

Palliative and End-of-Life Care Pre-Course Handbook

1st edition

Authors

- Dr Steven Moore, Clinical innovation fellow, Great Western Hospital NHS Foundation Trust
- Dr Andrea Ling, Clinical education fellow, Great Western Hospital NHS Foundation Trust
- Dr Benjamin Stone, Internal medical trainee, Torbay and South Devon NHS Foundation Trust
- Dr Natasha Wiggins, Palliative medicine consultant and clinical lead, Great Western Hospital NHS Foundation Trust
- Dr Joanna Lutyens, Palliative medicine consultant, Somerset NHS Foundation Trust

Contents

Introduction	4
What is palliative care?	4
Why is this course so important?	4
Aims of the course	4
Aim of the handbook.....	5
Who to Call	5
Palliative care specialist	5
General practitioner (GP)	5
Out-of-hours clinician.....	5
District nurse	5
Pharmacy.....	6
SWASFT senior clinical advisor	6
Reflection	6
Recognising and Assessing the Need for Palliative Care	6
Gold standards framework.....	6
Recognising the dying patient.....	7
Assessing psychological, emotional, and spiritual distress	8
Reflection	8
Legal Considerations	8
Advance decision to refuse treatment (ADRT).....	8
Advance care plan (ACP)	9
Emergency care and treatment plan.....	9
Lasting power of attorney (LPA) for health and welfare	9
Next-of-Kin or independent mental capacity advocate	9
Reflection	9
Complex Conversations	10
Top tips.....	10
What to do if the patient doesn't speak English	10
Breaking bad news	10
Discussing treatment options with people	11
What if the patient lacks capacity to make treatment decisions?	12
Collusion	12
Common questions with people who are dying	13
Are they dehydrated? Do they need fluids?	13
Would oxygen help their breathlessness?.....	13
Are they hungry? Should we be trying to feed them?.....	13
Are they suffering?	13

Can they hear me?	14
Prognosis?	14
Reflection	14
Use of Just-in-Case Medications	14
Palliative and Oncological Emergencies	16
Bleeding	16
Diabetes care	17
Hypoglycaemia	17
Hyperglycaemia	17
Hypercalcaemia	18
Seizures	19
Malignant spinal cord compression (MSCC)	20
Neutropenic sepsis	21
Superior vena cava obstruction (SVC0)	21
Reflection	22
Symptom Control	23
Golden rules of symptom control	23
Nausea and vomiting	23
Confusion/Delirium/Agitation	25
Pain	26
Breathlessness	28
Secretions	29
Reflection	29
Implantable cardiac defibrillators (ICDs) and pacemakers	29
Non-emergency situation	29
Emergency situation	29
After death	30
After Death Care	30
Verifying an expected death and next steps	30
Personal care	31
Family care	31
Reflection	31
Appendix	32
Opioid conversion	32
Opioid side effects	34
Abbreviations	34

Introduction

What is palliative care?

Palliative care provides care to an individual with an incurable illness with a focus on quality of life.

Considering this definition, palliative care does include care for people who are dying but it has a much wider scope than this. It offers care to anyone with a chronic condition that cannot be cured. As you can imagine, this covers a huge proportion of the population and many different conditions, including cancer, heart failure, chronic obstructive pulmonary disease and chronic kidney disease to name a few.

Enhancing somebody's quality of life can be achieved in numerous ways. Offering treatment to improve people physical symptoms is an important aspect but palliative care extends far beyond this. It also considers psychological, emotional, spiritual and social needs. An important aspect of this care is placing the needs and preferences of the person at the centre of decision making.

Importantly, palliative care can be provided alongside conventional, life-prolonging treatment and can take a greater or lesser role as illnesses progress.

Why is this course so important?

Conventionally prehospital care aims to save life. However, in the UK more people are now living longer and develop chronic incurable illnesses. This change in demographic presents a unique challenge to ambulance clinicians, who now must appropriately tailor management to the individual.

Ideally, patients have already had conversations with health professionals around their preferred care wishes with regards to likely progression of their illness. However, often this has not happened or an unforeseen crisis has occurred. It is in these situations that ambulance clinicians will most commonly encounter this cohort of patient. Commonly, there is no pre-existing relationship with the patient, no knowledge of their condition or treatment preferences. Family members are often having to be consulted, as the patient is too unwell, which presents its own challenges. In this difficult context, time critical decisions must be made. These can be distressing high stake decisions, where staying at home can feel risky.

At one of the most critically important moments in someone's life, the impact of these interactions, the decisions that are made, and the care that is provided to the patient and their family cannot be underestimated. The skills needed to make these decisions are also complex and difficult to master, they need practice and development like any other skill. This course is designed to give you the tools to manage this cohort of people with confidence.

