Lancashire & South Cumbria Medicines Management Group

NHS North West Coast Clinical Networks

Palliative Care Clinical Practice Summary

Guidance on consensus approaches to managing Palliative Care Symptoms

North West Coast Clinical Network

Lancashire and South Cumbria Consensus Guidance

First Published: August 2017
Reviewed: March—October 2021
2nd Edition: November 2021

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Lancashire & South Cumbria Clinical Practice Summary For Palliative Care Symptoms	
Version number:	2.0
Published (first):	25.8.17
Reviewed:	March 2021—October 2021
Approved	24.11.21
Publication Type:	FINAL
Review date:	01.04.2025
Classification:	OFFICIAL

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). These have been reviewed and updated in 2021.

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. 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:

Wilcock A, Howard P, Charlesworth S, (eds) (2020) Palliative Care Formulary, 7th Edition, Palliativedrugs.com Ltd. Nottingham

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

BNF 81 September (2021) BMJ Group and Pharmaceutical Press London

Dickman A, Schneider J (2012) The Syringe Driver. Continuous Subcutaneous Infusions in Palliative Care (4th Edition) Oxford University Press

Lancashire and South Cumbria Consensus Guidance Clinical Practice Summary - August 2017

References

Diabetes end of life guidance 2018

Advance Care Planning

Advance Care Planning—North West Coast initiative
NHS England and NHS Improvement North West » Advance care planning
Deciding Right—North East initiative around Advance Care Planning
http://www.northerncanceralliance.nhs.uk/deciding-right/
North West Anticipatory Clinical Management Planning Guidance including DNACPR

Knowledge Hub around end of life care and medication

Ambitions Learning Hub
http://www.palliativedrugs.com/

NICE guidance

Care of the dying adult in last days of life (2015) www.nice.org.uk/guidance/ng31
Palliative care for adults: strong opioids for pain relief (2016) www.nice.org.uk/guidance/cg140
Neuropathic pain in adults (2020) www.nice.org.uk/guidance/cg173

Covid Guidance

NICE COVID guidance ng191
RCGP Covid-19 latest guidance in your area
APM Covid-19 and Palliative and End of Life Guidance

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 coordination for people in the last months 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 2021—2026 and the 6 key principles.

Each person is seen as an **individual** and
Receives **fair access** to care
We **maximise comfort & wellbeing**
Care is coordinated
All staff are prepared to care
Each **community** is prepared to help

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

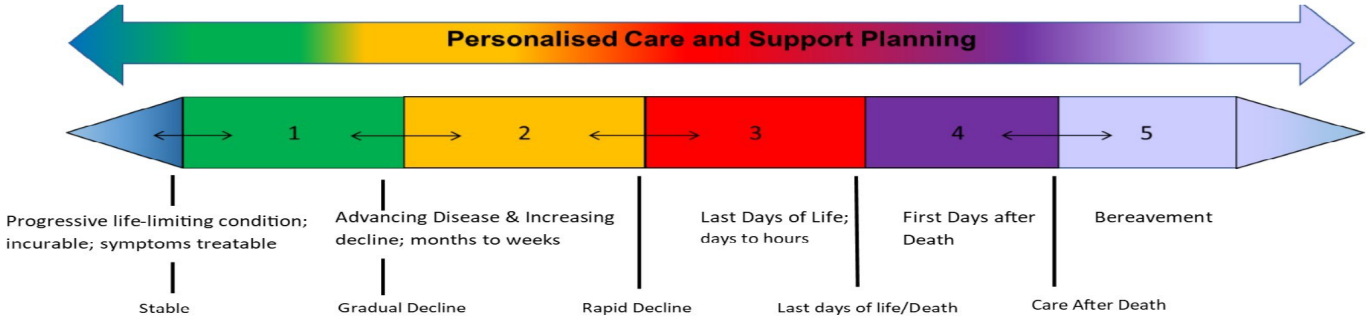
- Preferences and possibilities that could constitute an **Advance Care Plan**
- Sensitive communication about care in the last days of life including Do Not Attempt Cardiopulmonary Resuscitation (**DNACPR**) decisions. Record these decisions and share with key organisations, including Out of Hours care 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) if 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 and 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 and wellbeing 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.
- **Hydration** is not covered in these guidelines; see NICE Guidance **NG31**. Clinically Assisted Hydration at End of Life can be found on page 21.
- **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

North West Model for Life Limiting Conditions

Supporting people to live well in the last years of their life before dying in the place of their choice with peace and dignity; supporting families and carers through bereavement.



Caring for a patient with life-limiting condition is about:

- ◊ Recognition and timely identification of patients with a life limiting illness (Proactive Identification Guidance)
- ◊ The person, their carers and those important to them.
- ◊ Meeting the supportive and palliative care needs for all those with a progressive incurable illness or frailty, to live as well as possible until they die.
- ◊ Support in the last year (s), months and days of life and through to bereavement.

Care should be:

- ◊ Individualised and person-centred; " What matters to me and my priorities"
- ◊ Underpinned by shared decision making that involves the person, and those important to them;
- ◊ Education and empowerment of patients and their carers to support self-care and wellbeing
- ◊ Collaborative, coordinated, and delivered with kindness and compassion;
- ◊ Delivered by a competent, confident and capable workforce
- ◊ Underpinned by continuity of care through good communication across all systems
- ◊ Supported through compassionate communities.

This model gives an overview of the assessment and planning process for patients with a progressive incurable illness or frailty. The Good Practice Guide on page 2 identifies key elements of practice within each phase to promote individualised, personalised care and support planning, with core principles that apply to all phases.

Specialist Palliative Care (SPC) is the total care of patients living with progressive, advanced disease and limited prognosis. The care is provided by a multi-professional team who have specialist palliative care training. SPC includes (but is not limited to) physical, psychological and spiritual assessment and management of symptoms; analysis of complex clinical decision-making challenges applying ethical and legal reasoning alongside clinical assessment; care and support to those important to the person, including bereavement care; specialist advice and support and education and training of the wider care team providing core palliative care.

CORE PRINCIPLES (MAINTAINED FROM STABLE THROUGH TO THE LAST HOURS OF LIFE AND INTO BEREAVEMENT)

- * Communication should be sensitive and unambiguous;
- * Offer an Advance Care Planning (ACP) discussion; personalised care and support plan (PCSP) to be put in place; could include TEP / PPC / ADRT / LPA / Making a will;
- * Needs of those identified as important to the person are explored, respected and met as far as possible;
- * Assessments should be holistic to include physical, psychological, spiritual & social aspects, rehabilitation and quality of life. Review when condition changes or as required;
- * The principles of the Mental Capacity Act 2015 must underpin all practice;
- * Review Prescribing;
- * Access Specialist Palliative Care Services (with consent) when needs or symptoms are difficult to manage.

