Harrogate and District
NHS Foundation Trust

Guidance to accompany Medical and Nursing Care Plans for Last Days or Hours of Life

Palliative Care Team:

- Monday- Friday 8:00-16:00: x3464 or team mobiles
- Out-of-hours: contact Saint Michael's Hospice on 01423 872658. Medical advice is available after review of the patient by a doctor of specialist trainee grade or above.

Further guidance on symptom management and additional information is available on the Palliative Care Team page on the intranet (trust wide/palliative and end of life care)

PCT June 2020 Review June 2023

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Introduction

This guidance supports the care of patients who are thought to be in the last days and hours of life.
It is to be used in conjunction with the medical and nursing Care Plans for Last Days or Hours of Life.

Recognising dying: could the patient be in the last days or hours of life?

There are no ways of telling accurately when a patient is in the last days of life and it can sometimes be difficult to recognise dying. It is therefore important to take into account as much information as possible about the patient's background and current situation when considering this. It is also important to communicate any uncertainty about the time ahead to patients and/or families, while being as open and honest as possible.

Recognising and acknowledging dying should be done by the senior clinician responsible for the patient, in conjunction with the rest of the MDT. As a minimum, the MDT should include a senior member of the patient's medical team (Specialist Trainee or above) and the qualified nurse co-ordinating the patient's care. If the patient is felt to be in the last 2-3 days of life, the doctor should sign and date the decision to support the patient's care with the Care Plan for Last Days of Life (CPLD) in the Medical Care Plan.

> Difficult decision-making around the recognition of dying should be avoided out-of-hours unless it is urgent and clearly in the best interests of the patient

When thinking about whether or not a patient could be dying, take into consideration the following:

- Do any of the following apply to the patient?
  - In bed most or all of the time
  - Only able to take sips of fluid or minimal food
  - Sleeping most or all of the time
  - Struggling to swallow oral medication
  - Deteriorating rapidly (over hours or days)

- Does the patient have any of the following symptoms and signs which indicate active dying?
  - Agitation
  - Cheyne-Stokes breathing
  - Deteriorating conscious level
  - Mottled skin
  - Noisy respiratory secretions

- Does the patient have a known irreversible life-limiting illness of any cause?

- What are the patient's wishes and preferences about life-prolonging treatment?

- Have reversible causes for the patient's current deterioration have been considered and appropriately managed, eg opioid toxicity, renal failure, hypercalcaemia, infection?

- Have intensive care and CPR been considered by the team and deemed inappropriate?

- Is specialist referral needed eg to the palliative care team or a second opinion?

Priorities for care of patients in the last days or hours of life

Recognise & prioritise	• Consider reversible causes • Prompt action if any reversible causes • Communicate clearly if patient is likely to die soon • Ask about views and preferences • Review • Seek advice from Palliative Care Team?
Involve	• Identify those who are important to the patient • Identify senior healthcare professionals responsible for care • Ensure best interests in decision-making if lacks capacity • Discuss wishes and choices for care with patient and family
Plan & do	• Develop care plan • Symptom control and pain relief • Physical, emotional, psychological, social, spiritual, religious and cultural needs • Eating and drinking support if required • Ensure doctor assesses changes daily
Communicate	• Open and honest • Clear and understandable • Listen • Be sensitive • Check understanding
Support	• Families' and carers' needs • Recognise anxiety and emotions • Provide information • Listen to needs and wishes • Involve and inform in all decisions if patient lacks capacity

Care Plan for Last Days or Hours of Life (CPLD)

- Each patient who is in the last days or hours of life must have an individual care plan according to their needs.

- The plan should be discussed openly with the patient and those identified as important to them.

- Find the medical and nursing care plans in the teal Last Days or Hours of Life box on the ward
    - Insert the medical care plan and progress sheets in the medical notes
    - Insert the nursing care plan in the nursing Kardex
    - Make all documentation in the medical and nursing notes as usual

- **The care plan must be reviewed on a daily basis**

- Document the following on the medical progress sheets each day:
    - Is it still felt that the patient is in the last days/hours of life?
    - Current symptoms and management plan
    - How hydration and nutrition needs are being managed
    - Conversations with family

Communication with patient and family

- **Document** in the medical notes details of:

    - Information given to the patient and/or family about:
        - recognising dying
        - likely prognosis, including any uncertainty
        - the focus and plan of care
        - ceilings of care
        - changes to medication (including explanation about syringe drivers and reasons for use)

    - The patient's and/or family's understanding of the situation

    - Any concerns raised or requests made

- **Provide** to family:

    - Information leaflet 'What to expect when someone important to you is dying'

    - Comfort bag containing toiletries etc

Decisions

Consider the following:

1. Capacity

Does the patient have capacity to make decisions about their care?
If not, do they have a lasting power of attorney (LPA) for health and welfare who can make treatment decisions on their behalf?
Consider the need for an Independent Mental Capacity Advocate (IMCA) or DOLS.

2. Advance Care Plan

Does the patient have an advance care plan or an advance decision to refuse treatment?
Document their wishes regarding treatment such as DNACPR, antibiotics for infections, ventilation, and care at the time of and after death.

3. Preferred place of death

Does the patient have a preferred place of death? If so, where is it? Is it possible to achieve this?
Liaise with Discharge Team if rapid discharge home or to nursing home is required.
Refer to the Palliative Care Team for consideration for hospice transfer.

4. DNACPR

For almost all patients who are in the last days of life, CPR would not be successful and it is not appropriate. A DNACPR form should be signed and filed at the front of the medical notes, and any discussion with the patient and/or relatives about this documented as usual. The patient and/or family should be informed of the decision unless doing so would cause physical or psychological harm. If a form has been completed but not discussed with the patient and/or family, clearly state the reason for this.
Refer to HDFT DNACPR policy.

