

Palliative Care Clinical Practice Summary

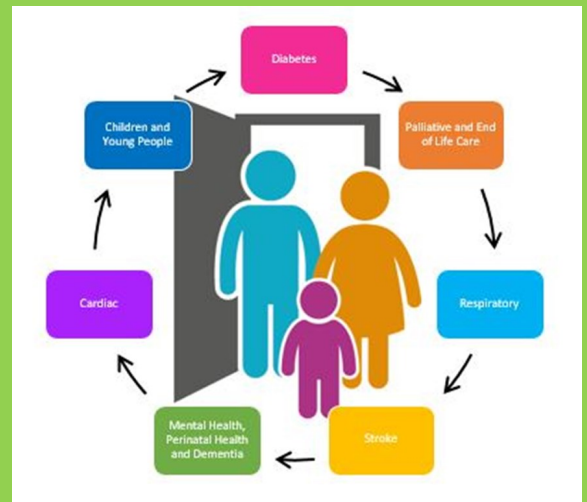
Generalist guidance on consensus approaches to managing Palliative Care Symptoms

North West Coast Clinical Network

Consensus Guidance for Cheshire & Merseyside and Lancashire & South Cumbria

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CONTENTS

Guidance	Page
Background and resources	3
Introduction & aide memoire	4
North West Model for Life Limiting Conditions and Good Practice Guide (2-page revised model 2021)	5
Symptoms:	
Pain	6 / 7 / 8
Complex pain & equivalent dose guide	9
Nausea & Vomiting	10
Breathlessness	11
Constipation	12
Bowel Obstruction	13
Corticosteroids in Palliative Care	14
Palliative care Emergencies:	
Neutropenic sepsis, Seizures, Superior Vena Caval Obstruction	15
Spinal cord compression, Major haemorrhage	16
Hypercalcaemia	17
Care in last weeks or days of life:	
Key priorities & Diabetes management	18
Pain in last days of life	19
Nausea & Vomiting, Breathlessness in last days of life	20
Respiratory tract secretions , Agitation in last days life	21
Continuous Subcutaneous Infusions (CSCI)	22
THEME – Renal Failure, Clinically Assisted Hydration in last weeks of life	23
Proactive Identification Guidance (PIG) Gold Standards Framework 6th edition , Alternative: The Supportive & Palliative Care Indicators Tool (SPIC TM) http://www.spict.org.uk	24 / 25
Acknowledgements and Glossary of terms	26

Disclaimer

The intended audience using this consensus guidance are those working outside of speciality palliative care. The authors cannot be held responsible for any liability incurred as a consequence of the use or application of any contents of this consensus guidance. Recommendations contained in this consensus guidance cannot be appropriate for every situation and so professionals using this book should make their own decisions regarding safe and appropriate patient care.

The editorial team make no representation, express or implied, that the drug dosages in this book are correct. Readers must therefore always check the product information and data sheets provided by the manufacturers and the most recent codes of conduct and safety regulations. Mention of specific product brands does not imply endorsement.

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These practice summaries are a place to begin and the intended audience is those working outside of specialist palliative care. 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

The North West Coast Clinical Practice Summary has been reviewed and updated in 2025. The 2025 updated guidance is based on previous editions developed in 2012 and reviewed in 2014, 2017 and 2021 separately in LSC and C&M and latterly across the North West Coast.

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)

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

BNF 88 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 - November 2021

Palliative Care Formulary (PCF)

Bowers B., Pollock K., Polak L., Barclay S. (October 2023) Enhancing Anticipatory Prescribing in End of Life Care BMJ [Anticipatory Prescribing at the End of Life](#)

<https://rightdecisions.scot.nhs.uk/shared-content/palliative-care-syringe-pumps/compatibility-and-stability-tables-for-subcutaneous-infusion-using-syringe-pumps-syringe-drivers/>

References

[End of Life Care \(November 2021\) | Diabetes UK](#)

[UKONS Acute Oncology Initial Management Guidelines :: UK Acute Oncology Society](#)

[Scottish Palliative Care Guidelines | Right Decisions](#)

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](#)

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

Introduction and Aide Memoire

These easy reference guidelines are based on guidelines from Merseyside & Cheshire Palliative Care Network Audit Group , Northern England SCN (2016), Lancashire & South Cumbria Palliative Care Prescribing(2014), North West Coast Clinical Practice Summary published 2017 and reviewed in 2021. All medication doses are cross referenced against the Palliative Care Formulary (PCF).

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 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

Anticipatory prescribing offers an opportunity to have a conversation, through shared decision making, with the person and those important to them. Ensure you have considered the following:

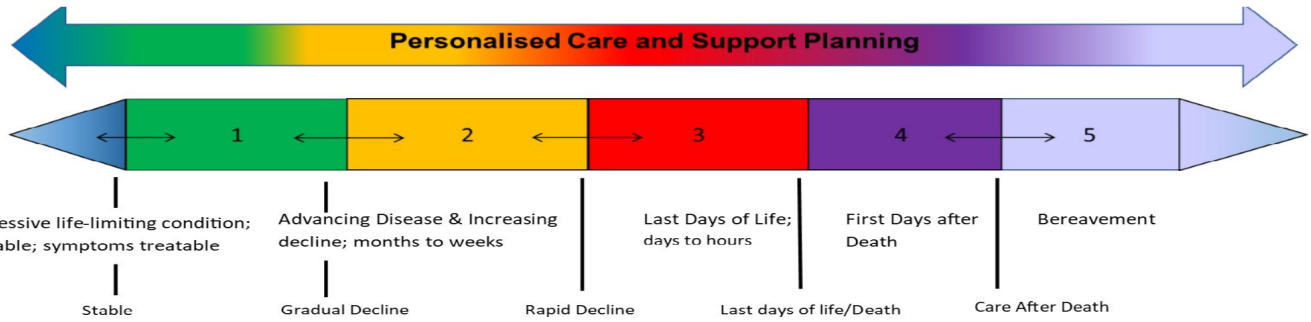
- Preferences and possibilities that could constitute an **Advance Care Plan**
- Sensitive communication about care in the last days of life including Do Not Attempt Cardiopulmonary Resuscitation (**DNACPR**) decisions. Record these decisions and share with key organisations, including Out of Hours care 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 [P23](#).
- **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	Gradual Decline	Rapid decline	Last Days of Life	Care After Death
<ul style="list-style-type: none"> ◊ 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 <p>Early Identification guides: Primary care— EARLY Care Homes—Six Steps / Shadow NEWS2</p>	<ul style="list-style-type: none"> ◊ 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 	<ul style="list-style-type: none"> ◊ 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 	<ul style="list-style-type: none"> ◊ 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 	<ul style="list-style-type: none"> ◊ 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

