

## Symptom Management for The Dying Adult



LIVERPOOL HEART AND CHEST HOSPITAL  
ENTRANCE

By the end of this session you will be able to:

- List common reasons why practice can fall short of what patients need and identify potential solutions
- Discuss symptoms that commonly arise in the last days to hours of life
- Describe how to address the dying person's comfort
- Understand how to manage diabetes in the last days to hours of life
- Write a typical prescription and authorisation for medication used to control symptoms at the end of life
- Understand the advantages and disadvantages of prescribing these drugs in anticipation of these symptoms developing

The ability to enable patients to die in comfort, without troubling symptoms, is an essential skill for nurses and doctors. To be able to help achieve a peaceful, dignified death, when others have said:

There's nothing more we can do...

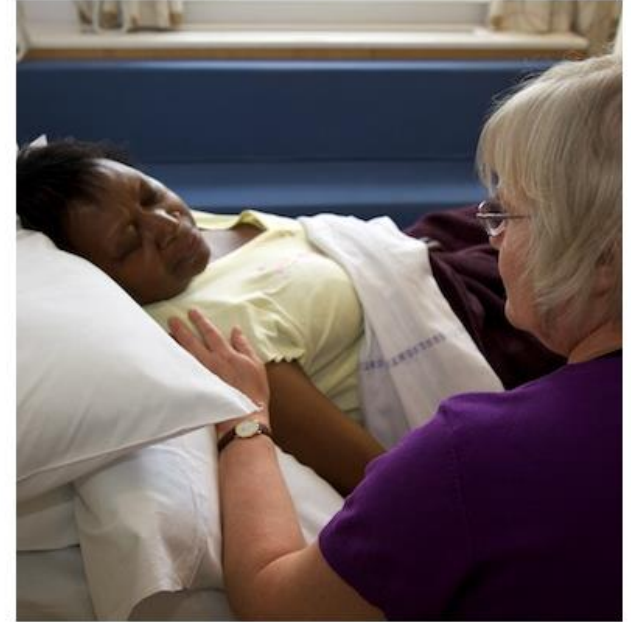
...can be one of the most satisfying and **rewarding parts of being a nurse or doctor.**

Poorly relieved suffering in the days before death increases a patient's anxiety and distress. It is always remembered by relatives which makes grieving and bereavement even more difficult.

This session describes how to manage distressing symptoms experienced by patients in the last days to hours of life. It looks at the use of medications to manage such symptoms and the importance of having access to these medications in a timely fashion.

This session is designed to complement, not replace, local guidelines and is based on the 2015 NICE guidelines 'Care of dying adults in the last days of life'

There is some legitimate variation in local practices with respect to choice of drugs and hence the practices described here may not precisely reflect your local ones. The choice and dose of drugs used for symptom control in this session are based on the Scottish Palliative Care Guidelines



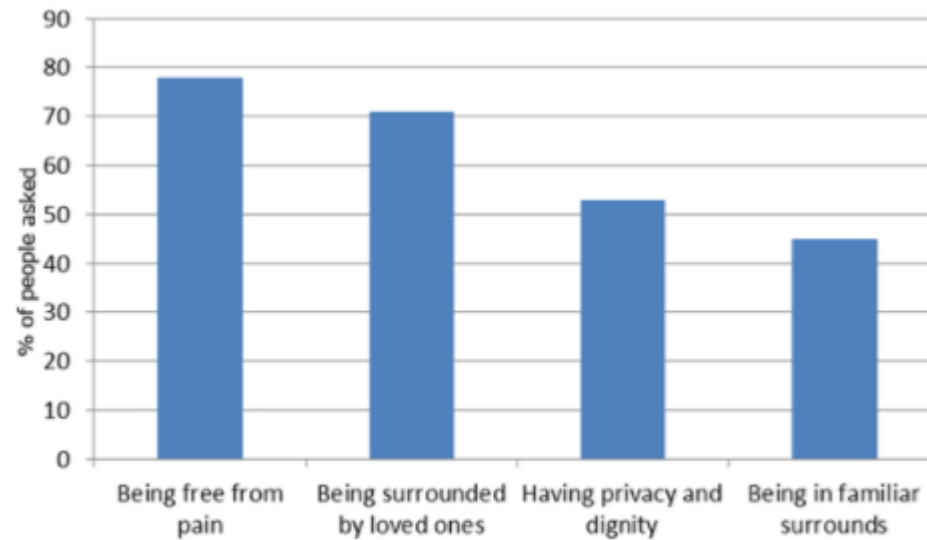
"How people die remains in the memory of those who live on." Dame Cicely Saunders (1918 - 2005) - founder of the modern hospice movement

# Symptom Management

## Barriers to Good Symptom Management

A survey commissioned by the charity, Sue Ryder, in 2013, asked people their views on end of life care and found that their most important priority was to have symptoms controlled. People rated this as more important than being surrounded by loved ones, having privacy and dignity, and being in familiar surroundings.

Despite this, barriers to effective symptom management unfortunately exist.