Stable

- ◊ **Person diagnosed with life-limiting condition; treatable symptoms, but incurable**
- ◊ Supportive care to help prevent or manage adverse effects of disease and/or treatment
- ◊ Offer ACP discussion to put PCSP in place; consider how soon/how likely capacity may be lost; ***may include*** *CPR discussion*
- ◊ Record EPACCS / equivalent, with consent
- ◊ Benefits review for person and carers: e.g. grants, prescription exemption, Blue Badge scheme
- ◊ Consider any possible crises; agree anticipatory clinical plan with the person / those important to them
- ◊ Monitor and support; consider timely referral to other specialist services
- ◊ ICD discussion about possible future deactivation, if applicable

Early Identification guides:

Primary care– EARLY

Care Homes—Six Steps / Shadow NEWS2

Gradual Decline

- ◊ **Person identified as deteriorating despite optimal therapeutic management of underlying medical condition(s)**
- ◊ Exclude reversible causes of deterioration; investigate and treat as appropriate
- ◊ Include on primary care supportive/palliative care register; review regularly
- ◊ District Nurse referral for assessment of care needs (if at home)
- ◊ Consider if the care is still in line with PCSP, or offer an ACP discussion to put PCSP in place; may include TEPs and CPR discussion
- ◊ Record EPaCCS or equivalent, with consent (Data Protection)
- ◊ Share important clinical and social information with all health and social care professionals
- ◊ Benefits review for person and carers: e.g. DS1500, attendance allowance
- ◊ Early identification of symptoms and holistic needs
- ◊ Consider referral to other services based on needs assessment
- ◊ Consider Continuing Health Care Funding
- ◊ ICD discussion, if applicable

Rapid decline

- ◊ **Person identified as in rapid decline despite optimal therapeutic management of underlying medical condition (s)**
- ◊ Exclude reversible causes of deterioration; investigate and treat as appropriate
- ◊ Review at supportive/palliative care meeting
- ◊ Discuss and prescribe anticipatory medication
- ◊ District Nurse referral for assessment of care needs (if at home)
- ◊ Enable rapid discharge to PPC/PPD (if in hospital)
- ◊ Monitor frequently, consider any possible crises; ensure people have contact details of who to call in time of crisis
- ◊ Review, or offer, ACP discussion to put PCSP in place; record EPaCCS or equivalent with consent
- ◊ Consider Continuing Health Care funding
- ◊ Consider DS1500
- ◊ Assessment of equipment needs
- ◊ ICD discussion/deactivation, if applicable
- ◊ CPR considered/discussed; document conversation and decision
- ◊ Share information with OOH/NWAS, include CPR status and ACP; update EPaCCS
- ◊ Refer to other specialist services as needed

Last Days of Life

- ◊ **MDT agree person is in the last days of life—NICE guidance**
- ◊ Exclude reversible causes of deterioration; investigate and treat as appropriate
- ◊ Agree individual plan of care for the dying person, supported by local documentation, coordinated and delivered with compassion; review regularly Priorities for care of the dying person / One Chance to Get it Right
- ◊ Anticipatory medication prescribed and authorized for use by MDT
- ◊ Monitor frequently, consider any possible crises; ensure people have contact details of who to call in time of crisis
- ◊ Implement care of the dying nursing interventions
- ◊ ICD discussion and deactivation, if not previously initiated
- ◊ Community patients: share information about expected death with OOH/NWAS, include CPR status and ACP; update EPaCCS
- ◊ Sensitive communication with carers/family, including what to expect when someone is dying
- ◊ Respect and support cultural/religious faith customs

Care After Death

- ◊ **Verification of death**
- ◊ Medical Certification of death
- ◊ Respect and support cultural/religious faith customs
- ◊ Post death reporting: Notifiable diseases, Significant Event Analysis, Coroner referral
- ◊ Family, carers and those important to the person offered practical and emotional support (signpost to bereavement services)
- ◊ What to do after a death: https://www.gov.uk/when-someone-dies
- ◊ Update supportive/palliative care record and EPaCCS with date and place of death
- ◊ Inform all relevant agencies: CCG, GP, social care, ambulance service, OOH, Specialist Palliative Care Team, Allied Health Professionals, equipment store
- ◊ Timely debrief and identify if staff support required

ACP—Advance Care Planning
ADRT—Advanced Decision to Refuse Treatment
CPR—cardiopulmonary resuscitation
EPaCCS—Electronic Palliative Care Coordination System
ICD—implantable cardioverter defibrillator
LPA—Lasting Power of Attorney
MDT—Multidisciplinary Team
OOH—Out of Hours
NWAS—North West Ambulance Service
PPC / D—Preferred Place of Care / Death
PCSP—Pesonalised Care and Support Plan
TEP—Treatment Escalation Plans

In most cases pain can be improved for patients. If not improving, seek Specialist Palliative Care advice

COMMON TYPES OF PAIN

Visceral / Soft Tissue Pain (nociceptive)
Constant dull pain; Poorly localised
Usually opioid responsive

Bone Pain (somatic nociceptive)
Usually well localised; worse on movement; localised tenderness
Partly opioid responsive; may be NSAID responsive.
If cancer diagnosis radiotherapy or IV Bisphosphonates may help

Nerve Pain (neuropathic)
Try opioids first, but may be less responsive.
Consider adjuvant neuropathic analgesia

WHO STEP 1
Non-Opioids
e.g. Paracetamol 1 g qds PO
+/- ADJUVANT

WHO STEP 2
Non-Opioid plus Weak Opioid
e.g. Codeine 30-60 mg qds PO
+/- ADJUVANT

WHO STEP 3
Non-Opioid plus Strong Opioid
e.g. Morphine
+/- ADJUVANT

ADJUVANTS
- **Neuropathic Pain Agents**
  Gabapentin start 100 mg to 300 mg nocte
  Pregabalin start 25 mg OD or BD
  Amitriptyline 10 mg nocte
  (*starting doses in clinical frailty, requires titration to effects*)
- **Anti-inflammatories** (Ibuprofen 400 mg TDS or Naproxen 500 mg BD or Celecoxib 100—200 mg BD) with food

ALSO

Conventional Opioid Titration
IMMEDIATE RELEASE MORPHINE
(4 hourly duration of action)

Regularly: Morphine Oral Solution 2.5 mg - 5 mg 4 hourly
PRN: Morphine Oral Solution 2.5 mg - 5 mg 1 hourly

If clinically frail or eGFR less than 60ml/min use lower doses or reduced frequency of dose e.g. regularly 6 or 8 hourly.
Assess response of background pain to opioids and if necessary increase dose by 30-50% every 24-48 hours to achieve pain control.
If not seek Specialist Palliative Care advice.

If eGFR less than 30ml/min *see renal failure page 21*
Ensure breakthrough dose of immediate release opioid is also prescribed, roughly 1/6th of the total 24 hour background dose.

When pain controlled on steady dose, convert to sustained release morphine. Calculate total daily dose of 4-hourly immediate release morphine, and divide by two.

