

Clinical Practice Summary

Guidance on consensus
approaches to
managing Palliative
Care Symptoms



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Alternatively- The Supportive & Palliative Care Indicators Tool (SPICT™) is available via link http://www.spict.org.uk	

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These practice summaries are a place to begin.

They cannot replace advice from experienced clinicians.

Fundamental to the practice of palliative and end of life care is the individualised care of the patient and those important to them. If symptoms fail to respond to usual measures, or you are concerned that the guidance here may not be appropriate to the clinical situation you are in, contact your local specialist palliative care service for advice.

IF IN DOUBT ASK.

Background

In 2012 Lancashire and South Cumbria Specialist Palliative Care group wrote prescribing guidelines around managing common symptoms in a palliative care setting. These were well received and in 2014 were updated. In 2016, Lancashire and South Cumbria joined with Mersey and Cheshire in a new Strategic Clinical Network based around the North West Coast. As a result, this new version was developed, based on the guidance produced by our neighbouring Northern Strategic Clinical Network's Guidelines (2016) and a Mersey and Cheshire Clinical Practice Summary (2017).

We have worked hard to try and achieve consensus and base the practice summaries on the best available evidence. We hope that in doing this we can help to ensure a consistency of approach to managing common symptoms, particularly for those individuals who receive care in a number of different locations.

Whilst every care has been taken to ensure accuracy and clarity, prescribers and clinicians must make all their decisions based on a full clinical assessment and their assessment of the risks and benefits of any intervention. They must also take into account any local guidance where it exists. **In some areas the first line injectable opioid is Diamorphine not Morphine**, contact your local Specialist Palliative Care team if advice required.

The evidence-base for prescribing in palliative care is not extensive or robust, which means that some guidance is based on a consensus of expert opinion. Many medications are used beyond licence and at doses that differ from other areas of clinical practice. This makes it impossible to produce guidance that contains definitive statements about what to prescribe and when.

Key Expert Resources:

Twycross R, Wilcock A, Howard P (eds) (2014) Palliative Care Formulary, 5th Edition, Palliativedrugs.com Ltd. Nottingham

Twycross R, Wilcock A, (2016) Introducing Palliative Care (IPC5), 5th Edition, Palliativedrugs.com Ltd.

BNF 72 September (2016) BMJ Group and Pharmaceutical Press London

Dickman A, Schneider J (2012) The Syringe Driver. Continuous Subcutaneous Infusions in Palliative Care (3rd Edition) Oxford University Press

Palliative and End of Life Guidelines for Generalists (2016) 4th Edition - Northern England Strategic Clinical Networks

Useful websites

Advance Care Planning

Advance Care Planning—North West Coast initiative
www.nwscnsenate.nhs.uk/strategic-clinical-network/our-networks/palliative-and-end-life-care/advance-care-planning/

Deciding Right—North East initiative around Advance Care Planning
www.nescn.nhs.uk/common-themes/deciding-right

Recommended summary plan for emergency care and treatment (ReSPECT) - National Resuscitation Council Guidelines around summary care plans about patient's preferences for care
www.respectprocess.org.uk

Knowledge Hub around end of life care and medication

<http://endoflifecareambitions.org.uk/>
<http://www.palliativedrugs.com/>

NICE guidance

Care of the dying adult in last days of life (2015) www.nice.org.uk/guidance/ng31

End of life care for infants, children and young people with life-limiting conditions: planning and management (2016)
www.nice.org.uk/guidance/ng61

Palliative care for adults: strong opioids for pain relief (2016)
www.nice.org.uk/guidance/cg140

Neuropathic pain in adults (2017) www.nice.org.uk/guidance/cg173

Introduction and Aide Memoire

These easy reference guidelines are based on the Merseyside and Cheshire Palliative Care Network Audit Group Guidelines, Northern England Strategic Clinical Network Palliative and End of Life Care Guidelines 2016 and the Lancashire and South Cumbria Palliative Care Prescribing Guidelines 2014. They support decision-making in symptom management and care co-ordination for people in the last weeks of their life. If there is any doubt regarding clinical decisions for individuals, help should be sought from local Specialist Palliative Care services.

Ambitions for Palliative and End of Life Care - supporting people in the last weeks of life

All approaches regarding palliative and end of life care should reflect Ambitions for Palliative and End of Life Care, a national framework for local action 2015-2020 and the 6 key principles



Ensure that you have considered the following in communication with the person and those important to them:

Preferences and possibilities that could constitute an **Advance Care Plan**

Sensitive communication about care in the last days of life including decisions about Do Not Attempt Cardiopulmonary Resuscitation (**DNACPR**) Orders or “allow natural death” decisions. Record these decisions and share with key organisations including “out of hours” care providers via Electronic Palliative Care Coordination System (EPaCCS) in line with local policies.

Ensure that there is a plan for the management of complex interventions such as non-invasive ventilation or Implantable Cardioverter Defibrillator (ICD) is in place, so they can be safely withdrawn when it is appropriate to do so.

Ensure that all relevant Out of Hours services are made aware of any critical documentation e.g. using **special note notification** in community or in hospital settings, that clear **treatment escalation plans** are made

Anticipatory prescribing to relieve common symptoms in the last weeks of life should be considered in a timely manner and individualised to avoid delay in managing distressing symptoms (Care of dying adults in the last days of life, NICE guideline NG31)

One Chance to Get it Right - Care in the last days and hours of life

Recognise deterioration and **consider if this is potentially reversible**, e.g. infection, or if the person is likely to die from irreversible causes. Potentially reversible causes should be treated provided that this is in accordance with the person’s wishes or in their best interests.

If the person is likely to die from irreversible causes in the next hours or few days **communicate** this clearly and sensitively.

Involve the dying person and those important to them in day-to-day decisions about personal care and clinical treatments.

Avoid undertaking **investigations** that are unlikely to affect care in the last few days of life unless there is a clinical need to do so (NG31) e.g. curtailing renal monitoring in advanced heart failure.

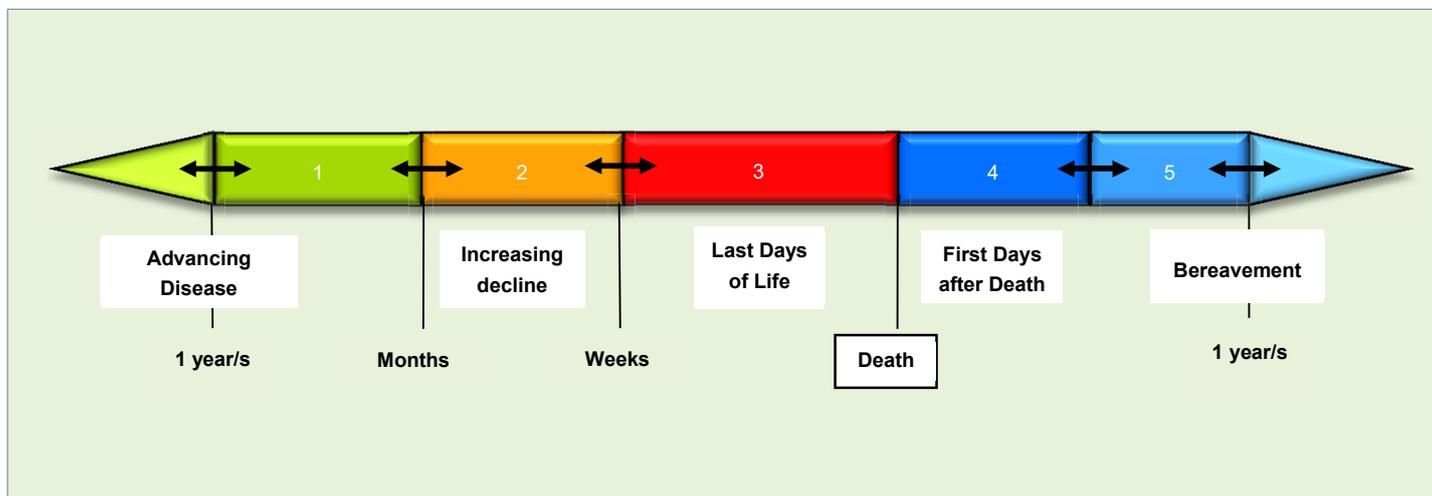
Construct **an individual plan of care**, which includes food and drink, symptom control and psychological, social and spiritual support.

Deliver this plan of care sensitively and review frequently, especially if symptoms are not controlled, there is concern from family members or the person shows sign of improvement

(**Hydration** is not covered in these guidelines but guidance can be found in the NICE Guidance NG31)

The North West End of Life Care Model

Supporting the people of the North West to live well before dying with peace and dignity in the place of their choice



End of life care

- Is about the individual and those important to them
- Is about meeting the supportive and palliative care needs for all those with an advanced progressive incurable illness or frailty, to live as well as possible until they die'.
- Support may be needed in the last years, months or days of life.

It should include:

- A person centred approach to care - involving the person, and those closest to them in all aspects of their care including the decision making process making process around treatment and care
- Open, honest and sensitiv communication with the patient and those important to them
- Care which is coordinated and delivered with kindness and compassion
- The needs of those identified as imprtant to the person to be actively explored, respected and met as far as possible
- All discussions to follow guidance set within the Mental Capacity Act (MCA 2005)

Key recommended Training for health and care staff:

Communication skills

Holistic assessment to include: physical, psychological, spiritual and social care

Symptom control

Advance care planning

Caring for carers

Priorities for care of the dying person

Bereavement support

Mental Capacity Act

The model supports the assessment and planning process for patients from the diagnosis of a life limiting illness or those who may be frail. The model comprises 5 phases and the Good Practice Guide (overleaf) identifies key elements of practice within each phase to prompt the assessment process as relevant to each setting.

End of Life Care Good Practice Guide

LAST YEAR OF LIFE Year/s	INCREASING DECLINE Months/Weeks	LAST DAYS OF LIFE Days	CARE AFTER DEATH 1 Year/s
<ul style="list-style-type: none"> • Patient identified as deteriorating despite optimal therapeutic management of underlying medical condition(s) • Clear, sensitive communication with patient and those identified as important to them • Person and agreed others are involved in decisions about treatment and care as they want • Needs of those identified as important are explored, respected and met as far as possible • Patient included on Supportive Care Record /GP Gold Standards Framework register and their care reviewed regularly • Request consent to share information and create EPaCCS record • Holistic needs assessment : physical, psychological, spiritual & social • Keyworker identified • Identify when there is an opportunity to offer an Advance Care Planning discussion . PPC/ ADRT/LPA • Making a will • DNACPR discussion if appropriate • Benefits review of patient and carer including: grants/prescription exemption • Provide information on Blue Badge (disabled parking) scheme • Agree on-going monitoring and support to avert crisis • Referral to other services e.g. Specialist Palliative Care • OOH/NWAS updated including Advance Care Plan/DNACPR • ICD discussion if applicable 	<ul style="list-style-type: none"> • Medical review • All reversible causes of deterioration explored • Clear, sensitive communication with patient and those identified as important to them • Person and agreed others are involved in decisions about treatment and care as they want • Needs of those identified as important are explored, respected and met as far as possible • Prioritised as appropriate at Gold Standards Framework meeting • On-going District Nurse support • Agree on-going monitoring and support to avert crisis • Holistic needs assessment • Ongoing communication with Keyworker • Review or offer advance care plan discussion, share information with patients consent • Consider Continuing Health Care funding/DS1500 • Equipment assessment • Anticipatory medication prescribed and available • DNACPR considered and discussed, outcome documented, information shared appropriately including ambulance service • Out of Hours/NWAS updated including DNACPR status and Advance Care Plan • Referral to other services e.g. Specialist Palliative Care • Update EPaCCS Record as and when necessary • ICD discussion and deactivation 	<ul style="list-style-type: none"> • Medical review • All reversible causes of deterioration explored • Multidisciplinary Team agree patient is in the last days of life • Clear, sensitive communication with patient and those identified as important to them • Dying person and agreed others are involved in decisions about treatment and care as they want • Agree on-going monitoring and support to avert crisis • Advance Care Planning discussion offered or reviewed • On-going District Nurse support • ICD discussion and deactivation if not previously initiated • Decisions made are regularly reviewed and revised accordingly • Individual plan of care for the dying person including holistic assessment, review of hydration and nutrition, symptom control etc. is agreed, coordinated and delivered with compassion • Anticipatory medication prescribed and available to prevent a crisis • Needs of those identified as important are explored, respected and met as far as possible • OOH/NWAS updated • Update EPaCCS Record as and when necessary • Review package of care if necessary • Referral to other services e.g. Specialist Palliative Care 	<ul style="list-style-type: none"> • Nurse verification of death where indicated • Certification of death • Clear sensitive communication • Relatives supported • Department for Work & Pensions 011 Booklet; What to do after a death or similar • Post death Significant event analysis • Update Supportive Care Record/ Gold Standards Framework Register/EPaCCS with date and place of death • Inform all relevant agencies ; social care, ambulance service, OOH, Specialist Palliative Care Team, Allied Health Professionals equipment store • Funeral attendance if applicable and to include carer permission if appropriate • Follow up bereavement assessment to those identified as important • Referral of those identified as important to bereavement counselling services as required • Staff supported