Priorities at end of life

### Barriers from a patient's point of view

Patients may:

- Not reveal their distress or problems
- Believe that nothing will help
- Be reluctant to use medication believing it may render it ineffective later when symptoms are worse
- Fear being sent into hospital
- Want to avoid upsetting carers
- Fear side effects of medication
- Perceive staff as too busy
- Want to avoid being a burden
- Be anxious about medications hastening death
- Fear giving up

### Barriers from a healthcare professional's point of view

Healthcare professionals may:

- Not diagnose that a patient is dying
- Pursue interventions to treat the cause of deterioration at the expense of treating the symptoms
- Lack knowledge about how to prescribe for symptom management
- Lack the ability to communicate effectively with the patient and family
- Prioritise inadequately – "I'll prescribe the medications tomorrow – he doesn't need them yet."
- Not anticipate symptoms
- Fear foreshortening life
- Fail to give medication in a timely fashion allowing fear and anxiety (and symptoms such as pain and breathlessness ) to escalate

# Symptom Management

## Common Symptoms in the Dying Patient

Symptoms commonly experienced by a dying patient include:

- Pain
- Breathlessness
- Nausea and vomiting
- Restlessness and agitation
- Respiratory secretions



# Symptom Management

## Common Symptoms in the Dying Patient

### **Pain**

40-99% of dying patients experience pain. The pain may be due to their underlying condition, as an effect of being bedbound, or because they can't take or absorb their current oral pain killers.

When asked about the important aspects contributing to dying well, most people rate the control of pain as the most important.

### **Breathlessness**

50-80% of patients may experience the feeling of being breathless in their last few days. There are many different causes of breathlessness. For example, the breathlessness may be because of fatigue, it may be positional, it could be due to infection or pulmonary oedema, or due to hypoxia or anxiety.

### **Nausea and vomiting**

Nausea and/or vomiting may be experienced by about 70% of dying patients. There are many potential causes which include metabolic or drug toxicities, terminal bowel obstruction, gut oedema of right side heart failure, omission of previous antiemetics and anxiety

### **Restlessness and agitation**

Delirium, restlessness and agitation may be experienced by up to 80% of patients who are in the last few days of life. The causes are multiple and include uncontrolled fear, anxiety, pain, metabolic abnormalities, medication toxicities, thirst, faecal impaction, urinary retention or incontinence and spiritual distress.

### **Respiratory secretions**

Noisy gurgly breathing (the death rattle) occurs in up to 90% of patients who are within the last day or two of life. It usually occurs when the patient has become semi-conscious or unconscious because the patient can no longer clear oro-pharyngeal secretions. This is not distressing for many patients but it may be distressing for their relatives to hear.

It's important to think about patient factors when treating symptoms in a dying patient.

### **How am I going to assess the impact of the symptom on the patient?**

Often patients in the last few days of life are increasingly drowsy and communication can be difficult. It is important to look out for non verbal signs of pain and distress, take into account carers' thoughts and the views of other professionals looking after the patient.

### **Are any symptoms preventable?**

Many symptoms are preventable by provision of excellent supportive care. For example, supporting the patient to take drinks for as long as they are able to will reduce thirst; the use of an alternating pressure mattress will reduce pain by minimising pressure and avoiding skin breakdown; and good bladder and bowel care will reduce agitation secondary to urinary retention and constipation.

### **How often do I need to assess for symptoms?**

Symptoms in dying patients can change rapidly and a plan to 'review tomorrow' may not deliver effective care. Patients should be reviewed every time a new symptom develops and again soon after to assess the impact of any intervention.

### **Does the patient have any comorbidities such as Parkinson's disease, renal impairment or heart failure?**

This influences the choice of drug that can be used to help control their symptoms. It will also be important to consider which drugs may need to be continued to avoid deterioration in symptoms. For example, continuing diuretics in heart failure.

### **What medication is the patient already taking?**

Are these to help control their symptoms or are they no longer of benefit and could be stopped?

### **Do I need to change the route of administration of the medication?**

Assume that the oral route will not be possible, if not immediately, then in the near future and prescribe medication for symptom management by the subcutaneous (SC) route in anticipation of this.

It's important to think about treatment factors when treating symptoms in a dying patient.

Questions to consider include:

### **Is the cause of the symptom reversible without medications?**

E.g. repositioning to help respiratory secretions, the use of a catheter to reduce agitation secondary to urinary retention.

### **Is the cause of the symptom reversible with specific medication?**

E.g. the use of furosemide to treat pulmonary oedema or the use of suppositories to help faecal impaction.

### **Which medication can be given to ease the symptom regardless of cause?**

As well as considering which medication to give it is vital to plan who is going to give the medication, how the medication can be accessed and given in a timely fashion, and the best way (route) of giving that medication if the patient can't swallow. For many patients accessing the medications in a timely way can be challenging and requires clear planning.

### **What side effects do these medications have? Are these side effects acceptable to the patient?**


It is always important to consider the balance of benefits and burdens of treatment.

# Addressing Pain


## Case Study: Mr Reynolds

Dr Smith, a junior doctor on-call, has been asked to review Mr Reynolds, an 83 year old gentleman, who is clearly dying. The nurses report that his family feel that he is in pain.


### Dr Smiths Thoughts




How do I know if the patient is in pain?




What is the cause of the pain?




Can the pain be managed without medicines?




Can the pain be managed with simple analgesia such as paracetamol – how would I give that?



Is stronger analgesia needed?