SUSTAINED RELEASE MORPHINE
(12 hourly preparation)
Zomorph capsules BD, MST tablets BD, Morphgesic SR BD, Filnarine SR BD
e.g. 5 mg morphine used 4 times = 20 mg oral morphine in 24 hours = 10 mg sustained release morphine (12 hourly) twice a day

Alternative Opioid Titration
SUSTAINED RELEASE MORPHINE
(12 hourly duration of action)

Regularly: Morphine MR 10 mg BD 12 hourly
Zomorph capsules , MST tablets , Morphogesic MR Filnarine SR
PRN: Morphine oral solution 2.5 - 5 mg 1 hourly

Assess response of background pain to opioids and if necessary, increase dose by 30 - 50% every 24-48 hours to achieve effective breakthrough dose – consider co-analgesics.

If clinically frail or eGFR less than 60ml/min use modified release medication with caution. If eGFR less than 30ml/min *see renal failure page 21*

When pain controlled calculate total daily dose of modified release morphine and any immediate release morphine taken in a 24 hour period and divide by 2 to get a 12 hourly dose.

Ensure breakthrough dose of immediate release opioid is also prescribed, roughly 1/6th of the total 24 hour background dose.

If converting from regular codeine to morphine a higher starting does may be appropriate, e.g. if previously taken codeine phosphate 240 mg/24h consider starting morphine MR 20—30 mg BD

ANTICIPATE OPIOID SIDE EFFECTS

Consider co-prescribing regular laxatives
Senna or Docusate as first line; [alternative Co-danthramer or Macrogol]

and consider PRN anti-emetics such as
Metoclopramide 10 mg TDS PO
Or
Haloperidol 500 micrograms - 1.5 mg PO at teatime
Or
cyclizine 50 mg TDS PO
or
levomepromazine 3 to 6 mg PO nocte

Guidance in the Last Days of Life (page 17)

In most cases pain can be improved for patients. If not improving, seek Specialist Palliative Care advice.

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 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 - see page 21)*
- Cognitive impairment, compliance or concordance issues

New prescriptions of Fentanyl patches are not recommended out-of-hours, unless on specialist advice.

Commencing transdermal fentanyl or Buprenorphine patches:

- Do not start if opioid naïve. Titrate 4-hourly immediate release morphine/oxycodone or titrate modified release morphine/oxycodone as above until pain is controlled, and then convert to equivalent strength Fentanyl or Buprenorphine patch (see opioid conversion chart for guidance)
- Remember, a Fentanyl 25micrograms/hour patch is equivalent to a 60-90 mg daily dose of oral morphine and a Buprenorphine 10 micrograms/hr patch is equivalent to 30mg daily dose of oral Morphine.
- Ensure immediate release oral morphine (or oxycodone) is available for breakthrough pain (see opioid conversion chart for guidance)
- Stick patch to dry, hairless skin; clip (do not shave) hair. When changing patches use a new area of skin.
- Fentanyl patches are changed every 72 hours for most patients.
- Buprenorphine patches are changed either every 7 days (Butrans) or every 4 days (Transtec)
- After application, it takes at least 12-24 hours to take analgesic effect and a steady state may not be achieved for 72 hours. Additional PRN doses may be needed for the first few days. When converting from:
  - ◊ 4-hourly oral morphine/oxycodone, give regular doses for the first 12 hours after applying the patch
  - ◊ 12-hourly modified release morphine/oxycodone, apply the patch and give the final modified release dose at the same time
  - ◊ 24-hourly modified release morphine/oxycodone, apply the patch 12 hours after the final modified release dose
- A depot of drug remains in the patch when removed; fold in on themselves and discard safely

Guidance in the Last Days of Life (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 that twice start CSCI in addition to patch
- Ensure PRN dose calculated to reflect total background dose adequate for both patch & CSCI
- **Seek Specialist Palliative Care advice for support if needed**

If eGFR less than 30ml/min see Renal Failure page 21

In most cases 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 120 mg morphine in 24 hours;
- Difficulty in managing pain due to adverse effects of medication or compliance or administration.

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

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

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

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

Start with either an anticonvulsant or an antidepressant and titrate dose as above. Response takes a number of days to become apparent. For common side effects see BNF.

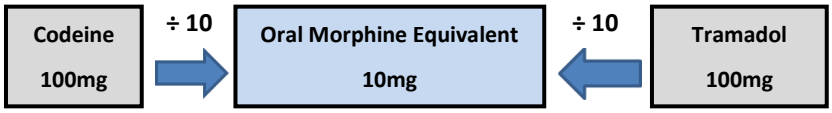
A GUIDE TO EQUIVALENT DOSES OF OPIOID DRUGS

Use the table as a guide (not a set of definitive equivalences) to identify an appropriate starting point for your prescribing decision. **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. For guidance on conversion to a transdermal fentanyl patch see Pg 7. For guidance on conversion to CSCI see Pg 20.

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

Consider prescribed doses of moderate opioids (Codeine and Tramadol). Factor these in when converting to regular morphine (or other strong opioid) or when calculating PRN dosages.



	Morphine (mg)					Oxycodone (mg)					Fentanyl Patch (mcg/hr)	Buprenorphine Patch (mcg/hr)
Route	Oral			SC		Oral			SC			
	24hr total	12hrly MR dose	PRN	CSCI 24h	PRN	24hr total	12hrly MR dose	PRN	CSCI 24h	PRN		
Dose	20	10	3	10	2	10	5	2	5	1	-	-
	30	15	5	15	3	15	*	3	7.5	1	12 micrograms	10 micrograms
	40	20	7	20	3	20	10	3	10	2	-	-
	50	25	8	25	4	25	*	6	13	2	-	20 micrograms
	60	30	10	30	5	30	15	5	15	3	25 micrograms	-
	70	35	12	35	6	35	*	6	18	3	-	30 micrograms
	80	40	13	40	7	40	20	7	20	3	-	-
	100	50	17	50	8	50	25	8	25	4	-	-
	120	60	20	60	10	60	30	10	30	5	50 micrograms	-

Seek specialist advice for higher doses

* When equal divided doses not possible due to tablet strength e.g. Oxycodone 25mg/24hrs . Prescribe equal doses at higher or lower level e.g. 10mg BD or 15mg BD, dependent on clinical judgement *

Manufacturer's ratios (2:1) have been used to convert oral morphine to oral oxycodone and to convert oral oxycodone to SC oxycodone. Experimentally determined ratios (100:1) have been used to calculate opioid equivalent doses for Fentanyl & Buprenorphine transdermal patches

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

Is the patient already established on an anti-emetic?

Yes

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.