ADRT - Advance Decision to Refuse Treatment

DNACPR - Do Not Attempt Cardio Pulmonary Resuscitation

EPaCCS - Electronic Palliative Care Coordinating System

GP - General Practitioner

ICD - Implantable Cardioverter Defibrillator

NWAS – North West Ambulance Service

OOH – Out of Hours

PPC - Preferred Priorities of Care

QUICK GUIDE	BOWEL OBSTRUCTION
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Nausea and Vomiting and Medical Management of Malignant Bowel Obstruction

Assessment / Description

Malignant bowel obstruction is a recognised complication of advanced pelvic or abdominal malignancy. May be made worse by adhesions from previous surgery/ radiotherapy. Common symptoms associated with malignant bowel obstruction include abdominal pain, abdominal colic, nausea and vomiting. The evidence base for management of malignant bowel obstruction is weak. An individualised approach to management is recommended for each patient and specialist palliative care advice should be sought.

- The diagnosis is made clinically through history and examination
- This may be confirmed with imaging (abdominal X-ray or CT scan) depending on Individual circumstance and preferences
- Consider if there are any surgical interventions possible
- Treat constipation if appropriate
- Consider absorption of modified medications when deciding route

IMPORTANT CONSIDERATIONS:**Symptom Control**

Pain:

- Opioid analgesia should be titrated to control continuous abdominal pain.
- Colic should be managed with the reduction in dose or discontinuation of prokinetic drugs such as metoclopramide followed by the commencement of an anti-spasmodic such as hyoscine butylbromide

Reduction of secretions:

- Patients experiencing large volume vomiting should be prescribed anti-secretory treatment.
- Octreotide is the recommended first line anti-secretory medication

Reduction of nausea and vomiting:

- Anti-emetics should be administered via the subcutaneous route. Prokinetics are not advised in a bowel obstruction affecting the small bowel or in a complete obstruction at lower levels of the bowel

Corticosteroids:

- A five day trial of Dexamethasone 8mg daily orally, or similar dose, subcutaneously should be considered in all patients to reduce tumour related oedema

Laxatives:

- The use of stimulant laxatives should be avoided. The use of stool softeners may be appropriate

Interventions

Medication Delivery:

- Medication should be delivered via the subcutaneous route due to potential problems with absorption

Nasogastric Tubes:

- A wide bore nasogastric tube should be considered for patients with upper gastrointestinal obstruction or large volume vomiting.

Venting Gastrostomies:

- Venting gastrostomies or jejunostomies should be considered for patients with malignant bowel obstruction who have a prognosis of greater than 2 weeks.
- Venting gastrostomies have been shown to be cost effective with low morbidity and mortality.

Pharmacology options for Symptom Control in Malignant Bowel Obstruction

Dose adjustments may need to be made depending on renal and hepatic function

Indication(s)	Drug name	Dose (over 24 hours via CSCI unless otherwise stated)	Notes
Relief of constant pain	Opioid via CSCI/24 hours or transdermal Fentanyl patch	Dependent on previous dose	Absorption of oral formulation via gut may have been impaired, therefore when converting from oral to CSCI, consider adjusting the dose accordingly.
Relief of colic	Hyoscine Butylbromide	60mg - 240mg	Do not combine with Cyclizine in CSCI as can cause crystallisation
	Glycopyrronium	600micrograms - 2.4mg	Does not crystallise
Reduce volume of gastrointestinal secretions	Octreotide	300 - 600micrograms. Doses may be increased up to 1.2mg in some cases under specialist guidance	Can be considered first line. Alternatively use Hyoscine Butylbromide but do not combine with cyclizine in CSCI as can cause crystallisation
	Hyoscine Butylbromide	60mg - 240mg	Do not combine with Cyclizine in CSCI as can cause crystallisation
	Glycopyrronium	600micrograms - 2.4mg	Does not crystallise with other common injectable drugs
	Ranitidine Not licenced for SC use	100mg - 200mg	Does not crystallise with other common injectable drugs
Reduce tumour oedema. Reduce nausea and vomiting	Dexamethasone	6.6 mg subcutaneously OD or 3.3 mg subcutaneously BD (in morning)	Given as a single dose or divided into 2 doses (before 12 noon). Late administration may cause insomnia /agitation
Reduce nausea and vomiting	Cyclizine	150mg	Do not combine with Hyoscine Butylbromide in CSCI as can cause crystallisation
	Haloperidol	1.5mg - 5mg	Watch for extra-pyramidal side effects
	Levomopromazine	2.5mg - 25mg	May cause sedation. Use the lowest effective dose. Higher doses may cause sedation.
	Metoclopramide (avoid in complete bowel obstruction)	30mg - 60mg There is an increased risk of neurological adverse effects at doses higher than 30mg/24hour and if used for longer than 5 days.	Contraindicated in complete bowel obstruction. Dose may be increased under Specialist Palliative Care advice. Monitor for increased abdominal colic.
	Ondansetron Not licenced for SC use	8mg - 16mg	seek Specialist Palliative Care advice if over 16mg

QUICK GUIDE	BREATHLESSNESS (FOR LAST DAYS OF LIFE - SEE PAGE 19)
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Breathlessness

Assessment / Description

Causes of breathlessness can be multi-factorial: physical, psychological, social and spiritual factors can all contribute to a person feeling breathless. Assessment is vital, particularly in a new presentation. Undertake a history and clinical examination, including oxygen saturations. Investigations such as chest x-ray may be necessary and management will depend on clinical diagnosis. Treat what may be caused by an acute event and reversed, e.g. infection, anaemia, pulmonary oedema etc.

Treat reversible causes of breathlessness and monitor response
PLUS
Start appropriate non pharmacological interventions (blue boxes)



If breathlessness persists and causes distress consider appropriate pharmacological options (purple boxes)



As condition improves, reduce monitoring and evaluate treatment and stop interventions that are no longer needed

Non-Pharmacological options for managing breathlessness

- Calm Environment
- Acknowledgment and explanation
- Adequate positioning of the patient to aid breathing
- Use of fan or cool air across face
- Breathing exercises and relaxation training
- Acupuncture, aromatherapy and reflexology

Pharmacological Options

Opioids: Morphine oral solution 2.5mg QDS regularly and 4 hourly PRN. The maximum dose of oral Morphine that is likely to be helpful for breathlessness is 30mg/24 hour period.

If patient is unable to tolerate oral meds, subcutaneous Morphine Sulphate – 2.5mg 4 hourly prn (1.25mg in opioid naïve patients)

If the patient's eGFR is <30mls/min an alternative opioid should be considered. There is currently no evidence for the use of alternative opioids in the management of breathlessness

Oxygen: The evidence for efficacy is limited.

A trial of oxygen should be considered in patients known to have O₂ saturation less than 90%. PRN use of Oxygen should be avoided.

Considerable care should be taken in patients with known COPD/Type 2 respiratory failure - watching for CO₂ retention headache, flushed skin, fast pulse, hand flap, drowsiness etc.

Corticosteroids: may help in patients with tumour compression or lymphangitis carcinomatosis.

No evidence of benefit in non specific dyspnoea.

Dose: (before 2pm)

Dexamethasone 4mg – 8mg daily PO

Or 8mg – 16mg PO in lymphangitis or Superior Vena Caval Obstruction (SVCO)

Nebulised Medication: Sodium Chloride 0.9% may help as a mucolytic, 2.5 - 5ml 4hrly PRN

Consider a bronchodilator for bronchospasm e.g. Salbutamol 2.5mg 6hrly PRN (may be used more frequently in some cases)

Benzodiazepines: Lorazepam 500micrograms - 1mg SL PRN 2- 4 hourly (max dose 4mg in 24 hour period).

If patient unable to tolerate oral medication, consider subcutaneous Midazolam 2.5mg - 5mg 4hrly prn.

If effective this can be incorporated into a syringe pump over 24 hours

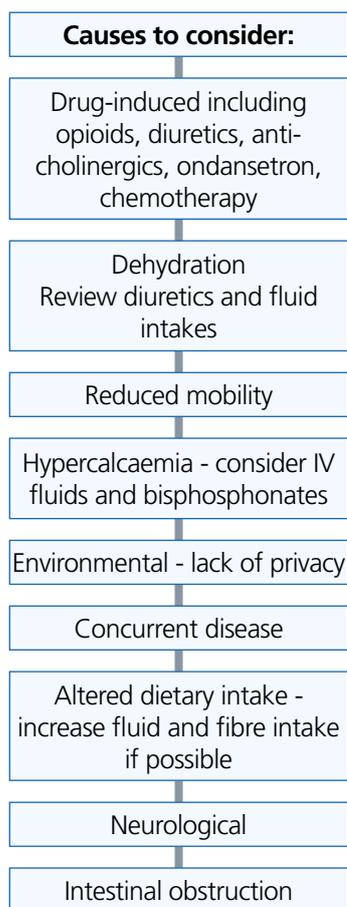
Be careful of the risk of both dependence and tolerance if used for the more than 7 days.

QUICK GUIDE	CONSTIPATION
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Constipation

Assessment/Description

Constipation is defined by the patient and is a symptom not a disease. The cause of the constipation should be identified and treated, managing bowel obstruction where appropriate. Aim to prevent constipation by the early introduction of laxatives, especially if patients are taking pain killers regularly.