What should I use, how much should I give and how should I give it?



What should I do if stronger pain killers are ineffective?

# Addressing Pain

## Case Study: Mr Reynolds

Dr Smith assesses Mr Reynolds. He is extremely drowsy, but clearly uncomfortable – he is moaning and grimacing. His family say he was complaining of an ache in his back a couple of days ago, for which he had paracetamol which didn't help. Mr Reynolds' catheter is draining and he opened his bowels yesterday.

What do you think Dr Smith should do?

### Feedback

Dr Smith should prescribe strong analgesia, such as morphine, which should be given by a subcutaneous injection. A typical starting prescription for an opioid naïve patient would be 2mg Morphine SC Stat. The type of strong analgesia, dose and frequency may vary according to local guidelines, for example, many guidelines suggest that alfentanil or fentanyl should be used if the patient has severe renal impairment. The co-prescribing of an antiemetic and a laxative should also be considered when commencing opioids.

Dr Smith should discuss this plan with Mr Reynolds, at a minimum checking out Mr Reynolds' response to the intent to use a strong pain killer by injection. Although Mr Reynolds may not have capacity to make a decision, the information should be shared and his view heard. Dr Smith and/or the nurses should also share the plan with the relatives.

Dr Smith should ensure that the nurses are happy to give the medication, and that they know what to do if the medication is ineffective or the pain returns.

# Addressing Pain

## Case Study: Mrs Stones

Dr Smith is then asked to see Mrs Stone, a 46-year-old lady with metastatic breast cancer, who is also dying.

The nurses are concerned because Mrs Stone has been unable to take her regular morphine tablets.

Read Dr Smith's thoughts by viewing each image.

Dr Smith assesses Mrs Stone and finds that she is comfortable. Her pain from her liver metastases has been well controlled on modified release morphine 30mg 12 hourly. However, since early evening Mrs Stone has become more sleepy and is struggling to wake to take her medication.



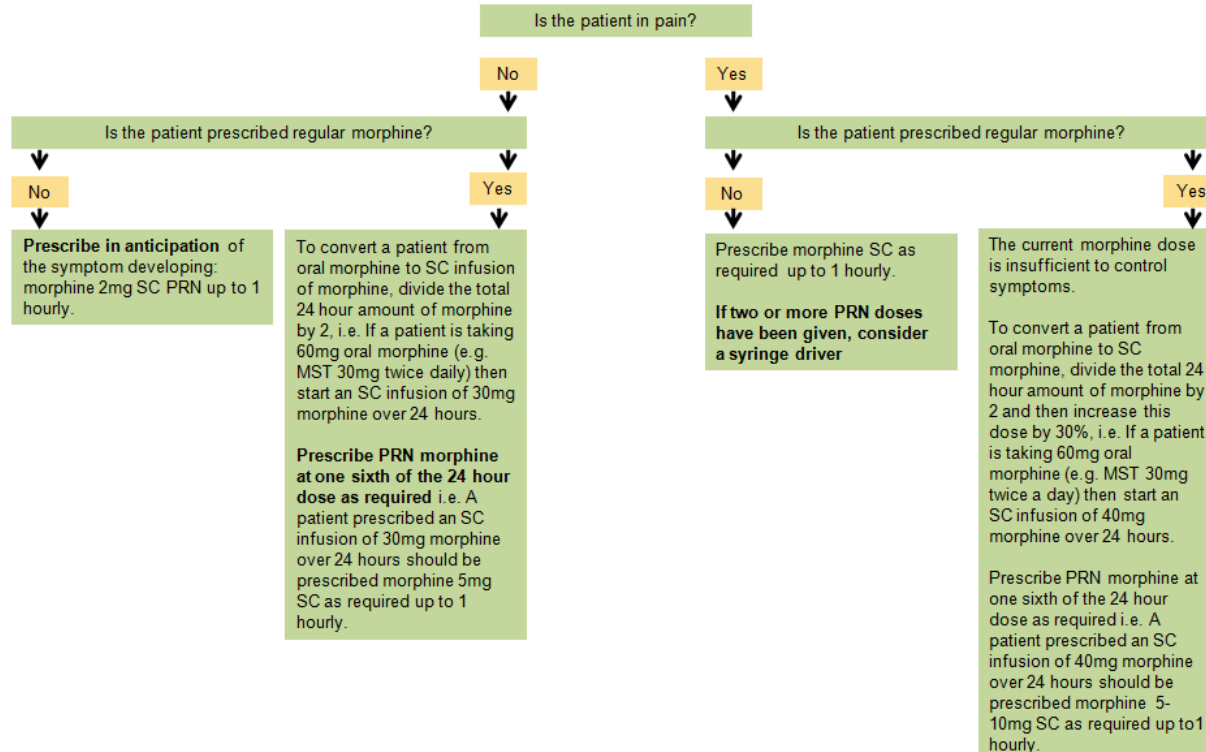
**Question:** What should Dr Smith do?

**Answer:** Dr Smith should ensure that Mrs Stone has the equivalent amount of analgesia via a continuous subcutaneous infusion.

Here you can see an algorithm that can be used to summarise the treatment of pain in a dying patient.

If a patient has a fentanyl or buprenorphine patch on, this should remain insitu and further advice should be sought from the local palliative care team as needed.