No

Initial Treatment

Patients who become nauseated or start vomiting:
For gastritis, gastric stasis, functional bowel obstruction - Prokinetic anti-emetic:
Metoclopramide 10 mg TDS PO/SC or CSCI 30 mg/24 hours [above 30 mg with specialist advice] (*avoid in complete bowel obstruction—see guidance on bowel obstruction). There is an increased risk of neurological adverse effects at doses higher than 30 mg/24hours and if used for longer than 5 days.*

Domperidone 10mg BD - 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

For most chemical causes of vomiting (e.g. medication, hypercalcaemia, renal failure)
Centrally acting anti-emetic:
Haloperidol 500 micrograms - 1.5 mg at bedtime PO/SC or CSCI/24 hours (*monitor for undesirable effects when switching route at higher doses as some patients may require a dose reduction when switching from the oral route to SC)*
Metoclopramide also has a central action.

For vestibular symptoms - anti-emetic acting in vestibular system and vomiting centre:
Cyclizine 50 mg BD - TDS PO/SC or CSCI 75 mg - 150 mg / 24 hours

Sometimes it is necessary to convert to a broad spectrum anti-emetic
Broad- spectrum anti-emetic:
Levomepromazine 6.25 mg PO or 2.5 mg SC at bedtime, or 6.25 mg CSCI/24 hours — to maximum 25 mg/24h

Reversible causes of nausea, vomiting or regurgitation to be considered:

- Medication
- Hypercalcaemia
- Infection
- Constipation
- Reflux/Gastritis
- Uncontrolled pain
- Cough
- Anxiety
- Urinary retention causing renal impairment
- Oral/oesophageal candidiasis

Alternative anti-emetics may be more appropriate in certain circumstances

- **Bowel Obstruction:**

See guidance on bowel obstruction—page 12

- **Parkinson's Disease / Lewy Body Dementia:**

Avoid anti-emetics with a dopamine receptor antagonist effect e.g. haloperidol, levomepromazine and metoclopramide
Domperidone 10 mg BD - TDS PO first line — see caution above

- **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 3.3 mg - 6.6 mg OD - BD
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, use levomepromazine with caution as this can lower the seizure threshold**

- **Severe Heart Failure:**

Levomepromazine 6.25 mg PO or 2.5 mg SC at bedtime, or 6.25 mg – CSCI/24 hours.
Avoid anti-emetics with anti-muscarinic side effects, such as Cyclizine, that may cause tachy-arrhythmias.

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 where appropriate.

Treat reversible causes of breathlessness where appropriate and monitor response
PLUS
Start appropriate non-pharmacological interventions ***(blue box)***

↓

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

↓

If 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 other holistic remedies may help

Pharmacological Options

Opioids: start modified release morphine, e.g. MST or Zomorph at 5mg BD, consider using 2.5mg Immediate Release morphine PRN if needed. Slower titration can be considered with regular IR morphine e.g. 1 - 2.5mg QDS (particularly if concerns about undesirable effects). If opioids help breathlessness, usually only a low dose is needed; usual maximum dose 30mg/24 hours.

If patient is unable to tolerate oral medication sub cutaneous morphine via CSCI is an option.
If eGFR <30 ml/min an alternative opioid should be considered and used with caution in this setting; seek specialist palliative care advice if necessary**.**

Oxygen: In a small number of patients oxygen can be helpful, specifically if people have demonstrable hypoxia and are symptomatic; benefits should be assessed over time

Considerable care should be taken in patients with known COPD/Type 2 respiratory failure—watching for CO_2 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.

Lymphangitis or Superior Vena Caval Obstruction (SVCO): treatment dose of dexamethasone in this setting is 16mg orally or parenterally in one or two divided doses. Please seek specialist advice.

Steroids should ideally be given before 2pm. See page 13 for further advice.

Nebulised medication: Sodium Chloride 0.9% may help as a mucolytic, 2.5 - 5 ml 4 hourly PRN
Consider a bronchodilator for bronchospasm e.g. salbutamol 2.5 mg 6 hourly PRN (may be used more frequently in some cases)

Benzodiazepine can be considered when opioids and non-pharmacological measures have failed to control breathlessness and the patient remains anxious/distressed:
Lorazepam 0.5 - 1mg SL/PO PRN 2-4 hrly (max dose 4mg/24hrs or 2mg/24hrs for frail/elderly). If patient unable to tolerate oral medication, consider subcutaneous midazolam 2.5 mg - 5 mg 4hrly prn.

If effective this can be incorporated into a continuous subcutaneous infusion (CSCI) over 24 hours.

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; review and discontinue any possible contributory medication as appropriate
- Focus on clinical assessment through history; abdominal examination, auscultation and rectal examination when appropriate
- Consider checking 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

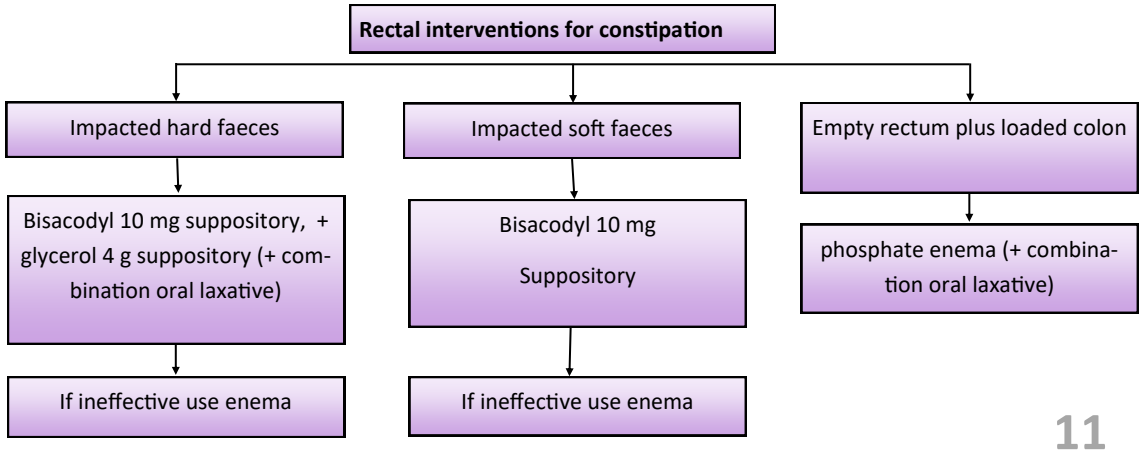
Causes to consider:

- Drug-induced including opioids, diuretics, anti-cholinergics, ondansetron, chemotherapy
- Dehydration
- Review diuretics and fluid intake
- Reduced mobility
- Hypercalcaemia—consider IV fluids and bisphosphonates
- Environmental—lack of privacy
- Concurrent disease
- Altered dietary intake—increase fluid and fibre intake if possible
- Neurological
- Intestinal obstruction
- review meds and de-prescribe as appropriate

- 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.
- Consider bowel regime for Metastatic Spinal Cord Compression
- Enemas including phosphate and sodium citrate versions - follow local guidance.