5. Implantable Cardiac Defibrillator (ICD)

If an ICD is in place it should be deactivated.
Contact the cardiology department on x3323 Monday to Friday 8am to 5pm to arrange this.
Refer to the ICD deactivation policy and the magnet application policy if deactivation is required outside these hours.

6. Tissue Donation

Does the patient wish to donate tissue after their death? If they do, refer to the guidelines on organ donation.

Nutrition and hydration

- Decisions about the use of clinically assisted nutrition and hydration (CAN and CAH) should be made by a senior clinician, supported by the MDT.

- Review the need for CANH bearing in mind the following:
    - Patients should **always** be supported to eat and drink for as long as tolerated.
    - If there is a risk of aspiration, patients with capacity may wish to accept this risk and continue to eat and drink. For patients without capacity, a best interests decision should be made in the usual way.
    - At all stages, good mouth care is essential for comfort.
    - A reduced need for food and fluids is part of the normal dying process. For many patients the use of CANH will not be required or tolerated.

- It is important to weigh up the likely benefits and burdens of CANH.

Clinically Assisted Hydration (CAH) (IV or SC fluids, or fluid via PEG, PEJ, NJ or NG tube):

- Some groups of patients may benefit from CAH, eg patients with bowel obstruction or head and neck malignancy who are unable to take or keep down oral fluids, and who are thirsty. However, in other patients, as urine output falls in the last days of life, CAH may cause fluid overload and lead to limb oedema and respiratory secretions, without improving dry mouth or thirst. In these patients, if CAH is already in place, consider stopping it or reducing the rate and/or volume according to individual need. If CAH is required, consider using the SC route rather than IV.

- If a patient and/or family is keen for the patient to have CAH, it may be appropriate to do to this with an agreement to stop at a certain point if or when the burdens outweigh the benefits eg if IV cannulation becomes too difficult.

- There is no evidence that CAH alters prognosis at the end of life.

Clinically Assisted Nutrition (CAN) (feeding via PEG, PEJ, NJ or NG tube or TPN):

- Artificial enteral feeding (feeding via PEG, PEJ, NJ or NG tube) can cause side effects such as aspiration, abdominal pain, nausea and diarrhoea. For patients who have been receiving TPN there will need to be careful consideration about benefits and burdens of treatment. It is an invasive intervention requiring regular blood tests and has potential complications such as central line infection and fluid overload.

- In the last days of life, it is important to think about the goals of treatment and what the likely benefits are. If CAN is already in place, consider stopping it or reducing the rate and/or volume according to individual need.

The patient's nutritional and hydration status and needs should be assessed DAILY and decisions documented.

Eating and drinking in the last days or hours of life

Please follow the guidance below and document any discussion with the patient or carers

1. Is the patient responsive?

Yes: Offer food/fluids. If a swallow is unsafe* consider modified food/fluid options. Normal fluids may be given unless cause distress. Referral to SLT/Dietetics is NOT appropriate at this time.

Review patient's responsiveness on each review

Drowsy/Semi-responsive: If able to take food/drinks (e.g. if they respond to a teaspoon being put to the lips by opening mouth or suck on mouth-care sponge) then reposition into safe 'sit up' position and offer food/drinks, even if their swallow is known to be unsafe. If the patient is unable to manage fluids from a cup, consider offering fluids via teaspoon.

Review patient's responsiveness on each review

No: Provide regular mouth-care as per HDFT Last Days of Life Symptom Management Guidance

Review patient's responsiveness on each review

2. Does the patient have clinically assisted hydration (IV/SC or via NG/NJ/PEG/RIG)?

Yes

Is it appropriate to continue? Discuss with patient (if able) and those important to them. If it is continued then the medical team must review this decision daily. If stopped then continue to offer food/fluids (see Q1)

No

Continue to offer food/fluids (see Q1)

3. Does the patient have clinically assisted nutrition (NG/NJ/PEG/RIG/TPN)?

Yes

Is it appropriate to continue?
Discuss with patient (if able) and those important to them to consider either stopping or reducing volume of feed to reduce discomfort/bloating.
If an enteral feeding tube is in place consider providing fluids via this route rather than IV/SC.
These decisions can be made with the help of the dietician.
The medical team must review this decision daily.

No

Continue to offer food/fluids (see Q1)

*Unsafe swallow is defined as 'if all oral intake, including modified consistency diet and thickened fluids, poses a high risk of aspiration'. Patients who are Nil By Mouth (NBM) due to an unsafe swallow should **NOT** remain NBM once entering the last days of life.

Interventions

- Review the following interventions and consider whether or not it is appropriate to continue them, bearing in mind that the focus of care is on controlling symptoms:

    - Routine blood tests
    - Oral or intravenous antibiotics
    - Blood glucose monitoring
    - Recording of vital signs
    - Oxygen therapy
    - Anticoagulants eg tinzaparin

Medication

- Review regular medications and discontinue any that are not contributing to symptom control.

- Convert medications essential for symptom control to an alternative route. If required, these are usually given via a continuous SC infusion via a syringe driver or as a stat SC dose.

- See the guidance in the following pages for management of specific symptoms and conditions.

