University Hospitals of North Midlands NHS
NHS Trust

Accompanying guidance for care in the last days of life

Version	**5**
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Name of responsible committee/individual	**UHNM End of Life Group**
Date issued	**13/5/24**
Review date	**13/5/27**
Date of first issue	**14/9/15**
Target audience	**All health professionals in UHNM**

VERSION CONTROL

Document name: Accompanying guidance for care in the last days of life		
Version	**Valid From**	**Valid To**
1	14/9/15	14/9/16
2	22/7/16	22/7/18
3	12/7/19	12/7/21
4	19/6/23	19/6/26
5	13/5/24	13/5/27

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Introduction

More than half of deaths locally and nationally occur in acute hospitals. Care of the dying patient is a core part of our work. High quality care for the patient in the last days of life is essential for ensuring a peaceful and dignified death. Caring for dying patients can involve complex decision making and can be emotionally challenging. This guideline has been produced to help you in dealing with some of the issues that may arise when caring for a dying patient. This guidance is intended to accompany the use of the Individualised Care Bundle for the last days of life which should be used to document the care plan and care given to the patient.

Recognition of dying

It may be difficult to ascertain when a patient is approaching the last hours or days of life. The decision that a patient is in the last days of life is based on clinical assessment. Unfortunately there is no test to make this diagnosis. It is important that a full assessment of the patient takes place. Some reversible conditions can mimic dying and potentially reversible causes of the patient's condition such as renal failure, infection and hypercalcaemia should be checked for. If a potentially reversible cause is identified, treatment should be considered. However, if the patient is clearly in the dying phase of their illness there should be careful consideration of whether treating potentially reversible causes will benefit the patient. The patient's condition and care needs should be assessed by the multidisciplinary team involved in their care. The decision that the patient is in the last days of life should be clearly documented in the medical and nursing documentation. The medical document for the last days of life, page 3 of the Individualised Care Bundle for Last Day of Life can be completed by any member of the medical team with the agreement of the responsible consultant but should be signed by the consultant within 24 hours. This document provides a framework for documentation and care planning.

Determining when a patient is in the last days of life is difficult and there are occasions when a patient who is thought to be dying improves or lives longer than expected. Patients who are thought to be in the last days of life should be reviewed on a regular basis for any change in their condition or in their care needs. If the patient is no longer thought to be in the last days of life discontinuing these documents should be considered. In some cases when there is uncertainty over whether the patient is in the last days of life, it may be helpful to seek a second opinion from another consultant or from the Specialist Palliative Care Team.

Responsibility

All patients should have a named consultant who is responsible for their care both in and out-of-hours. Unless it is urgent and unavoidable, the decision that a patient is dying and any changes in treatment plan should be made in-hours by the responsible consultant in consultation with the multidisciplinary team involved in the patient's care. Making such decisions during on-call periods should be avoided wherever possible.

Each patient should have a named nurse or team of nurses for each shift of care who are responsible for their care. This nurse is responsible for providing and co-ordinating the patient's care, communicating effectively with the patient and family and ensuring any concerns are addressed.

Consent

Valid patient consent or a decision in a patient's best interests is required before beginning any treatment or other intervention for a patient. The Individualised Care Bundle for Last Days of Life documentation is not a single intervention, and does not determine a particular course of treatment. The Individualised Care Bundle for Last Days of Life document is a place to document the patient's plan or care and any decisions that have been taken. Consent, or a best interest's decision, is however required for each of the treatments that comprise the patient's medical plan and this should be fully discussed with the patient (when they are able to participate) and their relatives or carers. Where the medical plan includes a decision that it would not be clinically appropriate to initiate or continue a particular treatment or intervention, this decision does not require consent. However, it is very important to consult the patient and their relatives or carers about this decision. The recent Court of Appeal judgement regarding DNACPR has emphasised the importance of consulting patients and families about such decisions. Although these discussions can be difficult and sensitive, the desire to avoid upsetting patients or families members is not a valid reason for failing to inform them about important decisions about their care. The same principle applies to the Individualised Care Bundle for Last Days of Life documentation. Although the Individualised Care Bundle for Last Days of Life documentation is not a single decision, the documentation should not be started without consulting the patient (when they are able to participate) and their relatives or carers. A patient and carer information leaflet should be offered complete with a named member of staff who can be contacted. This leaflet can be found and detached from page 5 of the Individualised Care Bundle for Last Days of Life.