Treatment and Management : Oral laxatives commonly used in palliative care

Indications (Bristol Stool Chart)	Type of laxative	Drug name	Starting dose	Additional notes
Soft, bulky stools - low colonic activity	Stimulant laxatives *Avoid if possibility of bowel obstruction*	Senna tablets	1-2 tabs at night	Takes 8-12 hours to have effect. May cause abdominal colic.
		Senna syrup	5-10 ml at night	See above—Reduce dose if colic develops.
		Bisacodyl tablets	1-2 tabs at night	
Hard dry faeces	Softener (weak stimulant at higher doses)	docusate sodium	Start at 100 mg BD or TDS	Takes 24-48 hours to have an effect. Mainly acts as softener, but doses over 400 mg may have weak stimulant action. Syrup is available but the taste is unpleasant.
Colon full and colic present	Osmotic laxatives	Macrogols	1—3 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	15 ml BD	Can be associated with flatulence/ abdominal colic. Can take 48 hours to have an effect.
Colon full, no colic	Combination laxatives (stimulant + softening agent)	senna + docusate		Use senna alone initially.
		senna + lactulose		
		co-danthramer suspension	5-10 ml 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.
Hard faeces - colon full		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)
Opioid induced constipation resistant to above methods		Naloxegol	25 mg OD (12.5 mg in frailty)	For opioid induced constipation that has failed to respond to standard measures (oral laxatives and rectal intervention) - seek specialist advice.



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

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 other-wise 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	60 mg - 120 mg	**Do not combine with cyclizine in CSCI as can cause crystallisation**
	Glycopyrronium	600 micrograms - 2.4 mg	Does not crystallise
Reduce volume of gastrointestinal secretions	Octreotide	300 - 600 micrograms. Doses may be increased up to 1.2 mg 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	60 mg - 120 mg	**Do not combine with cyclizine in CSCI as can cause crystallisation**
	Glycopyrronium	600 micrograms - 2.4 mg	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 subcutane-ously BD (in morning)	Given as a single dose or divided into 2 doses (before 2 p.m.) Late administration may cause insomnia /agitation
Reduce nausea and vomiting	Levomepromazine	2.5 mg - 25 mg	May cause sedation. Use the lowest effective dose. Higher doses may cause sedation.
	Metoclopramide *avoid in complete bowel obstruction*	30 mg - 60 mg *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.
	Haloperidol	1.5 mg - 5 mg	Watch for extra-pyramidal side effects. May cause sedation
	Cyclizine *be aware cyclizine is gut slowing*	150 mg	**Do not combine with hyoscine butylbromide in CSCI as can cause crystallisation**
	Ondansetron *Not licenced for SC use*	**seek Specialist Palliative Care advice**	

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 8 mg 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 gastronomies have been shown to be cost effective with low morbidity and mortality.

QUICK GUIDE	CORTICOSTEROIDS IN PALLIATIVE CARE (Follow local guidelines if available)

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. 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 2 p.m. 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: 4 - 8 mg daily.
Obstructive syndromes e.g. bowel obstruction, upper airways compression, SVCO, lymphangitis carcinomatosis: 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 2 p.m. to prevent insomnia.
- Dyspepsia: Give after food. Usual practice would be to co-prescribe a PPI for the duration of the steroids. Be aware that PPIs cause hyponatraemia: to minimise risk of hyponatraemia, preferred PPI would be lansoprazole.
- 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.

Drug interactions: see BNF.
Anti-epileptics: accelerate steroid metabolism so patients may require higher doses of steroids.
Warfarin: steroids alter the metabolism of warfarin increasing INR. Monitor INR more regularly.

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 4 mg/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: Subcutaneous dexamethasone can be used for those patients who are unable to take oral medications but who are benefiting from steroid therapy. In these situations give as a once or twice daily injection, the second dose taken before 2.00pm (to avoid insomnia). Dose calculated based on oral equivalent dose for the indication (as above). The recommended maximum single subcutaneous injection is 2ml.

For patients in the last few hours or days of life, the inability to swallow oral medication is often the factor leading to discontinuation of their corticosteroid treatment. For some individuals e.g. patients with brain metastases and significant symptoms that have benefited from steroid use, it may be appropriate to continue with subcutaneous corticosteroid to maintain symptom management.

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 neutropenic sepsis needs to be suspected in any patients who have had treatment in the last 6 weeks.
SEE LOCAL ACUTE ONCOLOGY GUIDANCE

Early signs
Flu like symptoms
Temperature of 38°C
Rigors

Late signs
Anxiety, confusion
Hypotension
Tachycardia

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, buccal or intramuscular midazolam 5 mg to 10 mg **OR**
  - ◊ Diazepam 10 mg-20 mg rectally

Once settled consider ongoing seizure management with relevant specialists. Other anticonvulsants are available; please seek specialist advice,

IF SEIZURES CONTINUE despite above measures after 10—20 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 has required two or more doses of a benzodiazepine, consider continuous subcutaneous infusion with starting dose of 10-30 mg midazolam over 24 hours. Seek specialist advice if considering other anticonvulsants, if there are ongoing seizures or patient has eGFR <30.

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 16 mg orally or parenterally in one or two divided doses - IMMEDIATELY URGENTLY (ideally the same day) discuss with Oncologist about future management

SYMPTOMS/SIGNS:

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

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.

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

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

SAME DAY- MEDICAL ASSESSMENT

Full history and neurological examination,.

Assess fitness to treat

SAME DAY –CONTACT :-

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

IF SUSPECTED:
- Give dexamethasone 16 mg 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

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

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

MAJOR HAEMORRHAGE

- 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. Consider gauze soaked adrenaline (1in1000) or tranexamic acid for superficial bleeding (apply with pressure 10mins)
- It may be a terminal event in both advanced cancer and non-malignant disease.

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

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 10 mg IM, SC, buccal or sublingual.
- The subcutaneous route may be less affective 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 family and those in attendance
- 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.

QUICK GUIDE	CARE IN THE LAST WEEKS OR DAYS OF LIFE

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 - stop those no longer needed; switch others to a route which ensures they continue and provide benefit
  - Anticipatory prescribing of medication for the common symptoms at end of life (i.e. pain, breathlessness, respiratory tract secretions, agitation, nausea and vomiting) and other problems specific to that individual, such as management of seizures or bleeding, etc.
  - Review ICD / Ventilation

QUICK GUIDE	DIABETES MANAGEMENT IN THE LAST WEEKS OF LIFE
Reference	Diabetes UK (2018) End of Life Diabetes Care: Clinical Care recommendations. For full algorithm please follow link www.diabetes.org.uk/resources-s3/2018-03/EoL_Guidance_2018_Final.pdf - (page 023)