### The management of pain with morphine in the last few days of life




Joy is a district nurse and has been called by Jack O'Malley who is anxious about his partner, Patrick Brown.


Mr Brown has severe COPD and is now dying. He wants to remain at home, but his breathing is really frightening him.

What should Joy do?


Joy's Thoughts




Is there any reversible aspect to the breathlessness?




Has he got an infection?




Does he need to go into hospital?




Does he need to go into hospital?



Which medication can I give to help the feeling of breathlessness?



I hope there is some medication in the house I can give him.



Who do I need to call to prescribe this medication if there isn't any in the home?

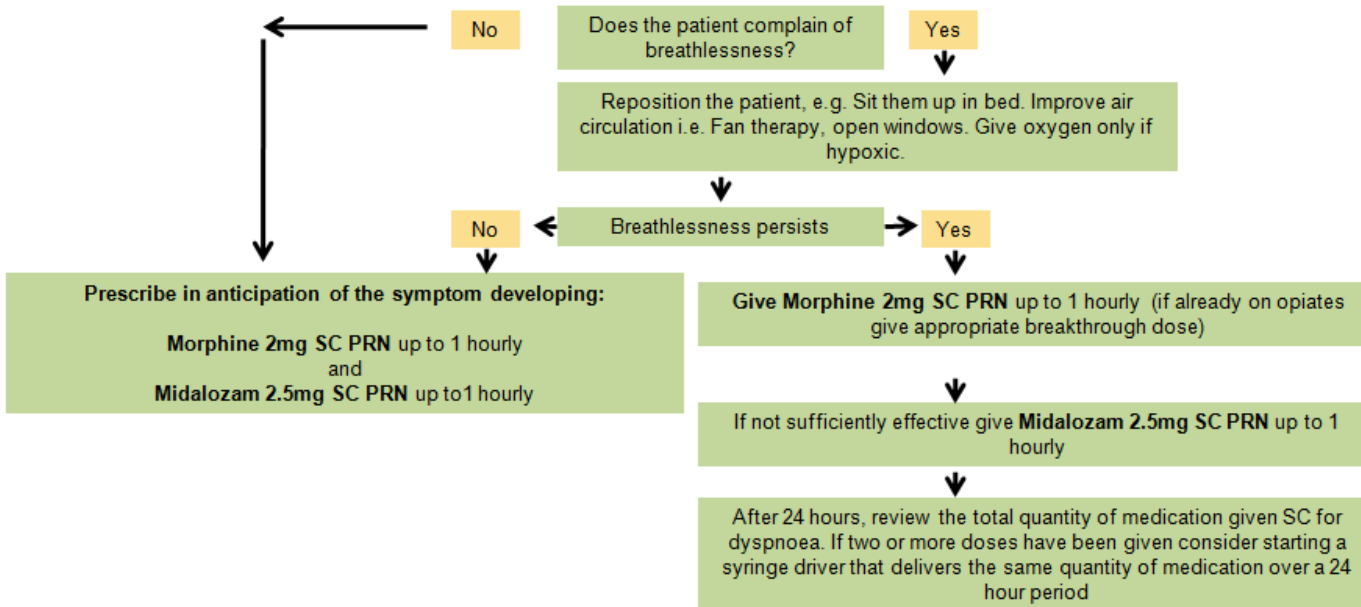
Joy sits Mr Brown up, and Mr O'Malley finds a fan to put by his side which Mr Brown says helps a bit.

Joy discovers that there are no medications for terminal breathlessness in the house. She calls the GP, Dr Goodyear, who visits.



Here you can see an algorithm that can be used to summarise the treatment of breathlessness in a dying patient.

## The management of breathlessness in the last few days of life



### Supportive information

**Morphine** is used for the relief of the sensation of dyspnoea.  
**Midazolam** is used for the anxiety associated with dyspnoea.


To convert oral morphine to subcutaneous morphine divide the oral dose by 2.  
Give PRN morphine at one sixth of the 24 hour dose

# Addressing Nausea and Vomiting


## Case Study: Miss Coleman

Dr Singh is a junior hospital doctor who has been asked by the nurses to review Miss Coleman, who is dying from metastatic bowel cancer.


Miss Coleman is feeling nauseated and has vomited several times. Her nausea was previously controlled by oral cyclizine 50mg Three times a day (TDS), but she is now vomiting up her medications.




Why is she being sick – can I fix the cause?



If I can't fix the cause, what should I do?



What medication might help the feeling of nausea regardless of cause?



Is there any reason why the patient cannot have certain medications?