Communication and capacity

Communication with the patient and their family is central to providing effective end of life care. Although discussing dying can be difficult, open and honest communication helps to build confidence and trust.

A person must be assumed to have capacity to make their own decisions unless it established that they lack capacity. Each area of decision-making should be assessed separately to enable the person concerned to participate in decision making as far as possible. It is essential that the people who know the person best are involved as fully as possible. If it has been assessed that a patient lacks capacity to make a particular decision it will be necessary to determine what action would be in the person's best interests along with consulting relevant family members and determining previous wishes and feelings about care.

Communication with a patient who is in the last days of life can be challenging. It is not uncommon for patients to become fatigued, confused or to have a reduced level of consciousness. However, it should not be assumed that all patients in the last days of life are not able to or do not want to receive information or be involved in decisions about their care. Although some individuals may find conversations about poor prognosis and dying distressing, many do wish to have this information. It is important to explore the patient and their family's current level of understanding and ascertain how much information they wish to know. If the patient wishes to have a family member present when sensitive or distressing issues are discussed, this should be facilitated. When the patient is not able or does not wish to be involved in this discussion, communication should take place with the patient's family or carers.

An honest and sensitive conversation should take place following the trust guideline for breaking bad news. An explanation should be given that the patient is in the last days of life. Any changes to the plan of care should be explained. It is important to always acknowledge that there is uncertainty around the exact prognosis and explain that the patient's condition and care plan will be reviewed regularly. Always allow the patient and their family the opportunity to discuss any issues and to ask questions. This conversation is an opportunity to find out if the patient and family have any wishes about their care in the last days of life or if there are any cultural or spiritual practises that are important to them. This conversation can be supported with the trust leaflet "Coping with Dying and Purple Bow Scheme" found on Page 7 of the Individualised Care Bundle for Last Days of Life.

Review of current treatment and plan of care

When the decision is made that the patient is in the last days of life, the goals of care may change. When the patient is dying and this is irreversible, treatments aimed at reversing acute medical problems or treatments for controlling chronic conditions may no longer be as relevant. However, some treatments may still be beneficial. A full review should be undertaken of all treatments and interventions that the patient is receiving. For each intervention, assess whether it will provide a benefit to the patient such as making them more comfortable or helping to plan the patient's care. It is also important to consider whether the intervention is unpleasant or difficult for the patient such as invasive or painful procedures. The benefits and burdens should be carefully weighed up for each intervention. If changes are made to the plan of care this should be clearly documented and communicated to the patient if appropriate and their family. The medical document for care in the last days of life, found on Page 3 of the Individualised Care Bundle for Last Days of Life, can be used to document this. The plan of care should be reviewed on a regular basis and adjusted if needed to best meet the patient's needs.

As well as reviewing current interventions it is helpful to consider interventions that may be considered in the future. This is often referred to as a treatment escalation and limitation plan (TELP). This can help to guide the team caring for the patient which interventions would be appropriate to consider and which would not. For example starting new invasive investigations or treatments may not be appropriate when the deterioration in the patient's condition is irreversible. The ReSPECT form can be used to document TELP decisions.

Cardiopulmonary resuscitation

It is important to consider the patient's resuscitation status in the last hours or days of life if this has not already been addressed. The cessation of cardiac and respiratory function is part of the natural dying process. Resuscitation cannot reverse the dying process and is not indicated in this situation. Putting in place a DNACPR decision as part of completion of the ReSPECT form is important to ensuring a peaceful and dignified death. Decisions about resuscitation should be made by a senior clinician. It is best practice to discuss resuscitation decisions with the patient, whenever possible, and their family. Discussing resuscitation can be difficult and this should be undertaken in a sensitive way.