Anticipatory prescribing

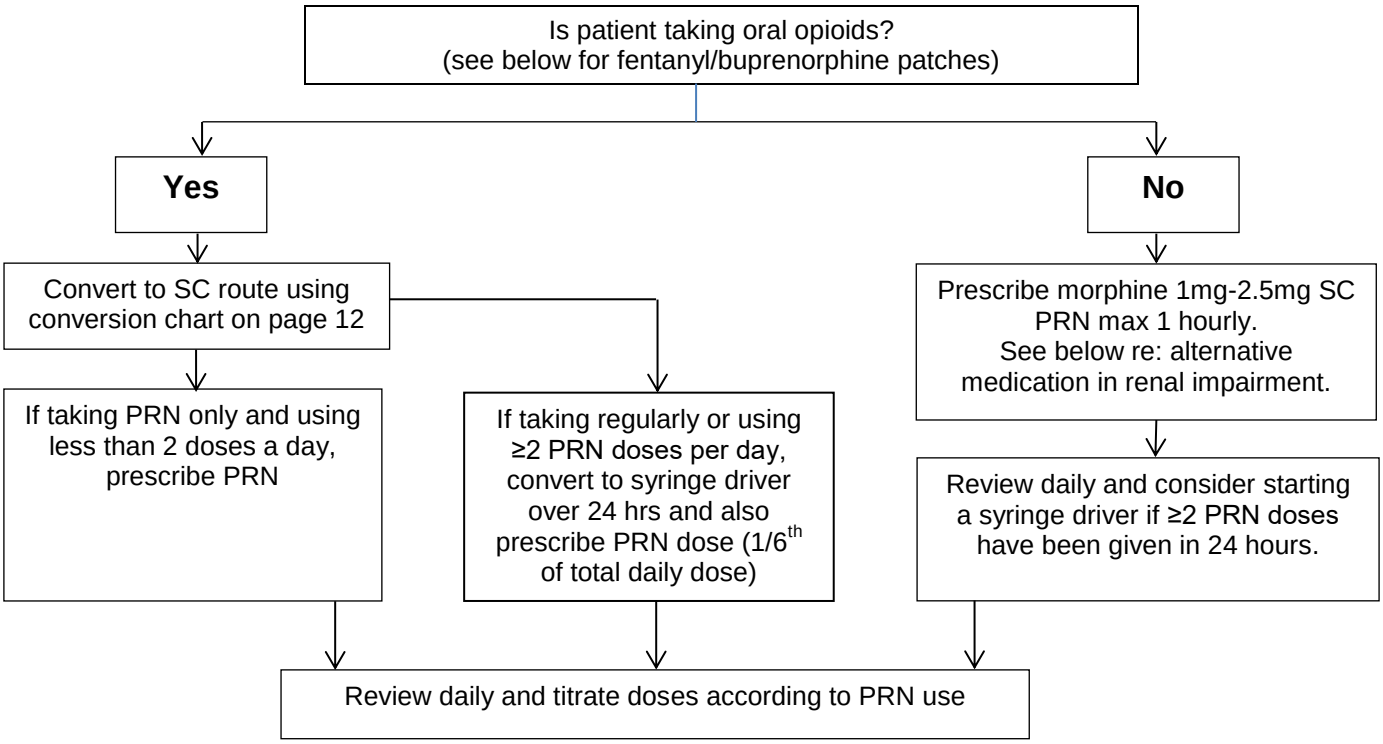
- In order to enable symptoms to be controlled without delay, all patients should have 'as required' (PRN) SC medication for symptom control prescribed for the relief of:
    - pain
    - nausea/vomiting
    - restlessness
    - shortness of breath
    - respiratory tract secretions
- Follow the guidance in the following pages and see also:
    - Yorkshire and the Humber Guide to Symptom Management in Palliative Care
    - End of Life protocol on ePMA

Always prescribe the following 4 SC PRN medications:

- **Opioid analgesic**: choice and dose depends on the patient and previous opioid use (see page 11)
    - 1/6th of 24 hour dose of any regular opioid max 1 hourly
    - If not on a regular opioid, morphine 1mg-2.5mg max 1 hourly (oxycodone 0.5mg-1.5mg max 1 hourly in renal impairment)
- **Anti-emetic**: choice depends on the patient and previous anti-emetic use (see page 14)
    - If not nauseated and not on a regular anti-emetic, levomepromazine 2.5mg-6.25mg max 4 hourly
- **Midazolam** 2mg-5mg max 1 hourly
- **Hyoscine butylbromide** 10-20mg max 1 hourly

- Where a dose range has been prescribed, start with the lowest dose, assess benefit and titrate as clinically indicated.
- If more than 2 doses in 24 hours are required, consider the use of a syringe driver.
- If the patient is at risk of **sudden deterioration** eg catastrophic haemorrhage or tracheal obstruction, agree an anticipatory care plan with the patient, family and treating team, and prescribe appropriate PRN medication eg midazolam 5-10mg IM.