EPaCCS—Electronic Palliative Care Coordination System

MDT—Multidisciplinary Team

PPC / D—Preferred Place of Care / Death

ADRT—Advanced Decision to Refuse Treatment

ICD—implantable cardioverter defibrillator

OOH—Out of Hours

PCSP—Personalised Care and Support Plan

CPR—cardiopulmonary resuscitation

LPA—Lasting Power of Attorney

NWAS—North West Ambulance Service

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

(usually no role for weak opioids in managing cancer pain; proceed directly from step 1 to step 3 (PCF 8 p 376 and 378)
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** - SEE BOX ON [PAGE 8](#)
- **Anti-inflammatories:** Celecoxib 100-200mg BD (usually the preferred choice due to lower risk of GI bleeding unless the patient has significant cardiovascular disease) or Ibuprofen 400mg TDS or Naproxen 500mg 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 P23](#)
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, Morphesic 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
PRN: Morphine oral solution 2.5 - 5 mg 1 hourly (alternatives include Actimorph and Sevredol)

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 P23](#)

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 previously taking Codeine Phosphate 240mg/24 hours consider starting Morphine MR 10 mg BD, ensuring Codeine is stopped.

**ANTICIPATE
OPIOID
SIDE EFFECTS**

Consider co-prescribing regular laxative (needed by almost all patients on regular opioids)
[P12](#)

Consider PRN anti-emetics
[P10](#)

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 P23](#)
- 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 seven days or every four days depending on the brand and strength. Always check before prescribing.
- 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

If pain is escalating and already on opioid patch seek SPC advice early before increasing the dose. Buprenorphine doses above 20 mcg may not be suitable for uncontrolled pain in palliative setting.

[Guidance - Care in the Last Days of Life \(P18\)](#)

- 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 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 P23](#)

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

- Complex, multiple pain 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 – seek Specialist Palliative Care advice if the stated maximum dose is reached and is ineffective.

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—wean down the dose and stop if no response after 2 months. Maximum dose 60 mg BD

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.

If no apparent response seek advice from Specialist Palliative Care.

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 from Specialist Palliative Care

Consider if it could be appropriate to add or increase the dose of adjuvant medication(s) before changing to a different strong opioid or changing the route of delivery. For guidance on conversion to a transdermal fentanyl patch see [Pg 7](#). For guidance on conversion to CSCI see [P22](#).

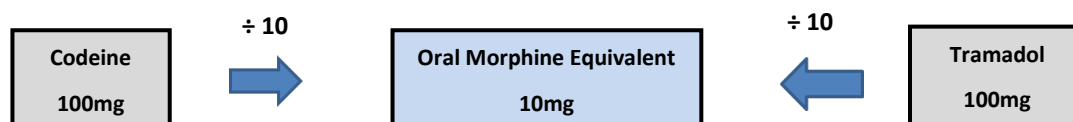
Consider reducing prescribed opioid dose by 30-50% if converting from one strong opioid to another or changing the route the strong opioid is delivered by (e.g. oral to subcutaneous) or there is concern about opioid toxicity (confusion, drowsiness, myoclonic jerks, slowed respiration).

If there is evidence of **severe opioid toxicity**, e.g. slowed respiration seek **URGENT SPECIALIST ADVICE**.

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

Consider prescribed doses of weak opioids (Codeine and Tramadol). Factor those in when converting to regular morphine (or other strong opioid) or when calculating PRN dosages. The table below is based on the manufacturer's ratio of 2:1 for the conversion of oral morphine to oral oxycodone and oral oxycodone to subcutaneous oxycodone.

Published studies and bioavailability data suggest this ratio is closer to 1.5:1, which practitioners may see advised elsewhere, including the BNF. The 2:1 ratio is advised here as it is simple and safe for most of these conversions, which are between oral morphine and oral oxycodone and oral oxycodone and subcutaneous oxycodone.



If eGFR less than 30ml/min [see Renal Failure P23](#)

Use this table as a guide when converting oral MR opioids to SC or converting from Morphine to either Oxycodone, Fentanyl patches or Buprenorphine patches. **DO NOT** use for other opioid conversions.

Always go to and from total oral morphine equivalent dose when converting between opioids

Morphine (mg)				Total Oral Morphine Daily Dose (mg)	Oxycodone (mg)			
Sub-Cutaneous		Oral			Oral		Sub-Cutaneous	
S/C PRN Dose	S/C over 24hrs	PO PRN Dose	PO MR Dose (every 12hrs)		PO MR Dose (every 12hrs)	PO PRN Dose	S/C over 24hrs	S/C PRN dose
1-2.5	10	2.5-5	10	20	5	2.5	5	1
2.5	15	5	15	30	*	2.5	7.5	1-2.5
2.5-5	20	7.5	20	40	10	2.5-5	10	1-2.5
5	25	7.5-10	25	50	*	5	12.5	2.5
5	30	10	30	60	15	5	15	2.5
5-7.5	35	10-12.5	35	70	*	5-7.5	17.5	2.5-5
7.5	40	15	40	80	20	7.5	20	2.5-5
7.5-10	50	17.5	50	100	25	7.5-10	25	5
10	60	20	60	120	30	10	30	5

Seek specialist advice for higher doses or for conversion of opioids from the subcutaneous route to oral.