Hydration and nutrition

For the patient in the last days of life, attending to nutrition and hydration needs continues to be an essential part of care. The patient's ability to take oral nutrition and hydration should be assessed when it is determined they are in the last days of life. It is often part of the natural dying process for oral intake to reduce. In some cases this is due to reduced appetite but often it occurs due to reducing level of consciousness in the last days of life. All patients in the last days of life should receive good, regular mouth care. The patient should be supported to take food and fluids whenever possible. The decision of whether to continue or commence clinically assisted nutrition or hydration should be made on an individual basis. These interventions are regarded as medical treatments. The benefits and burdens of these treatments should be weighed up in the same way as other parts of the treatment plan. Occasionally continuing or commencing treatment may benefit the patient. However, providing assisted nutrition or hydration in the last days of life can cause distressing problems such as aspiration in the case of assisted nutrition and subcutaneous or pulmonary oedema in the case of assisted hydration. Concerns about nutrition and hydration in the last days of life can be emotive and distressing for the patient and their family. Decisions around withholding or withdrawing clinically assisted hydration or nutrition should be discussed sensitively. This conversation can be supported by providing written information. The trust leaflet "Coping with Dying and Purple Bow Scheme" can be used.

Anticipatory prescribing and symptom control

The following symptoms occur commonly in patients in the last days of life:

- Pain
- Dyspnoea
- Nausea and vomiting
- Agitation
- Respiratory secretions

All patients in the last days of life should have subcutaneous medications prescribed to treat these symptoms if they occur. This practice of “anticipatory prescribing” minimises delay in responding to symptoms when they occur. Medication should only be given when needed, in an appropriate dose.

If the patient experiences symptoms or if they are prescribed regular oral medications for symptom control such as strong opioids, they may require a continuous subcutaneous infusion of medication. This is given using a syringe driver pump.

Medical conditions such as renal or hepatic impairment should be taken into account and medications and doses adjusted if necessary. Guidance on anticipatory prescribing and symptom control using syringe driver pumps can be found at the end of this guideline. If the patient experiences symptoms in the last days of life they should be referred to the Specialist Palliative Care Team. This team can provide further advice and support to control the patient’s symptoms.

Spiritual, Pastoral, Religious Care Support (SPaRC)

The SPaRC-Chaplaincy team offers support with assessing spiritual need as well as providing Spiritual, Pastoral, Religious Care to patients, visitors and staff. They help patients and their families make sense of what they are going through whether or not they have a particular faith or belief. They can also offer rituals and rites for patients, their families and carers, such as baptism, emergency marriages and civil partnerships. A patient/family member does not need to feel they are a religious person or be a regular worshipper to make use of the SPaRC service. In some situations the funeral rituals of patients who die in the Trust become the responsibility of the SPaRC team. In this situation they will liaise with the family, to design and deliver an appropriate service for the individual.

The Chaplaincy team are available 24 hours a day, 7 days a week. Normal working hours are 08:30am to 16:30pm Monday to Sunday. A Chaplain is also available outside these hours for urgent calls and referrals for both hospitals by calling 01782 676400. Staff may also obtain on call information through Rota Watch.

Bereavement

The bereaved should be offered a “Helping you cope with Bereavement” booklet, which is available across both hospital sites. The booklet advises the deceased’s family to contact the Bereavement Centre at UHNM the next working day, where a dedicated team of staff are available to support them through the practical steps they need to take after a death (such as how to register the death and arrange a funeral). The family should not make an appointment to register the death until the Bereavement Centre staff have advised that the medical certificate has been emailed to the Registrar. As part of the Bereavement Centre’s processes, the family will be given an opportunity to ask questions or raise any concerns, before they register the death.