Assessment/Description

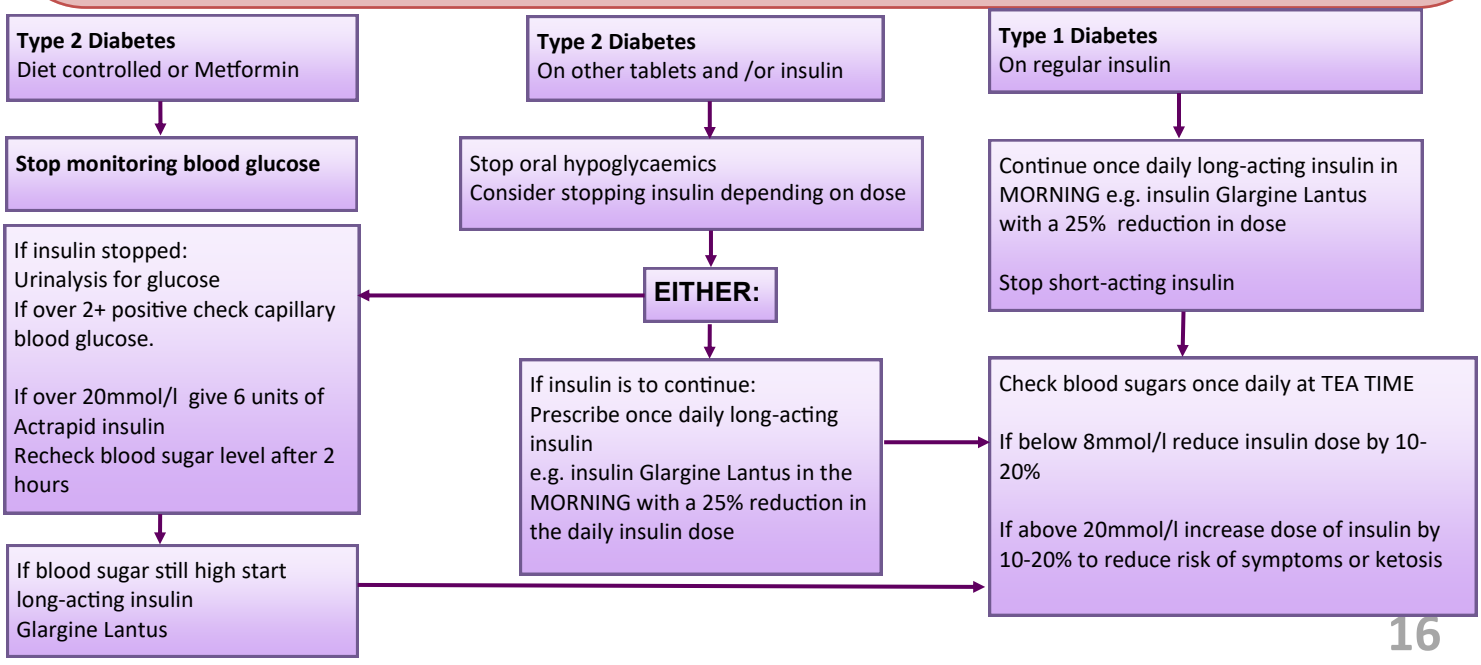
Explore with the individual and those important to them changing the approach to diabetes management including:

- 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:

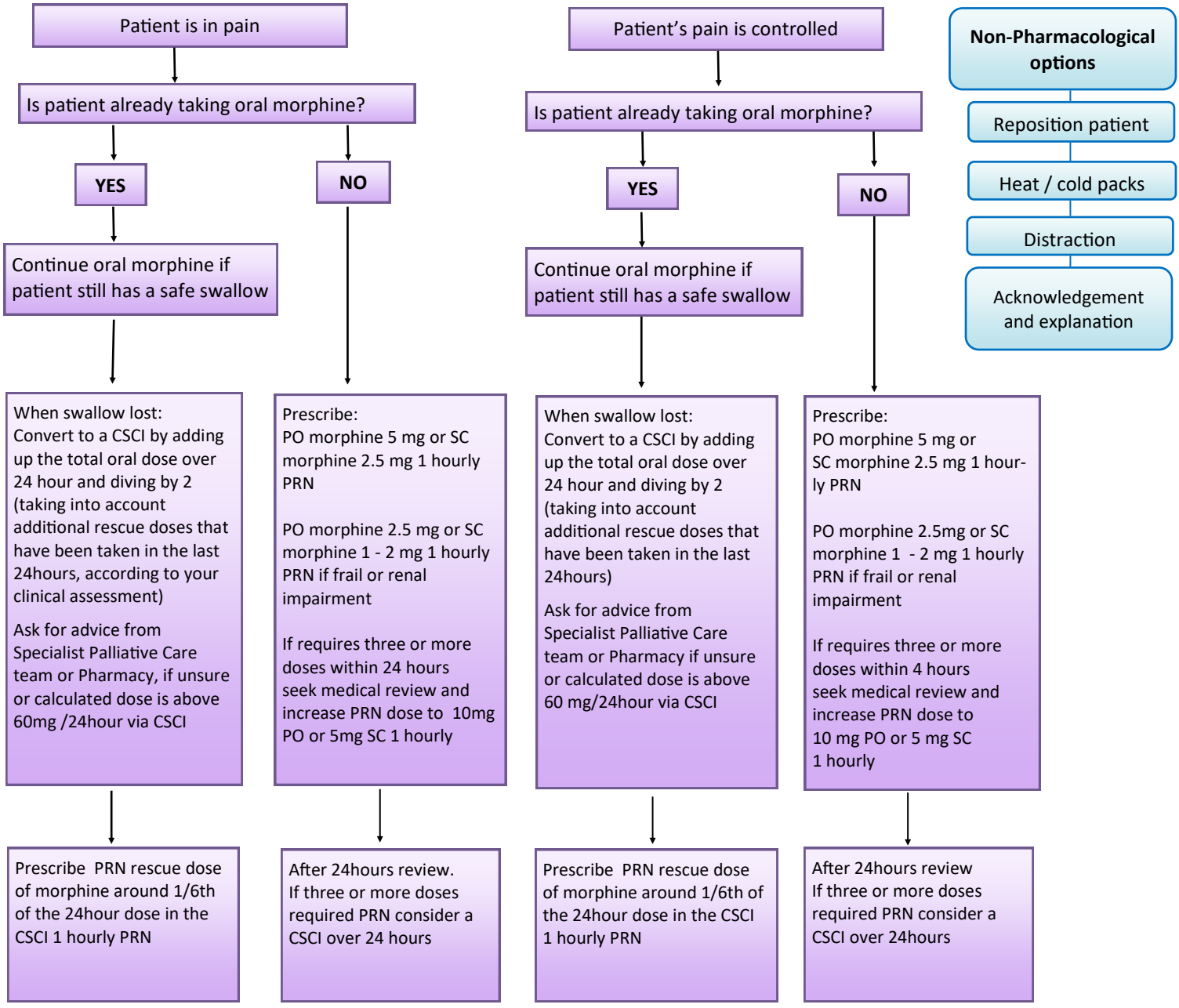
- Keep invasive tests to a minimum
- Be alert to symptoms that may be due to hypo or hyperglycaemia and have appropriate medication / interventions available to address these if they develop

AIM for a Target BM reading between 6 and 15.