- History, normal bowel habit, medicines other causative factors
- Abdominal palpation and auscultation and digital rectal examination
- Investigation abdominal x-ray, check calcium levels
- Treatment should be individualised to the patient and what they are able to tolerate. In most cases the oral route to manage constipation should be used initially. If constipation is not resolved after 5-7 days seek Specialist advice

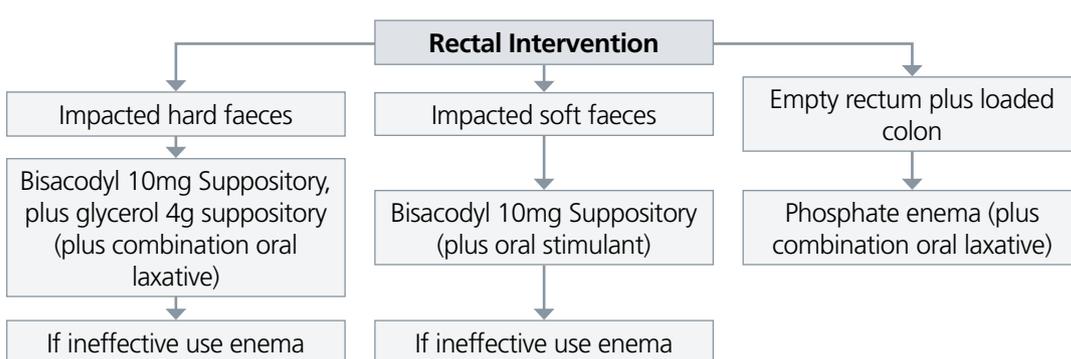


- For patients with established constipation, it is usually most effective to combine faecal softeners and stimulant laxative. If necessary, an osmotic agent can then be added on a prn or regular basis
- Oral laxatives should be reviewed every 3 to 4 days using stool consistency chart (e.g. Bristol stool chart)
- The use of rectal interventions should be guided by the findings on rectal examination
- Enemas including phosphate and sodium citrate versions - follow local guidance

Treatment and management

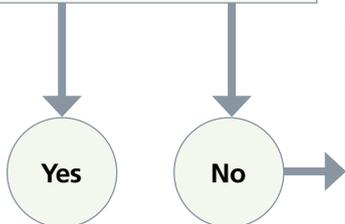
Oral laxatives commonly used in palliative care			
Type of laxative	Drug name	Starting dose	Additional notes
Stimulant laxatives	Docusate sodium	Start at 100mg BD or TDS	Takes 24-48 hours to have an effect. Mainly acts as softener, but doses over 400mg may have weak stimulant action. Syrup is available but the taste is unpleasant.
	Senna tablets	1-2 tabs at night	Takes 8-12 hours to have effect. May cause abdominal colic.
	Senna syrup	5ml-10ml at night	See above - Reduce dose if colic develops.
	Bisacodyl tablets	1-2 tabs at night	
Combination laxatives	Codanthramer Suspension	5ml-10ml at night and increase to BD as needed	Only licensed for use in terminally ill patients of all ages. May cause abdominal colic. May cause skin irritation - avoid in faecal incontinence
	Codanthramer Strong Capsules and Codanthramer strong suspension	See BNF for additional guidance	May cause skin irritation - avoid in faecal incontinence (More expensive and may be hard to source)
Osmotic laxatives	Macrogols	1 sachet BD	May be used to treat faecal impaction. Give 8 sachets in 1 litre of water, over 6 hours. Contraindicated in complete bowel obstruction
	Lactulose	10ml-20ml BD	Can be associated with flatulence/abdominal colic. Can take 48 hours to have an effect.
	Magnesium hydroxide	30-45ml at bed time	Should be avoided in patients with cardiac disease or poor renal function.
Opioid induced constipation	Naloxegol	25mg OD (12.5mg in frailty)	For opioid induced constipation that has failed to respond to standard measures (oral laxatives and rectal intervention) - seek specialist advice

Rectal interventions for constipation



QUICK GUIDE	NAUSEA & VOMITING (FOR LAST DAYS OF LIFE - SEE PAGE 17)
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Nausea and Vomiting

Is the patient already established on an anti-emetic?



Patients who have previously been nauseated and established on an anti-emetic should have the anti-emetic reviewed.

If still appropriate, it should be converted to a subcutaneous route and reassessed after 24 hours. If still not controlling nausea and vomiting, change to an alternative and/or seek specialist advice.

Assess the likely cause for nausea to guide the anti-emetic most likely to relieve symptoms
Review reversible causes (see boxes below)

Initial Treatment

Patients who become nauseated or start vomiting:
Gut causes
 Metoclopramide 10mg TDS PO/SC or CSCI 30mg/24 hours
 (avoid in complete bowel obstruction—see guidance on bowel obstruction). There is an increased risk of neurological adverse effects at doses higher than 30mg/24hours and if used for longer than 5 days.

Domperidone 10mg TDS PO.
 There is an increased risk of cardiac side effects at dose higher than 30mg/24hour and if used for longer than 7 days.—see BNF for more information

Non gut causes (e.g. medication, renal failure, biochemical disturbances, or cerebral causes)
 Metoclopramide 10mg TDS PO/SC or 30mg CSCI—see warning above
 Haloperidol 500 micrograms– 3mg PO/SC at night or CSCI 1.5mg to 5mg
 Cyclizine 50mg TDS PO/SC or CSCI 150mg over 24 hours in water for injection
 Levomepromazine 6mg PO or 2.5mg SC at night or CSCI 6.25mg-12.5mg (can use 3mg PO if sedation a problem)

Alternative anti-emetics may be more appropriate in certain circumstances

1. Severe Heart Failure:
 Levomepromazine 6mg PO or 2.5mg SC at night or CSCI 6.25mg-12.5mg (can use 3mg PO if sedation a problem)
 Avoid anti-emetics with anti-muscarinic side effects, such as Cyclizine, that may cause tachy-arrhythmias .

2. Toxicity or metabolic or biochemical cause of vomiting (medication related, renal failure, uraemia, hypercalcaemia)
 Haloperidol 500 micrograms - 3mg PO/SC at night or CSCI 1.5mg to 5mg
 Cyclizine 50mg TDS PO/SC or CSCI 150mg over 24 hours in water for injection
 Levomepromazine 6mg PO or 2.5mg SC at night or CSCI 6.25-12.5mg (can use 3mg PO if sedation a problem)

3. Parkinson's Disease / Lewy Body Dementia:
 Avoid anti-emetics with a dopamine receptor antagonist effect e.g. Haloperidol, Levomepromazine and Metoclopramide.
 Domperidone 10mg TDS PO first line - see caution above
 Ondansetron 4mg PO/SC PRN can be considered .

4. Raised Intracranial Pressure (ICP):
 If taking oral Dexamethasone for symptoms of raised ICP, this should continue to be given daily via the SC route.
 Aim to maintain at the lowest maintenance dose that controls the symptoms of raised intracranial pressure.
 Dexamethasone subcutaneously 3.3mgs to 16.5mg max daily dose in 1 or 2 divided doses.
 All doses of dexamethasone should be given before 2pm
***Dexamethasone can raise blood sugar levels and capillary blood glucose levels should be checked as per local guidance**

If there is a risk of seizures, e.g. in brain metastasis, avoid the use of levomepromazine which can lower the seizure threshold

5. Gastric Outlet Obstruction / Reflux:
 This can occur due to autonomic neuropathy (paraneoplastic) medication (anti-cholinergics), metabolic causes (e.g. hypercalcaemia), mechanical obstruction.
If complete bowel obstruction is excluded:
 Metoclopramide 30mg in CSCI over 24 hours - higher doses can be used - seek specialist advice
 Avoid the concurrent prescribing of a prokinetic e.g. metoclopramide and an anti-cholinergic (e.g. Cyclizine) which will inhibit it's prokinetic action. Metoclopramide can cause colic.

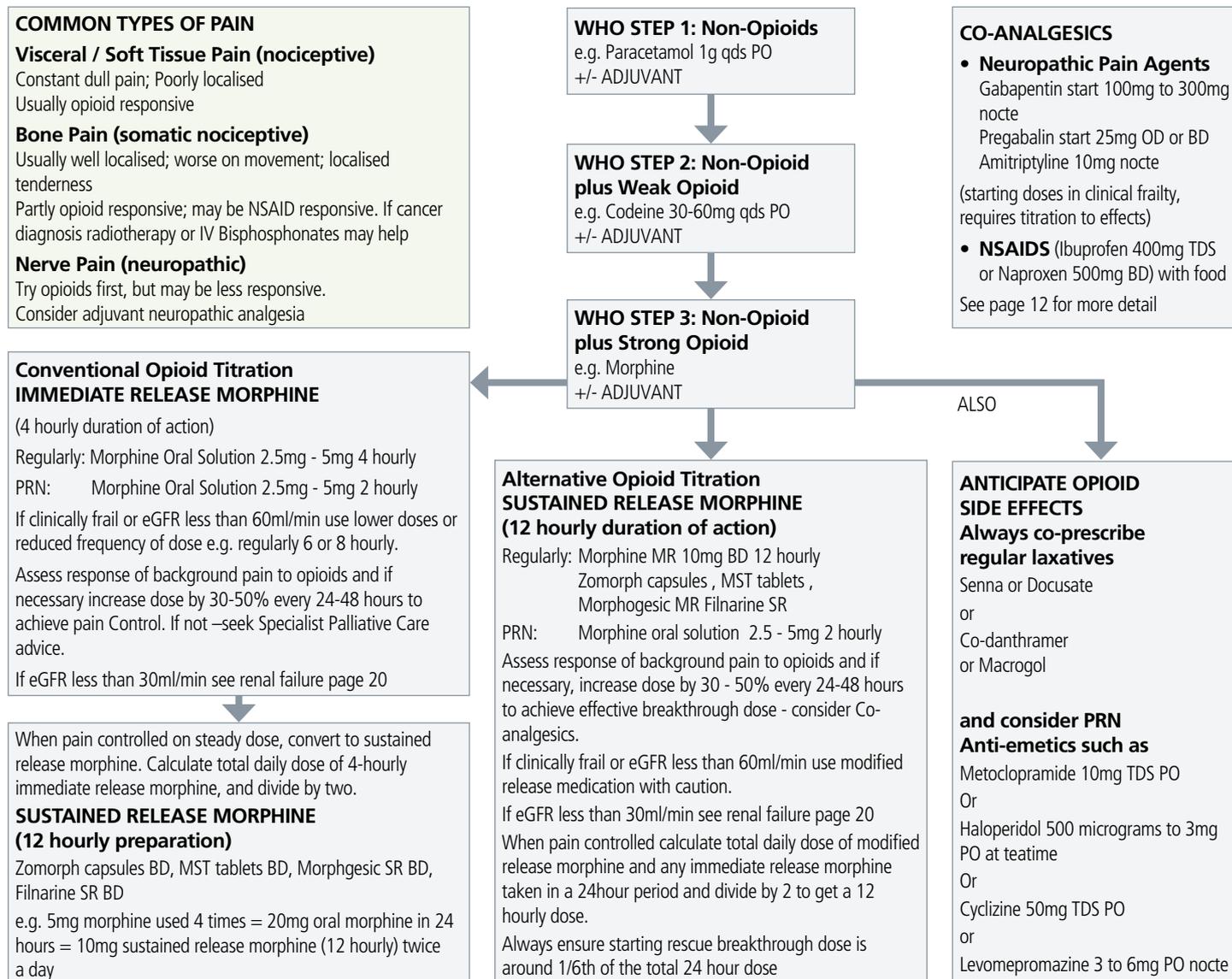
6. Bowel Obstruction:
 See guidance on bowel obstruction -page 7

- Reversible causes of nausea, vomiting or regurgitation to be considered:**
- Medication
 - Hypercalcaemia
 - Constipation
 - Reflux/Gastritis
 - Uncontrolled pain
 - Cough
 - Anxiety
 - Urinary retention causing renal impairment
 - Oral/oesophageal candidiasis

QUICK GUIDE	PAIN (PART 1) - OUTLINE OF THE USE OF OPIOIDS (FOR LAST DAYS OF LIFE SEE PAGE 17)
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Neuropathic Pain, Symptom Control Medication in the Dying Person, Opioid Substitution, Transdermal Opioids in Palliative Care

Pain can be improved for patients. If not improving, seek Specialist Palliative Care advice

"Dose adjustments may need to be made for renal failure" - See renal failure page 20



USE OF TRANSDERMAL OPIOID PATCHES

Only consider if:

- Pain is stable, and NOT rapidly changing
 - Oral route not appropriate or poorly absorbed in the long term (for short term management consider a continuous subcutaneous infusion) (CSCI)
 - Unacceptable side effects from other opioids despite opioid rotation, e.g. unmanageable constipation with opioids despite optimisation of laxatives
 - Renal impairment.
- (seek Specialist Palliative Care advice in renal failure) New prescriptions of Fentanyl patches are not recommended out-of-hours, unless on Specialist advice.