Aims of the course

- Improve confidence interpreting and using treatment escalation forms, advanced directives, lasting power of attorney documents or living wills.
- Improve confidence in identifying patients who are dying.
- Improve confidence in managing common symptoms in the dying patient, including breathlessness, pain, nausea and vomiting, agitation and secretions.
- Improve confidence in having complex discussions with patients and their family, regarding topics, such as admission to hospital, medication options and the dying process.

- Improve confidence in managing oncological emergencies, for example, major haemorrhage, malignant spinal cord compression, neutropenic sepsis, superior vena cava obstruction and seizures.
- Improve confidence in caring for patients and their families after death.
- Improve knowledge of where to find guidelines and who to contact for help and advice.

Aim of the handbook

By reading the handbook and watching the embedded videos, you will have a solid foundation of knowledge that will be built upon in the recorded teaching sessions. We expect this handbook will generate thoughts and questions. It is imperative that, as you work through the handbook, you make a note of these reflections because you will have the opportunity to discuss these in the live discussion session.

Who to Call

You know you probably need to call someone, but who? Even if you are not sure who the right person is, it is better to call somebody. Most of the time that person will help you, if they cannot, they are often knowledgeable about what services are available in the area and will be able to direct you to the appropriate person. Midos and Service Finder are the online platforms to find the right people to speak to and can be accessed through EPCR and through the JRCALC app.

Palliative care specialist

Palliative care specialists can often be contacted through the hospices. Some hospices, such as St Peter's hospice in Bristol and St Margaret's Hospice in Somerset explicitly state on their website that the patient does not even need to be known to them for them to be happy to give advice. Sometimes, they can be contacted through the local hospital, for example, in Gloucestershire. These services are 24-hours a day 7-days a week. Local palliative care services also provide specialist care at home and this can be organised, at very short notice, through the helplines. The palliative care specialists are always more than happy to give advice so please call.

General practitioner (GP)

GP surgeries commonly have duty doctors available over the phone. They can give more information about a patient, offer management advice and prescribe medications. They may be able to review the patient the same day or, depending on time of day and capacity, the next day. If, due to capacity, GPs are struggling to get out to review the patient, this can be done by district nurses or palliative care teams.

Out-of-hours clinician

All areas of the Southwest have out-of-hours clinicians available. They can offer similar things to the GP.

District nurse

In many areas in the Southwest the district nurses provide a 24-hour service and can help with various issues. They help with clinical equipment like catheters, wound dressings and syringe pumps. They can prepare and administer JIC medications and syringe pumps. They also have fantastic local community knowledge so if you are unsure of which service to contact, they can help you.

Pharmacy

If out-of-hours doctors prescribe medication, there are 24-hour pharmacies that should be able to dispense what is needed but it is helpful to call the pharmacy first to make sure this is possible. You can find the closest pharmacy to your location using the following website:

<https://www.nhs.uk/service-search/pharmacy/find-a-pharmacy> If the pharmacy is not able to dispense this medication, then out-of-hours GPs or the local hospice may be able to supply a few vials of urgent medication.

SWASFT senior clinical advisor

These people can offer a wealth of advice both with regards to the clinical situation but also practical advice about who to contact in the community.

Reflection

Have there been any times where you were unsure who to call?

Has there been a time that you called and it wasn't helpful?

Are there other contacts that have not been discussed and you are unsure when to speak to them?

Document any thoughts or questions so you can discuss them at the live discussion session.

Recognising and Assessing the Need for Palliative Care

Sometimes it is clear that a palliative approach is required due to the previous decisions that have been made with other health professionals. However, frequently, ambulance clinicians find themselves in situations where this is not obvious. This section offers tools to help navigate these situations and make decisions regarding whether a palliative approach should be considered.

The first and most crucial step to recognising that palliative care may benefit someone is to think about it. Try and have it in the forefront of your mind. When you receive the details of the job. When you see the patient for the first time. Pause and think "Should I be considering an approach which takes into account quality of life as well as prolongation of life?". Without this mental step, we often can miss these opportunities.

The second step is to identify any written documentation, such as treatment escalation plans that might suggest palliative care input is required. This is invaluable information that would help direct treatment. Please note that in certain areas of the Southwest it is now possible to view these documents digitally before arriving on scene. If you are not able to view it directly, please consider contacting the patient's GP or the local 24 palliative care help line so they can convey vital information.

Gold standards framework

This framework is designed to enable all health care providers to recognise whether an individual is likely in the last year of life and, therefore, whether palliative care may benefit them. The practical application of the framework will be discussed below but a pdf of the framework can also be found by clicking [here](#). It may be useful to download the pdf onto your phone to help answer some of the questions.

You can use the framework by asking yourself three questions:

1) Would it surprise me if this person were to die in the next year?

If the answer is 'no' then consider whether a more balanced approach involving palliative care might be required. This might also involve flagging this person up to local services such as their GP to have discussions regarding their future care wishes.

