



Palliative Medicine Refresher

Pennine GP Learning Group

14.11.2023

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Consultant in Palliative Medicine, Overgate and CHFT

Agenda

- Symptom control
 - Analgesia
 - Nausea and vomiting
 - Steroids
 - Breathlessness
 - Anticonvulsants
- Documentation
 - NEW – community palliative MARS chart (“pink chart”)
 - OOH palliative care handover form
 - ReSPECT
 - SR1 – online
- Emergencies in palliative medicine
- Hot Topics
 - Substance misuse and last weeks of life
 - Day Hospice Services

Symptom control - Analgesia

- Mary – 74yo
- Non-small cell lung cancer with liver metastases
- Hx COPD
- Starting to get abdominal pain – generalised, not colic, not constipated
- Paracetamol 1g QDS regular (wt>50kg)
- What next?

Doses and titration

Co-codamol

30/500 ii QDS regular

- 240mg codeine / 24hrs
- Oral morphine equivalent = 24mg/24hrs
- **No upward titration**

Oral morphine solution

2-4mg PRN

- x6/24hrs max = 24mg max
- ?tests if tolerates
(peaks/troughs → **side effects/pain**)

Fentanyl Patch

12 micrograms/hr

~ 45 mg /24 hrs oral morphine

~ **double max Co-codamol**

Buprenorphine patch

15 micrograms/hr

~26mg oral morphine/24 hrs

Slow to titrate

Morphine sulphate modified release

10mg BD

- Equivalent of 200mg codeine/24 hrs
- Scope to **titrate / faster** titration

Doses and titration

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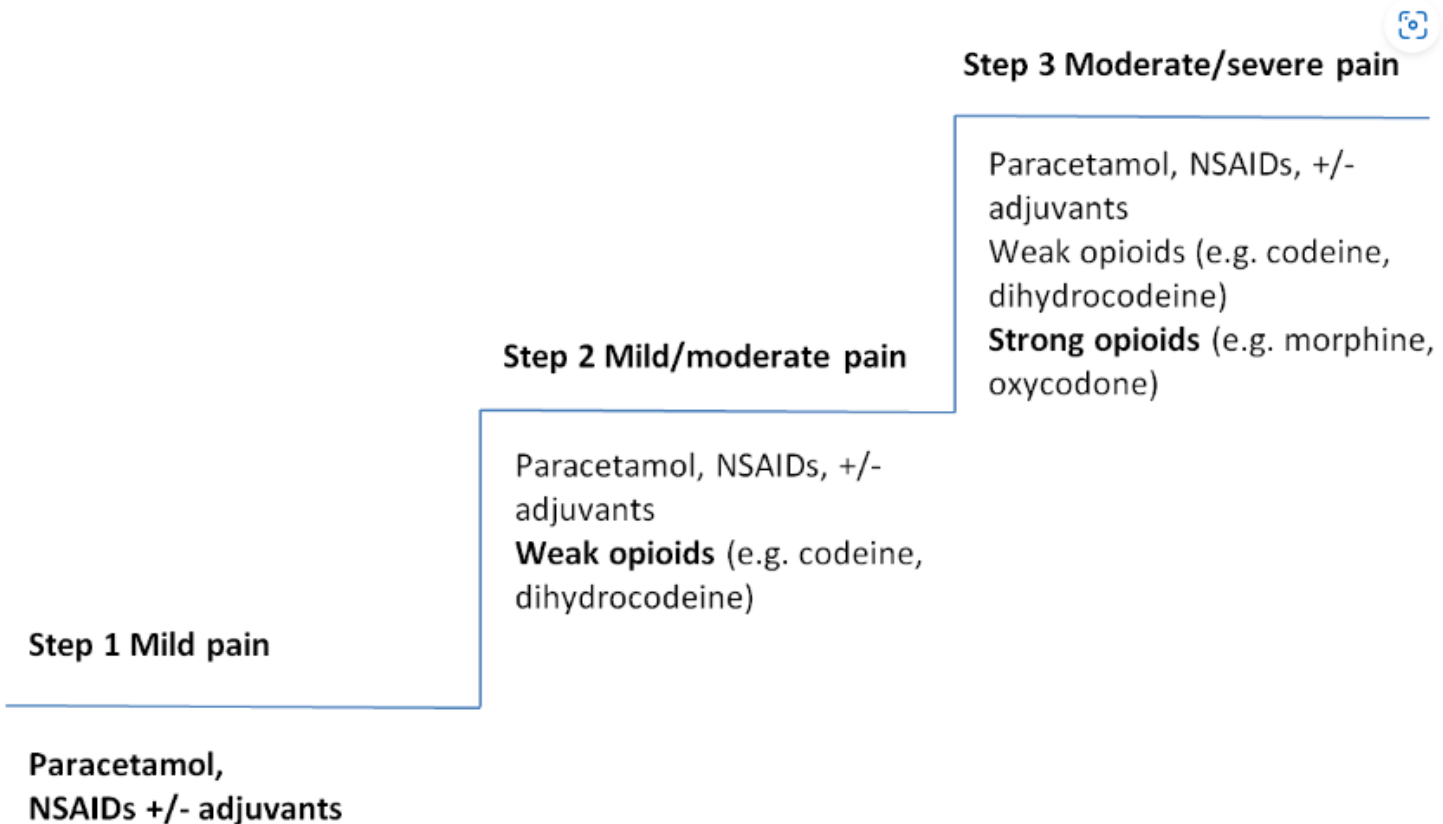
Slow to titrate

Morphine sulphate modified release

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- Scope to titrate / faster titration

Analgesic ladders



WHO pain ladder

By the ladder, by mouth, by the clock

Co-codamol

30/500 ii QDS regular

- 240mg codeine / 24hrs
- Oral morphine equivalent = 24mg/24hrs
- No upward titration

3 step ladder

By the ladder, by mouth, by the clock

2 step ladder

Fentanyl Patch

12 micrograms/hr

~ 45 mg /24 hrs oral morphine

~ double max Co-codamol

Buprenorphine patch

15 micrograms/hr

~26mg oral morphine/24 hrs

Slow to titrate

By the ladder, by mouth, by the clock

Oral morphine solution

2-4mg PRN

- x6/24hrs max = 24mg max
- ?tests if tolerates
(peaks/troughs → side effects/pain)

2 step ladder

By the ladder, by mouth, by the clock

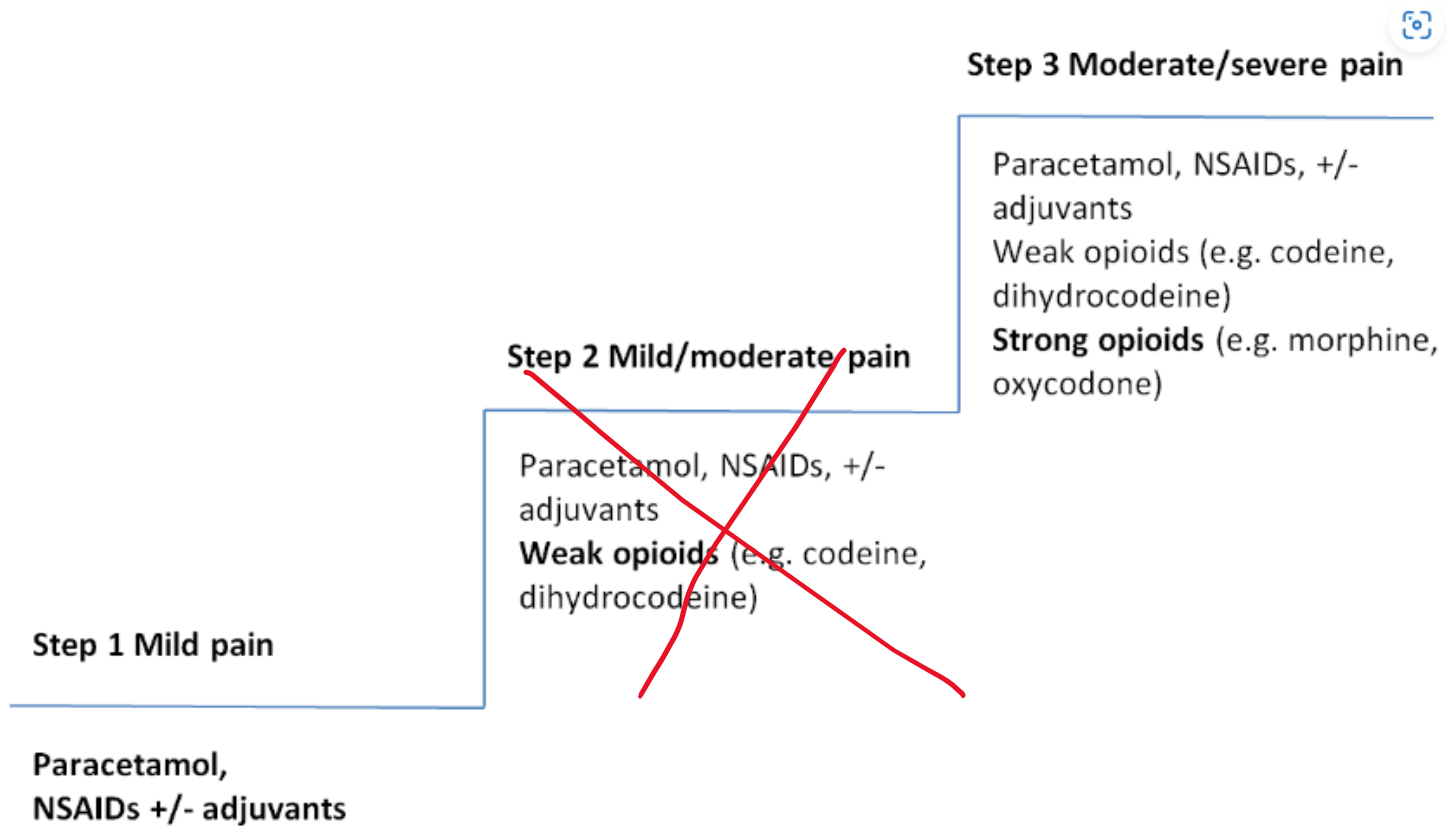
2 step ladder

Morphine sulphate modified release

10mg BD

- Equivalent of 200mg codeine/24 hrs
- Scope to **titrate** / **faster** titration

Analgesic ladders



WHO pain ladder

Use a 2-step analgesic ladder?