Commencing transdermal opioid (patches):

- Titrate with 4 hourly immediate release oral Morphine, until pain is controlled
- Remember a Fentanyl 25micrograms/hour patch is equivalent to a 60-90mg total daily dose of oral Morphine
- Stick patch to hairless skin; clip (do not shave) hair
- Initial analgesic effect will take at least 12-24 hours, and a steady state may not be achieved for 72 hours
- Ensure immediate release oral Morphine (or alternative) is available for breakthrough pain
- Change patch every 72 hours; use a new area of skin
- A 12-24 hour depot of drug remains in the patch when removed; fold in on themselves and discard safely out of the reach of children / vulnerable adults
- Opioid withdrawal may occur when switching from Morphine to Fentanyl; manage with PRN Morphine.

Guidance in the Last Days of Life (see page 17)

- When a patient is in the dying phase, **LEAVE PATCH IN SITU**, and change regularly as before.
- If patient has pain use an appropriate subcutaneous dose of opioid PRN for breakthrough pain
- If PRN doses are needed more than twice start CSCI in addition to patch
- Ensure PRN dose adequate for both patch & CSCI
- Seek Specialist Palliative Care advice for support if needed

QUICK GUIDE	PAIN (PART 2) - COMPLEX PAIN
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Neuropathic Pain, Symptom Control Medication in the Dying Person, Opioid Substitution, Transdermal Opioids in Palliative Care

If eGFR less than 30ml/min see RENAL FAILURE Page 20

Pain can be improved for patients. If not improving; seek Specialist Palliative Care advice, especially if:

- Complex, multiple pains where assessment is difficult
- Pain appears to be resistant to usual measures or not responding to Morphine doses equivalent to or exceeding 120mg Morphine in 24 hours
- Difficulty in managing pain due to adverse effects of medication or compliance

CONCEPT of TOTAL PAIN

Should prompt healthcare professionals to consider ALL possible influences on the individual's pain experience:

- **PHYSICAL**
- **SPIRITUAL**
- **SOCIAL**
- **PSYCHOLOGICAL**

Success in pain management depends on:

- Regular review of the pain and its causes
- Effectiveness of treatment
- Acceptability of the proposed treatment to the patient

The patient's understanding, fears, concerns and previous experience of pain, as well as their expectations of treatment will all influence each individual's experience of pain and its effective management.

NEUROPATHIC PAIN AGENTS

AMITRIPTYLINE - start 10mg OD increased to 25mg OD after 3-7 days and then by 25mg every 1 - 2 weeks to a maximum of 75mg daily

GABAPENTIN - start 100mg OD increase to 100mg BD after 2-3 days to 100mg TDS after 2-3 days and then by increments of 100mg every 2-3 days depending on response to a maximum dose of 900mg TDS

PREGABALIN - start 25mg BD and increase by 25mg every 2-3 days to a maximum dose of 300mg BD

DULOXETINE - start at 30mg OD and increase to 60mg OD after 2 weeks - stop if no response after 2 months. Maximum dose 120mg OD

Start with either an anticonvulsant or an antidepressant and titrate dose as above. Response takes a number of days to become apparent. If no apparent response seek advice from Specialist Palliative Care team.

NB Prescribing of the above for some types of neuropathic pain is beyond licence. The prescriber should follow relevant professional guidance, taking full responsibility for the decision.

Informed consent should be obtained and documented.

A GUIDE TO EQUIVALENT DOSES OF OPIOID DRUGS

This table of doses is a guide - not a set of definitive equivalences.

Use the table to identify an appropriate starting point for your prescribing decision. Ask if the pain is opioid responsive. ALL prescribing decisions must be based on a full clinical assessment. **Higher opioid doses may be needed for some patients - seek advice**

Think about the role of adjuvant medication before rotating opioids, changing the dose or route.

Consider reducing prescribed opioid dose by 30-50% if converting from one route to another route (e.g. transdermal to oral or oral to subcutaneous) or there is concern about opioid toxicity (confusion, drowsiness, myoclonic jerks, slowed respiration, pin-point pupils)

Be aware of drug interactions and remember individual patients may metabolise different drugs at varying rates.

Never increase an opioid dose by more than 50% of the previous 24 hour regular dose without SPECIALIST ADVICE

Oral Morphine		Oral Oxycodone		Transdermal Buprenorphine		Transdermal Fentanyl	Subcutaneous Morphine		Subcutaneous Oxycodone	
4-hr dose (mg) (break-through dose)	12 hourly dose (mg)	4-hr dose (mg) (break-through dose)	12 hourly dose (mg)	BuTrans (mcg/hr) change every Seven days	Transtec (mcg/hr) change every Four days	Fentanyl (mcg/hr) change every Three days	4-hr dose (mg) (break-through dose)	24-hr CSCI dose (mg)	4-hr dose (mg) (break-through dose)	24-hr CSCI dose (mg)
1.25	5	-	-	5	-	-	0.5	-	-	-
2.5	10	-	-	10	-	-	1.25	5	-	-
5	15	2.5	10	15	-	12	2.5	15	1.25	10
10	30	5	15	25	-	25	5	30	2.5	15
15	45	10	30	35	35	37	7.5	45	5	30
20	60	15	45	-	52.5	50	10	60	7.5	45
SEEK SPECIALIST ADVICE				SEEK SPECIALIST ADVICE			SEEK SPECIALIST ADVICE			
30	90	20	60		70	75	15	90	10	60
40	120	25	75		105	100	20	120	12.5	75
50	150	30	90		122.5	125	25	150	15	90
60	180	40	120		140	150	30	180	20	120

QUICK GUIDE	PALLIATIVE CARE EMERGENCIES - Part 1
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Anti-epileptics and Hypercalcaemia

NEUTROPENIC SEPSIS

Consider if recent chemotherapy or extensive radiotherapy with either curative or palliative intent in ANY patient who appears to be deteriorating - especially if relatively unexpected.
Most likely between 7-10 days after treatment but can be up to one month post treatment.
SEE LOCAL ACUTE ONCOLOGY GUIDANCE

Early signs
Flu like symptoms
Temperature of 38oC
Rigors

Late signs
Anxiety, confusion
Hypotension
Tachycardia
Cold and clammy
Diarrhoea

Remember
both NSAIDs and PARACETAMOL affect temperature so may mask condition / sepsis

DO NOT DELAY
If suspected, ADMIT to HOSPITAL URGENTLY for IV fluids and IV antibiotics

EPILEPTIC SEIZURES

ACUTE SEIZURES

- May settle spontaneously
- Ensure airway secure and administer oxygen if available
- If seizure does not stop within 5 minutes give either
 - Subcutaneous, intranasal or buccal midazolam 5mg to 10mg OR
 - Diazepam 10mg-20mg rectally

Once settled consider long term seizure management with relevant Specialists if not in last weeks/days of life. Alternative medication may be considered - please see local guidance

IF SEIZURES CONTINUE despite above measures for a further 5 minutes - Repeat measures above

- Decide if transfer to hospital for emergency management is needed or if care will continue in the current care setting
- For acute management - a secure airway should be established, oxygen should be administered, cardiorespiratory function should be assessed and intravenous access should be established.
- If patient is to stay at home or hospice and two doses needed, consider a continuous subcutaneous infusion of Midazolam 20- 30mg over 24 hours, seek Specialist advice.

SUPERIOR VENA CAVAL OBSTRUCTION (SVCO)

- Compression / invasion or thrombosis of SVC due to tumour or nodal mass within mediastinum, preventing venous drainage from head, arms and upper trunk
- Commonest causes (95%) – lung cancer, non-Hodgkin’s lymphoma
- Usually onset over weeks or months, but occasionally occurs rapidly over days

MANAGEMENT:
Administer Dexamethasone 16mg orally or parenterally in one or two divided doses -IMMEDIATELY URGENTLY (ideally the same day) discuss with Oncologist about future management Consider the possibility of radiological stenting.

HYPERCALCAEMIA

- Hypercalcaemia is common in cancer of breast, myeloma, lung, head and neck, kidney, thyroid and cervix.
- Primary hyperparathyroidism should be considered as a possible cause (6% of cancer patients)

Presentation:

- Symptoms of hypercalcaemia include: fatigue, weakness, constipation, nausea, vomiting, polyuria, polydipsia, cardiac arrhythmias, delirium, drowsiness and coma.
- Corrected serum calcium >2.7mmol/L (some variation between laboratories)

ASSESSMENT:
Clinical assessment of the patient is crucial in determining whether treatment of hypercalcaemia is appropriate, as it generally requires IV fluids and admission to an institution.
Generally a decision to treat should be motivated by the patient’s symptomatology rather than absolute calcium level. The most important goal of treatment is to improve clinical symptoms. Hypercalcaemia may be a poor prognostic sign in cancers such as lung and cervix.
Onset of symptoms raising clinical suspicion should be investigated. Bloods should be checked for urea and electrolytes (U&Es), estimated glomerular filtration rate (eGFR), liver function tests (LFT’s) and calcium.

TREATMENT:
May require in-patient unit care in hospital or hospice. (Refer to local guidelines around bisphosphonate dosing)
The patient should be rehydrated with 1-3 litres of parenteral 0.9% sodium chloride before the administration of bisphosphonates. The volume and rate of fluid replacement should be adjusted in each patient according to their age, the severity of hypercalcaemia, the degree of dehydration and the ability of the cardiovascular system to tolerate rehydration.

- The treatment of choice after rehydration is intravenous bisphosphonate - pamidronate, zoledronic acid or ibandronate depending on local formulary choices.
- Corrected calcium levels should be rechecked at 5-7 days after the bisphosphonate infusion. Checking calcium levels prior to this is not appropriate, as the bisphosphonate will not have achieved it’s maximal effect.
- Consider Advance Care Plan about how and where to manage further episodes in the future.

SYMPTOMS/SIGNS:

- Swelling of face, neck, arms
- Headache
- Dizziness/ Visual disturbance
- CNS depression
- Seizures
- Dyspnoea
- Dilated veins – neck, trunk, arms
- Hoarse voice
- Stridor
- Cyanosis

QUICK GUIDE	PALLIATIVE CARE EMERGENCIES - Part 2
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Metastatic Spinal Cord Compression Major Haemorrhage

METASTATIC SPINAL CORD COMPRESSION

- Affects 5-10% of patients with cancer
- Most common in prostate, lung, breast cancer and myeloma
- Catastrophic event – aim is to prevent establishment of permanent loss of function
- Symptoms may be vague, there should be a high index of suspicion if a patient goes "off their legs", becomes unsteady, struggles to get out of a chair or climb stairs.
- Patients with cancer and neurological signs or symptoms of spinal cord compression should be treated as an oncological emergency

FOLLOW LOCAL ONCOLOGY GUIDANCE

SAME DAY- MEDICAL ASSESSMENT

Full history and neurological examination,
Assess fitness to treat

SAME DAY - CONTACT :-

METASTATIC SPINAL CORD CO-ORDINATOR at Oncology centre to discuss case
(for Lancashire and South Cumbria 01772 71656 Or Bleep 2664)

IF SUSPECTED:

- Give Dexamethasone 16mg BY MOUTH or convert to SC
- Prescribe medication for gastric protection
- Give adequate analgesia (opioid if necessary) to enable transfer for admission / investigation
- Nurse flat if pain / symptoms suggest spinal instability
- Request urgent admission and MRI scan

POST DIAGNOSIS

May have radiotherapy or spinal surgery to stabilise spine and relieve pressure on spinal cord. Aim to maintain function and continence as much as possible. Involve physiotherapy and occupational therapy as soon as possible. Titrate steroids down to the lowest dose over 2 - 4 weeks dependent on patient's symptoms and condition. In many cases developing metastatic spinal cord compression is a poor prognostic sign

SYMPTOMS– particularly new or changing:

Back/Spinal Pain:

- may radiate in a radicular, 'band-like' pattern
- progressive / unremitting
- may be worse on coughing or straining
- may be nocturnal, pain preventing sleep
- may not be present

Nerve root pain in limbs.