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 as usual in last days of life
If pain occurs a rescue dose of an appropriate oral or injectable opioid is administered—see page 8 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 CSCI to work out the new rescue dose (roughly 1/6th 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 | NAUSEA AND VOMITING IN THE LAST DAYS OF LIFE

Assessment/Description
Patient complains of nausea, or is vomiting

Pharmacological Options:

INITIALLY → Levomepromazine 2.5 - 6.25 mg SC 6 hourly PRN (max dose 25 mg / 24 hours). Lower dose may avoid undue sedation in some patients.
See below for alternative anti-emetics.

ONGOING → Continue to use Levomepromazine 2.5 - 6.25 mg SC PRN 6 hourly
Review dosage after 24 hours.
If 2 or more doses given consider a CSCI with 6.25 -12.5 mg over 24 hours.

Alternative anti-emetics include:
- Haloperidol 500 micrograms - 1.5 mg SC PRN 8 hourly (max dose 5mg / 24 hours)
- Cyclizine 50 mg SC PRN 8 hourly (max dose 150 mg / 24 hours)
- Buccastem 3 - 6 mg BD

Nausea and vomiting can be complex to manage - if patient is not settling seek specialist advice.

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).

Non-Pharmacological options

- Reposition patient
- Eliminate known precipitants / strong odours
- Acknowledgement and explanation

QUICK GUIDE | BREATHLESSNESS IN THE LAST DAYS OF LIFE

Assessment/Description
Breathlessness can be really frightening. 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. At the end of life, the aim is for comfort, not to maintain oxygen saturations.
Low doses of opioids are helpful in relieving breathlessness and evidence shows they are better given by continuous infusion (or MR oral medication), than PRN or regular stats. However, opioids can be trialled on a PRN basis and given as a stat dose if a patient is distressed'

Pharmacological Options:

INITIALLY: → If patient not on an opioid regularly:
Morphine 2.5 mg SC 4 hourly PRN. Or 2.5 - 5 mg PO 4 hourly PRN if safe swallow.

ONGOING: → If tolerated, start a CSCI with morphine sulfate 5 -10 mg over 24 hours; alternative opiates e.g. oxycodone can be used as appropriate (seek specialist advice if unsure).

If there is associated anxiety and fear, benzodiazepines such a lorazepam and midazolam can be helpful. Midazolam can be added to the CSCI if required. Sometimes doses as low as 5 mg/24hrs can be helpful. Other patients may require more, and it is essential that we recognise the priority to relieve distress and suffering in patients who are imminently dying, in a proportionate but effective manner.

ONGOING: → Breakthrough doses can be prescribed, such as morphine 2.5 - 5 mg SC PRN 1 hourly and midazolam 2.5 - 5 mg SC PRN 1 hourly.
Seek specialist advice if symptoms remain challenging.

Non-Pharmacological options

- Reposition patient- Sit up / lean forward
- Reassurance and explanation
- Gentle air flow with fan / open window
- Regular mouth care

QUICK GUIDE | RESPIRATORY TRACT SECRETIONS IN THE LAST DAYS OF LIFE

Assessment/Description

At the end of life, people may struggle to clear secretions from their upper airways. This is normal, is usually a sign of diminished consciousness, and many patients will be unaware. Such secretions can make breathing noisy. Acknowledgement and explanation of these noises to those present is important. Sometimes repositioning a patient may help. A pharmacological intervention may not always be necessary. However, it is worth remembering that treating early is often more successful, and medications will not remove existing secretions. Decisions to treat with medication involve the balance of these elements, and should centre around good communication, and an assessment of the discomfort and distress caused to the patient, and to those around them.

Pharmacological Options:

INITIALLY:

Glycopyrronium 200 micrograms SC PRN 1 hourly
or (alternative) hyoscine butylbromide 20 mg SC PRN 1 hourly
Third line option: Hyoscine Hydrobromide 400micrograms SC PRN 1 hourly

ONGOING:

Anti-cholinergics	Dose Range via CSCI/24 hours
Glycopyrronium	600 micrograms to 1.2mg
Hyoscine butylbromide	60mg to 240mg
Hyoscine hydrobromide	1.2mg to 2.4mg (causes sedation)

In significant renal impairment use Glycopyrronium
Seek Specialist Palliative Care advice if patient not settling

- Anti-cholinergic side effects can arise: treat this with frequent mouth care which may include artificial saliva replacement gels or sprays.
- 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.**

Non-Pharmacological options

- Reposition patient
- Active surveillance
- Acknowledgement and explanation

QUICK GUIDE | AGITATION / TERMINAL RESTLESSNESS IN THE LAST DAYS OF LIFE

Assessment/Description

Look for any reversible cause of agitation, such as urinary retention, constipation, pain or fever and, if identified, institute appropriate management plans, (e.g. catheter, enema, analgesia, anti-pyretic PR if not swallowing).

Consider, and where possible, address physical, psychological and spiritual factors as well as environmental factors such as light and noise.

Pharmacological Options:

INITIALLY:

Midazolam 2.5mg - 5 mgs SC up to 1 hourly PRN
If eGFR < 30 consider giving a reduced dose of midazolam, e.g. 1 mg - 2.5 mg SC PRN 1 hourly

DELIRIOUS:

Consider Haloperidol 0.5—1.5 mg SC 2 hourly PRN or
Levomepromazine 6.25mg SC 2 hourly PRN (monitor for extrapyramidal side effects)

If 2 or more doses of medication required to settle the patient in a 24hour period consider setting up a continuous subcutaneous infusion (CSCI)

ONGOING:

Agitation	Dose Range via CSCI/24 hours
Midazolam for agitation	up to 30 mg
Haloperidol for agitation	up to 5 mg
Levomepromazine	up to 25 mg

Seek Specialist Palliative Care advice if doses above 30 mg of midazolam, 5 mg of haloperidol or 25mg of levomepromazine are needed.

QUICK GUIDE	CONTINUOUS SUBCUTANEOUS INFUSIONS (CSCI) - also see local guidelines

Assessment/Description

Continuous subcutaneous infusion (CSCI) are used to administer medication over a 24 hour 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. CSCIs are not just for use in the last days/hours of life. Administering medications via continuous subcutaneous infusion can be effective until oral medications can be tolerated again.

Diluent **Most commonly used** medication in a CSCI should be diluted with **water for injection.** Drugs may be diluted with saline 0.9% except cyclizine or Diamorphine (doses above 40 mg) which should be diluted in water for injection.