- Bandieri E et al 2016. Randomized trial of low-dose morphine versus weak opioids in **moderate cancer pain**. *Journal of clinical oncology* **34**:436-442

- n=240

- Primary**

Outcome:

number of patients who had a reduction of pain intensity of 20% on a numerical rating scale

Outcome	Morphine	Weak opioid
20% reduction in pain ($p < 0.001$, difference seen by 1/52)	88%	58%
30%+ reduction in pain ($p < 0.001$)	83%	47%
50%+ reduction in pain ($p < 0.001$)	75%	42%
Trial drop out due to side effects/intolerance	N=5	N=5
Median Edmonton Symptom Assessment System score ($p < 0.001$)	10	19

By the ladder, by mouth, by the clock

2 step ladder

Morphine sulphate modified release

10mg BD

- Equivalent of 200mg codeine/24 hrs
- Scope to **titrate** / **faster** titration

Titration, PRNs, conversions

Increasing background
dose

~ 1/3-1/2 of 24-hour background

PRN

~ 1/6th of 24-hour background dose

Dose conversions:

Overgate Opioid Conversion Chart

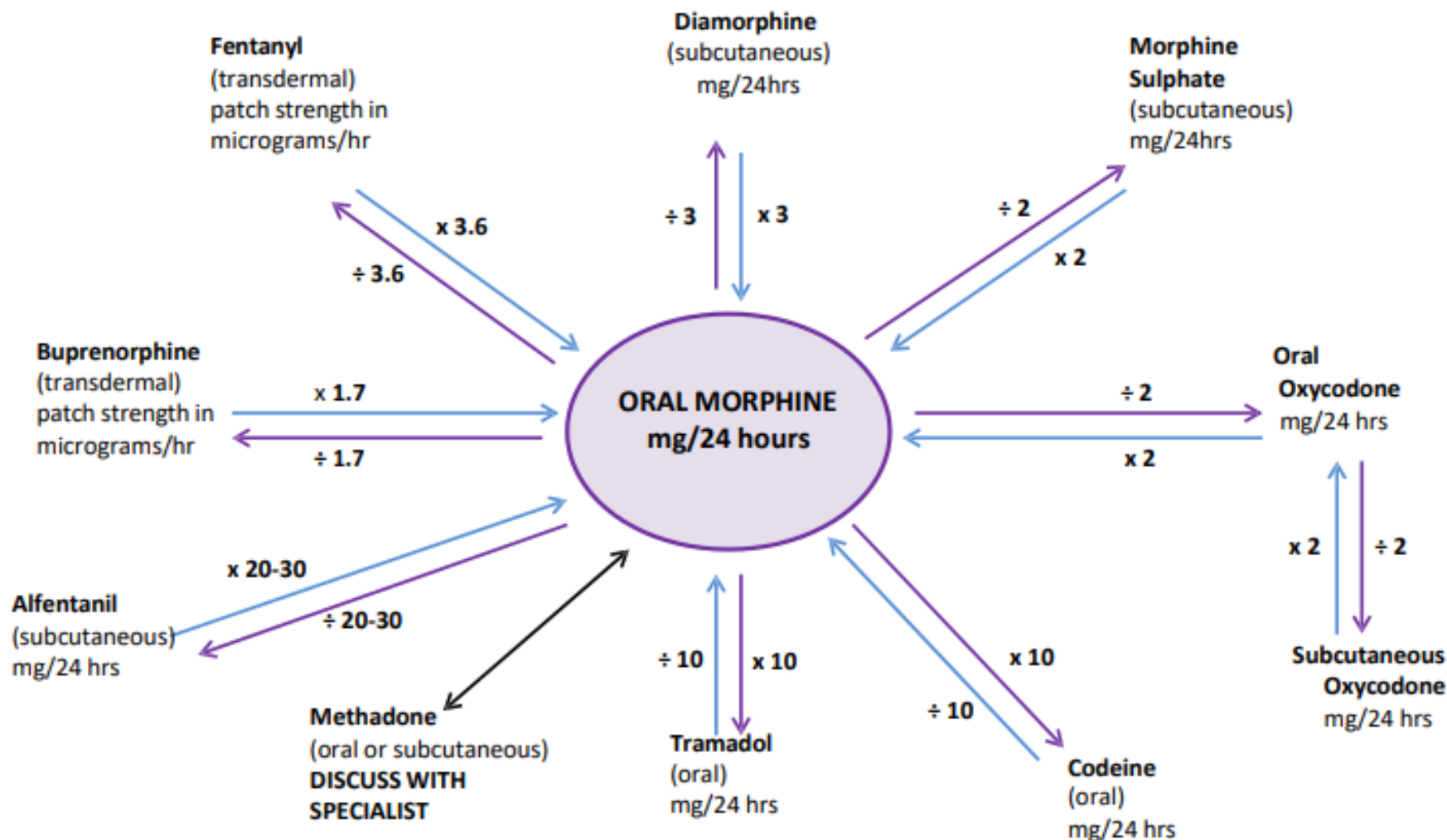
[PowerPoint Presentation \(overgatehospice.org.uk\)](http://overgatehospice.org.uk)

Yorkshire and Humber Symptom Control Advice

[A Guide to Symptom Management in Palliative Care
\(leedspalliativecare.org.uk\)](http://leedspalliativecare.org.uk)

Pre-calculated opioid conversions

[Opioid conversion chart 11thAug2014 \(yorkhospitals.nhs.uk\)](http://yorkhospitals.nhs.uk)



Always go through the centre of the chart (via oral morphine) when converting between opioids

If in any doubt, please contact the specialist palliative care team for advice:

Monday – Friday, 9am-5 pm - Calderdale Community Specialist Palliative Care Team 01422 310874

Outside these hours - Overgate Hospice 01422 379151

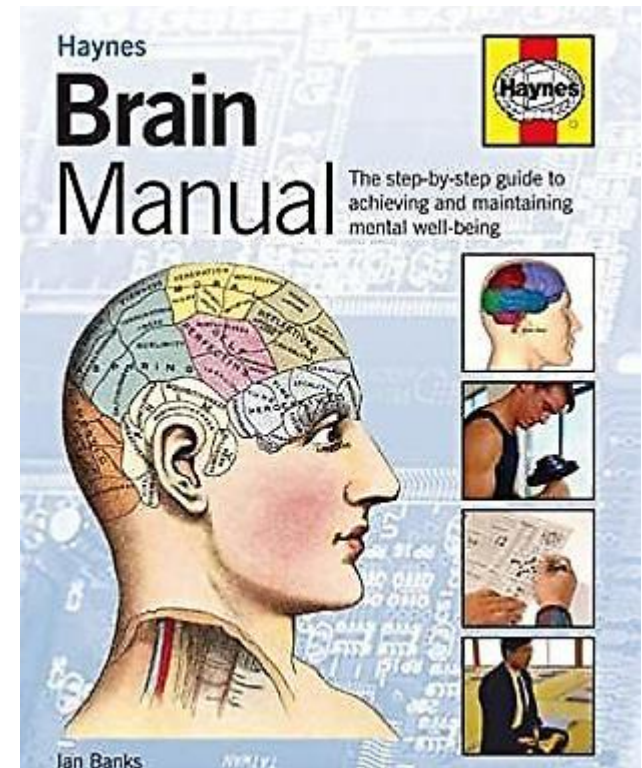
Symptom control – Nausea & Vomiting

- Mary – 74yo
- Lung cancer with liver metastases
- Pain controlled with paracetamol 1g QDS + **morphine 10mg BD**
- Now feeling sick and vomiting every day
- What next?