Weakness of limbs (out of proportion to general condition of patient)

Difficulty walking.

Sensory changes - tingling, numbness, "my legs don't belong to me."

Difficulty passing urine – usually a late presentation.

Constipation or faecal incontinence.

SIGNS: Do not wait for signs. Act on the symptoms

Localised spinal tenderness

Weakness of limbs

Reflexes: Absent / increased. Extensor plantars.

Altered sensation - look for a sensory level

Distended bladder

Contact local Specialist Palliative Care Team if advice on symptom management required

MAJOR HAEMORRHAGE

CLINICAL PRESENTATION:

- Cardiovascular compromise – hypotension, tachycardia (>100bpm = significant recent bleed)
- Identifiable bleeding source – haematemesis, haemoptysis, PV or PR bleeding, haematuria, melena
- Erosion of an artery by a malignant ulcer or superficial/fungating tumour
- Bleeding of all types occurs in 14% of patients with advanced disease - seek Specialist advice if time and clinical situation permit
- Haemorrhage causes death in approximately 6% patients
- Catastrophic external haemorrhage less common than internal bleeding
- It may be a terminal event in both advanced cancer and non-malignant disease.

MANAGEMENT:

A member of staff must remain with the patient to provide support at all times

- Plan ahead where possible, record and share information with key organisations via EPaCCS
- If there are warning signs or high anticipated risk of bleeding have a proposed management plan ideally discussed with patient and/or family and staff
- Record management plan in case notes and communicate this to all team members
- Provide dark coloured towel to disguise blood loss.
- Anticipatory prescribing of Midazolam 10mg IM, SC, buccal or sublingual.
- The subcutaneous route may be less effective in catastrophic bleeds due to peripheral shut down with unpredictable absorption of the medication

CATASTROPHIC BLEED:

- **Ensure patient is not left alone**
- Keep patient warm
- Use anxiolytic or analgesics as needed if the patient is distressed
- Support the patient and family
- Debrief for staff after the event

FURTHER CARE: It may be necessary to commence and continue an infusion of anxiolytic (Midazolam) and/or analgesic e.g. Morphine or Oxycodone) in the last hours of life. If bleeding temporarily stops further management will depend on overall clinical status and discussion with patient and family in relation to further acute interventions. Consider referral for diathermy, radiotherapy or embolisation depending on local availability and protocols. Seek specialist palliative care advice around other options to prevent re-bleeding

QUICK GUIDE	CARE IN THE LAST WEEKS OR DAYS OF LIFE
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Symptom Control in the Dying Person

FIVE KEY PRIORITIES

RECOGNISE:

- The possibility that a person is in the last weeks of life or they may die within the next few days or hours and communicate this clearly;
- Consider and address reversible causes where appropriate / possible
- Identify and where possible make decisions in accordance with the individual’s wishes and needs
- Review the assessment and decisions on a regular basis

COMMUNICATE:

- Sensitively with the individual and those important to them

INVOLVE:

- All relevant people in making decisions as far as they indicate they want to be

SUPPORT:

- The family and other people important to the dying person by exploring, respecting and meeting their needs where possible

PLAN:

- Create an individualised plan of care. This should include decisions around:
 - Cardiopulmonary resuscitation
 - Facilitating or preventing change in place of care
 - Supporting oral food and fluid intake
 - Stopping or continuing physical observations and / or investigations
 - Starting, stopping or continuing clinically assisted hydration and / or nutrition
 - Review of long term medication - stopping those that are no longer needed and switching others to a route which ensures they can continue and provide benefit
 - Anticipatory prescribing of medication for the common symptoms at end of life (ie pain, breathlessness, respiratory tract secretions, agitation, nausea and vomiting) and other problems specific to that individual such as management of seizures or bleeding, etc.

QUICK GUIDE	DIABETES MANAGEMENT IN THE LAST WEEKS OF LIFE
Reference	Northern England Strategic Clinical Network Guidance

Assessment/Description

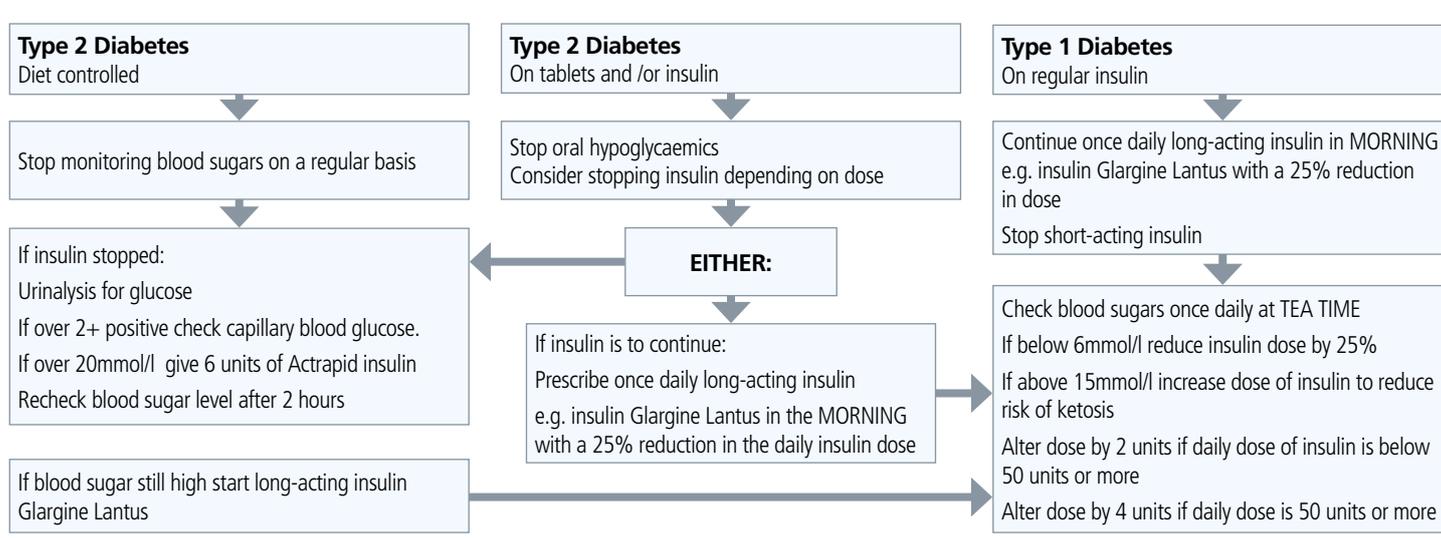
Explore with the individual and those important to them changing the approach to diabetes management including:

- The aim of management - avoiding hypoglycaemia rather than avoiding longer term complications due to hyperglycaemia
- The value of continuing to monitor blood glucose readings
- The method and frequency of checking blood glucose levels
- The type of management - tablets and / or insulin

Devise a management plan with the patient and those important to them. Ensure your local diabetes specialist team are involved if the patient remains on insulin. Aim to:

- Keep invasive tests to a minimum
- Be alert to symptoms that may be due to hypo or hyperglycaemia and have appropriate medication / interventions available to address these if they develop

AIM for a Target BM reading between 6 and 15.



QUICK GUIDE	CONTINUOUS SUBCUTANEOUS INFUSIONS (CSCI) /Syringe Pump - also see local guidelines
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Agitation, Anti-epileptics, Delirium, Symptom Control Medication in the Dying Person, Nausea and Vomiting, Opioid Substitution, Syringe pumps

Assessment/Description

Syringe PUMPS are used to administer medication by a continuous subcutaneous infusion (CSCI) over a 24 hours period. They are classed as high risk devices and should only be used by suitably trained clinicians.

Indications for commencing medication via continuous subcutaneous infusion (CSCI)

- Patient is unable to take oral medication due to:
 - Nausea and vomiting
 - Difficulty in swallowing
 - Intestinal obstruction
- Malabsorption / uncertain absorption of oral medication
- For care in last days of life when oral route is unreliable and regular medication is needed to maintain comfort

Diluent Most commonly used medication in a syringe pump should be diluted with **water for injection**. Drugs may be diluted with Saline 0.9% except Cyclizine or Diamorphine (doses above 40mg) which should be diluted in Water for injection.

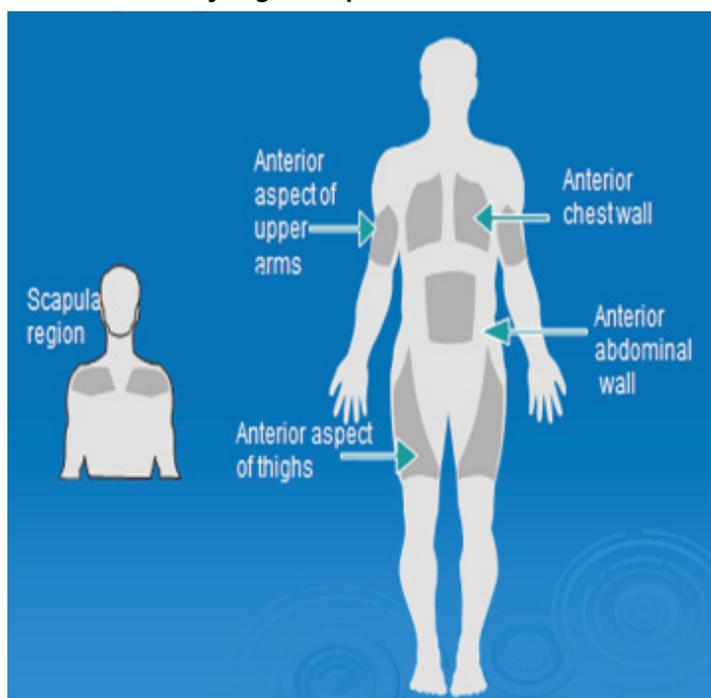
Syringe Pump

All syringe pumps must be serviced regularly according to local guidance and at least annually, whether used or not to ensure their function is maintained. Syringe pumps should be sent for maintenance checks immediately if they have been dropped, suffered fluid ingress (e.g. had fluid spilt over them or dropped in a bath) or if there is any doubt as to their functional operation whilst in use.