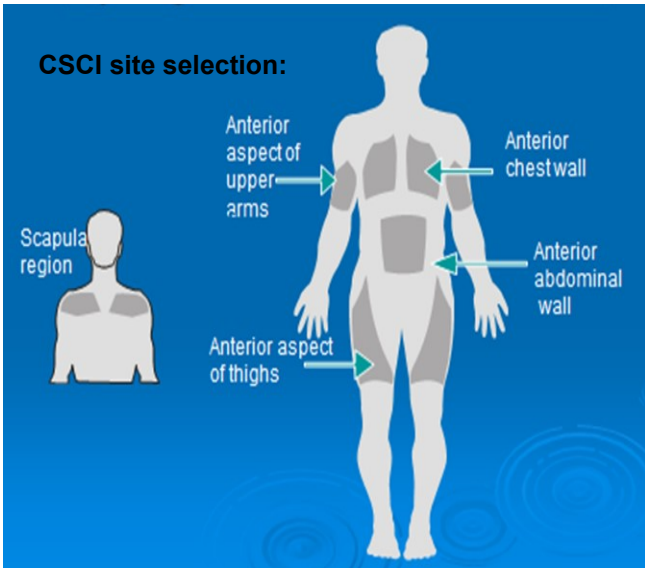
All CSCIs must be serviced regularly according to local guidance and at least annually, whether used or not to ensure their function is maintained. CSCIs should be sent for maintenance checks immediately if they have been dropped, suffered fluid ingress (e.g. had fluid spilt over them or dropped in a 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 CSCIs:

- 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**

How to commence a CSCI

- Explain to the patient and family the reason for the CSCI, how it works and the advantages and disadvantages for the patient
- If the patient has previously taken a regular strong opioid:
  - If symptoms are controlled, start the CSCI 2-4 hours before the next dose of oral opioid would have been given
  - If symptoms are uncontrolled, consider starting the CSCI immediately and give PRN doses of medication at the same time
  - Drugs are usually more bio-available by injection than orally. Generally, the dose of strong opioid in a CSCI should be half of the total oral daily dose
  - Seek advice if considering converting a transdermal patch to CSCI



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

SIGNIFICANT RENAL IMPAIRMENT - SEEK SPECIALIST PALLIATIVE CARE ADVICE

- Paracetamol at standard doses is safe in renal impairment
- **If the eGFR is below 30ml/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 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 60ml/min the dose and/ or frequency may need to be reduced to avoid toxicity. **See BNF for doses.**
- **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
- The use of benzodiazepines should be reduced in cases of renal impairment. See seizure management section.

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 emotive topics for families and patients when approaching the end of life. There is a 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 (IV) 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 IV route and may be provided in multiple care settings. 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

Potential complications

Line discomfort/infection
Oedema/ascites/effusions
Worsening secretions
Increased symptom burden as a result of above
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).

If CAH is given in the last days of life review the risks and benefits every 12 hours, as per NICE guidance.

The Gold Standards Framework Proactive Identification Guidance (PIG)

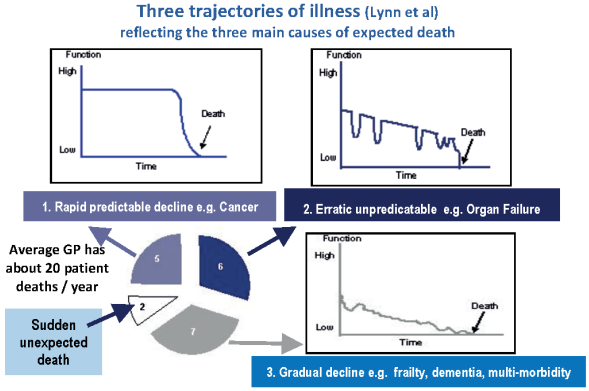
The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life leading to improved proactive person-centred care

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

Identify
patients who may be in their last year of life and identify their needs-based code/stage

Assess
current and future, clinical and personal needs

Plan
living well and dying well

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:

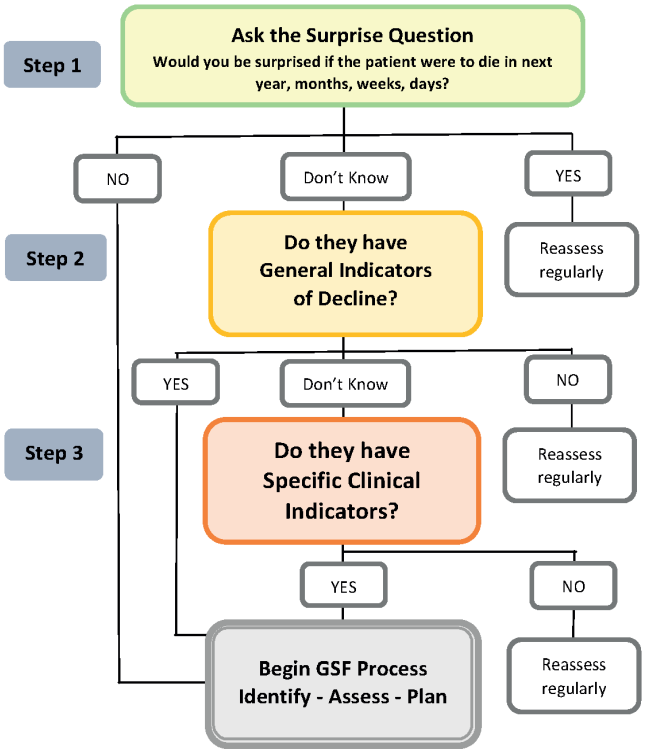
- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life threatening acute conditions caused by sudden catastrophic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

Acknowledgements:

With thanks to the multidisciplinary task and finish group who undertook a collaborative review of the Lancashire and South Cumbria Consensus Guidance in 2021, with support from the North West Coast Palliative and End of Life Care Clinical Network.

◊ Jayne Denney, Clinical Nursing Lead for Palliative and EoLC (community), University Hospitals of Morecambe Bay NHS Foundation Trust

◊ Sarah Price, Consultant in Palliative Medicine, University Hospitals of Morecambe Bay NHS Foundation Trust

◊ Andrew Fletcher, Consultant in Palliative Medicine, St Catherine's Hospice, Preston

◊ Martin Davidson, Consultant in Palliative Medicine, Trinity Hospice, Blackpool

◊ Josephine Candlin, Head of Nurse Specialists, St John's Hospice, Lancaster

◊ Maria Debattista, Consultant in Palliative Medicine, Lancashire Teaching Hospitals NHS Foundation Trust

◊ Anna MacPherson, Consultant in Palliative Medicine, East Lancs Hospital Trust

◊ Claire Capewell, Consultant in Palliative Medicine, St Catherine's Hospice, Preston

◊ Adam John Grainger, Senior Medicines Performance Pharmacist – Lancashire | Medicines Management

◊ Kath Davies, Clinical Network Coordinator, North West Coast Palliative & End of Life Care Clinical Network

Glossary of Terms:

CAH	Clinically assisted hydration
CSCI	Continuous subcutaneous infusion
DNACPR	Do not attempt cardiopulmonary resuscitation
EPaCCS	Electronic Palliative Care Coordination Systems
ICD	Implantable Cardioverter Defibrillator
ICP	Intracranial Pressure
SVCO	Superior Vena Caval Obstruction