Nausea & vomiting

Little RCT evidence in palliative care
Extrapolated data

- **Mechanistic approach**
quicker relief¹
successful for most patients^{2,3}
- **Treat any underlying cause**



1 Hardy J et al (2018) BMC Cancer. **18**: 510

2 Bentley A and Boyd K (2001) Palliative Medicine. 15:247-253

3 Stephenson J and Davies A (2006) Supportive Care in Cancer. 14:348-353

Mechanical

Raised intracranial pressure

VIIIth nucleus compression

Cough

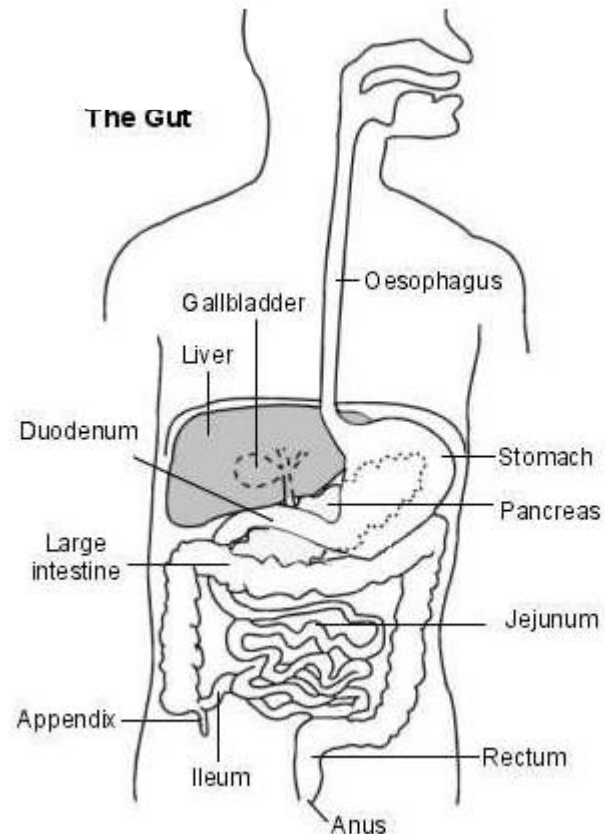
GI irritation

Bowel obstruction

Delayed gastric emptying

Constipation

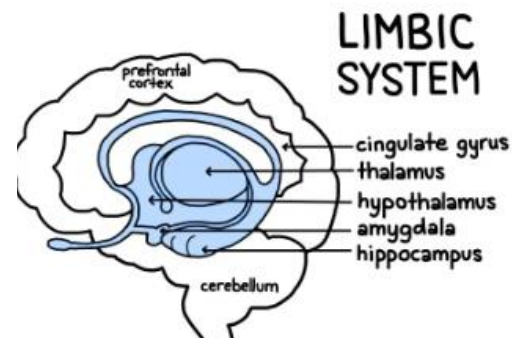
Faecal impaction



Central / chemical

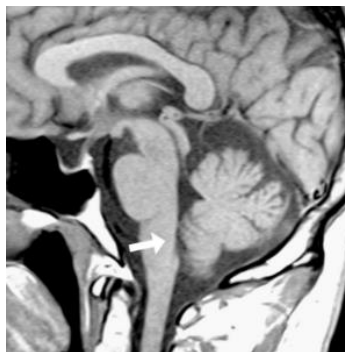
Cerebral Cortex

- Conscious thoughts/feelings - linked to limbic (emotional) system



Chemoreceptor Trigger Zone (CTZ)

- Area Postrema



Chemical

DRUGS

- chemoRx
- opioids
- digoxin
- oestrogens

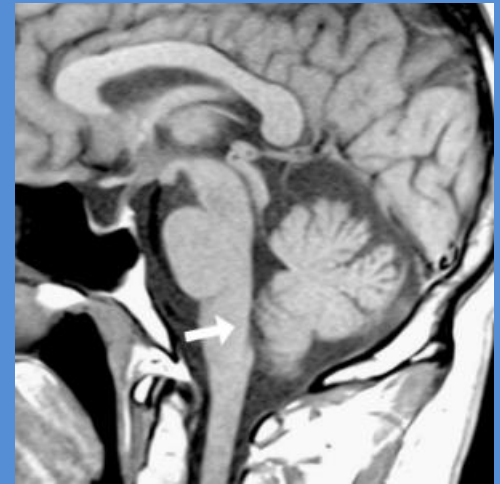
Altered Biochemistry

- $\uparrow\text{Ca}^{2+}$
- $\downarrow\text{Na}^+$
- renal failure
- ketosis

Infection

- UTI
- LRTI

Chemoreceptor Trigger Zone (CTZ)



Nausea & vomiting - Mary

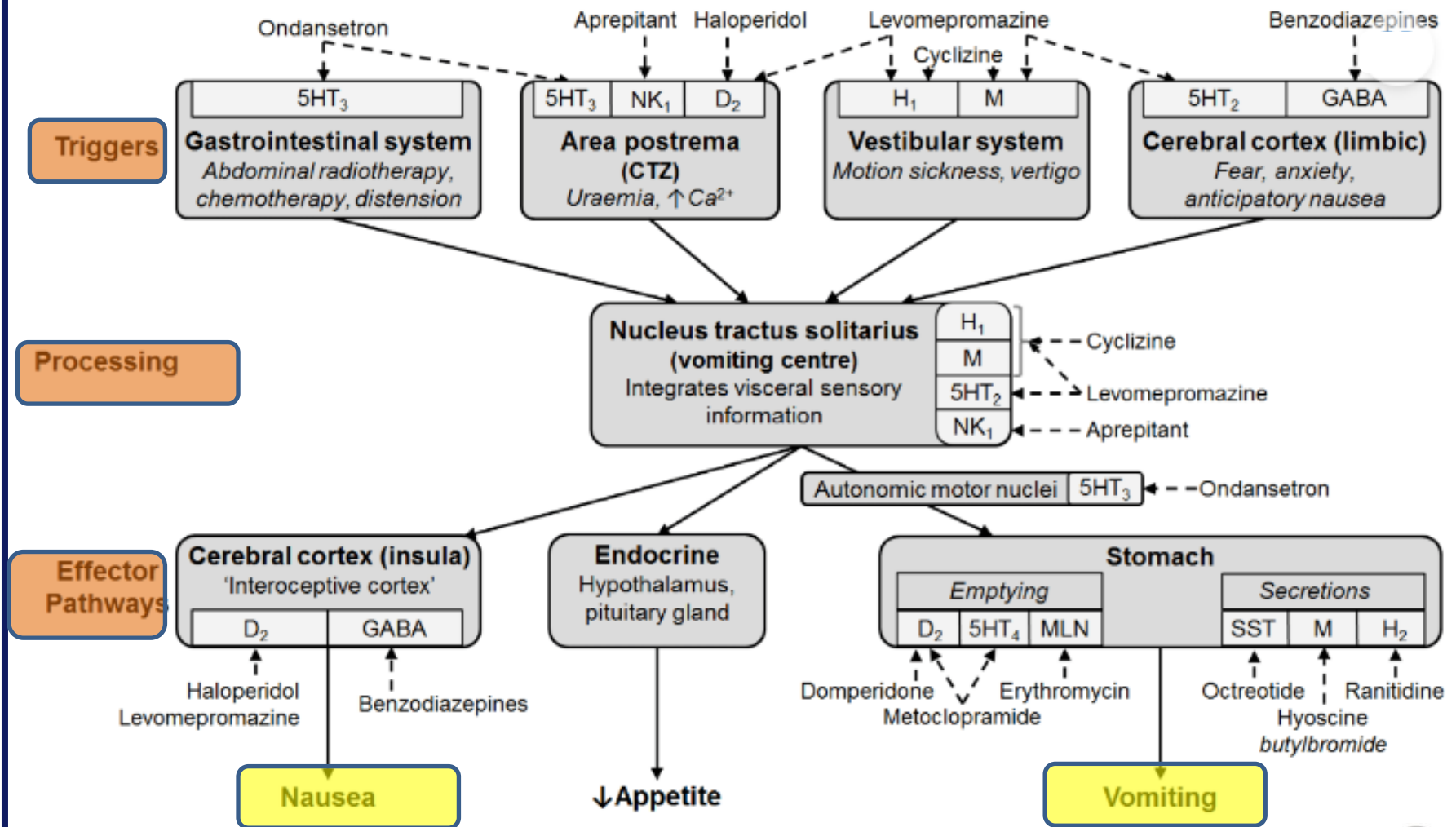
Mechanical

- Cough
- Delayed gastric emptying (big liver)
- Gastric irritation (if on steroids)
- Constipation
- Brain metastases