The following points should be taken into account when using syringe pumps:

- Protect the syringe from direct sunlight whenever possible
- Carry out a visual inspection of the solution within the syringe at each monitoring (refer to local policy) check and discard if evidence of crystallisation or precipitation, cloudiness or change in consistency
- Avoid mixing medicines in one syringe if compatibility data is not available; **do not mix more than three medicines unless on the advice of a palliative care Specialist**

Syringe Pump site selection:



The following sites should be avoided:

- Oedematous areas including lymphoedematous arms (poor drug absorption, and increased risk of infection/exacerbation of oedema)
- Bony prominences (poor absorption and discomfort)
- Irradiated sites (may have poor perfusion and hence poor drug absorption)
- Skin folds, sites near a joint and waistband area (movement may displace cannula or cause discomfort)
- Broken skin

QUICK GUIDE	PAIN IN THE LAST DAYS OF LIFE
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Symptom Control in the Dying Person

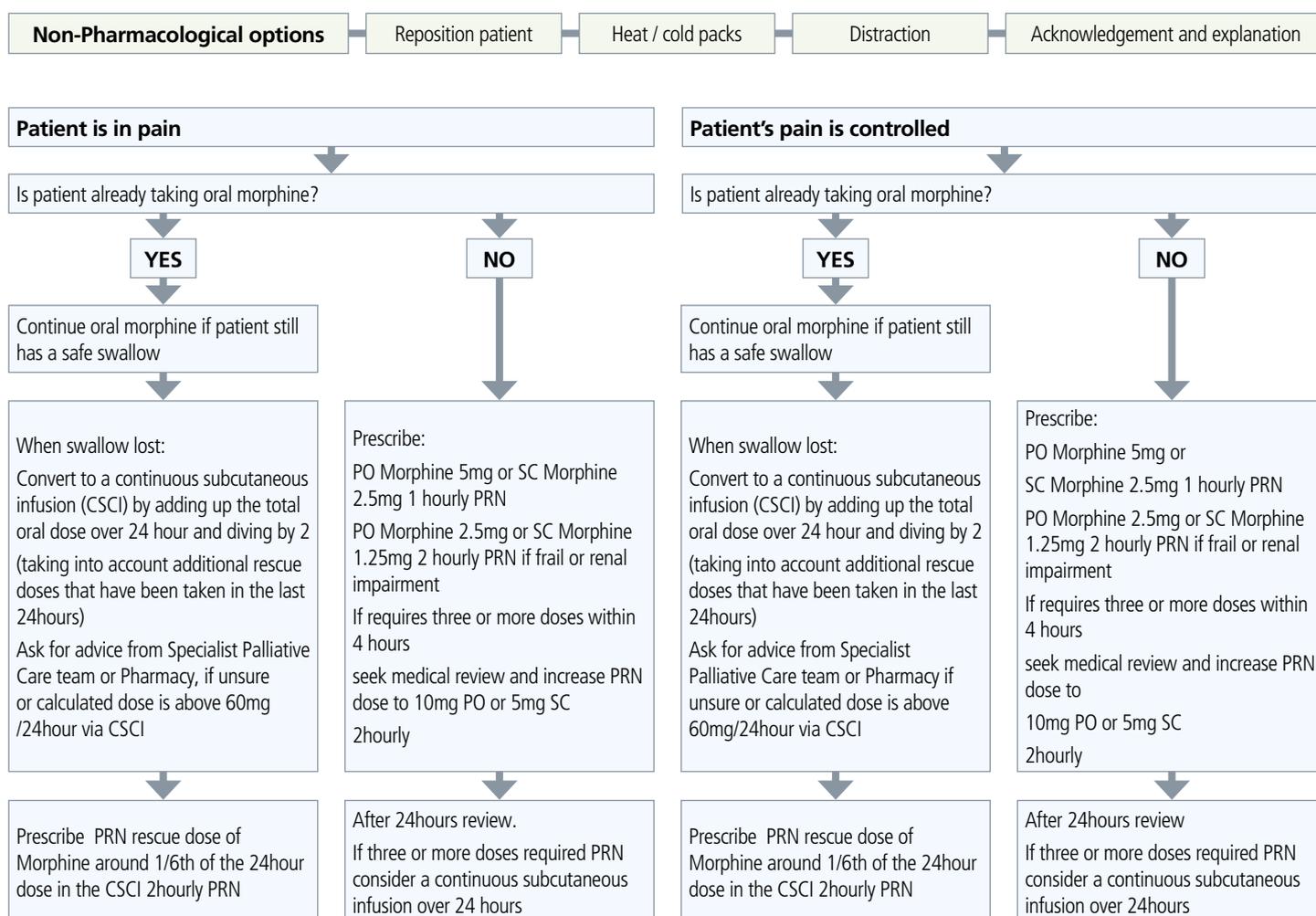
GENERAL COMMENTS

In the majority of cases injectable Morphine is the first line opioid of choice in the last days of life.

If patient has been well established on an alternative opioid such as Oxycodone continue it and follow the principles outlined in the flow diagrams.

For patients who have not previously been given medicines for pain management, start with the lowest effective dose of pain killer and titrate as clinically indicated.

Alternative opioids may be needed if the patient has significant renal impairment - seek specialist advice.



ADDITIONAL INFORMATION

Transdermal opioid patches at end of life (Fentanyl /Buprenorphine)

It is recommended that opioid patches are left in place and changed regularly in last days of life

If pain occurs a rescue dose of an appropriate injectable opioid is administered - see page 10 for guidance about equivalent doses.

If 2 or more rescue doses are needed in 24hours consider setting up a CSCI with the total dose of rescue medication given in the previous 24 hours up to a maximum of 50% of the existing regular opioid (patch) dose.

Remember to combine the dose of the opioid patch and the dose of opioid in the syringe pump to work out the new rescue dose (1/6th - 1/10th of the total 24hour dose)

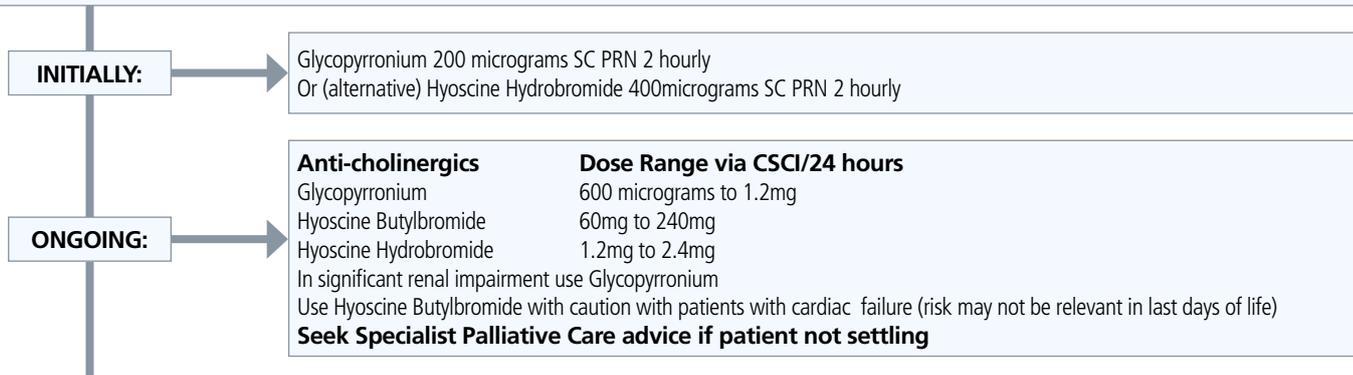
IF YOU ARE IN ANY DOUBT ABOUT HOW TO MANAGE A PATIENT'S PAIN IN THE LAST DAYS OF LIFE ASK FOR SPECIALIST ADVICE

QUICK GUIDE	RESPIRATORY TRACT SECRETIONS IN THE LAST DAYS OF LIFE
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Symptom Control in the Dying Person

Assessment/Description
 Patient unable to clear secretions from their upper respiratory tract properly, causing secretions to move as they breathe, creating noise

Non-Pharmacological options → Reposition patient → Active surveillance → Acknowledgement and explanation → Cautious suction

Pharmacological Options:

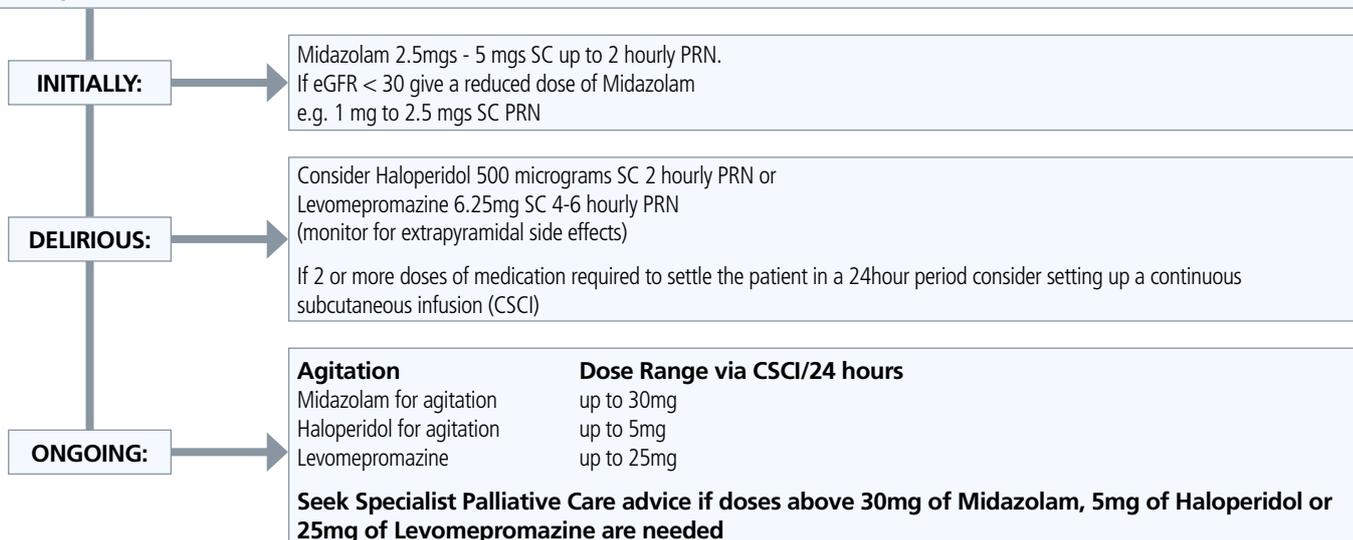


- Anti-cholinergic side effects can arise: treat this with frequent mouth care which may include artificial saliva replacement gels or sprays.
- Secretions which have already accumulated will not be removed by medication. Early treatment improves the prospect of achieving symptom control.
- If one agent doesn't work, try switching to the other after full titration to maximum dose over 24 hours; if there is still no improvement, consider stopping medication.
- Seek Specialist advice as required.
- Hyoscine Hydrobromide crosses the blood brain barrier and causes sedation.

QUICK GUIDE	AGITATION / TERMINAL RESTLESSNESS IN THE LAST DAYS OF LIFE
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Symptom Control in the Dying Person

Assessment/Description
 Look for any reversible cause of agitation, and if identified institute appropriate management plans, such as inserting a urinary catheter for urine retention, constipation, full stomach, managing pain, etc. Consider and where possible address physical, psychological and spiritual factors as well as environmental factors such as light and noise.