* 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 *

Total Oral Morphine Daily Dose (mg)	Buprenorphine Transdermal Patch (Micrograms/hr)	Fentanyl Transdermal Patch (Micrograms/hr)
12	5	
24	10	
30		12
36	15	
48	20	
60		25
84	35	
90		37.5
120		50
126	52.5	
Always seek specialist advice before titrating opioids above this level; pain is often poorly responsive to opioids and alternative analgesics may be required. (BNF, 2025)		
168	70	
180		75
240		100

Transdermal Patch

Opioid Equivalents

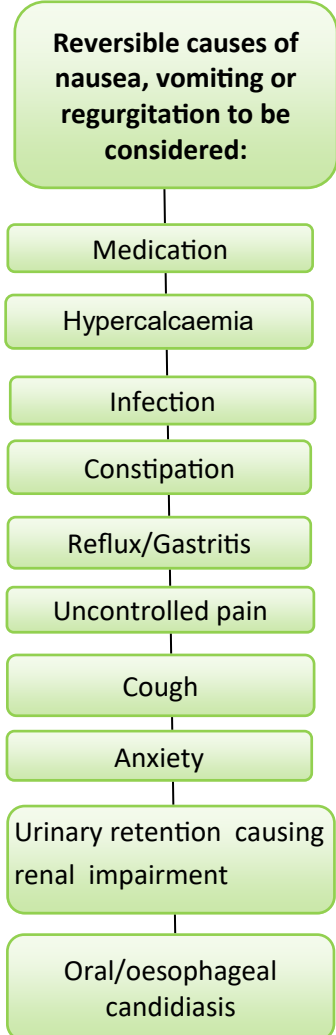
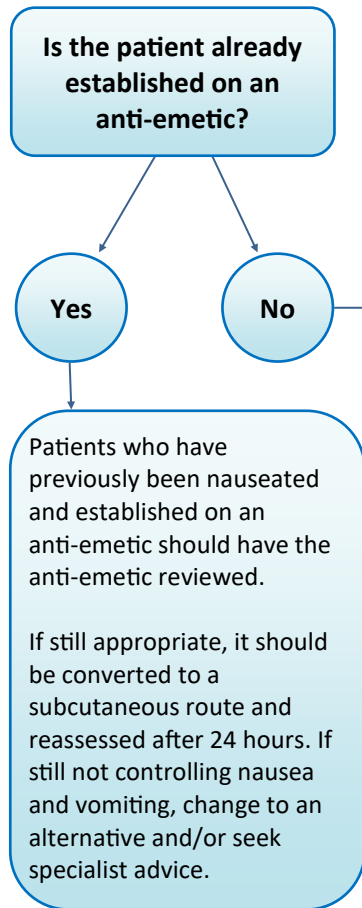
Please note that these equivalent doses are approximations. Individual patient factors should be taken into account when making conversion decisions.

A variety of formulations of buprenorphine and fentanyl patches are available. Patches should therefore be prescribed by brand, dose and duration to avoid confusion.

PRN doses should be based on the approximate total 24hr oral morphine equivalent. For suggested doses see the equivalence table above.

Figures are based on the Palliative Care Formulary 8th edition and BNF, 2025

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:

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 (not available SC)
 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 can be titrated up to 5 mg (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 - 6.25 mg SC at bedtime
 or 6.25 mg CSCI/24 hours — to maximum 25 mg/24h
 or Olanzapine 2.5 - 5 mg at bedtime PO - **should be started under specialist advice**

Alternative anti-emetics may be more appropriate in certain circumstances

- **Bowel Obstruction:**
 See guidance on [bowel obstruction P13](#)
- **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
 If SC route required: Cyclizine 50 mg BD/TDS or CSCI 75 - 150 mg/24 hours
- **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 tachyarrhythmias.

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.

Pharmacological Options

Opioids: start modified release morphine 5 mg 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 CO₂ retention headache, flushed skin, fast pulse, hand flap, drowsiness, etc.

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

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 P14](#) 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)

Benzodiazepines 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.

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

Description: Constipation is a symptom and can have various reasons. It is the passage of small, hard faeces infrequently or with difficulty (often involving straining), and less often than is normal for that individual. There can be a sensation of incomplete emptying or anorectal blockage. Constipation can cause unpleasant symptoms such as abdominal and rectal pain, distension, nausea and vomiting, and other negative effects on the patient’s wellbeing.

Assessment:

- Palliative care patients might have many reasons for developing constipation - try to identify and treat contributing factors (see box below)
- Take history: normal and current bowel habit (frequency, consistency, ease of passage, blood present, pain on passing stool); current and previous laxatives taken and their effectiveness; current drug history; clinical features (such as pain, nausea, vomiting, overflow diarrhea, urinary retention)
- Examination: abdominal and rectal or stomal examination, unless it would cause undue distress to patient. Gain consent for the examination
- To exclude bowel obstruction and to assess extent of faecal loading, an abdominal x-ray may be needed
- Oral laxatives should be reviewed every 3 to 4 days using stool consistency chart (e.g. [Bristol stool chart](#))

Goal of management:

- To achieve comfortable defaecation
- Prevention is the best management of constipation—all patients prescribed an opioid should be prescribed a stimulant laxative
- 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:

- Medication: opioids, diuretics, anti-cholinergics, ondansetron, chemotherapy, iron, antacids
⇒Review and de-prescribe as appropriate
- Secondary effects of illness: dehydration, immobility, change in diet, anorexia
- Hypercalcaemia
⇒Check Calcium level, if present see page 14
- Damage to spinal cord (incl MSCC), cauda equina or pelvis nerves
- Tumor in, or compressing, bowel wall
⇒see page 12 for bowel obstruction
- Concurrent disease such as diabetes, hypothyroidism, diverticular disease, anal fissure, haemorrhoids, Parkinson’s disease, hypokalemia

General advice for management:

- Encourage good oral fluid intake (2 litres per day if able) and review dietary intake
- Ensure patient has privacy and access to toilet facilities
- Encourage daily exercise according to ability
- Address any reversible factors contributing to the constipation
- Titrate laxative dose according to individual response
- Use oral laxatives 1st line
- Some palliative care patients need rectal measures, either because of failed oral treatment or electively (e.g. frail bedbound patients, patients with paralysis)
- Rectal measures should be avoided, where possible, in patients who are neutropenic and thrombocytopenic, because of risk of infection or bleeding

- **In Metastatic Spinal Cord Compression** develop individualised bowel regime, seek specialist advice. For compression at T6 or above, please be aware of autonomic dysreflexia and follow local guidance
- **Opioid-induced constipation** not responding to the above measures: peripherally acting μ opioid receptor antagonists (PAMORAs) can be considered, please seek specialist advice
- **For enemas** including phosphate and sodium citrate versions - follow local guidance.