Pain



Supporting information

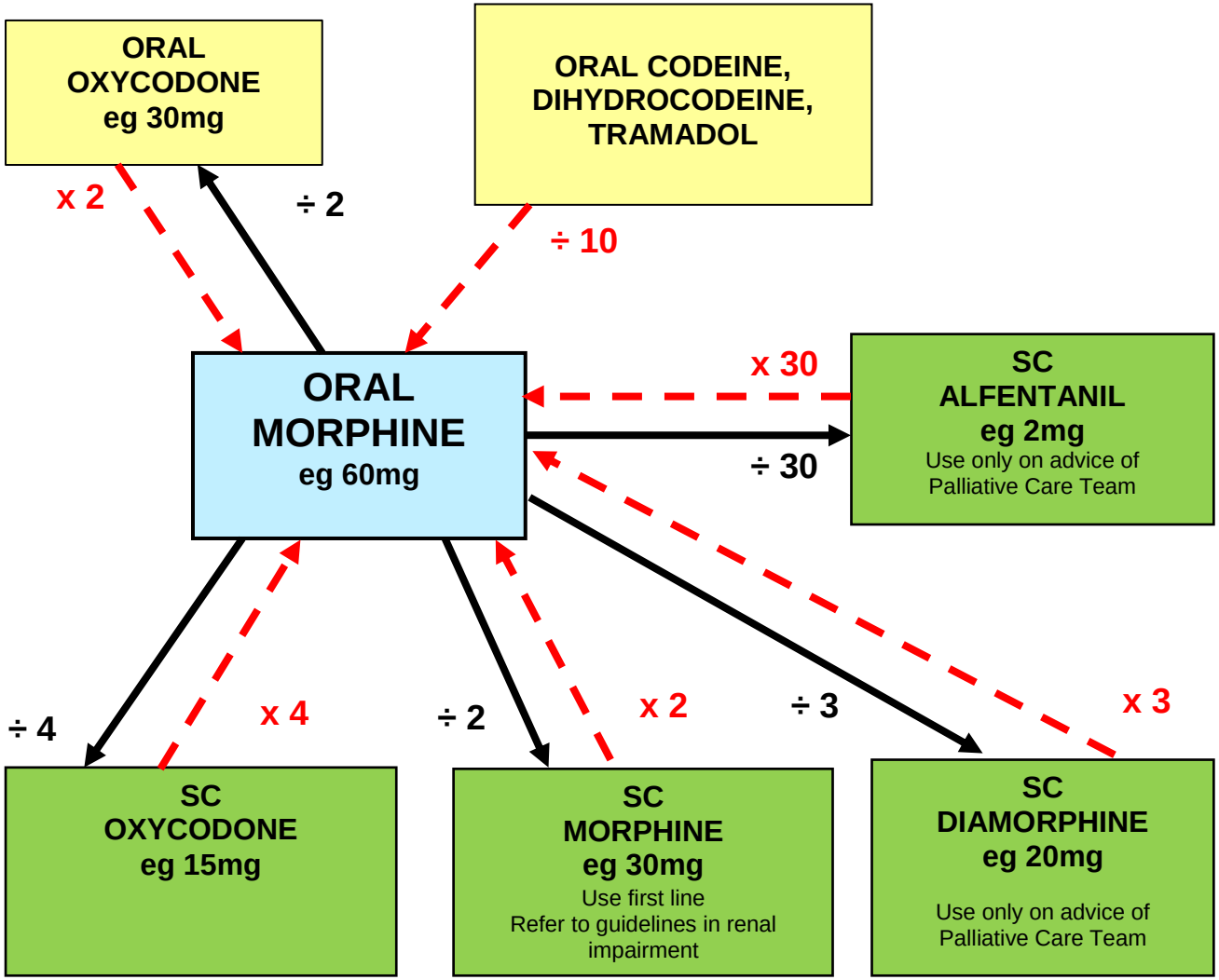
- For opioid conversions, see the conversion chart on page 12
- **If on oral oxycodone** use SC oxycodone instead of morphine
- The starting dose of SC oxycodone if opioid naïve is 0.5mg-1mg PRN max 1 hourly
- Morphine and its active metabolites accumulate in renal impairment and can cause opioid toxicity. Consider switching from morphine if the GFR is below 50ml/min. This may not be necessary if there are no opioid side effects and renal function is stable, however the use of morphine is not usually recommended below a GFR of 30ml/min.
- **If severe renal impairment, refer to the Palliative Care Team**
- Observe for signs of opioid toxicity eg drowsiness and twitching, particularly in patients with poor renal function
- **Fentanyl and buprenorphine patches:**
  - **Do not remove the patch(es) as this may lead to poor pain control**
  - If pain is uncontrolled commence a syringe driver containing opioid **in addition to the patch** according to the PRN doses that have been required
  - Administer breakthrough analgesia as required according to the chart below

Transdermal fentanyl patch dose	Breakthrough dose of SC morphine
12mcg/hr	2.5mg-5mg
25mcg/hr	5mg-7.5mg
37mcg/hr	7.5-10mg
50mcg/hr	10-15mg
62mcg/hr	12.5-17.5mg
75mcg/hr	15-22.5mg

  - If the patient is on both a patch and an opioid in a syringe driver, both will need to be taken into account when calculating the dose for breakthrough.

OPIOID CONVERSION CHART JUNE 2020

- To convert between opioids, always convert to equivalent dose of oral morphine first
- These conversions are approximate guides based on BNF and other specialist guidance and may differ from product specifications
- People metabolise opioids differently, so conservative conversions are recommended, especially at high doses, and it may be appropriate to consider a dose reduction
- Ensure that PRN medication is prescribed, review frequently and titrate as necessary
- Leave patches in place in dying patients and give additional opioid via a syringe driver if necessary