Pharmacological Options:

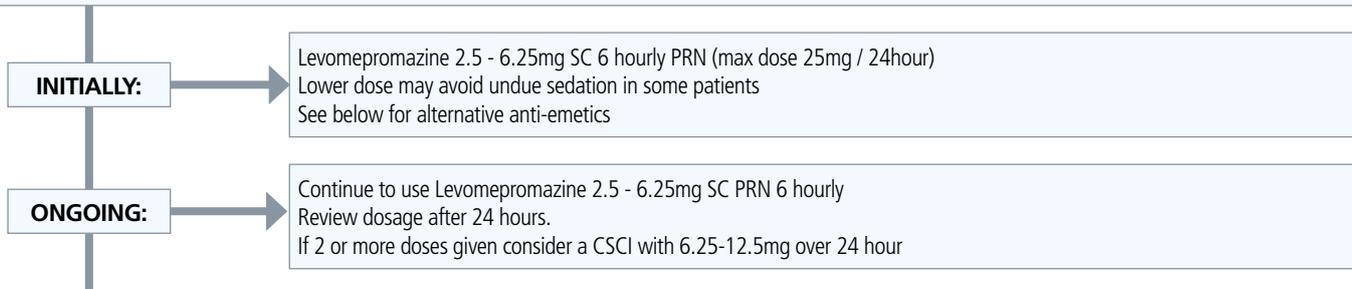


QUICK GUIDE	NAUSEA AND VOMITING IN THE LAST DAYS OF LIFE
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Symptom Control in the Dying Person

Assessment/Description
 Patient complains of nausea, or is vomiting

Non-Pharmacological options → Reposition patient → Eliminate known precipitants / strong odours → Acknowledgement and explanation

Pharmacological Options:



Alternative anti-emetics include:

- Haloperidol 500 micrograms – 1.5mg SC PRN 8 hourly (max dose 5mg/ 24hour)
- Cyclizine 50mg SC PRN 8 hourly (max dose 150mg / 24hour)

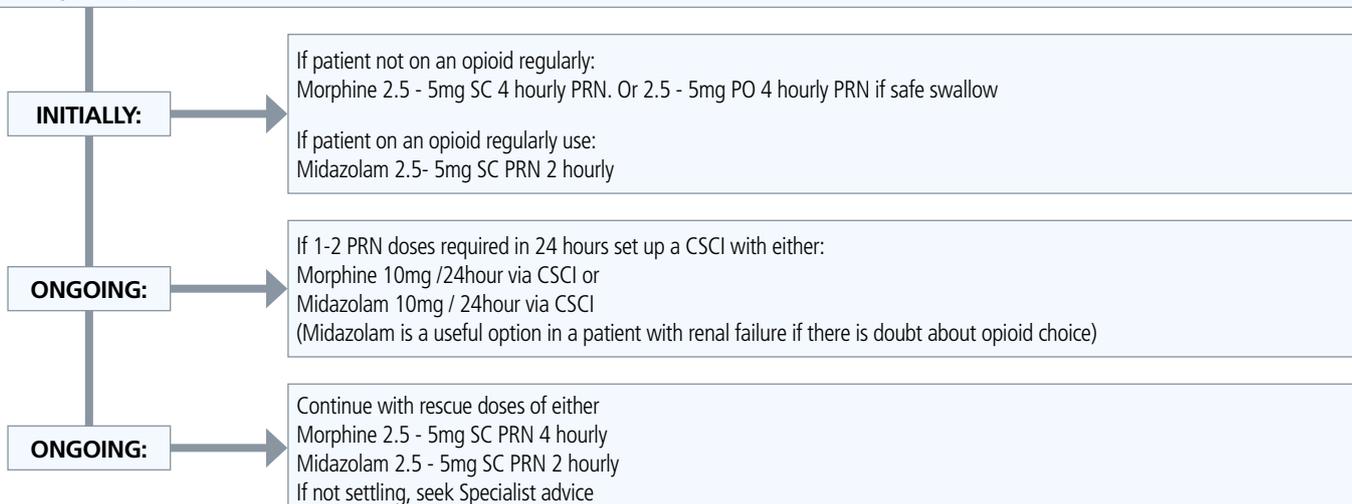
Nausea and vomiting can be complex to manage - if patient is not settling seek Specialist advice
 Remember that medication can be a profound cause of nausea and vomiting as can psychological issues
 Raised intracranial pressure due to brain metastases may cause nausea and/or vomiting that might respond to high dose steroids (3.3mgs - 6.6mgs Dexamethasone SC OD)
 See page 10 for further information

QUICK GUIDE	BREATHLESSNESS IN THE LAST DAYS OF LIFE
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Symptom Control in the Dying Person

Assessment/Description
 Breathlessness causes significant anxiety. If heart failure is a contributing factor consider a trial of a diuretic via a suitable route. Only use oxygen if patient has been shown to be hypoxic, the aim is for comfort not to maintain oxygen saturations. Do not exceed oxygen flow rates of 4 litres/min except with Specialist advice.

Non-Pharmacological options → Reposition patient - Sit up / lean forward → Acknowledgement and explanation → Gentle air flow with fan / open window → Regular mouth care

Pharmacological Options:



QUICK GUIDE	THEME - RENAL FAILURE
Reference	Merseyside and Cheshire Palliative Care Network Audit Group Guidelines on Prescribing in Renal Failure

SIGNIFICANT RENAL IMPAIRMENT - SEEK SPECIALIST PALLIATIVE CARE ADVICE

- Paracetamol at standard doses is safe in renal impairment
 - **If the eGFR is below 30mls/min (CKD 4/5)** there is an increased risk of toxic side effects with all opioids due to drug and metabolite accumulation. Opioids should therefore be used with caution and should be monitored on a regular basis. Watch for signs of opioid toxicity which may include hallucinations, myoclonic jerks, drowsiness or confusion.
 - When prescribing oral (**strong**) opioids, the immediate release forms are preferred. Long-acting opioid preparations should be avoided (e.g. MST/MXL) as the metabolites accumulate in renal failure. Fentanyl patches may be better tolerated in significant renal impairment but are difficult to titrate if pain is rapidly changing.
 - Whilst parenteral **Alfentanil** or **Fentanyl** are pharmacokinetically the safest analgesics to use in renal failure as the metabolites are non-toxic, **they may not be available in all localities and Oxycodone or Morphine or Diamorphine at reduced doses and / or frequency may be used but seek Specialist Palliative Care advice.**
 - **NSAIDS** should be avoided if possible, unless a patient is already on dialysis. If an NSAID must be prescribed for clinical reasons, the lowest effective dose should be used and the renal function should be re-checked within 5-7 days of starting the drug. If the renal function deteriorates further then a clinical decision is needed as to the benefits of continuing it's use.
 - Adjuvant analgesics: Gabapentin / Pregabalin are safe in mild renal failure but if eGFR is less than 20ml/min the dose and/ or frequency may need to be reduced to avoid toxicity.
 - **Anti-emetics: Haloperidol** is the drug of choice for nausea in patients with renal failure, but if eGFR is less than 10ml/min the dose should be reduced (250 micrograms to 500 micrograms PO or SC). **Levomepromazine** is an alternative starting at 3mg PO or 2.5mgs SC. Adjust dose depending on effectiveness and side effects. **Cyclizine** should be avoided due to the risk of hypotension / tachyarrhythmia. **Metoclopramide** should be avoided due to the increased risk of extrapyramidal reactions
- ALWAYS Seek Specialist advice from palliative care and the patient's renal unit for patients managed with Haemodialysis or Peritoneal Dialysis**

CLINICALLY ASSISTED HYDRATION (CAH) AT THE END OF LIFE

Nutrition and hydration are often emotional topics for families and patients when approaching end of life. There is need for ongoing sensitive discussions about goals of care and realistic expectations of treatment. The views of the patient and any Advance Care Planning should be considered throughout, and support for the carers when these decisions are being made is essential.

Within palliative care, clinically assisted hydration, either via intravenous or subcutaneous (SC) infusion, is provided with the intent of improving quality of life. SC fluids involve less discomfort, have fewer potential adverse effects than the intravenous (IV) route, may be provided in multiple care settings and are cheaper to provide. SC fluids should not be used to resolve severe dehydration, in emergency situations, or in patients with fluid overload.

There may be practical difficulties when considering SC fluids in the community setting. Equipment and training may be required. Refer to local guidelines and policy.

Due to the lack of any clear evidence, decisions to initiate Clinically Assisted Hydration will vary from patient to patient depending on the estimated burden to benefit balance. Treatment should always be in conjunction with other quality care, including good mouth care .

Potential indications

Symptomatic dehydration
Thirst (may be unrelated to fluid status)
Reversible renal impairment
Opioid toxicity
Excess sedation
Family/patient distress.

Potential complications

Line discomfort/infection
Oedema/ascites/effusions
Worsening secretions
Increased symptom burden as a result of above
Family/patient distress
Systemic fluid overload.

Management

There should be an agreed, clear indication of what is to be achieved by administering CAH, which should be discussed with the patient and family. Isotonic or hypotonic solutions only should be used (e.g. 0.9% NaCl). Rate of infusion will vary by patient, but is generally gravity fed with around 1 litre of fluid administered per 24hours. Infusion site should be under regular review for signs of infection, fluid accumulation or discomfort (at least every 48 hours).

QUICK GUIDE	CORTICOSTEROIDS IN PALLIATIVE CARE (Follow local guidelines if available)
Reference	Northern Strategic Clinical Network's Guidelines

Corticosteroids are used extensively in palliative care. Dexamethasone is the preferred choice due to its relatively high anti-inflammatory potency and lower incidence of fluid retention and biochemical disturbance. Whilst highly effective they should be used with caution and be constantly monitored to prevent avoidable complications. (Potency: Dexamethasone 1mg ~ Prednisolone 7.5mg).

Dexamethasone should be prescribed in terms of the 'base' (Dexamethasone) rather than the 'salt' (Dex Phosphate or Dex Sodium Phosphate). Tablets are formulated as the base. Prescribing injections can appear confusing. For practical purposes: 3.3mg/ml injection may be considered equal to 4mg tablet.

http://www.ukmi.nhs.uk/filestore/ukmiaps/ProductSafetyAssessmentforDexamethasone_Sept_2014.pdf

Treatment and Management

Standard starting doses for the different indications are not well established and must take account of patient factors. Ensure daily dose is administered before noon in order to minimise insomnia. Clinical response must be reviewed within 7 days. Titrate down to minimum effective dose as soon as is possible.

Anorexia: 2 - 6mg daily. Judge response within 2 weeks. Although enhanced effect can still be present at 4 weeks, short courses are recommended to reduce risk of side effects.

Adjuvant analgesic: 8 - 16mg in cancer-related pain (e.g. liver capsular pain, nerve compression).

Anti-emetic: for chemotherapy follow Oncology guidelines. Refractory nausea and vomiting: 8 - 16mg daily.

Obstructive syndromes e.g. bowel obstruction, upper airways compression, SVCO, lymphangitis carcinomatosa: 6 - 16mg daily.

Spinal cord compression: 16mg daily for 5 days. Maintain on 8mg daily during radiotherapy, then reduce dose over 2 weeks. If symptoms recur, increase to previous effective dose for at least 2 weeks before reducing again.

Raised intracranial pressure: 8 - 16mg daily for one week, and then reduce over 2-4 weeks to lowest dose which maintains benefit. (If treated with radiotherapy, steroids should be continued until one week post treatment, and then reduced as above). Consider trial of dose increase if symptoms recur.

ADVERSE EFFECTS:

- Glucose metabolism: Steroids can increase blood sugar levels. All patients on steroids should have regular blood glucose checks as per local guidance
- Insomnia: Give single or divided daily dose before noon to prevent insomnia.
- Dyspepsia: Give after food. Co-prescribe PPI if history of peptic ulcer disease or patient also taking Aspirin, NSAIDs, SSRIs or is anti-coagulated with Warfarin, LMWH or other agent.
- Psychiatric disturbance: depression, mania, psychosis, delirium.
- Change in appearance: moon face, truncal obesity, negative body image.
- Musculoskeletal problems: proximal myopathy, osteoporosis, avascular bone necrosis.
- Increased susceptibility to infection: especially oral/pharyngeal candidosis (examine mouth regularly).
- Skin changes: thinning, bruising, acne, impaired wound healing.
- Other: hypertension, oedema, pancreatitis.

SAFE USE: Monitoring and stopping treatment

Use the lowest effective dose for the shortest period of time. Close careful monitoring is essential. Steroid withdrawal: stop without tapering dose if total treatment duration of less than 3 weeks AND daily Dexamethasone dose of 6mg or less AND symptoms unlikely to relapse.

Gradual dose reduction: is necessary if any of following:

- 3 or more weeks treatment, daily dose of more than 6mg Dexamethasone,
- Risk of recurrent severe symptoms,
- Repeated courses of steroids,
- Other possible causes of adrenal suppression.

Daily dose can be reduced rapidly (e.g. halving dose) to 4mg/day, then more slowly by 1 - 2mg weekly in order to prevent a hypoadrenal crisis (malaise, profound weakness, hypotension).

