist, St Gemma's Hospice	Would like to see something about DN responsibility to ensure adequate stock and re-ordering of drugs in timely way as this seems to get overlooked when doses increased or coming up to weekends. Like the mouth care guidance. Helpful to have the pictures and practical advice as well as prescribing info.	Being addressed in practice

Guideline Consultation Process

Title of Document	**Symptom management guidance in the last days of life**
Author (s)	Sarah McDermott Palliative Care Service Lead Chris Toothill, Medicines Management Pharmacist Dr Jason Ward, Consultant in Palliative Medicine, St Gemma's Hospice Moira Cookson, Advanced Clinical Pharmacist Palliative Medicine, Leeds Hospices
New / Revised Document	Revised – Version 2
Lists of persons involved in developing the guideline	Neighbourhood Palliative Care Leads LCH End of life care facilitators (Care Homes) Gill Pottinger, GP EoLC Lead, LSE CCG St Gemma's Hospice Catherine Malia, Nurse Consultant Clinical Nurse Specialist Team Wheatfields Hospice Community CNSs Clinical Nurse Specialist Team
List of persons involved in the consultation process	Gill Armstrong, Quality Lead (Adults) Karen Benton, Service Lead, South Leeds Independence Centre and Community Intermediate Care Unit Angela Gregson, Clinical Pathway Lead Steph Lawrence, Deputy Director of Nursing and Quality Caroline McNamara, Clinical Lead, Adult Business Unit Julie Mountain, Clinical Head of Adult Services Carolyn Nelson, Head of Medicines Management Marcia Perry, Executive Director of Nursing

	Charles Stanley, Medical Director, Adult Business Unit Gill Whitehead, Clinical Service Manager, Long Term Conditions