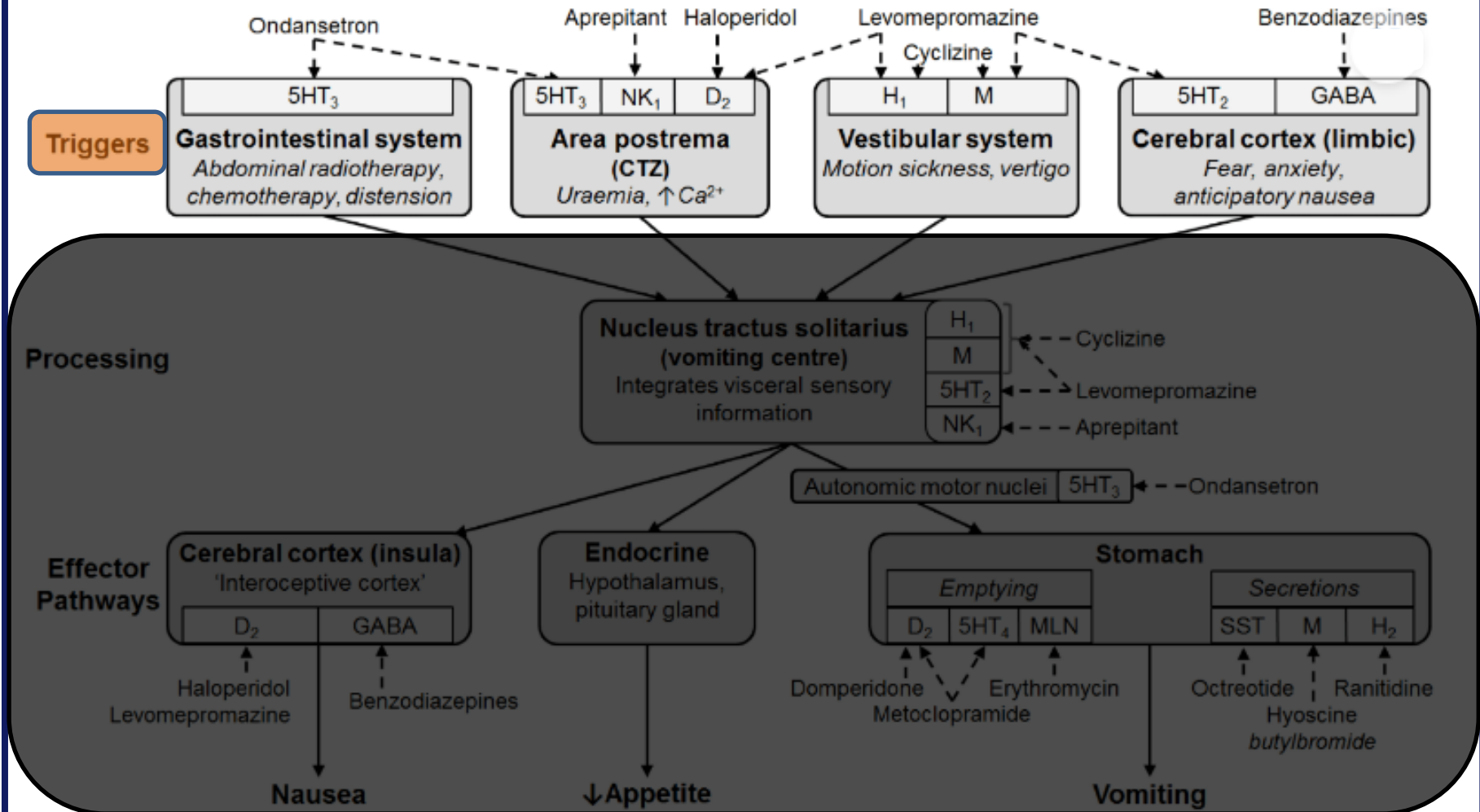
Central / Chemical

- Anxiety
- Opioids
- Chemotherapy
- $\uparrow\text{Ca}^{2+}$
- Chest infection

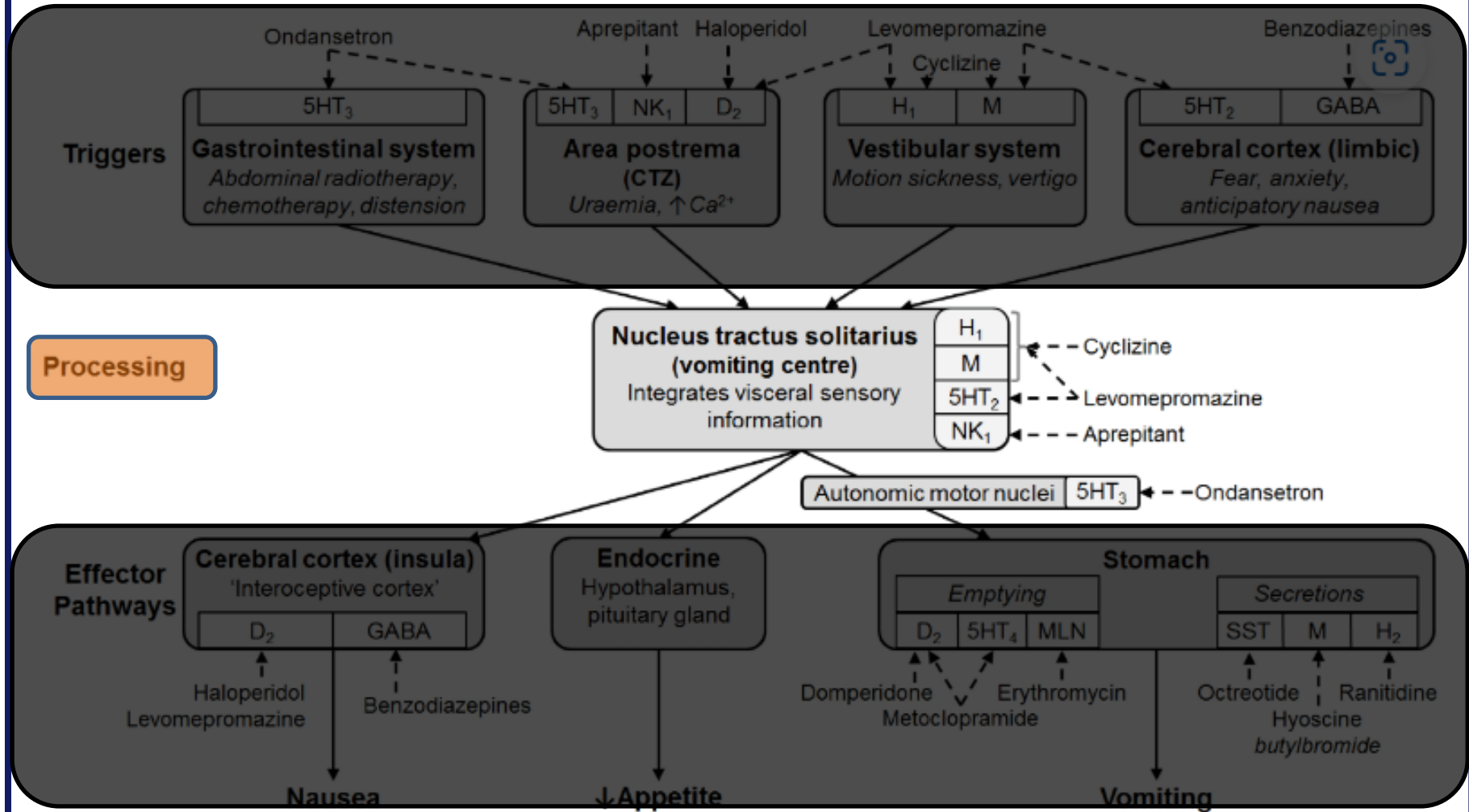
Mechanistic approach



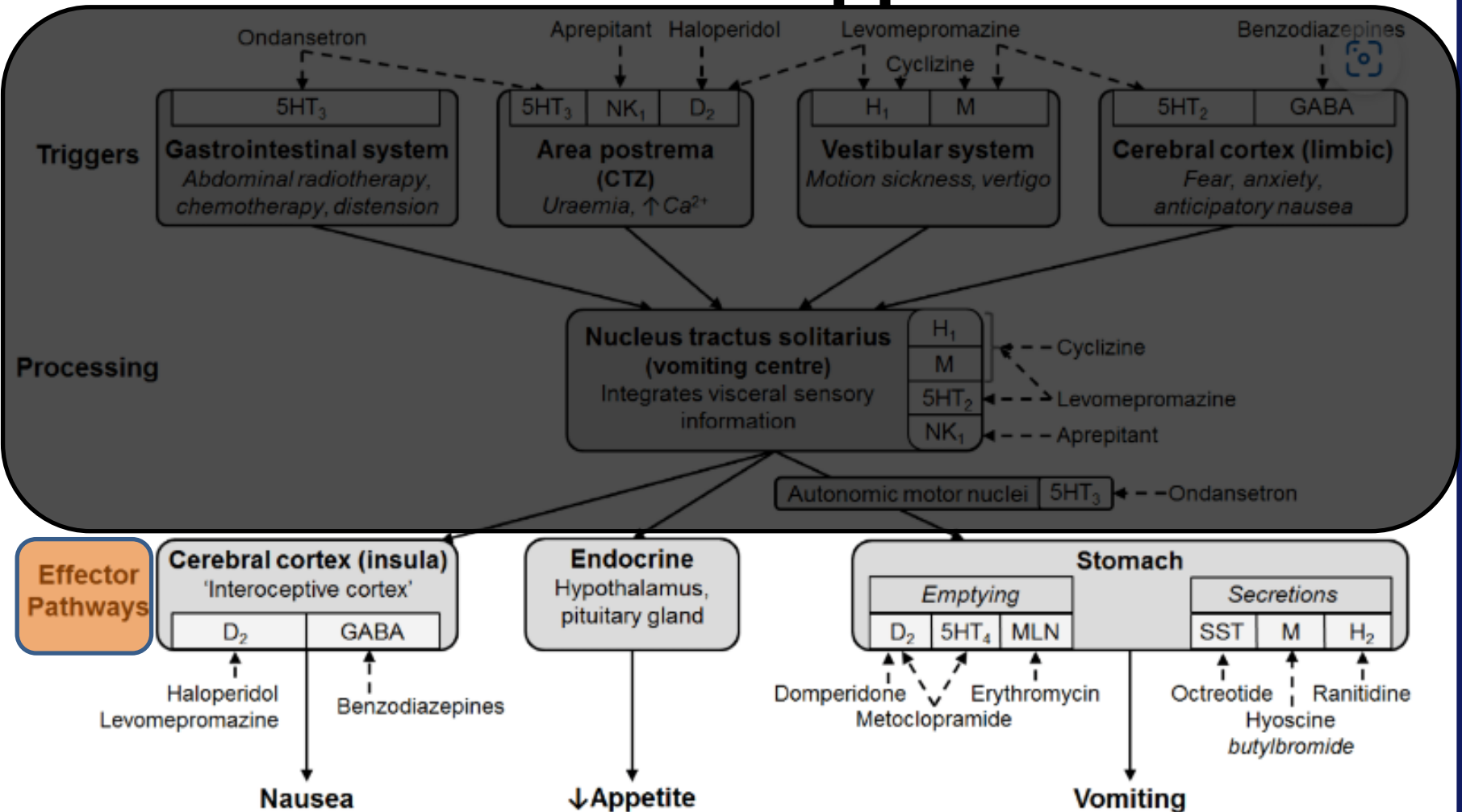
Mechanistic approach



Mechanistic approach



Mechanistic approach



Drugs vs Receptors

	<i>D₂</i> antagonist	<i>H₁</i> antagonist	<i>Muscarinic</i> antagonist	<i>5HT₂</i> antagonist	<i>5HT₃</i> antagonist	<i>NK₁</i> antagonist	<i>5HT₄</i> agonist	<i>CB₁</i> agonist	<i>GABA</i> mimetic
Aprepitant	-	-	-	-	-	+++	-	-	-
Chlorpromazine	+++	+++	++	++	-	-	-	-	-
Cyclizine	-	++	++	-	-	-	-	-	-
Domperidone	++	-	-	-	-	-	-	-	-
Haloperidol	+++	-	-	-	+	-	-	-	-
Hyoscine <i>hydrobromide</i>	-	-	+++	-	-	-	-	-	-
Levomepromazine	++	+++	++	+++	+	-	-	-	-
Lorazepam	-	-	-	-	-	-	-	-	+++
Metoclopramide	++	-	-	-	+	-	++	-	-
Nabilone	-	-	-	-	-	-	-	+++	-
Ondansetron, granisetron	-	-	-	-	+++	-	-	-	-
Olanzapine	++	+	++	++	+	-	-	-	-
Prochlorperazine	+++	++	+	+ / ++	-	-	-	-	-
Promethazine	+ / +++	++	++	-	-	-	-	-	-