Staff support

Many teams have excellent relationships and support each other well as they care for the dying. Occasionally staff may feel extra support is required. When this happens, sources of support include:

- Clinical supervision
- The Specialist Palliative Care Team
- Occupational Health
- Managers can be helpful in expediting an incident review and accessing the correct professionals
- Critical Incident Stress Management (CISM)
- SPaRC –Chaplaincy Team

Monitoring and compliance

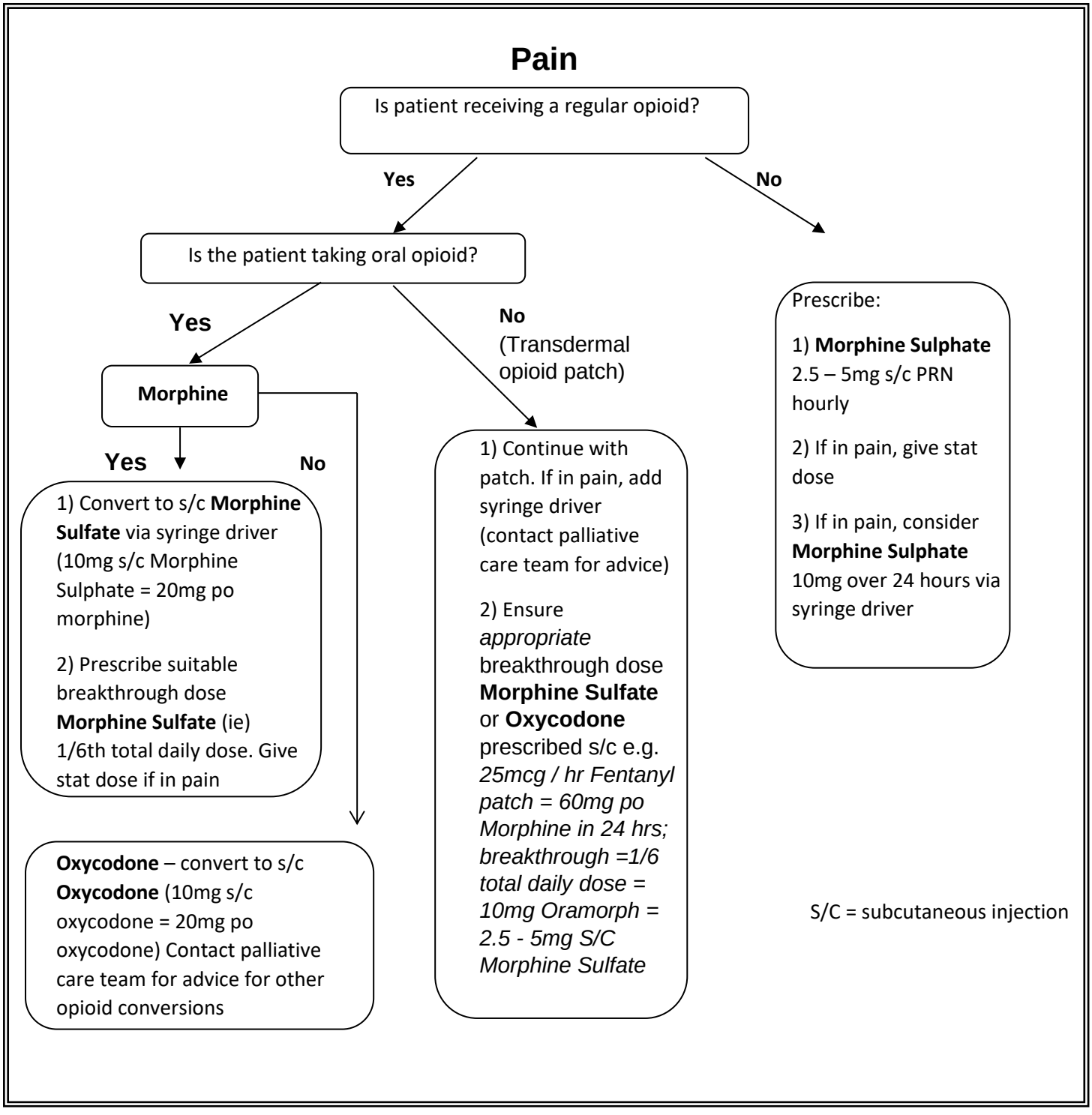
The UHNM End of Life Group will be responsible for monitoring the effectiveness of this guidance. The guidance will be reviewed every 3 years and updated.