Dr Singh assesses Miss Coleman. Miss Coleman has advanced colorectal cancer, with liver and brain metastases. She is fatigued and bed bound. She has recently been started on morphine 10mg 12 hourly for her pain. She has not opened her bowels for 4 days

### Feedback

Possible reasons for Miss Coleman's nausea and vomiting include:

- Gastric stasis due to drugs such as opioids
- Squashed stomach syndrome due to tumour or enlarged liver or ascites, or due to outflow obstruction by tumour
- Constipation
- Chemically induced nausea due to drugs, such as morphine and antibiotics, or metabolic causes such as renal or hepatic failure, hypercalcaemia, hyponatraemia or ketoacidosis
- Raised intracranial pressure due to brain metastases

# Addressing Nausea and Vomiting

## Case Study Conclusion

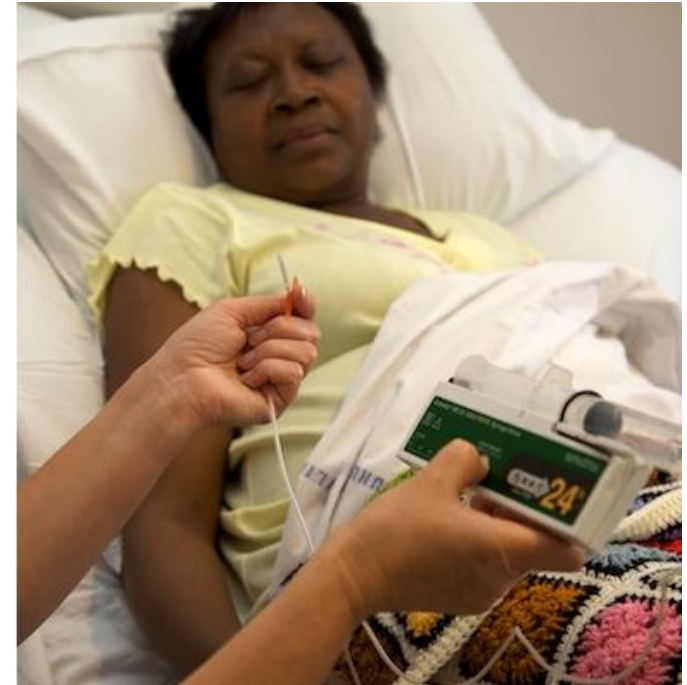
Dr Singh stops all of Miss Coleman's oral medications and starts a syringe driver with cyclizine 150mg/24 hours and morphine 10mg/24 hours.

He also prescribes a once only stat SC dose of 50mg cyclizine to be given now along with morphine 2mg. He prescribes the morphine 2mg SC PRN up to 1 hourly.

He also prescribes haloperidol 1mg SC up to 12 hourly (having checked that this is not contraindicated) in case Miss Coleman's nausea and vomiting does not respond well enough to the cyclizine.

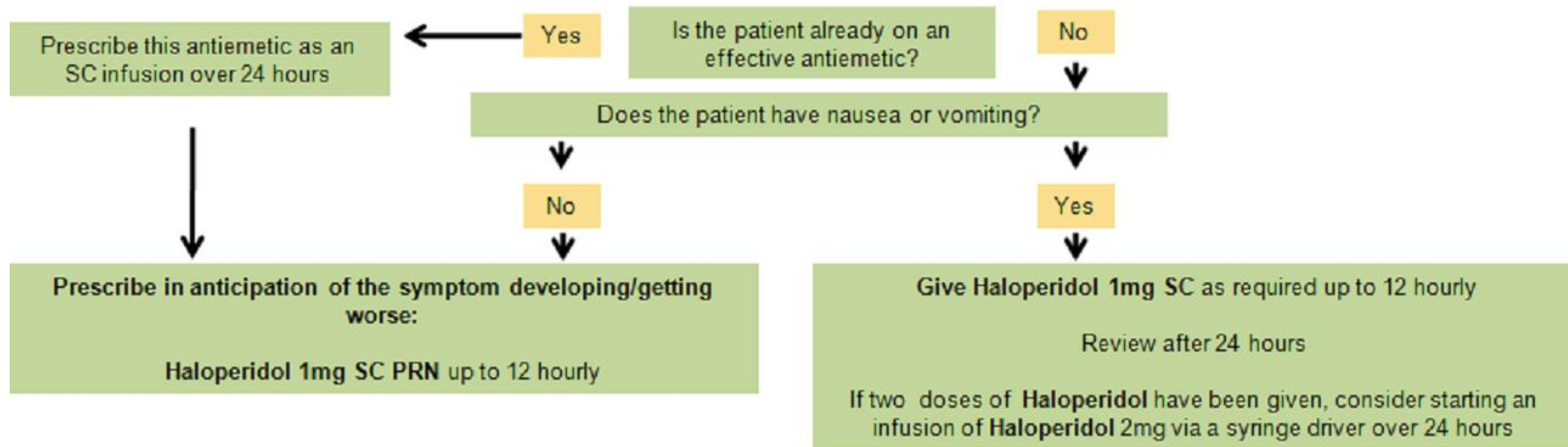
He returns later to find her comfortable - she no longer feels sick and has not had any more episodes of vomiting.

She dies later that night.



Here you can see an algorithm that can be used to summarise the treatment of nausea and vomiting in a dying patient.

## The management of nausea and vomiting in the last few days of life



### Supportive information

Alternative antiemetic: stop Haloperidol and prescribe **Levomepromazine 2.5mg SC PRN 12 hourly**, or an SC infusion of **Levomepromazine 5-12.5mg over 12 hours**

George is a nurse in a care home. He is looking after Barney, an 80-year-old gentleman who is dying from end stage dementia. Barney is barely conscious but his breathing has become very noisy.

His brother is distressed by this and tells George that he thinks Barney is drowning.