Laxative	Dosage
First Line (stimulant ± softener)	For patients with established constipation, it is usually most effective to combine faecal softeners and stimulant laxative. <ul style="list-style-type: none"> • Stimulant e.g. <ul style="list-style-type: none"> ⇒ Senna 15mg at night (can be increased to 30mg in divided doses) OR Bisacodyl tablets 5 to 10mg at night • Stool softener e.g. <ul style="list-style-type: none"> ⇒ Docusate Sodium 100mg bd, if necessary increase to 200mg bd If significant colic occurs, discontinue stimulant and try a softener instead.
Second Line (osmotic laxative)	If first line is ineffective and patient able to tolerate consider: <ul style="list-style-type: none"> • Macrogol (for example Laxido), 1 to 3 sachets daily If severe constipation, consider a higher dose for 3 days
In patients with established or severe constipation considering introducing rectal treatments early.	
Rectal treatment	Rectal intervention should be guided by the findings on rectal examination. <ul style="list-style-type: none"> • <u>Soft loading</u>: Bisacodyl 10mg suppository. If ineffective, use enema • <u>Hard loading</u>: Glycerol 4g suppository (as lubricant) + Bisacodyl 10mg suppository. If ineffective use enema • <u>If very hard loading</u>: arachis oil enema (except in those with nut allergy) overnight, followed by phosphate enema

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.

Refer early to Specialist Palliative Care to help manage this complex symptom.

Common symptoms: abdominal pain, abdominal colic, nausea and vomiting (often large volume, faeculent material), constipation, no flatus, abdominal distention.

- The diagnosis is made clinically, confirmed with imaging where appropriate.

Management: An individualised approach to management is recommended for each patient and specialist palliative care advice should be sought.

- Consider if there are any surgical interventions possible: malignant bowel obstruction is often multi-level and may not be amenable to surgery.
- Consider whether the obstruction is partial or complete.
- Treat constipation if appropriate.

Initial Management

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

Dietary considerations:

- Resting the GI tract for several days may allow an obstruction to settle spontaneously—consider IV/SC fluids if appropriate
- If taking diet orally, advise small amounts of low residue fluids and foods, consider resting bowel if symptoms worsen

Laxatives:

- Stimulant laxatives should be avoided. Stool softeners e.g. docusate may be appropriate.

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	60 mg - 120 mg	Do not combine with cyclizine in CSCI as can cause crystallisation
	Glycopyrronium	600 micrograms - 1.2mg	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 - 1.2mg	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 2 p.m.). Late administration may cause insomnia / agitation
Reduce nausea and vomiting	Levomopromazine	2.5 mg - 25 mg	May cause sedation. Use the lowest effective dose. Higher doses may cause sedation.
	Metoclopramide <i>avoid in complete bowel obstruction</i>	30 mg - 60 mg <i>There is an increased risk of neurological adverse effects at doses higher than 30mg/24hour and if used for longer than 5 days.</i>	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 <i>be aware cyclizine is gut slowing</i>	150 mg	Do not combine with hyoscine butylbromide in CSCI as can cause crystallisation
	Ondansetron	8—12 mg	Be aware can cause QT prolongation

Symptom Control

Subcutaneous Medication Recommended

Pain:

- **Constant pain:** Opioid analgesia
- **Colic:** -Discontinue prokinetic drugs e.g. metoclopramide, senna, bisacodyl
-Commence anti-spasmodic e.g. **hyoscine butylbromide**

Nausea:

- Anti-emetics should be administered via the subcutaneous route.
- **Levomopromazine** recommended first line
- Prokinetics are contraindicated in complete bowel obstruction.

Vomiting

- Patients experiencing large volume vomiting should be prescribed anti-secretory treatment.
- **Hyoscine butylbromide** can be use first line.
- **Octreotide** can also be use first line where rapid relief is required.
- Octreotide can be used alongside hyoscine butylbromide for patients who have colic but require additional antisecretory medication.

Interventions

Wide bore Nasogastric Tubes: Consider for patients with upper gastrointestinal obstruction or large volume vomiting.

Venting Gastrostomies: Consider for patients with malignant bowel obstruction who have a prognosis of greater than 2 weeks.

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 by subcutaneous injection may be considered equal to 4mg taken orally.

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: 4mg daily. Short courses (≤ 2 weeks) are recommended to reduce risk of side effects, consider other options before steroid trial. Consider treatment of any reversible causes (constipation, nausea, delayed gastric emptying). Counsel regarding small, frequent, palatable meals.

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 carcinomatosa: 8 - 16mg daily.

Spinal cord compression: Commence on 16mg daily (can be given in divided doses prior to 2pm after initial dose) and liaise with oncology. See [P16](#) for more information on spinal cord compression.

Brain metastases: 4-8mg daily for mild symptoms. For severe symptoms or at risk of herniation, doses of 16mg daily are recommended. Ideally reduce the dose after 1 week and discontinue after 2-4 weeks or to lowest effective maintenance dose. Continue dexamethasone for 1 week post whole brain RXT then taper over 2-4 weeks. Consider trial of dose increase if symptoms recur.

ADVERSE EFFECTS: (multiple—see BNF for full details. Drug interactions: see BNF):

- **Adrenal suppression:** see box below for withdrawal considerations. Patients taking 2mg daily dexamethasone or more for 4 or more weeks will need a temporary increase in steroid dose if there is any significant intercurrent illness, trauma or surgery; see national NPSA guidance for details.
- **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 and risk of GI bleed:** Give after food. Usual practice would be to co-prescribe a PPI for the duration of the steroids.
- **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. Consider the balance of potential benefit vs. risk.