Training on the use of the guidance and Individualised Care Bundle for Last Days of Life will be provided for clinical staff.

Medication guidelines for patients in the last hours or days of life

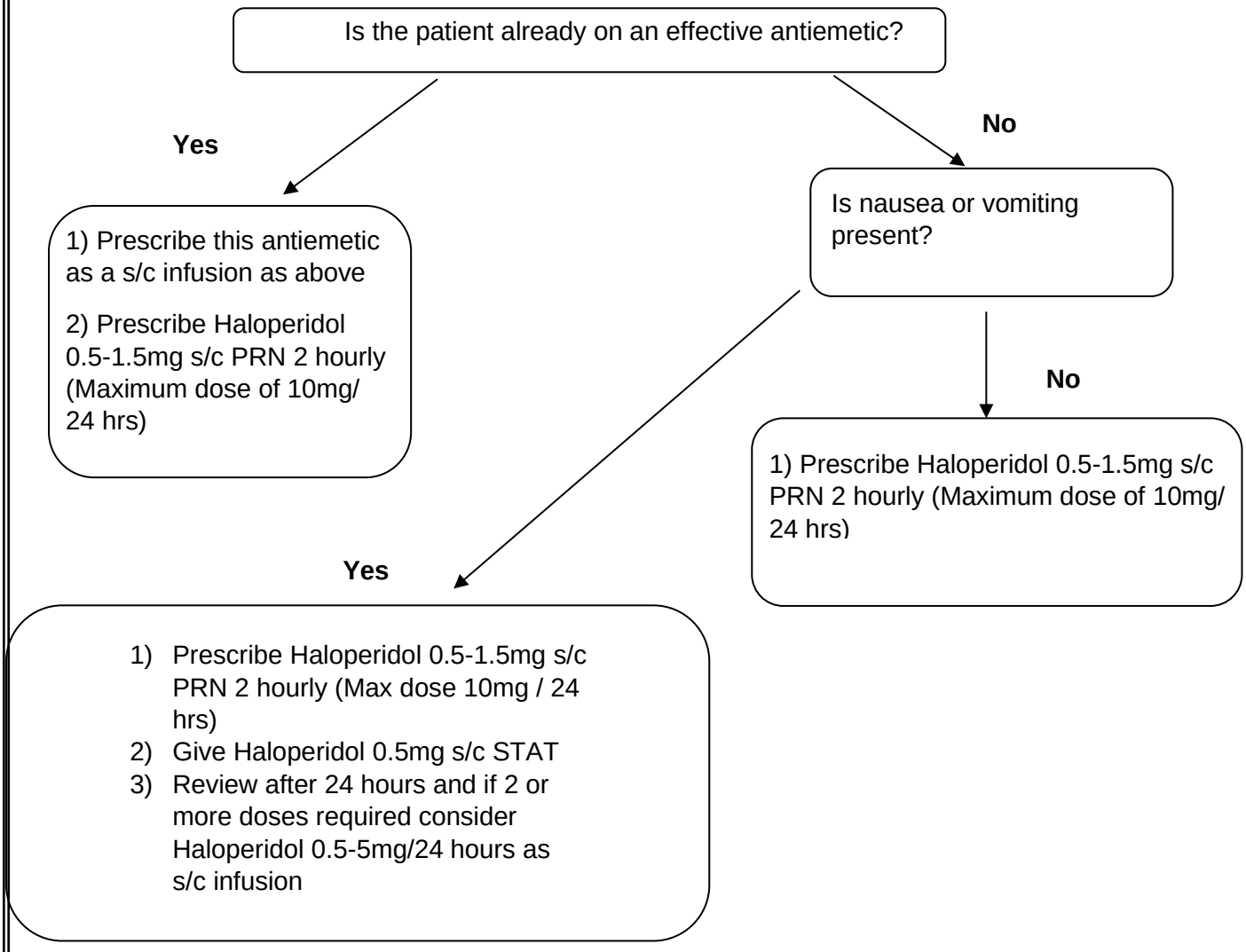
Remember:

- Not all patients need a syringe driver. However, if 2 PRN (as required) doses are given for a symptom in 24 hours, this is usually indicated.
- **Contact palliative care team for use of drugs in moderate to severe renal or hepatic failure and type 2 respiratory failure.**
- If eGFR less than 50, PRN Morphine Sulphate should be replaced with PRN Oxycodone.
- In charts below PRN means given as required. The minimum interval is indicated e.g. hourly



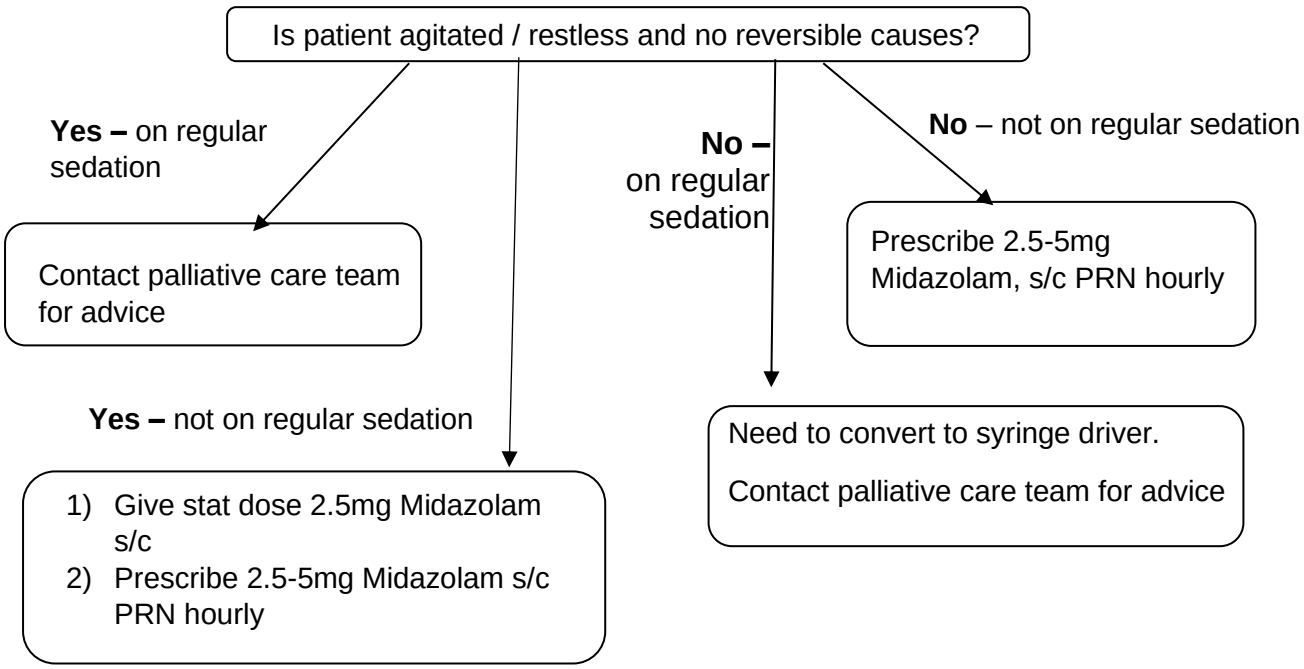
Nausea and vomiting

- To convert the patient's current antiemetic to a s/c infusion by syringe driver over 24 hours:
  - Metoclopramide 10mg tds po / IV = 30mg s/c via syringe driver
  - Cyclizine 50mg tds po / IV = 75mg Cyclizine via syringe driver over 24 hours
- Contact palliative care team if nausea or vomiting persist despite these measures