Nausea & vomiting - Mary

Central / Chemical

- Opioids
- Chemotherapy

Haloperidol, levomepromazine, (cyclizine)
(steroids)

- $\uparrow\text{Ca}^{2+}$

Rehydration, bisphosphonates, meds as above

- Chest infection

Antibiotics, meds as above

- Anxiety

Anxiolytics – pregabalin, antidepressant,
benzodiazepines

Nausea & vomiting - Mary

Mechanical

- Cough

Treat any chest infection
Cough suppressants (e.g. gabapentin)

- Delayed gastric emptying (big liver)

Steroids to reduce liver bulk? (PPI!)
Prokinetic (metoclopramide)

- Gastric irritation (e.g. if on steroids)

PPI

- Constipation

Default laxatives if regular opioids

- Brain metastases

Palliative Management of Bowel Obstruction

reduce any narrowing of the gut

- extrinsic compression (steroids)
- gut wall inflammation (steroids, ondansetron)

reduce gut secretions

- hyoscine, octreotide

increase gastric emptying

- metoclopramide

or

reduce motility (if colic)

- cyclizine, hyoscine

reduce nausea

- cyclizine, metoclopramide, levomepromazine, ondansetron

Get bowels going if you can

- docusate

Special circumstances

Parkinson's disease

✗ Avoid dopamine blockade

- Haloperidol ✗
- Metoclopramide ✗
- Prochlorperazine ✗

✓ Worth considering

- domperidone (DA blockade but doesn't cross BBB) - oral only ✓
- levomepromazine low dose despite DA activity (case series) – sedating ✓
- Ondansetron – constipating ✓

Special circumstances

CYCLIZINE

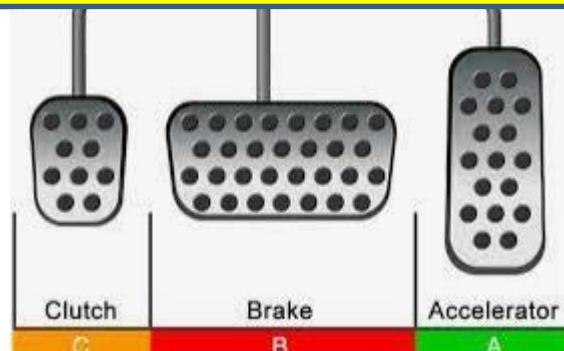
- Anti-muscarinic
- Anti-histaminergic
- Risk = constipation

METOCLOPRAMIDE

- Prokinetic
- DA block, 5HT4 agonist
- Risk = colic

PROKINETIC EFFECT BLOCKED

Potential toxicity of both with limited benefit



PPIs

• Side effects

- Diarrhoea
- Low sodium
- Try famotidine?

• Can't take/tolerate/absorb oral or orodispersible

- Can use syringe driver of **esomeprazole**
- **40mg over 24 hrs CSCI**
- NOT on red list

Symptom control – steroids

- Mary – 74yo
- Lung cancer with liver metastases
- Pain controlled with paracetamol 1g QDS + morphine 10mg BD
- Now feeling sick and vomiting every day
- ? Liver metastases and delayed gastric emptying
(other causes of N&V possible!)

Going to try some steroids to reduce liver capsule pain, reduce gastric emptying delay by reducing extrinsic pressure on gastric outlet from liver mets, ??central cause of N&V (brain mets).

- What dose?
- Will it work?
- What are the risks?

Symptom control – steroids

Hardy et al. Practice review: Evidence-based quality use of corticosteroids in the palliative care of patients with advanced cancer.

[Palliative Medicine](#) ISSN (Print): 0269-2163 - ISSN (Online): 1477-030X

Literature search

P	Population	Pts with advanced cancer PLUS other problems
I	Intervention	Use of systemic corticosteroids various doses – see specific reviews
C	Comparison	No steroids/steroids at other doses
O	Outcome	Relief of symptoms/QoL/ functional status – see specific reviews

Strong evidence:

DO

- use **for Sx of raised ICP** (4mg as effective as 16mg wrt performance status at 4 weeks)
- use **shortest course/lowest effective dose**
- **educate** patients properly
- use **1-2 doses/day** (not TDS/QDS)
- monitor capillary **blood glucose** when first starting steroids
- remember hyperglycaemia is common and of rapid onset
- long term steroids require regular review of Side Effects

DON'T

- stop abruptly if taking **>4mg dex/day**
for >5days

Moderate evidence

DO

- use for **MSCC** (not clear what dose is needed)
- **monitor for oral thrush**
- **document reason** for prescribing steroids
- monitor for efficacy and SE in long term use
- take a **full medicines history**
- keep to **<2 weeks if no benefit**

DON'T

- Prescribe **more than 12mg dex/day** if **Hx of neuropsychiatric illness**

Tentative evidence:

DO

- Use to speed resolution of **bowel obstruction**
- Use to treat SOB in **lymphangitis carcinomatosa**
- Use to prevent symptoms and complications of **SVCO**
- Use to treat **appetite**
- Use to treat **pain**
- Use **PPI or H2 antagonist if steroids for >2/52**
- **avoid** prior to diagnosis of a mass lesion that might be lymphoma **unless vital**

DON'T

- Px steroids without **risk assessment** (skin integrity/wound healing, GI risk, infection...)

Inadequate evidence for recommendation re :

- **N&V in liver metastases**
- oedema from obstructive lymphadenopathy
- bronchorrhoea
- **N&V other than due to chemorx**
- **fatigue**
- SOB
- cough from cancer
- QoL
- outcome in terminal care
- whether bursts reduce toxicity or have different efficacy
- **reversibility of side effects** on stopping Rx
- whether Ca Vit D helps
- whether prophylactic antifungals or Ab+ help
- **which is the steroid of choice**
- **starting dose irrespective of condition**
- **optimal weaning** esp for different conditions and people
- whether to continue when dying
- **what the optimal Rx of steroid induced hyperglycaemia**

Symptom control – Dyspnoea

- Mary – 74yo
- COPD, Lung cancer with liver metastases
- Pain controlled with paracetamol 1g QDS + morphine 10mg BD
- N&V controlled with **haloperidol 1.5mg nocte** & **docusate 100mg nocte**

Increasingly breathless

- What might be reversible/modifiable?
- Palliation







Treatable cause for SOB.... ?

- Infective exacerbation COPD
- PE
- Effusion
- Anaemia
- Anxiety





Treat the treatable if prognosis sufficient, and
benefits outweigh burdens.

Palliation of SOB

Non- pharmacological

-  Fans
-  Rectangle breathing
-  Relaxation
-  Mantra
 -  Lots of oxygen in my blood
 -  NOT my last breath *****

Drugs

-  Opioids
-  Benzodiazepines only if anxiety
-  Rx of depression & anxiety
-  ?? oxygen

FANS

-Schwartzstein R, Lahive K, Pope A et al. Cold facial stimulation reduces breathlessness induced in normal subjects. Am Rev Resp Disease 1987;136(1):58-61.

-Liss H, Grant B. The effect of nasal flow on breathlessness in patients with chronic obstructive pulmonary disease. Am Rev Respir Dis 1988;137(6):1285-8.

-Simon P, Basner R, Weinberger S et al. Oral mucosal stimulation modulates intensity of breathlessness induced in normal subjects. Am J Respir Crit Care Med 1991;144(2):419-422.

-Galbraith S, Fagan P, Perkins P et al. Does the use of a handheld fan improve chronic dyspnoea? A randomised, controlled, crossover trial. J Pain Sy Manage 2010;39(5):831-838.