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 6mg Dexamethasone or more for more than 1 week
- Risk of recurrent severe symptoms
- Repeated courses of steroids
- Other possible causes of adrenal suppression

Depending on other symptoms and the reason for taking steroids, the daily dose can be reduced rapidly (e.g. halving dose) to 2mg/day, then more slowly e.g. by 0.5-1mg weekly in order to prevent acute adrenal insufficiency or withdrawal symptoms. **Steroid treatment card: Patients on systemic steroids for > 3 weeks must be given a steroid treatment 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. **If ongoing symptomatic benefit is unlikely, it may be appropriate to discontinue steroids abruptly at this point.**

SEIZURES

ACUTE SEIZURES

Initial management 0 to 5mins

- Ensure airway secure and administer oxygen if available
- Check BM and treat hypoglycaemia

First line treatment 5 to 15minutes

• If seizure does not stop within 5 minutes give either Subcutaneous, intranasal, buccal or intramuscular Midazolam 5 to 10mg

OR Diazepam 10 mg to 20 mg rectally

- Observe for 5 minutes and readminister if seizure continues. *If seizure stops consider ongoing seizure management, seek specialist advice especially if already on antiepileptic medication*

Second line treatment 15mins onwards

- Decide if transfer to hospital for emergency management is needed or if care will continue in the current care setting

Last days of life If the 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.

Not in last days of life Seek specialist advice. Drug should be chosen based on diagnosis, previous antiepileptic therapy, comorbidity and drug interactions.

- If patient is not currently on antiepileptic medication and you are not able to access specialist advice in a timely manner, consider commencing levetiracetam.
- The dose of levetiracetam is adjusted according to creatinine clearance. There is a caution for use in patients with QT interval prolongation.

For all patients: Continue to administer midazolam (buccal subcutaneous, intranasal or intramuscular midazolam 5 to 10mg) to terminate breakthrough seizures.

Refractory Seizures

If seizures continue despite second line therapy, the patient is considered to have refractory status epilepticus and mortality rates are high. Seek advice from specialists in neurology, palliative medicine, or critical care.

Treating underlying cause

Consider reversible causes of seizures and commencing dexamethasone for intracranial oedema associated with brain metastases.

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

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

SYMPTOMS/SIGNS:

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

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.

If haematological diagnosis or new presentation, discuss with haematology urgently.

Treat breathlessness and other symptoms as per guidance.

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 or if develops new or sudden escalation in back pain
- 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 COORDINATOR at Oncology centre to discuss case
Lancashire and South Cumbria: 01772 716565 Or Bleep 2664
CCC MSCC coordinator: 07854 312049 (08.00-20.00), out of hours on call Registrar 0151 556 5000 bleep 9104 [MSCC Pathway](#)
The Christie MSCC coordinator M—F 9—5 0161 466 3000 via switchboard.
Out of hours on call hotline via switchboard (above) ask for on call clinical oncology specialist trainee or 0161 446 3658

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

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 **within 24 hours**—follow local processes including referral to MSCC co-ordinator

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

Continue 16mg dexamethasone daily and review post-treatment

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

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. 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.

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 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 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.

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 $>2.7\text{mmol/L}$ (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. Ambulatory or home treatment may be available in some areas.

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 adjusted calcium, urea and electrolytes (U&Es), phosphate and magnesium and liver function tests (LFT's). Check Vit D and PTH in patients presenting for the first time.

REVIEW MEDICATIONS: Stop calcium supplements, vitamins A and D and calcium antacids . Suspend NSAIDS, ARBs, ACEi and diuretics for 48 hours as these can worsen renal injury. If patient takes lithium inform their psychiatrist that the patient is being treated for hypercalcaemia. If patient takes thalidomide and antiangiogenic medication liaise with haematology/oncology.

TREATMENT:

May require in-patient unit care in hospital or hospice. Ambulatory or home treatment may be available in some areas.

- 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 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.
- Bisphosphonate dose should be adjusted according to creatinine clearance and is contraindicated if $\text{CrCl} < 30$
- Denosumab is an off-label treatment for hypercalcaemia that can be used instead of bisphosphonates in patients whose CrCl is < 30 or in patients with hypercalcaemia that is resistant to bisphosphonate treatment.
- A rare but serious side effect of bisphosphonates and denosumab is osteonecrosis of the jaw and risk should be minimised and patient counselled.

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
- Discuss with the individual and those important to them the recognition of dying

INVOLVE:

- The patient and all relevant people in making decisions as far as the dying person indicates they want them to be involved

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
 - * - 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 DAYS OF LIFE

Reference

End of Life Diabetes Care: Clinical Care recommendations [Diabetes guidance](#)

Assessment/Description

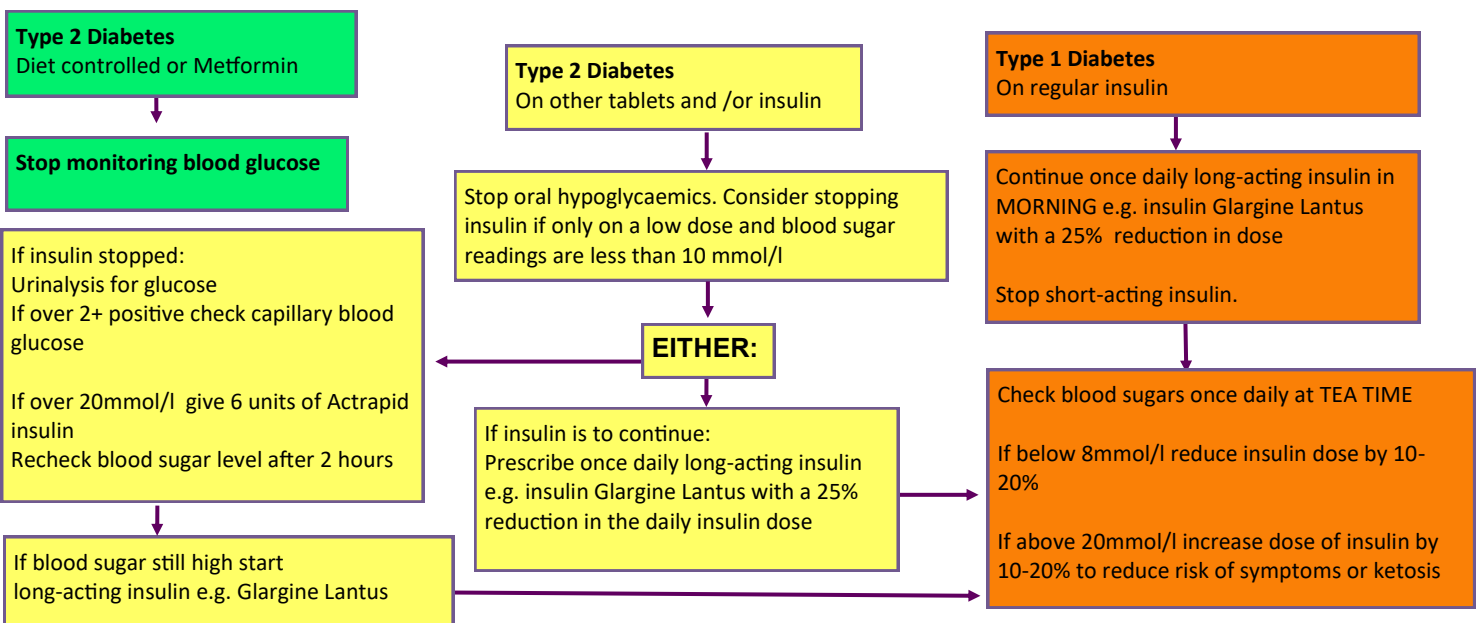
Explore with the individual and those important to them changing the approach to diabetes management including:

- 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. Consider involvement of your local diabetes specialist team if the patient remains on insulin. Aim to:

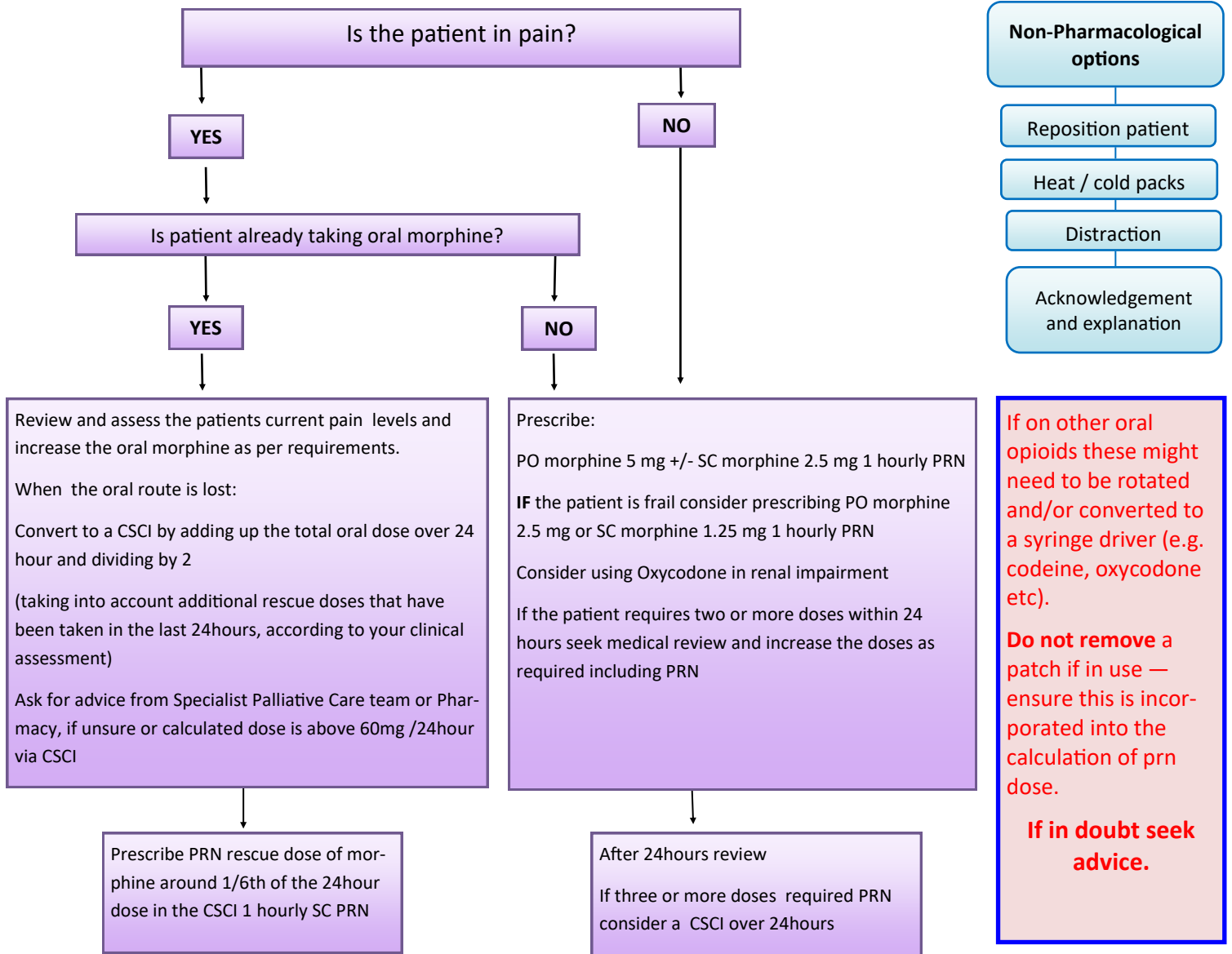
- Keep invasive tests to a minimum
- Be alert to symptoms that may be due to hypo or hyperglycaemia and have appropriate medication / interventions available to address these if they develop

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 eGFR < 30 or there is a morphine intolerance, use oxycodone.
- If the eGFR is < 10 seek specialist advice.
- If patient has been well established on an alternative opioid such as oxycodone continue it.
- 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.



ADDITIONAL INFORMATION

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

It is not recommended to commence transdermal preparations where there is loss of route in the last days of life. It is recommended that existing 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 P9](#) 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

Pharmacological Options:

INITIALLY

Levomopromazine 2.5 - 6.25 mg SC 4 - 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

Review dosage after 24 hours. If 2 or more doses given consider a CSCI with 6.25 -12.5 mg over 24 hours. Maximum dose 25 mg/24 hours.