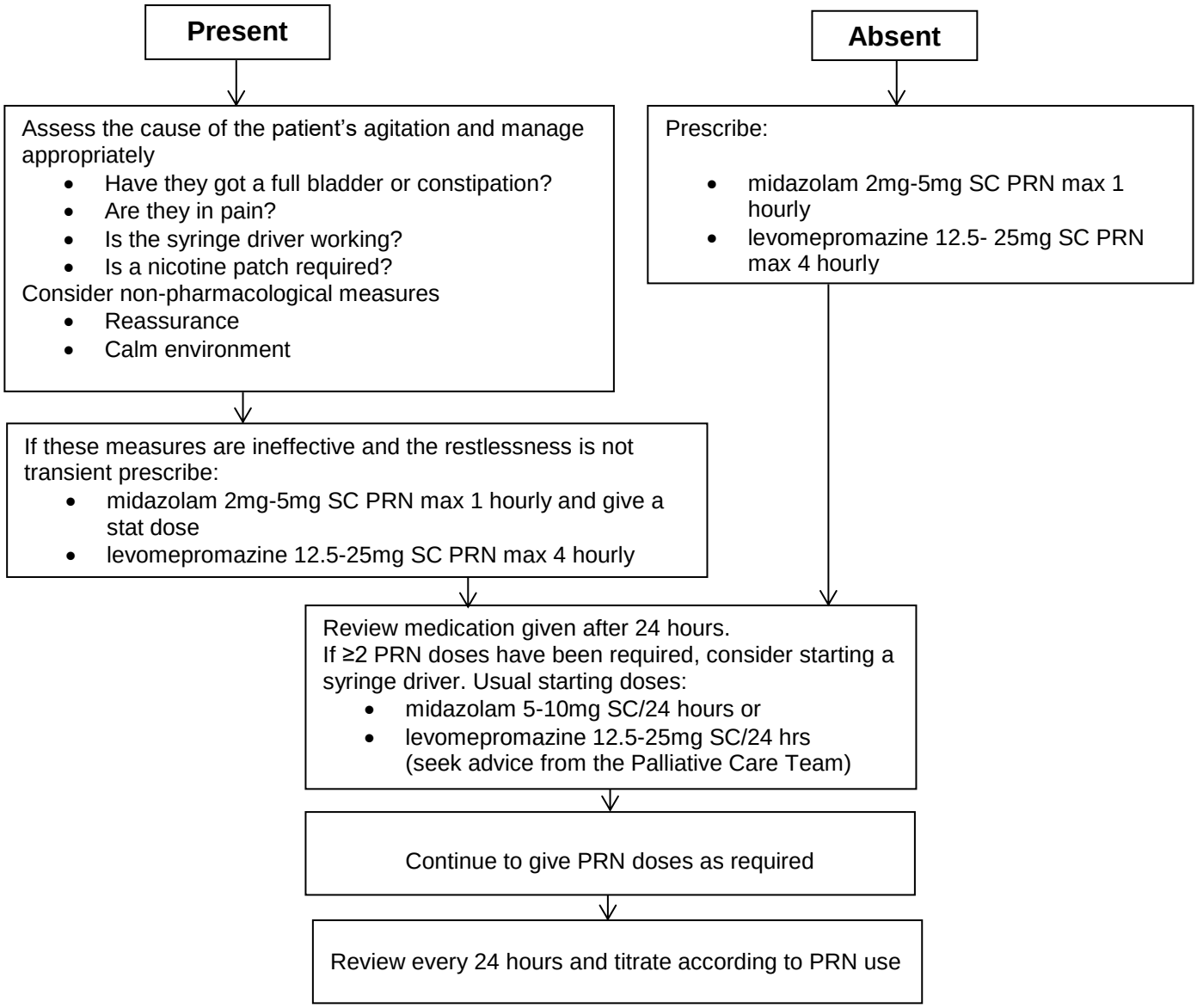


Fentanyl patch mcg/hr	Equivalent 24hr dose of oral morphine	PRN dose of Oramorph required
12	30-45mg	5-10 mg
25	60-90mg	10-15mg
37	90-135mg	15-20mg
50	120-190mg	20-30mg
62	150-220mg	25-35mg
75	180-310mg	30-45mg
doses >75mcg/hr: seek specialist advice		

Buprenorphine 7 day patch		
Buprenorphine Patch mcg/hr	Equivalent 24hr dose of oral morphine	PRN dose of Oramorph required
5	10-15mg	1-2mg
10	20-30mg	3-5mg
20	35-55mg	5-10mg

Buprenorphine 3 or 4 day patch (check frequency of patch change)		
Buprenorphine Patch mcg/hr	Equivalent 24hr dose of oral morphine	PRN dose of Oramorph required
35	60-95mg	10-15mg
52.5	95-145mg	15-20mg
70	125-190mg	20-30mg