Safety of Medication for chronic breathlessness

concern = respiratory depression

Ekstrom

COPD with LTOT – 4 year follow up
No increase in mortality or hospitalisation
on **30mg/day or less**

Bajwah

ILD

No increase in mortality or hospital
admission with doses **30mg/day or less**

Ekstrom 2014- BMJ	≤30mg morphine / 24 hrs	No Δ mortality
	>30mg morphine / 24 hrs	Increased mortality
	Benzodiazepines (any)	Increased mortality

Trials

- one case of harm with COPD and transmucosal fentanyl
 - NB – pt misused the fentanyl in that he took 10x the recommended no. of doses /day
- one case of harm with nebulised opioid on top of MR opioid
- one case of harm in COPD where pt had MR opioid and then a large dose of IR opioid

Opioids – efficacy for dyspnoea

Opioids for Breathlessness: a narrative review

Johnson & Currow BMJSPC 2020; 10:287-295

SOB experienced via CNS “threat centres” – rich in opioid receptors
SOB reduced by endogenous opioids

Role of frontal cortex

- Activated in chronic SOB vs healthy volunteers
- Anxiety and depression increase activation
- Pulmonary rehabilitation reduces activation

Most evidence is:

- for morphine
- in patients with COPD

Most trials are:

- Randomised
- placebo-controlled
- Double blinded
- Very long-acting opioid

2014 meta analysis

- benefit from steady state is more than from single doses
- Moderate evidence of efficacy and safety

2016 Systematic review

- moderate evidence of reduced SOB

Opioids & Dyspnoea

Background SOB

- Trial of low dose **MR morphine** for 1 week, starting at **10mg/24 hrs** (↑to 20mg - then 30mg - if no response)
- **2/3rd** had benefit
- Of those **70% at 10mg/day**, 20% at 20mg/day, 8% at 30mg/day
- Biggest benefit was in the first 24 hrs, but benefit **continued to ↑** for **6 days with no dose ↑**

→ **SLOW TITRATION**

Pre exertion PRN

- morphine immediate release
- Increased endurance, reduced SOB

Dyspnoea

The benefit of opioids is blocked by anxiety and depression

→ ?Anxiolytic antidepressants, pregabalin for anxiety

Oxygen

No symptomatic benefit over a fan unless significant hypoxia

Psychological tethering

Caution in CO₂ retention – can look like over-opiation
(Flap instead of jerks, reduced respiratory rate, drowsiness)

Symptom control – Seizures

- Mary – 74yo
- COPD, Lung cancer with liver metastases
- Pain controlled with paracetamol 1g QDS + morphine 10mg BD
- N&V controlled with haloperidol 1.5mg nocte & docusate 5ml nocte
- Low mood, anxious, pleural effusions (not for draining) – **using hand-held fan, mirtazapine** – breathlessness improving
- **New – episodes of right arm twitching over last few days**
- **Headache**
- **Generally deteriorated – prognosis ? weeks**
- What next?

Seizures - no previous anticonvulsant

- Brain Scan? (what will it change?)
- Steroids? (maybe if pressure symptoms/have time to titrate anticonvulsants)

Is the prognosis very short (\leq few weeks)?

NO

- **After 1st seizure**
(don't wait for 2nd)
- **Start:**
 - **levetiracetam 500mg BD** (can increase by 250-500mg BD each 2 weeks)
 - **valproate 150/200mg MR BD** (can increase by 150-200mg every 3 days)

YES

- **Start midazolam syringe driver 20-30mg/24 hrs**
- **PRN**
 - midazolam – 10mg SC or buccal (10mg/ml so small volume but expensive)
 - ?lorazepam 0.5-1mg PRN
 - (Diazepam – rectal solution)

Seizures - already on anticonvulsants

- Continue to titrate anticonvulsant if needed
- ? Steroid cover while titrating up if due to (suspected) brain metastases
- ? Midazolam cover while titrating up

Might lose swallow?
→ have S/C meds ready

BACKGROUND

- **Convert valproate or levetiracetam to syringe driver**
- Max VOLUME in 1 SD = 22ml
 - Valproate = 2200mg/24hrs
 - Levetiracetam = 2200mg/24 hrs

PRN

- **midazolam** – 10mg SC or buccal (10mg/ml so small volume but expensive)
- ?lorazepam 0.5-1mg PRN
- (Diazepam – rectal solution)

Seizures - bits a pieces

PRNs

Give if fitting ≥ 5 minutes

Midazolam 10mg PRN

Total 80mg max in 24 hrs (SD + PRN)

After midazolam max

- Use phenobarbital
- Start 100-200mg IM hourly max
- Once seizures settle, put cumulative dose in SD over 24 hrs
- Continue to give PRN if needed



Gabapentin /pregabalin

Abrupt withdrawal (e.g. loss of oral route when dying) can cause seizure (even if no Hx of seizures)

→ replace with midazolam in syringe driver



Midazolam may replace some of neuropathic analgesic effect

Anticipatory medications Parkinson's disease – dying/can't swallow

- Reduced movement/ facial expression
- Risk of poor control of other symptoms
- Stiffness, reduced movement, pressure areas, friction from tremor

ACTIONS

- Try to “unlock”
- Co-beneldopa
 - Buccal/crushed
- Replace background with ROTIGOTINE PATCH
- [\(optimal calculator\)](#)



Calculator for patients who cannot have an NG tube or with GI failure

Select your patient's usual medication, dosage and frequency from the drop down menus below.

After each selection click "Add Drug".

When you have entered all of the Parkinson's medication in their regime, click "Calculate" to see what to convert it to.

Click "Reset" to clear all selections.

Drug: Dosage: Frequency:

Reset

Add Drug

Calculate

Patient's Usual Drug

Dosage

Frequency

Drug: Dosage: Frequency:

Ropinirole (Requip) ▼

1mg ▼

TDS ▼

Reset

Add Drug

Calculate

Patient's Usual Drug	Dosage	Frequency
Co-beneldopa (Madopar)	125 (100/25)	TDS
Ropinirole (Requip)	1mg	TDS

Results

Convert to: Rotigotine Patch 12mg/24hrs.

If the patient has Dementia or Delirium we advise Rotigotine 8mg/24hrs.

Please note, maximum dose of Rotigotine is 16mg in 24 hours.

Do not cut patches to achieve required dose.

Requests for GP support from SPCT & Documentation

Who should you refer to GPC?

The SPICT™ – SPICT

Proactive Identification Guidance v7 (2022).pdf (goldstandardsframework.org.uk)



Supportive and Palliative Care Indicators Tool (SPICT™)



The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (e.g. The person stays in bed or in a chair for more than half the day).
- Depends on others for care due to increasing physical and/or mental health problems. The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer	Heart/vascular disease	Kidney disease
Functional ability deteriorating due to progressive cancer. Too frail for cancer treatment or treatment is for symptom control.	Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.	Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
Dementia/frailty	Severe, inoperable peripheral vascular disease.	Kidney failure complicating other life limiting conditions or treatments.
Unable to dress, walk or eat without help. Eating and drinking less; difficulty with swallowing. Urinary and faecal incontinence. Not able to communicate by speaking; little social interaction. Frequent falls; fractured femur. Recurrent febrile episodes or pneumonia.	Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations. Persistent hypoxia needing long term oxygen therapy. Has needed ventilation for respiratory failure or ventilation is contraindicated.	Stopping or not starting dialysis.
Neurological disease	Other conditions	Liver disease
Progressive deterioration in physical and/or cognitive function despite optimal therapy. Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing. Recurrent aspiration pneumonia; breathless or respiratory failure. Persistent paralysis after stroke with significant loss of function and ongoing disability.	Deteriorating with other conditions, multiple conditions and/or complications that are not reversible; best available treatment has a poor outcome.	Cirrhosis with one or more complications in the past year: • diuretic resistant ascites • hepatic encephalopathy • hepatorenal syndrome • bacterial peritonitis • recurrent variceal bleeds Liver transplant is not possible.
Review current care and planning.		
<ul style="list-style-type: none"> Review current treatment and medication to make sure the person receives optimal care; minimise polypharmacy. Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage. Agree a current and future care plan with the person and their family/people close to them. Support carers. Plan ahead early if loss of decision-making capacity is likely. Record, share, and review care plans. 		

Please register on the SPICT website (www.spirit.org.uk) for information and updates.



The Gold Standards Framework Proactive Identification Guidance (PIG)



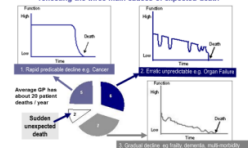
The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life, leading to improved proactive person-centred care.

GSF PIG 7th Edition June 2022 Keri Thomas, Max Watson (HUK), Julie Armstrong Wilson and the GSF team
For details see <https://www.goldstandardsframework.org.uk/PIG>, <https://www.goldstandardsframework.org.uk/PIG/PIG>, <https://www.goldstandardsframework.org.uk/PIG/PIG>

Proactive Identification Guidance – identifying patients' decline earlier, enabling more proactive care.

This updated 7th edition of the GSF Proactive Identification Guidance or PIG (previously known as the GSF Prognostic Indicator Guidance), aims to enable the earlier identification of people who may need additional supportive care as they near the end of their life (see GMC and NICE definition of end of life), to include final year of life as well as final days. This includes people with any condition, in any setting, given by any care provider (not just those needing specialist palliative care), following any trajectory of decline for expected deaths (see below). Additional contributing factors when considering prediction of likely needs include underlying co-morbidities, current mental health and social care provision etc.

Three Trajectories of Illness 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 as recommended in the NICE Long Term Plan (2019) and NICE guidance (2021). Earlier recognition of decline leads to earlier anticipation of likely needs, better planning, fewer crisis hospital admissions and care tailored to people's wishes, with better outcomes enabling more people to live and die where they choose. 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 – 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

Definition of End of Life Care General Medical Council

GMC: <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life>

NHS: <https://www.nhs.uk/conditions/end-of-life/care/what-it-is/involve-and-when-it-starts/>

The GMC definition of End of Life Care, used by the NHS, NICE and others is 'People are approaching the end of their life who 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 2021 identification

<https://www.nice.org.uk/guidance/ng146/chapter/Quality-statement-1-identification>

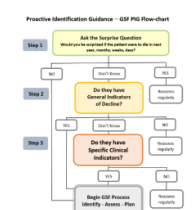
'To identify 1 Adults who are likely to be approaching the end of their life are identified using locally developed systems.'

NICE Service Delivery 2019 <https://www.nice.org.uk/guidance/ng146>

Services should develop systems to identify adults who are likely to be approaching the end of their life e.g. using tools such as GSF proactive identification guidance (PIG).