Non-Pharmacological options

Reposition patient

Eliminate known precipitants / strong odours

Acknowledgement and explanation

Alternative anti-emetics include:

Haloperidol 500 micrograms - 1.5 mg SC PRN 8 hourly (max dose 5 mg/24 hours)

Cyclizine 25 - 50 mg SC PRN 8 hourly (max dose 150 mg/24 hours)

Metoclopramide 10 mg SC PRN 6 hrly (max 30 mg/24hrs)

Raised intracranial pressure due to brain metastases may cause nausea and/or vomiting that might respond to high dose steroids 4 mg - 8 mg SC OD (equivalent to 3.3mgs - 6.6mgs dexamethasone base).

Nausea and vomiting can be complex to manage and it is not unusual for more than one anti-emetic to be needed - **if patient is not settling seek specialist advice.**

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. In the last days 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. **If the patient is already on opiates you may need to seek specialist advice.**

Pharmacological Options:

INITIALLY:

If patient not on an opioid regularly:
Morphine 2.5 mg SC 1 hourly PRN. Or 2.5 - 5 mg PO 1 hourly PRN if safe swallow.
If anxiety a significant problem also prescribe Midazolam 2.5-5mg PRN 1 hourly.

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). Occasionally a higher starting dose may be needed and please seek specialist advice.

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.

Non-Pharmacological options

Reposition patient- Sit up / lean forward

Reassurance and explanation

Gentle air flow with fan / open window

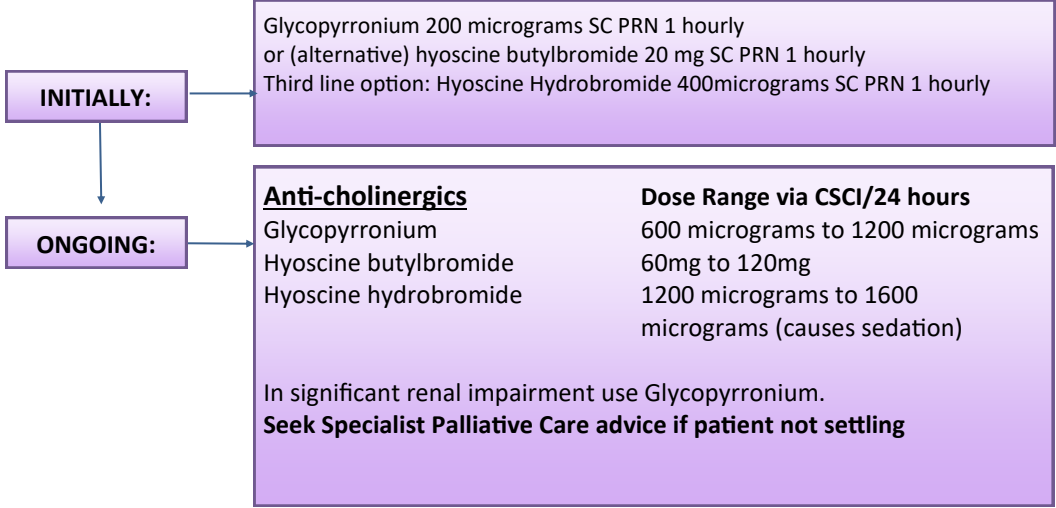
Regular mouth care

Seek specialist advice if symptoms remain challenging

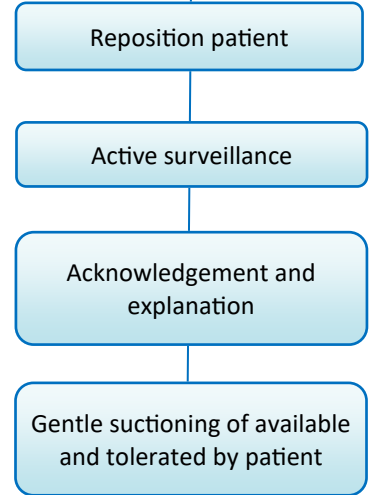
Assessment/Description

In the last days 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:



Non-Pharmacological options



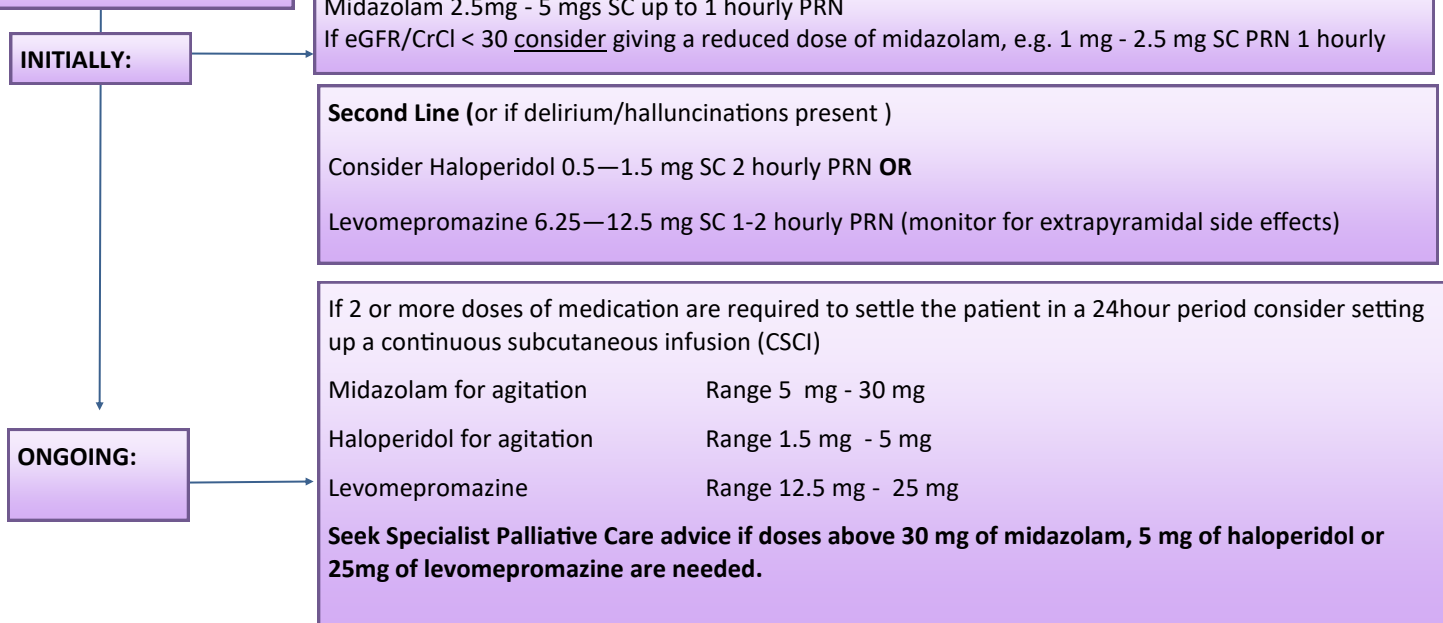
- Anti-cholinergic side effects can arise: treat this with frequent mouth care which may include artificial saliva replacement gels or sprays.
- If one agent doesn't work, try switching to the other after full titration to maximum dose over 24 hours; if there is still no improvement, consider stopping medication.
- Seek Specialist advice as required.
- **Hyoscine hydrobromide crosses the blood brain barrier and causes sedation.**