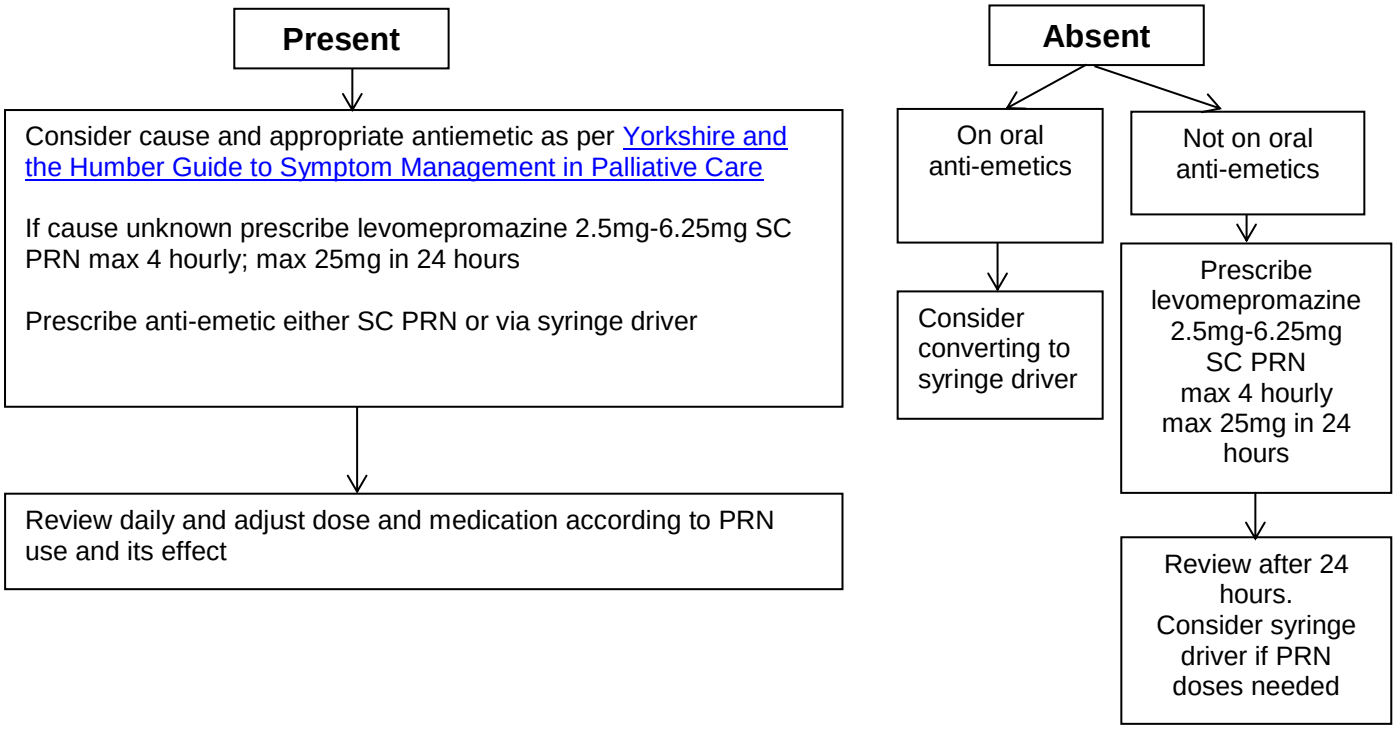
Terminal restlessness and agitation



Supporting information

- Midazolam should be used 1st line for restlessness and agitation
- Use levomepromazine if midazolam not effective or at doses of 40mg/24 hours or more, and seek advice from the Palliative Care Team
- Occasionally midazolam can cause a paradoxical increase in agitation

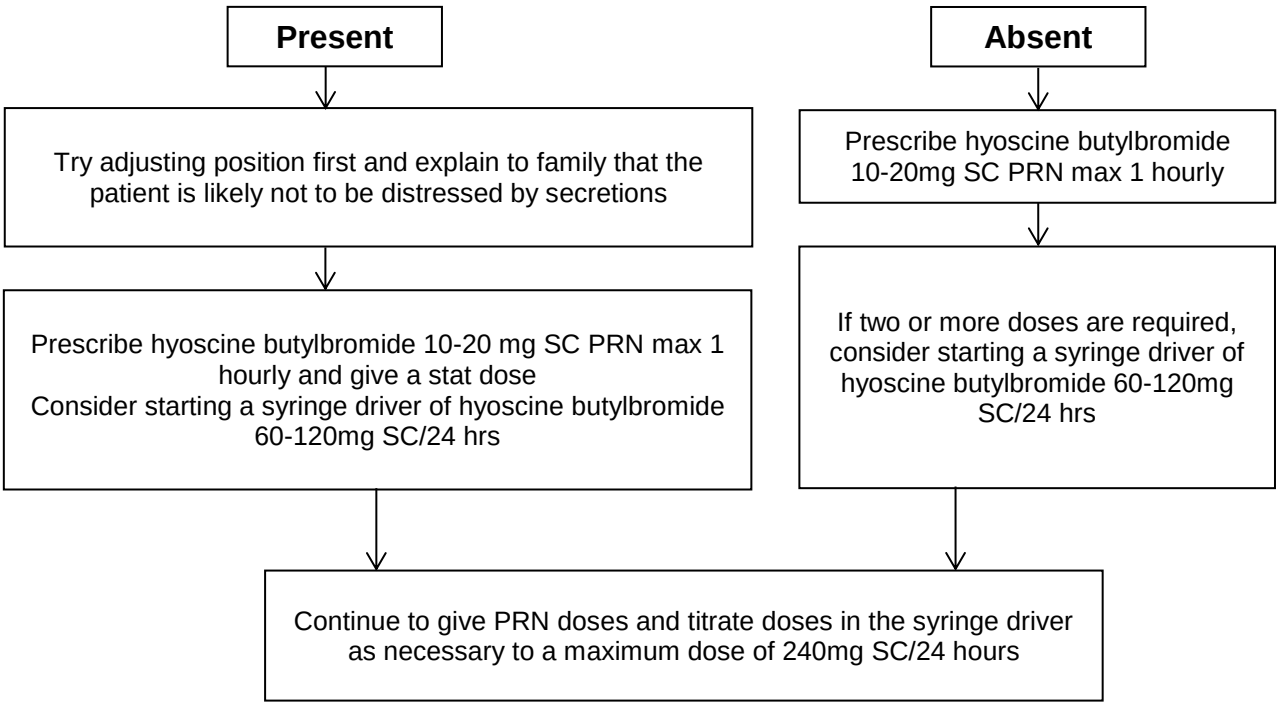
Nausea and vomiting



Supporting information

- Haloperidol, cyclizine and metoclopramide can be given SC
- Usual starting doses in a syringe driver are:
  - Haloperidol 1mg-5mg in 24 hours
  - Cyclizine 100-150mg in 24 hours
  - Metoclopramide 30mg in 24 hours
- Avoid cyclizine in heart failure as it may exacerbate symptoms
- Avoid metoclopramide and haloperidol in Parkinsonism
- **Do not prescribe metoclopramide and cyclizine together** as they have opposing actions