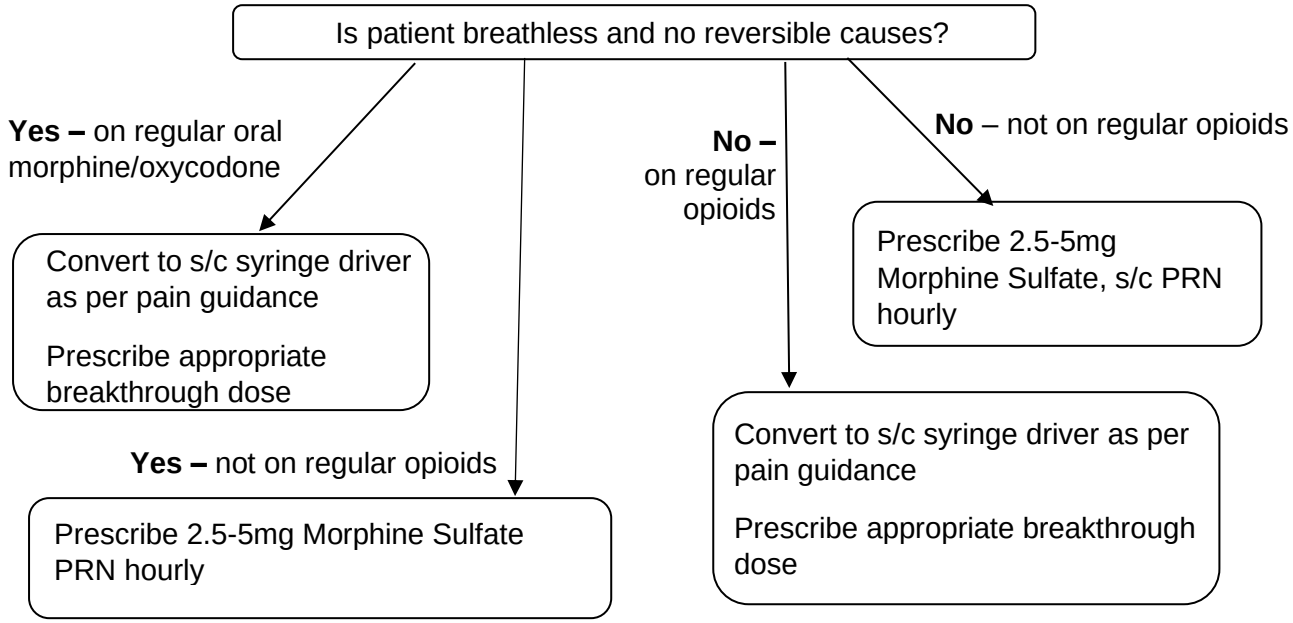
Agitation and restlessness

- Check for reversible causes e.g. urinary retention and constipation
- Consider dose reduction in renal or hepatic failure
- Contact palliative care team if the above not working / for advice if very distressed.



Breathlessness

- Try non-pharmacological measures e.g. fan / calm environment
- Consider dose reduction / use oxycodone in renal or hepatic failure
- Contact palliative care team if patient has severe COPD or type 2 respiratory failure
- Contact palliative care team if the above not working / for advice if very distressed.



RESPIRATORY TRACT SECRETIONS

- Medications are effective in preventing secretions, not removing them from the airways.
    - Repositioning and suction may help if there is a significant quantity of secretions
- Prescribe 20mg **Hyoscine Butylbromide** PRN 4 hourly s/c for secretions for all patients.
- Prescribe syringe driver of 60 – 120mg **Hyoscine Butylbromide** to start if stat dose required.
- If secretions persist contact palliative care team.

• Royal Stoke and County: The palliative care team take referrals by "ordercomms" and can be contacted 9am-5pm, every day on 01782 (6)74029.

• Out of hours advice for both sites is available from Douglas Macmillan Hospice on 01782 344300 or from the on-call consultant on Rotawatch.