SARS COVID 19 infections can cause rapid decline, emphasising the importance of early advance care planning and screening. Contributing factors include age, multi-morbidity, BAME and social status, etc. Pulse oximetry SpO2 of 92% or under triggers immediate treatment – more information see NHS guidance or [https://www.thelancet.com/journal/elsevier/article/S0140-6736\(20\)31240-0](https://www.thelancet.com/journal/elsevier/article/S0140-6736(20)31240-0)

GSF Proactive Identification Guidance Flow-chart



For information on the development of the GSF PIG, its use in practice, evidence base, applications and when referencing it, please refer to <https://www.goldstandardsframework.org.uk/PIG>, <https://www.goldstandardsframework.org.uk/PIG/PIG>, or contact info@goldstandardsframework.org.uk

STEP 1: The Surprising 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 future decline?

This includes proactive planning of care and treatments and offering advance care planning and DNACPR discussions as early as possible.

STEP 2: Consider the signs of decline and progression

- General physical decline, increasing dependence and need for support
- Repeated unplanned hospital admissions or acute crises at home
- Advanced disease – unstable, deteriorating, complex symptom burden
- Presence of significant multi-morbidities
- Decreasing activity – functional performance status declining (e.g., Barthel or Karnofsky performance score, Rockwood limited self-care, in bed or chair 50% of day and increasing dependence in activities of daily living)
- Decreasing response to treatment, decreasing reversibility
- Patient choice for no further active treatment, focus on quality of life
- Progressive weight loss (>10%) in past six months
- Sentinel Event (e.g., serious fall, carer distress, bereavement, transfer to nursing home, etc.)
- Severe albumin (<25g)
- Considered eligible for D55000 payment

STEP 3: Consider how patients related to single/multiple organ failure

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, IPDS, ECOG.

2. ORGAN FAILURE

Advanced heart failure – CHF NYHA Stage 3 or 4 with symptoms despite optimal HF therapy – shortness of breath at rest/no minimal exertion

Repeated admissions with heart failure – 3 admissions in 6 months or a single admission aged over 75 (50% 1-year mortality)

Heart failure patients with reduced ejection fraction (HFrEF) have a poorer prognosis than those with preserved ejection fraction (HFpEF)

Severe unresectable coronary artery or peripheral vascular disease. Difficult ongoing symptoms despite optimal tolerated therapy

Unresectability but other indicators include age, low EF, chronic heart disease/arrhythmia multi-morbidities including diabetes, obesity depression, hypotension, high BP, declining renal function, anaemia

See NICE guidance <https://www.nice.org.uk/guidance/ta296>

CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

Severe disease (e.g., FEV1 <30% predicted), persistent symptoms e.g., breathlessness despite optimal therapy, causing distress

Recurrent hospital admissions (at least 3 in last year due to COPD) Hypoxia/raising long term oxygen therapy criteria (SpO2 < 93%)

Too unwell for surgery or pulmonary rehabilitation

MRC grade 4/5 – shortness of breath after 100 metres on level surface Required ICU/HD during admission or ventilation contraindicated

Other factors e.g., right heart failure, anaemia, cachexia, >6 weeks steroids in preceding 6 months, despite specialist review/treatment optimisation, requires palliative medication for breathlessness.

KIDNEY DISEASE

Stage 4/5 Chronic Kidney Disease (CKD) deteriorating eGFR <30ml/min Repeated unplanned admissions (more than 3/year)

Patients with poor tolerance of dialysis with change of modality Patients choosing the 'no dialysis' option (conservative management), 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 or complicating other life limiting conditions – nausea and vomiting, anaemia, pruritus, reduced functional status, intractable fluid overload

LIVER DISEASE

- Advanced cirrhosis – see the Child-Turcotte-Pugh (CTP) score for chronic liver disease and cirrhosis mortality – See CTP calculator at <https://www.hepatitis.org.uk/portal/clinical-calculators/ctp>
- Hepatocellular carcinoma
- Liver transplant is considered potentially difficult or not amenable to treatment of underlying condition
- Other adverse factors including malnutrition, bacterial infection, raised INR, hyponatraemia

GENERAL NEUROLOGICAL DISEASES

- Progressive deterioration in physical and/or cognitive function despite optimal therapy
- No longer able to communicate basic needs
- Symptoms which are complex and too difficult to control
- Increased hospital admissions not returning to previous baseline Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure
- Speech problems: increasing difficulty in communication and progressive dysphasia
- Mobility problems and falls increasing
- Reduced independence, needs ADL help, similar to frailty below
- Deteriorating cognition/psychiatric signs (depression, anxiety, hallucinations, apathy)

PARKINSON'S DISEASE

- including the above, and more specifically - Drug treatment less effective or increasingly complex drug regime, less well controlled with increasing 'off' periods
- Dyskinesias, mobility problems and falls
- Considered eligible for the above, and more specifically - Episodes of aspiration pneumonia
- Low vital capacity (below 70% predicted), or initiation of NIV
- Predicting the prognosis after stroke should be challenging, yet 1-20 die within 72 hours. Care should include symptomatic comfort and not to treat burdensome restrictions
- Persistent paralysis after stroke with significant loss of function, medical complications, lack of improvement or ongoing disability
- Persistent vegetative, minimal conscious state or dense paralysis Cognitive impairment, post-stroke dementia
- FRAILTY, DEMENTIA AND MULTI-MORBIDITIES
- For older people with complexity and multiple comorbidities, with frequent fluctuations in health needs and deterioration
- Electronic Frailty Index (0.24 or more) or Rockwood Score (PS 7 or above)
- Comprehensive Geriatric Assessment (CGA) includes cumulative multiple morbidities, weakness, weight loss, fatigue, advancing frailty e.g., male over 85, health problems, reduced activity and need to stay at home, needs regular help, uses stick/walker regularly
- DEMENTIA
- Identification of moderate/severe stage dementia using a validated tool or Comprehensive Geriatric Assessment (CGA) of frailty, Clinical Frailty Scale (CFS), Functional Assessment Staging, Electronic Frailty Index (EFI) or Rockwood scale, identifying decline in dementia or frailty. Triggers to consider that someone is entering a later stage are:
- Unable to recognise family members or consistently unable to have meaningful conversations
- Completely dependent on others for care or unable to do ADL
- Recurrent episodes of delirium
- Aspiration pneumonia
- Urinary and faecal incontinence, and Barthel score <3
- PS: Weight loss, urinary tract infection, skin failure or stage 3 or 4 pressure ulcers, recurrent fever, reduced oral intake
- MULTI-MORBIDITIES
- Increasingly reliant in ageing population needing complex care 2 or more long term conditions including physical, mental, learning disability, frailty, sensory impairment, alcohol misuse
- Complex multi-morbidity approach to frailty, physical + mental conditions – not managing ADL or treatments, using multiple services, frequent falls or crisis admissions
- See NICE guidance – <https://www.nice.org.uk/guidance/ng66> RGS: <https://www.rgs.org.uk/healthcare/multi-morbidity>

The GSF Proactive Identification Guidance (PIG) June 2022 v7 © The Gold Standards Framework Centres in End of Life Care



SPICT © 2022

Urgent request for support from specialist palliative care CNS

“Face-to-face” review
- often re MCCD
(so includes video link during life)

Attended during last illness

- Access to records/results
- Must see in 28 days before death **OR** after death

Occasionally – no GP attended during last illness

- Must be seen in 28 days before death, or referred to coroner
- (e.g. self referral to A&E with symptoms, diagnosed with widely metastatic ca, wants to die at home, Fast Track discharge, **dies soon after return home**)

Request for physical examination

- Decisions about reversible treatments - ? Ascites for drainage or constipation?
- Chest infection warranting treatment or other cause of breathlessness.

Request to write/amend pink chart



Pink form = anticipatory + SD

Recognition that forms could change to reduce risk of errors

- E.g. on discharge from hospital
- Nurse brings pink chart.
- Family comes to collect pink chart when done.
- If nurse finds an error → repeat



Chart revised to reduce errors

Pre-populated:

- Indications
- Frequency
- Maximum dose except for opioids

OPIOIDS

**maximum dose =
syringe driver + 6 PRNs**

Pink form - Syringe driver

COMMUNITY PALLIATIVE CARE CHART



Allergies and Adverse Drug Reactions – List the medicines or Substances & the nature of the reaction (write NKDA if none)		
It is mandatory to complete this section		
Medicine/Substance	Reaction	
Sign	Date	
Print Name	GMC/NMC number	
Allergy status unconfirmed. Authority to administer ceases after 24 hours	Sign (NAME) GMC/NMC	Date

First Name	Surname
Address:	
NHS No:	DOB:
Consider the administration of a stat dose when starting a new syringe <u>driver</u>	

**Maximum
volume
22ml**

**(23ml if
line primed)**

SC SYRINGE DRIVER OVER 24 HOURS

Syringe driver	Dose	*Dose titration (community use)
Drug (1)		
Drug (2)		
Drug (3)		
Diluent:		
Prescriber sig	Prescriber name (print)	Date



‘WHEN REQUIRED’ DRUGS

Please remember to issue a prescription of Water for injection to allow these drugs to be administered

Drug	ROUTE	Prescriber sig (Print name)	Date
MORPHINE	SC		
Dose		Frequency One hourly	
Indications Pain/dyspnoea	Max dose in 24 hours including syringe driver content:		

Drug	ROUTE	Prescriber sig (Print name)	Date
MIDAZOLAM (10mg/2ml)	SC		
Dose 2.5-10mg		Frequency One hourly	
Indications Anxiety, dyspnoea, agitation, restlessness	Max dose in 24 hours – 80mg		
Indications 10mg to be given for seizure or major haemorrhage			

Drug	ROUTE	Prescriber sig (Print name)	Date
HYOSCINE BUTYLBROMIDE	SC		
Dose 20mg		Frequency One hourly	
Indication Respiratory secretions	Max dose in 24 hours - 120mg		
Indication Colic	Max dose in 24 hours - 300mg		