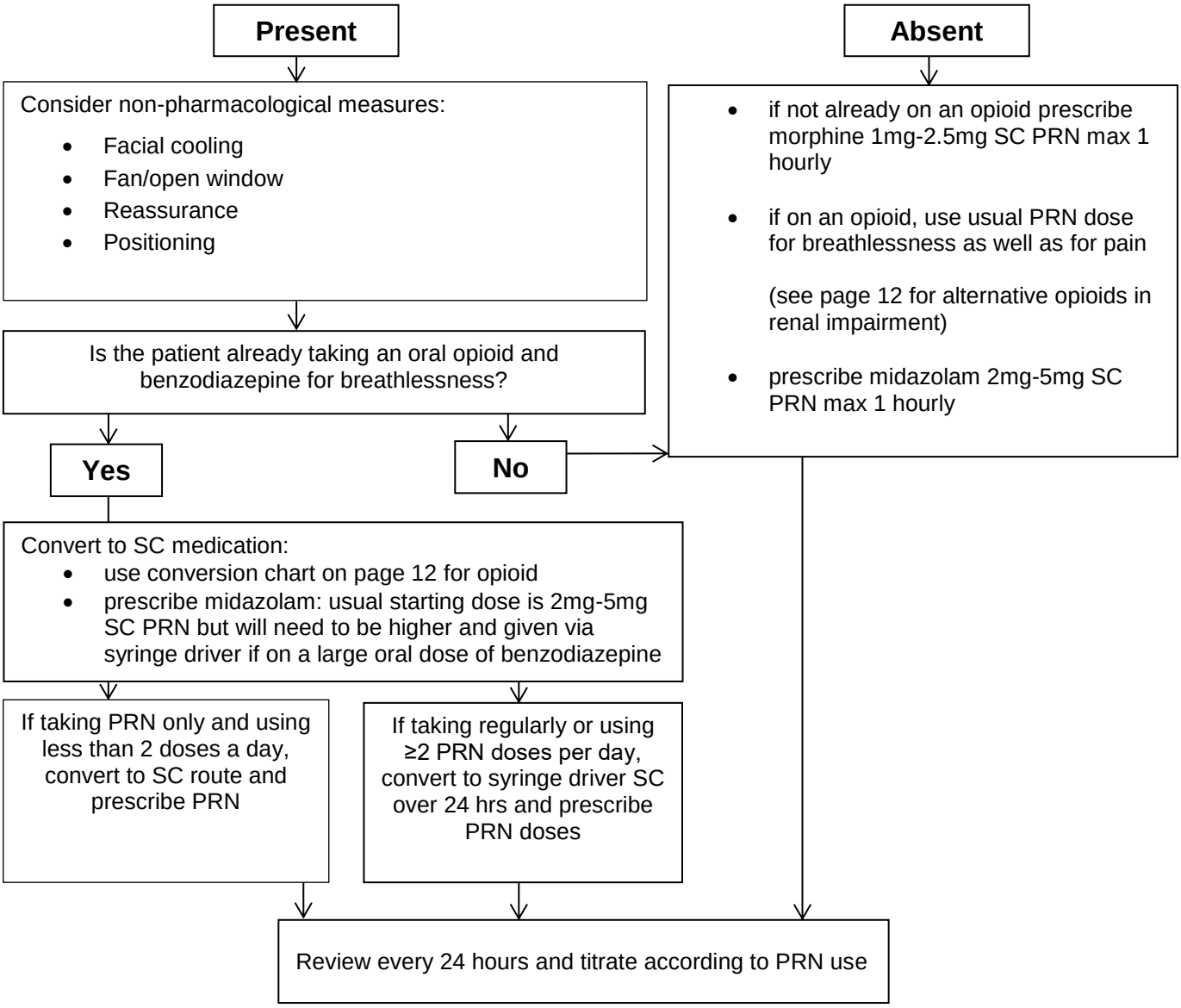
Respiratory tract secretions



Supporting information

- Avoid the use of suction/nebulisers
- Monitor for side effects of hyoscine butylbromide such as dry mouth

Breathlessness



Supporting information

- Oxygen is usually only appropriate if saturations are <90% and if oxygen increases sats and improves symptoms
- Always consider whether or not it would be appropriate to treat the underlying cause of the dyspnoea to relieve symptoms eg with antibiotics, steroids or pleural tap

Seizures

- **In dying patients** with epilepsy or who have brain pathology causing seizures, once oral anti-epileptic medication can no longer be taken orally, seizures should be prevented with subcutaneous midazolam:
  - Prescribe midazolam 20-30mg SC over 24 hours via syringe driver and midazolam 10mg SC PRN
  - Increase the syringe driver dose if PRN doses are needed and effective
  - If seizures persist despite midazolam 40mg/24hrs, seek advice from the Palliative Care Team

- **For patients who are not imminently dying** but who are unable to swallow oral anti-epileptic medication, contact the Palliative Care Team for advice.