“This is clearly really upsetting for the family, but Barney is not aware and does not appear distressed”

“If I explain why this is happening maybe that will reassure them”

“I know that if I sit Barney up, or put him on his side, this might help to reduce the noise”

“Gentle suctioning of secretions in the mouth may help”

“If these measures don't work, I could try an injection of glycopyrronium which was prescribed in anticipation of this symptom developing”



# Addressing Respiratory Secretions

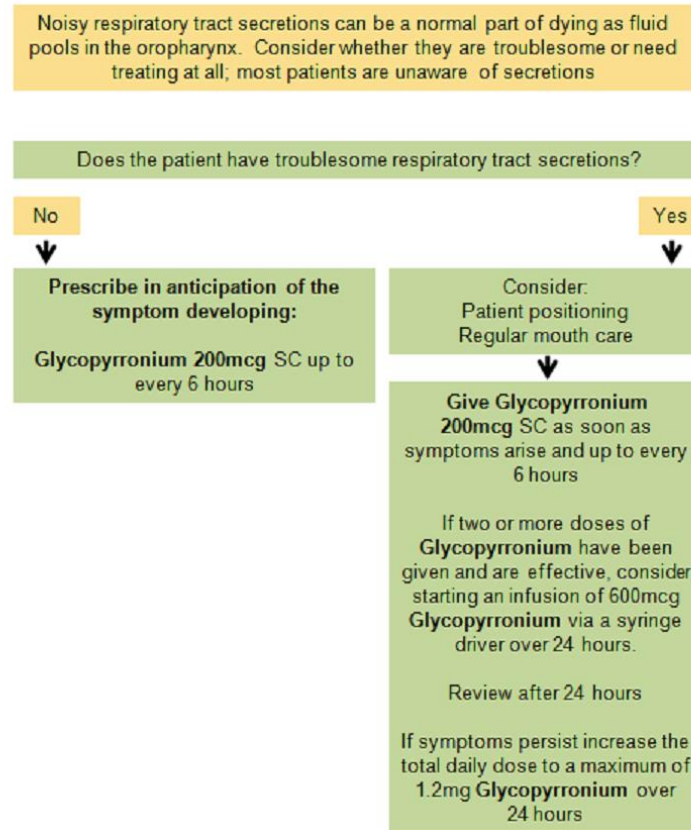
## Case Study Conclusion

George gently repositions Barney, sitting him up.  
George reassures Barney's brother and family.  
Barney's breathing sounds less gurgly and he does not require suctioning.  
Barney dies peacefully a few hours later.



Here you can see an algorithm that can be used to summarise the treatment of respiratory secretions in a dying patient.

## The management of respiratory secretions in the last few days of life



# Addressing Agitation and Restlessness

## Case Study: Betty

Dr Johnson, a surgical junior doctor on call, has been asked by the ward sister to review Betty, a 92-year-old lady who was admitted a few days ago with an ischaemic bowel.

Dr Johnson arrives on the ward to find Betty distressed, agitated and confused. She is trying to climb out of bed, plucking at the bed sheets, and calling out for her mother.

Betty had been having intravenous fluids, but has pulled out her cannula.

She is being treated symptomatically with analgesia and is expected to die within a few days.

“What is happening?”

“Is there a reversible cause to this agitation?”

“What would help this situation other than medication?”

“If I need to use medication, which drugs should I use, at what dose, and how should they be given?”

“What should I do if this doesn't work?”

“What should I do about the fluids?”

“Does Betty need another cannula?”

“Would she pull it out again?”



Can you think of some potentially reversible causes of agitation and restlessness in a dying patient?