Steroid treatment card: Patients on systemic steroids for > 3 weeks must be given a steroid card.

STEROIDS in last days of life: For ongoing symptom control, continue at the most convenient SC dose. If recent and/or low oral dose prescription for appetite stimulation, discontinue. If long-term, oral dose for whatever indication consider continuing at physiological dose, Dexamethasone 1.1mg SC.

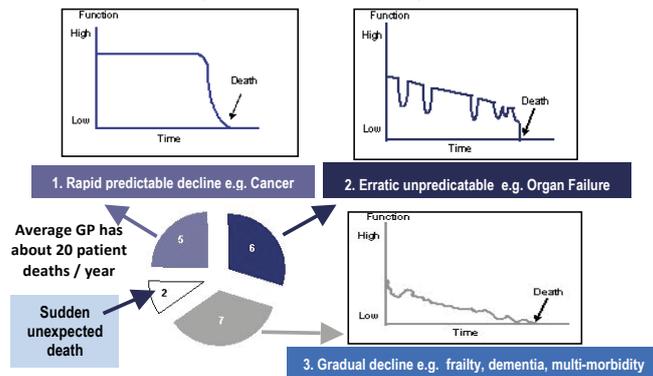
The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life leading to improved proactive person-centred care

GSF PIG 6th Edition Dec 2016 K Thomas, Julie Armstrong Wilson and GSF Team, National Gold Standards Framework Centre in End of Life Care <http://www.goldstandardsframework.org.uk> for more details see **GSF PIG**

Proactive Identification Guidance – proactively identifying patients earlier.

This updated 6th edition of the GSF PIG, renamed as Proactive Identification Guidance and formally known as Prognostic Indicator Guidance, aims to enable the earlier identification of people nearing the end of their life who may need additional supportive care. This includes people who are nearing the end of their life following the three main trajectories of illness for expected deaths – rapid predictable decline e.g. cancer, erratic decline e.g. organ failure and gradual decline e.g. frailty and dementia. Additional contributing factors when considering prediction of likely needs include current mental health, co-morbidities and social care provision.

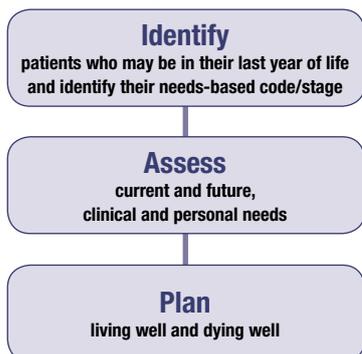
Three trajectories of illness (Lynn et al) reflecting the three main causes of expected death



Why is it important to identify patients early?

Earlier identification of people who may be in their final stage of life leads to more proactive person-centred care. About 1% of the population die each year, with about 30% hospital patients and 80% of care homes residents in their last year of life. Most deaths can be anticipated though a minority are unexpected (estimated about 10%). Earlier recognition of decline leads to earlier anticipation of likely needs, better planning, fewer crisis hospital admissions and care tailored to peoples' wishes. This in turn results in better outcomes with more people living and dying in the place and manner of their choice. Once identified, people are included on a register and where available the locality/electronic register, triggering specific active supportive care, as used in all GSF programmes and in GSF cross boundary care sites.

The 3 key steps of GSF



PIG and GSF – Early proactive identification of patients is the crucial first step of GSF, used by many thousands of doctors and nurses in the community and hospitals. For more information on GSF, how it is used in practice to help identify patients early, assess needs and wishes through advance care planning discussions and plan care tailored to patient choices, see the GSF website.

National Policy support for earlier identification.

General Medical Council – 2010

www.gmc-uk.org/static/documents/content/End_of_life.pdf

The GMC definition of End of Life Care; 'People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

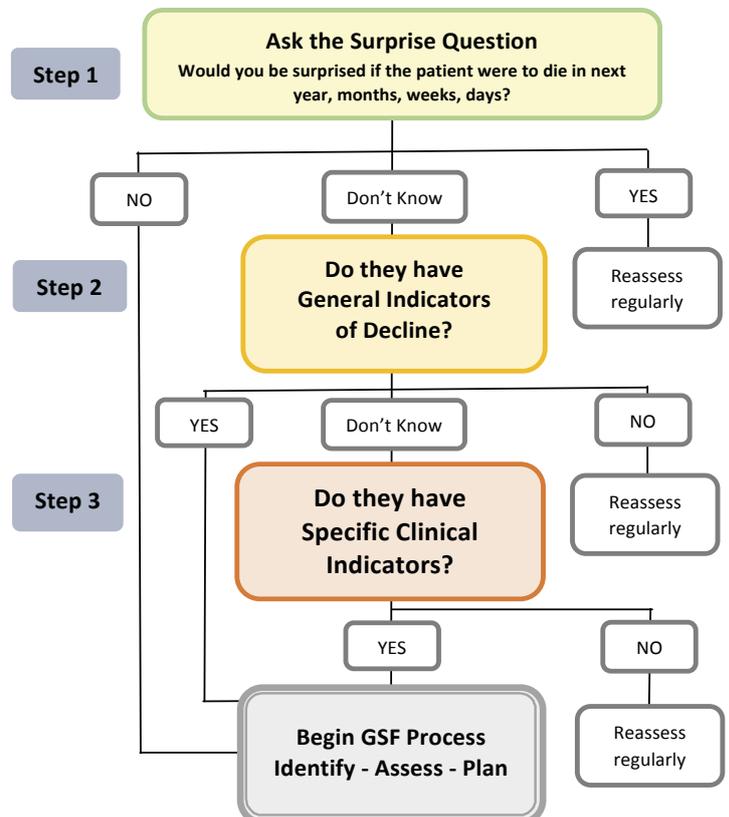
- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life threatening acute conditions caused by sudden catastrophic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

NICE Guidance in End of life care 2011 Quality statement 1

<https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-1-Identification>

- 'Identification – People approaching the end of life are identified in a timely way.
- Systems – Evidence of local systems in place to document identification of people approaching the end of life.'

Proactive Identification Guidance – GSF PIG Flow-chart



The GSF PIG 2016 – Proactive Identification Guidance

Step 1 The Surprise Question

For patients with advanced disease or progressive life limiting conditions, would you be surprised if the patient were to die in the next year, months, weeks, days? The answer to this question should be an intuitive one, pulling together a range of clinical, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

Step 2 General indicators of decline and increasing needs?

- General physical decline, increasing dependence and need for support.
- Repeated unplanned hospital admissions.
- Advanced disease – unstable, deteriorating, complex symptom burden.
- Presence of significant multi-morbidities.
- Decreasing activity – functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day and increasing dependence in most activities of daily living.
- Decreasing response to treatments, decreasing reversibility.
- Patient choice for no further active treatment and focus on quality of life.
- Progressive weight loss (>10%) in past six months.
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home.
- Serum albumin <25g/l.
- Considered eligible for DS1500 payment.

Step 3 Specific Clinical Indicators related to 3 trajectories

1. Cancer

- Deteriorating performance status and functional ability due to metastatic cancer, multi-morbidities or not amenable to treatment – if spending more than 50% of time in bed/lying down, prognosis estimated in months.
- Persistent symptoms despite optimal palliative oncology. More specific prognostic predictors for cancer are available, e.g. PPS.

2. Organ Failure

Heart Disease

At least two of the indicators below:

- Patient for whom the surprise question is applicable.
- CHF NYHA Stage 3 or 4 with ongoing symptoms despite optimal HF therapy – shortness of breath at rest on minimal exertion.
- Repeated admissions with heart failure – 3 admissions in 6 months or a single admission aged over 75 (50% 1yr mortality).
- Difficult ongoing physical or psychological symptoms despite optimal tolerated therapy.
- Additional features include hyponatraemia <135mmol/l, high BP, declining renal function, anaemia, etc.

Chronic Obstructive Pulmonary Disease (COPD)

At least two of the indicators below:

- Recurrent hospital admissions (at least 3 in last year due to COPD)
- MRC grade 4/5 – shortness of breath after 100 metres on level
- Disease assessed to be very severe (e.g. FEV1 <30% predicted), persistent symptoms despite optimal therapy, too unwell for surgery or pulm rehab.
- Fulfils long term oxygen therapy criteria (PaO₂<7.3kPa).
- Required ITU/NIV during hospital admission.
- Other factors e.g., right heart failure, anorexia, cachexia, >6 weeks steroids in preceding 6 months, requires palliative medication for breathlessness still smoking.

Kidney Disease

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least two of the indicators below:

- Patient for whom the surprise question is applicable.
- Repeated unplanned admissions (more than 3/year).
- Patients with poor tolerance of dialysis with change of modality.
- Patients choosing the 'no dialysis' option (conservative), dialysis withdrawal or not opting for dialysis if transplant has failed.
- Difficult physical or psychological symptoms that have not responded to specific treatments.
- Symptomatic Renal Failure in patients who have chosen not to dialyse – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

Liver Disease

Hepatocellular carcinoma.

Liver transplant contra indicated.

Advanced cirrhosis with complications including:

Liver Disease *continued*

- Refractory ascites
- Encephalopathy
- Other adverse factors including malnutrition, severe comorbidities, Hepatorenal syndrome
- Bacterial infection current bleeds, raised INR, hyponatraemia, unless they are a candidate for liver transplantation or amenable to treatment of underlying condition.

General Neurological Diseases

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Symptoms which are complex and too difficult to control.
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure.
- Speech problems: increasing difficulty in communications and progressive dysphasia.

Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments.
- Reduced independence, needs ADL help.
- The condition is less well controlled with increasing "off" periods.
- Dyskinesias, mobility problems and falls.
- Psychiatric signs (depression, anxiety, hallucinations, psychosis).
- Similar pattern to frailty – see below.

Motor Neurone Disease

- Marked rapid decline in physical status.
- First episode of aspirational pneumonia.
- Increased cognitive difficulties.
- Weight Loss.
- Significant complex symptoms and medical complications.
- Low vital capacity (below 70% predicted spirometry), or initiation of NIV.
- Mobility problems and falls.
- Communication difficulties.

Multiple Sclerosis

- Significant complex symptoms and medical complications.
- Dysphagia + poor nutritional status.
- Communication difficulties e.g., Dysarthria + fatigue.
- Cognitive impairment notably the onset of dementia.

3. Frailty, dementia, multi-morbidity

Frailty

For older people with complexity and multiple comorbidities, the surprise question must triangulate with a tier of indicators, e.g. through Comprehensive Geriatric Assessment (CGA).

- Multiple morbidities.
- Deteriorating performance score.
- Weakness, weight loss exhaustion.
- Slow Walking Speed – takes more than 5 seconds to walk 4 m.
- TUGT – time to stand up from chair, walk 3 m, turn and walk back.
- PRISMA – at least 3 of the following:

Aged over 85, Male, Any health problems that limit activity?, Do you need someone to help you on a regular basis?, Do you have health problems that cause require you to stay at home?, In case of need can you count on someone close to you?, Do you regularly use a stick, walker or wheelchair to get about?

Dementia

Identification of moderate/severe stage dementia using a validated staging tool e.g., Functional Assessment Staging has utility in identifying the final year of life in dementia. (BGS) Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score >3

Plus any of the following: Weight loss, Urinary tract Infection, Severe pressures sores – stage three or four, Recurrent fever, Reduced oral intake, Aspiration pneumonia. NB Advance Care Planning discussions should be started early at diagnosis.

Stroke

- Use of validated scale such as NIHSS recommended.
- Persistent vegetative, minimal conscious state or dense paralysis.
- Medical complications, or lack of improvement within 3 months of onset.
- Cognitive impairment / Post-stroke dementia.
- Other factors e.g. old age, male, heart disease, stroke sub-type, hyperglycaemia, dementia, renal failure.