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:



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. Not all medications are compatible together in a CSCI. Water for injection is generally used as the standard diluent, although there are occasions where alternatives may need to be used. Always check the compatibility of combination and diluent in the [relevant reference sources](#).

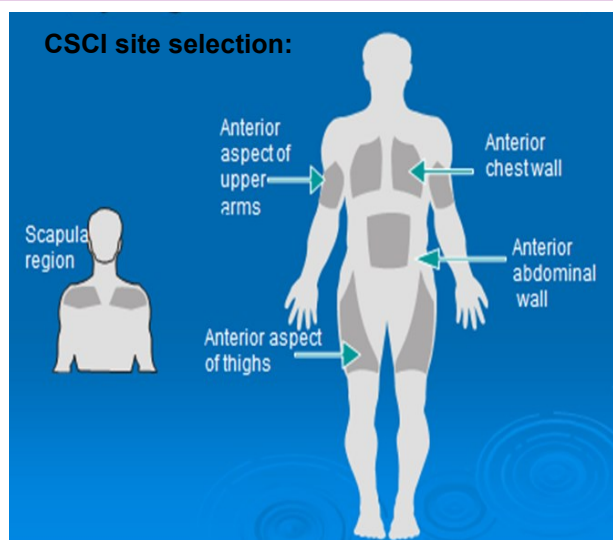
All CSCIs must be serviced regularly according to local guidance and at least annually, whether used or not to ensure their function is maintained. CSCIs should be sent for maintenance checks immediately if they have been dropped, suffered fluid ingress (e.g. had fluid spilt over them or dropped in a 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
- **Please check compatibility when using multiple medications. If in doubt seek specialist advice**
- Ensure battery life has been checked before the commencement of the syringe pump (as per local policy)

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 - [see P7](#)

**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 CrCl 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](#).

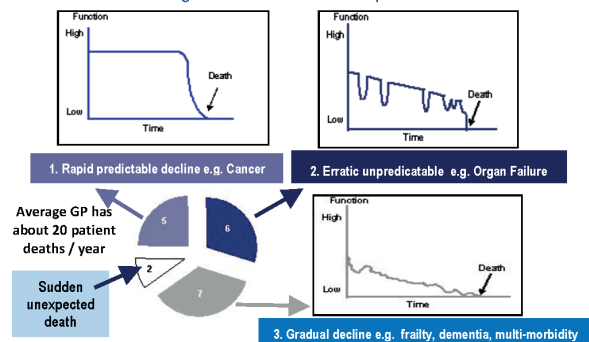
The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life leading to improved proactive person-centred care

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.

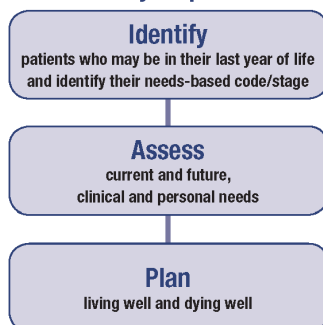
Three trajectories of illness (Lynn et al) reflecting the three main causes of expected death



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:

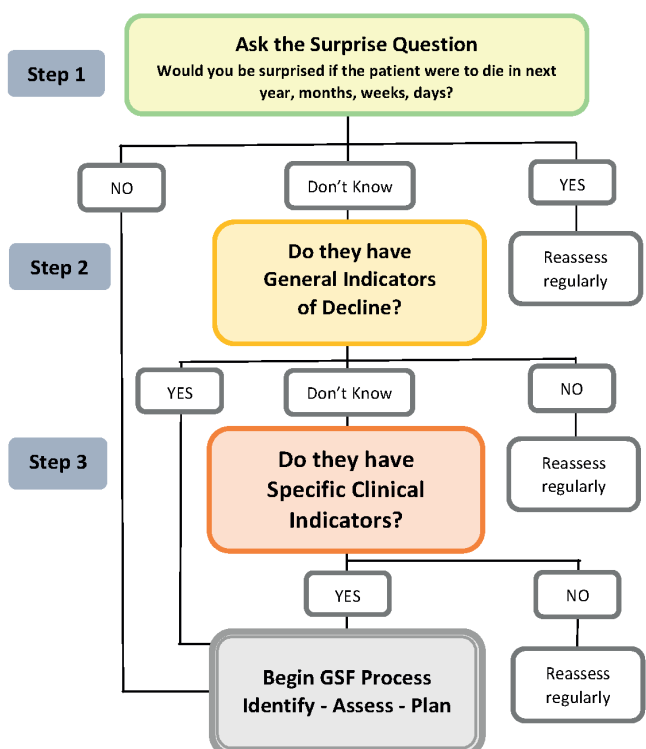
- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life threatening acute conditions caused by sudden catastrophic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

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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
SC	Subcutaneous