### **Feedback**

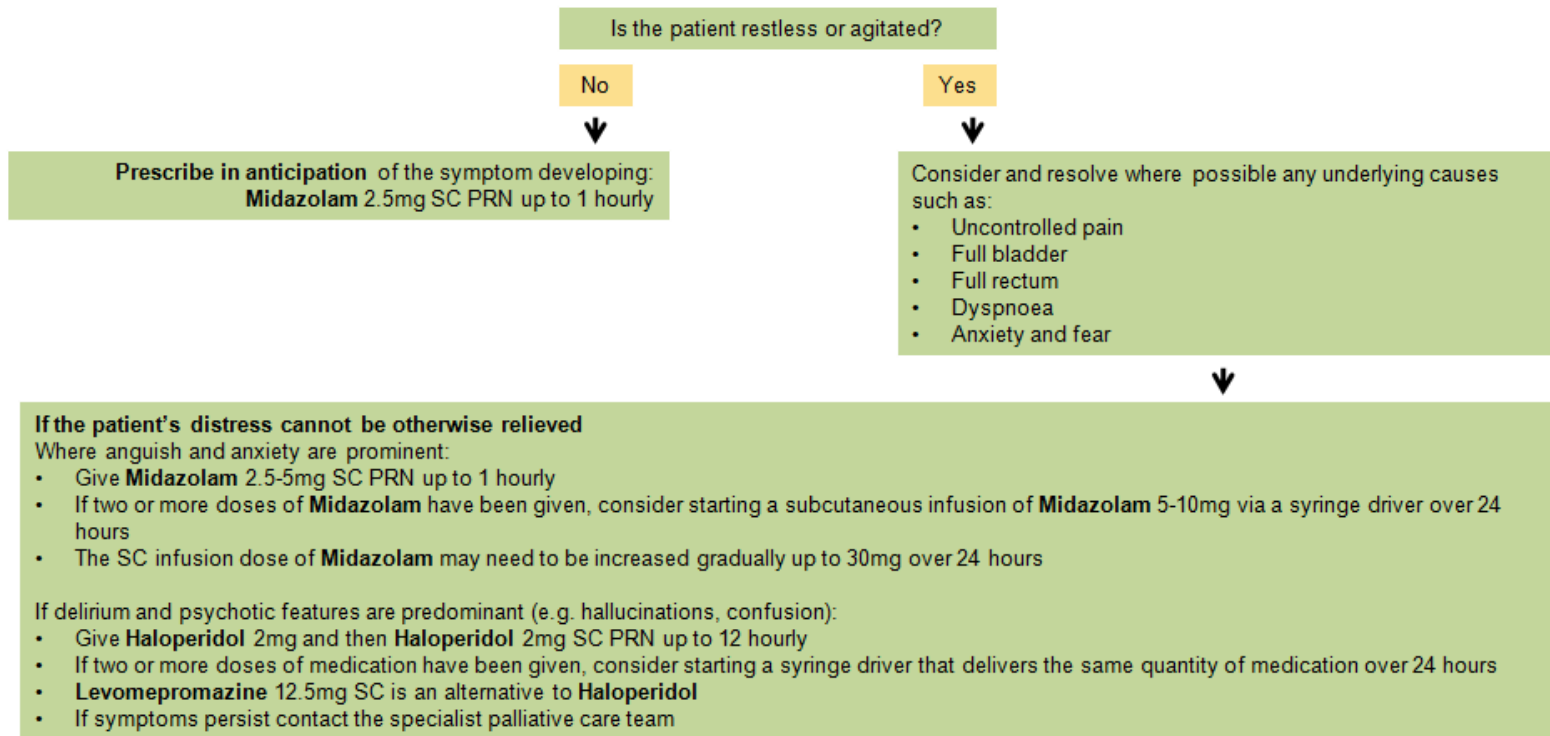
Potentially reversible causes of agitation and restlessness in a dying patient include:

- Confusion
- Uncontrolled pain
- Urinary retention
- Constipation
- Breathlessness
- Thirst
- Anxiety
- Fear

These can all cause agitation and restlessness and should be resolved where possible.

Here you can see an algorithm that can be used to summarise the treatment of agitation and restlessness in a dying patient.

## The management of agitation and restlessness in the last few days of life



When caring for a dying patient it is important to think of the patient's comorbidities and the appropriateness of continuation of treatment directed at these. Many medications such as antihypertensives, anticoagulants and cholesterol lowering medication are no longer helpful and can simply be stopped when the patient is reaching their final few days.

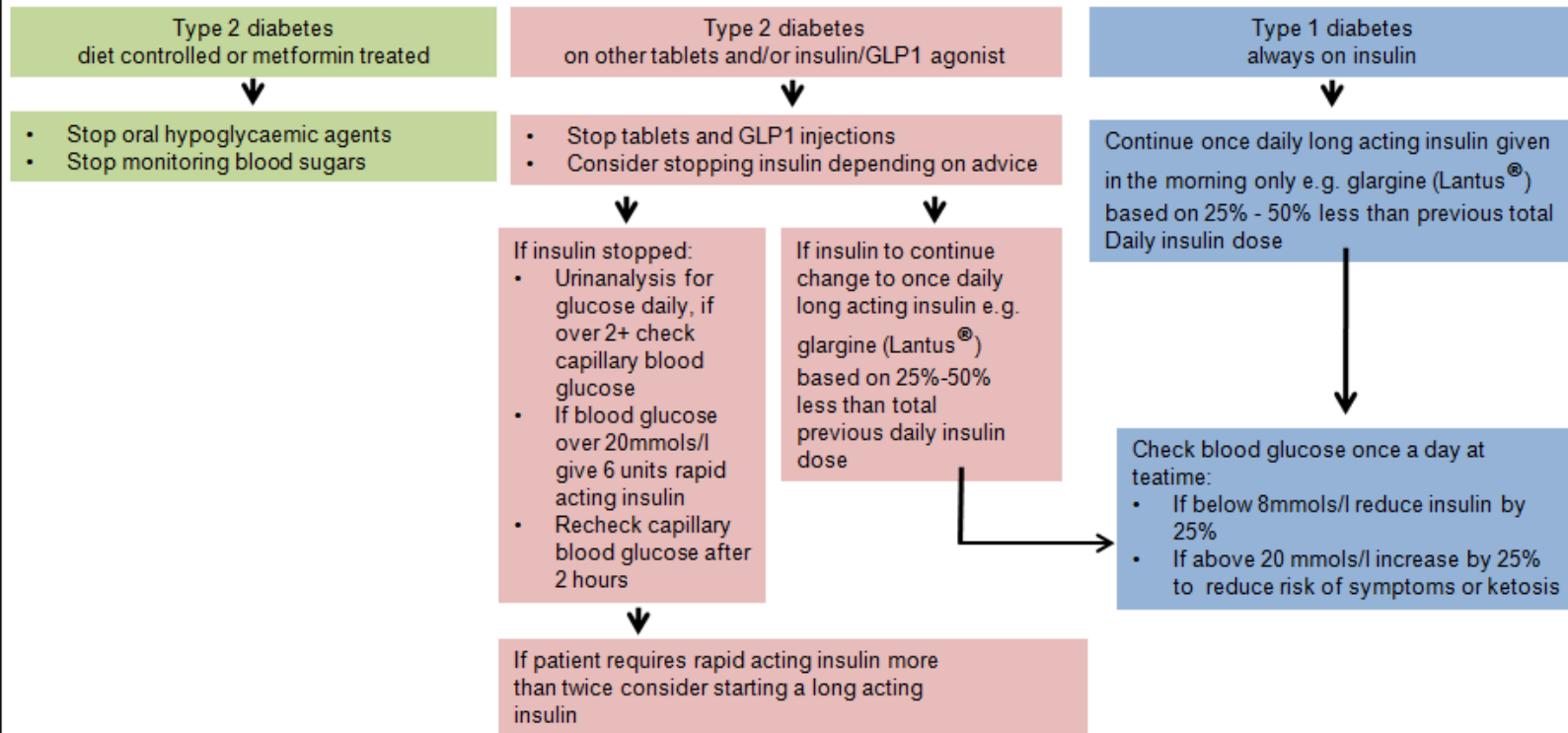
The management of diabetes in the final days should also be simplified, to avoid symptomatic hypo and hyper glycaemia, but also to keep invasive testing to a minimum. However, the symptoms of hypoglycaemia (feeling shaky, sweating, tiredness, lack of concentration, headaches, confusion) and hyperglycaemia (thirst, tiredness, lethargy) are difficult to elicit in a dying person, and blood glucose levels should be checked if hypoglycaemia or hyperglycaemia is suspected.