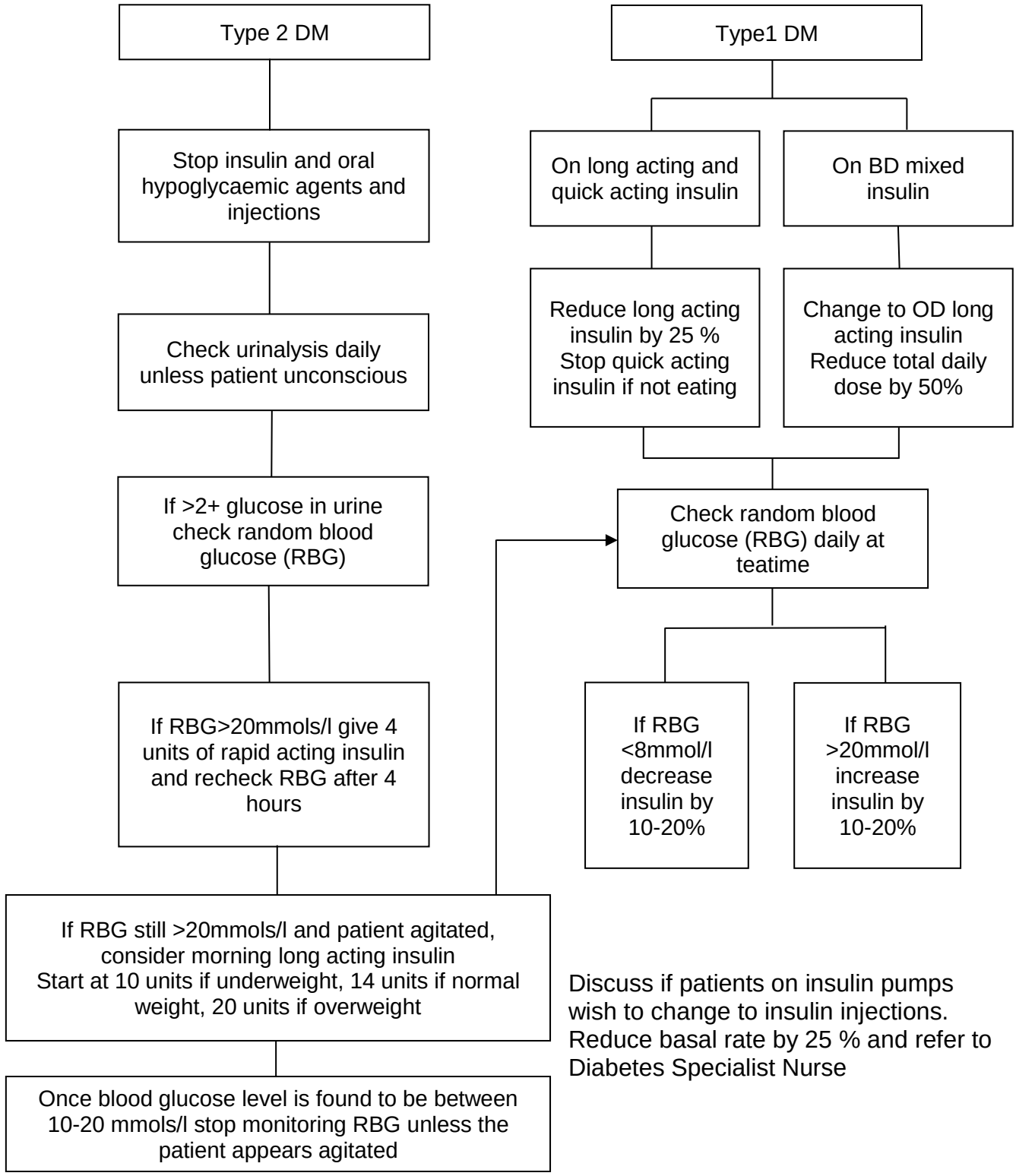
Steroids

- **Steroids not contributing to symptom relief**:
  - Stop at the end of life when the oral route is no longer available
  - If the patient is actively dying, Addisonian withdrawal effects are not usually relevant

- **Steroids contributing to symptom relief** (ie symptoms likely to recur if steroids stopped eg severe headaches or vomiting due to brain metastases):
  - Convert to a subcutaneous (SC) bolus of dexamethasone each morning
  - Seek advice from the Palliative Care Team if needed

Diabetes Mellitus

Discuss changes with patient/carer where possible. Refer to Diabetes Team for advice as needed.



Discuss if patients on insulin pumps wish to change to insulin injections. Reduce basal rate by 25 % and refer to Diabetes Specialist Nurse

Ensure an appropriate range of insulin dose is prescribed
Please contact the Diabetes Team for advice if needed

Oral Care

- Dry mouth and thirst are common symptoms in people who are dying.
- Good mouth care can help prevent thirst and maintain comfort.
- Patients may be able to manage sips and should continue to be offered oral fluids.
- Where patients can no longer manage oral fluids, staff must provide regular mouth care.

General Care

- Ensure that the mouth is examined and reassessed regularly.

- Where patients can no longer manage oral fluids, offer hourly mouth care as a minimum. Family/carers may be able to perform mouth care, giving them greater involvement.

- Gently remove coatings, debris and plaque from soft tissues, lips and mucosa. Use of a small soft tooth brush is preferable. Foam mouth swabs are an alternative.
  Check the foam head is firmly attached. Do not leave swabs soaking because of risk of detachment and choking. Dispose after single use.

- Apply yellow soft paraffin to dry lips after mouth care. Consider a water based alternative (e.g. lubricating jelly) if on oxygen.

- Remove dentures

Dry Mouth

- Review medications; medicines used in the last days of life can often cause dry mouth.

- Oxygen therapy may aggravate dry mouth. Consider whether this is still required, or whether it could be administered via nasal cannulae rather than a face mask. Consider humidification if on > 4l/28% via face mask.

- Suggestions:
  - Frequent sips of cold unsweetened drink (if able)
  - Topical dry mouth moisturising gels:
    - First line: BioXtra® gel/spray
    - Second line: Oralieve

    Massage into all areas of the mouth (cheeks, palate, tongue) using a gloved finger, toothbrush or foam swab.

Coated Tongue

This indicates poor salivary gland function.

- Brush tongue gently with a soft small tooth brush.
- Pineapple is sometimes suggested, but caution is suggested with the use of acidic substances, as they can increase risk of dental caries/infections. The importance of this depends on the person's prognosis and whether they still have teeth.

Sore or Ulcerated Mouth

- If conscious and able to spit out, consider use of Gelclair® alcohol free mouthwash or normal saline mouthwash.
- Topical analgesia options: benzydamine hydrochloride (Difflam®), choline salicylate (Bonjela®)
- If not responsive to the above measures, seek specialist advice. Systemic analgesics may need to be considered