Drug	ROUTE	Prescriber sig (Print name)	Date
HALOPERIDOL	SC		
Dose 0.5-3mg		Frequency Two hourly	
Indications Nausea, Agitation, Hallucinations	Max dose in 24 hours - 5mg		

Drug	ROUTE	Prescriber sig (Print name)	Date
	SC		
Dose		Frequency	
Indications	Max dose in 24 hours –		

Pink form
= anticipatory + SD

Pink form = anticipatory + SD

PRN opioids

1/6th of 24hr background dose

Opioid naïve

Morphine 2.5-5mg SC PRN

**lower dose if frail, thin, elderly,
sensitive to side effects**

Oxycodone 1-2mg SC PRN

eGFR <40



morphine
accumulates



use
oxycodone

Pink form = anticipatory + SD

PRN opioids

1/6th of 24hr background dose

Opioid naïve

Morphine 2.5-5mg SC PRN

**lower dose if frail, thin, elderly,
sensitive to side effects**

Oxycodone 1-2mg SC PRN

eGFR <40



morphine
accumulates



use
oxycodone

Anticipatory Meds



- SYSTMONE – anticipatory meds prescribing
- Only for Morphine 10mg/ml Injection
- “personal administration” – NEEDS TO BE MANUALLY **UN**TICKED
- otherwise prescription does not get electronically transferred to pharmacy
- automatically unticked on the other strengths
- needs to be changed at ICB level – has been requested.

Anticipatory Meds

Other Details... Exact date & time Fri 03 Nov 2023 16:39

Changing the consultation date will affect all other data entered. To avoid this, cancel and press the 'Next' button [Hide Warning](#)

Medication start: Fri 03 Nov 2023

Drug prescribed:  **Morphine sulfate 10mg/1ml solution for injection ampoules** CD       

Script type: ☒ NHS Issue ☐ Private Issue ☐ Instalment Dispensed Issue

Dose:   Times & Doses


















Total quantity: ☒ Number 5 ☐ Packs ☐ Free Text ampoule



















Script notes: Presets 














Administrative notes: [Batch Number] (Pack Size) Presets 

















Issue duration: 1 Days End date: 04 Nov 2023  

















☐ Automatically create a Repeat Template based on this issue

















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

















                   














                   













                   
















                   


















                   



















                   









                   

Pink form = anticipatory + SD

- Mary may soon start to die
- Might soon not be able to swallow.....

• Needs PRN

- Morphine
 - Midazolam
 - Hyoscine butylbromide
 - Haloperidol
- } 5 ampoules of each
- Ampoules of water / saline

- If on levetiracetam (or valproate)
 - ensure enough SC to start a syringe driver
- If on steroids to control seizures
 - ensure daily SC dose

ReSPECT

ReSPECT
Recommended Summary Plan for Emergency Care and Treatment
Microsoft Word version 3.5

1. This plan belongs to:

Full name	
Date of birth (dd/mm/yyyy)	
Address	
NHS/CHI/Health and care number	
Preferred name	
Date completed (dd/mm/yyyy)	

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

2. Shared understanding of my health and current condition

Summary of relevant information for this plan including diagnoses and relevant personal circumstances:

Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer):

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - ☐ yes/no
if yes provide details in Section 3

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me ☐ Quality of life and comfort matters most to me ☐

What I most value:

What I most fear / wish to avoid:

4. Clinical recommendations for emergency care and treatment

Prioritise extending life	or	Balance extending life with comfort and valued outcomes	or	Prioritise comfort
Clinician signature		Clinician signature		Clinician signature

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

CPR attempts recommended Adult or child ☐ For modified CPR Child only, as detailed above ☐ CPR attempts NOT recommended Adult or child ☐

Clinician signature

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Page 1 of 2 Copyright 2020 Resuscitation Council UK

- Not just for palliative care patients
- Significant illness => complete before it gets to palliative phase
- ReSPECT – EPaCCS – use high priority alert and tick box on EPaCCS
- Will replace DNA CPR

OOH handover form

PALLIATIVE CARE HANDOVER FORM	
<i>(Please send electronically if possible)</i>	
PATIENT DETAILS Name: Address: Postcode: Telephone/Mobile:	CARER DETAILS Name: Relationship: Address: Telephone/Mobile:
FORM COMPLETED BY: Name (print): Designation: Signature: Date:	
BACKGROUND <i>Include main diagnosis, medical conditions, past and current treatment, current problems, relevant recent blood tests in particular renal function/EGFR to aid opioid prescribing.</i>	
FUTURE PLANNING Preferred place of care <div> <input type="checkbox"/> Home <input type="checkbox"/> Care home <input type="checkbox"/> Hospice <input type="checkbox"/> Hospital </div>	DNACPR decision Is there a form in the patient's house? Yes <input type="checkbox"/> No <input type="checkbox"/>
WHICH ANTICIPATORY DRUGS ARE AVAILABLE IN THE HOME? Opioid: Antiemetic: Anti-secretory drugs: Sedative:	
ANY OTHER RELEVANT INFORMATION (e.g. would patient not want further hospital admission, or is any other advance care plan, ACP, in the house?)	
Before considering hospital admission out of hours, for Kirklees residents contact District Nurses on 0300 304 5555 or Kirkwood Hospice on 01484 557910. For Calderdale residents, contact District Nurses on 07917 106263 or Overgate Hospice on 01422 379151 You can contact the hospices for advice even if the patient is not known to them.	
<ul style="list-style-type: none"> ONCE COMPLETE SEND THIS FORM TO THE PATIENT'S GP VIA SECURE NHS.NET EMAIL and to Local Care Direct on patientforms.LCD@nhs.net IN THE EMAIL SUBJECT HEADING PLEASE INSERT 'URGENT PALLIATIVE CARE HANDOVER'. A PAPER VERSION OF THIS FORM MUST STAY IN THE PATIENT'S HOME. 	
CHFT Specialist Palliative Care Team September 2019 Review September 2021	

- Scan -> secure email to NHS111
- Patientforms.LCD@nhs.net
- LCD practitioner gets flag when opening S1 and EMIS
- If completed by SPCT – there will be a high priority reminder on S1 Home Page

SR1 (formerly known as DS1500)

 <https://portal.national.ncrs.nhs.uk>

Important

Find out about the [changes to the Special Rules process \(opens in a new tab\)](#) in the benefit system.

Send an SR1 form

The SR1 form has replaced the DS1500 form. You can use it to support a benefit claim for a patient of any age made under the Special Rules.

Use this service to tell the Department of Work and Pensions (DWP) that you have a patient who:

- has a progressive disease and
- you would not be surprised if they were to live for less than 12 months

Start now >

Same info as on
paper

Option to save a
copy of the
submitted form – I
tend to upload to
S1.

PROGNOSIS

Too short to benefit from treatment?

Declines intervention despite knowing worst outcomes?

QoL likely to be adversely affected by treatment of underlying process rather than palliative of symptom?

SPCT +/- hospice

Emergencies

Reversible condition?

Prognosis > weeks

Or if shorter prognosis –
symptom won't be
adequately managed with
palliative medication

Patient agrees to acute
care

Emergencies

ACUTE ONCOLOGY
number

Mon-FRI 9-5

Via Switchboard
01422 222999

Emergencies

Malignant spinal cord compression

NICE – don't wait for development of neurological signs

Crescendo pain in known / suspected cancer

Especially radicular pain

High index of suspicion for MSCC

Dexamethasone 16mg stat

PPI

Urgent MRI whole spine via acute oncology

Emergencies

- Febrile neutropenia

- Acute oncology

- Blood cultures then IV Ab+ within the golden hour

Emergencies

SVCO


- Steroids
- PPI
- Acute oncology - ? XRT ? Stent

Substance misuse, last days of life

- Sublingual buprenorphine – complicated to convert to SC medication when cannot manage SC
- Recovery steps extremely helpful in advising on dose/formulation adjustments even if patient not known to them
- General recommendation for switch from buprenorphine to methadone in weeks leading up to death.... Easy to convert to Syringe driver when oral route lost.... Divide by 2

Hospice services

- Hubs – one for each PCN + Todmorden
- Time to Think – dementia – pt and carer
- Support and Wellbeing – pt only
- Bereavement groups – access if patient know to Overgate

 SPCT CNS team – 01422 310874

 7 days /week

CHFT Motor Neurone Disease Care Co-Ordinator

Beth Macdonald

Elizabeth.Macdonald2@cht.nhs.uk

- Is a qualified OT (not a nurse) – other job is working as OT for Locala in Huddersfield
- Works Tuesdays, Thursdays, Fridays
- Covers patients in Calderdale and Huddersfield
- Co-ordinates care, and works with Rachel Sheils in MND clinic - aim for 2 clinics/month – mix of in person at Acre Mill (Hudds) and online to improve accessibility

Yorkshire and Humber Symptom control guidance to follow shortly...



Will be a webpage rather than an app or booklet.

Summary

Symptoms

Treat underlying causes

Pain

-  Low dose morphine
-  Conversion guidelines





N&V

-  Mechanistic approach




Steroids

-  Evidence is sparse for most things

Breathlessness

-  Start low/go slow
-  Morphine 30mg/24 hrs max
-  Treat anxiety & depression
-  PRN for SOB ¼ of usual PRN opioid





Seizures

-  SD levetiracetam/valproate
-  Midazolam otherwise
-  Phenobarbital if still not resolved



Emergencies

-  Reversible or palliative Rx ?

Documentation

-  Pink chart
-  OOH handover form
-  ReSPECT
-  SR1

Hot Topics

-  Substance misuse –
Recovery steps
-  DH services