Take a few moments to study this flow chart that offers guidance on managing diet, tablet and insulin controlled diabetes.

Take a few moments to study this flow chart that offers guidance on managing diet, tablet and insulin controlled diabetes.

## The management of diabetes in the last few days of life

Discuss changing the approach to diabetes management with patient and/or family if not already explored. If the patient remains on insulin ensure the diabetes specialist nurses (DSNs) are involved and agree monitoring strategy



# Anticipatory Prescribing Introduction

So far we have seen how good symptom control requires an understanding of the cause of the symptom and an understanding of the different options available to treat each symptom.

We have seen that symptoms often respond to measures other than medication. We have also seen that if medications are needed, then they need to be given in a timely fashion to minimise distress.

We will now look at 'just in case' or anticipatory prescribing, which is an important strategy for helping patients get timely access to medications.



Anticipatory prescribing is based on the premise that many events in the last few days of life are predictable and a management plan can be put into place in advance.

Anticipatory prescribing is designed to ensure that there is a supply of drugs in the patient's home, combined with the apparatus needed to administer them, with the intention that they are available to an attending clinician for use after an appropriate clinical assessment.

For patients in hospital, hospice or care homes this is equally as important and anticipatory prescribing means that medications are in stock and their administration is authorised for immediate use if the patient develops a problem



# Anticipatory Prescribing

## Advantages and Disadvantages

Can you list some potential advantages and disadvantages of having just in case medications readily available?

### Feedback

#### Advantages

- Enables prompt symptom relief, regardless of day of the week or time of day
- Encourages conversations about goal of treatments, prognosis, and how to access appropriate care as the patient deteriorates
- Potentially reduces hospital admissions
- Reduces out of hour GP visits
- Makes it more likely that a patient will die at home if they want to
- Provides reassurance to patients and carers

#### Disadvantages

- The drugs may remain in the community for extended periods of time
- The drugs may not be used
- The drugs potentially might not be used by the patient, but by others for recreational purposes
- The availability of such medication may encourage their administration without proper assessment, for example, midazolam might be given for terminal agitation when a proper assessment would have revealed a distended bladder and the need for a catheter as the cause of the patient's distress

What is typically contained in a JIC bag/box

### **Paperwork**

- Symptom control guidelines
- 'Just in case' patient / carer information leaflet
- Authorisation chart
- Medicine stock record chart

### **Equipment**

- 5 x 1ml, 5 x 2ml, 5 x 10ml syringes
- 10 x 21 gauge green needles – for drawing up
- 10 x 25 gauge orange needles for subcut injections
- 3 x 25 gauge butterfly needles
- Small sharps disposal box
- Mediswabs
- Clear film adhesive dressing x3

### **Medication**

- 5 ampoules midazolam injection (10mg/2ml)
- 5 ampoules haloperidol injection (5mg/1ml)
- 5 ampoules of glycopyrronium injection (200mcg/ml)
- 5 ampoules of morphine sulphate injection (10mg/1ml)
- 10 ampoules of water for injection

- Pain, agitation and restlessness, breathlessness, nausea and vomiting, and respiratory secretions are commonly experienced by people who are dying
- These symptoms may be reduced by simple, non-drug interventions
- These symptoms can often be managed by four core medications. These medications need to be given in a timely fashion
- Medications for chronic medical conditions need to be reviewed and simplified when a patient is in the last few days of life
- Acute and chronic medical conditions (e.g. renal impairment, Parkinson's disease) should be taken into account when prescribing medication, even at the end of life