2) Are there general indicators of decline and increasing needs? General indicators of decline include:

- Decreasing activity – functional performance status declining, limited self-care, in bed or chair 50% of day) and increasing dependence in most activities of daily living.
- Comorbidity is regarded as the biggest predictive indicator of mortality and morbidity.
- Advanced disease - unstable, deteriorating complex symptom burden.
- Decreasing response to treatments, decreasing reversibility.
- Choice of no further disease altering treatment.
- Progressive weight loss (>10%) in past 6 months.
- Repeated unplanned/crisis admissions.
- Sentinel events, such as a serious fall, bereavement or transfer to a nursing home.

3) Are there any disease specific indicators which may indicate advanced illness?

This is the trickiest question. To answer it, the framework does have a list of indicators for most common illnesses, which can be found on the pdf linked above.

Recognising the dying patient

It is important to recognise when a patient is dying but this is not easy. Ideally, the patient should be reviewed by a GP or senior clinician in the community. When a patient has an advanced, progressive illness and is deteriorating with no reversible cause, dying might be recognised if they are:

- Becoming progressively weak and bedbound
- Drowsy for much of the day
- Having difficulty swallowing tablets
- Losing interest in food and drink
- Losing their attention span or becoming confused

It is important to consider potential reversible causes, particularly if the deterioration is sudden or unexpected, such as:

- Infection.
- Hypercalcaemia.
- Medication changes.
- Treatment consequences e.g., neutropenic sepsis.
- Palliative emergencies - if left untreated these illnesses may seriously threaten the patient's remaining quality of life. Discussed in more detail in the [palliative and oncological emergencies](#) section of the handbook.

It is ok if you feel you cannot say for definite that the person is dying. This uncertainty can feel uncomfortable but it is completely normal to be unsure. The key is to communicate your concerns that they might be dying. Focus on the patient's wishes, whilst frequently assessing their condition and responding appropriately. In these situations, you are heavily encouraged to phone a friend, whether that is within the ambulance service or external to the ambulance service, such as their GP or palliative care specialist.

Assessing psychological, emotional, and spiritual distress

It is not expected that you are an expert in managing these issues. They are often complex, requiring specialist input and can be present in both patients and their families. They can have a significant detrimental impact on a person's wellbeing. Remain vigilant of these issues and communicate your concerns to someone who may be able to help. This might be the GP or local palliative care services including the chaplaincy service. Often, help that is offered can have an incredibly positive impact on a person's quality of life and please consider phoning for support.

Reflection

Are there any specific cases where it was difficult to identify whether a patient would benefit from a palliative care approach? Why?

Are there any cases where it was difficult to identify whether someone was dying? Why?

Document any thoughts or questions so you can discuss them at the live discussion session.

Legal Considerations

Below is a diagram representing all the legal considerations that you may come across. The darker blue the box the more legal power it has. The Next-of-kin (NOK) or independent mental capacity advocate (IMCA) is highlighted in red because, whilst all the components are optional, it is a legal necessity that a person has either a NOK or an IMCA.



Advance decision to refuse treatment (ADRT)

Also known as an Advanced Decision, it is a formalised document allowing individuals to refuse a specific treatment in the future if they are unable to make the decision at the time. The specific treatments and the specific circumstances where they would be refused must be explicitly stated. If the treatment being refused is potentially lifesaving, it must acknowledge this with a statement like 'even if my life is at risk'. It must be signed by the individual and by a witness. The document remains valid if the individual has not said or done anything to contradict it, for example, saying they have changed their mind. This document takes precedence over decisions made by a NOK or best interest decisions. If someone were the Lasting Power of Attorney (LPA) for Health and Welfare, they are legally allowed to override the ADRT.

Advance care plan (ACP)

This is not legally binding and is a written document that sets out people's preferences and values with regards to their future care. The aim of this document is to act as a guide to anyone who may have to make decisions on behalf of the individual. It may refer to religious or spiritual beliefs to be reflected in their care or practical issues, like where they want to be cared for, whether they like baths rather than showers or who would look after their pets if they became unwell. It may also detail faith related wishes during the dying phase and after death.

Emergency care and treatment plan

This term refers to ReSPECT, Treatment Escalation Plan (TEP) and Allow Natural Death Order (ANDO) forms, which are used across the Southwest. They cover the individual's wishes with regards to emergency care. The decisions are made by a clinician trained to complete the forms, in discussion with the person and anyone else the person wants involved in the conversation. If the patient lacks the capacity to have these discussions, it is discussed with the NOK but if the individual regains capacity, it should be discussed with them at the earliest opportunity. It normally covers two main topics: Whether the person should receive CPR in the event of cardiorespiratory arrest and the appropriate ceiling of treatment, for example, whether they should be admitted to hospital or not. This document is not legally binding. If the form is digital with digital signatures, it is still valid. If it is photocopied in colour or black and white it is also still equally as valid. It also doesn't matter how long ago it was completed. If there are more than one version of a document, the one that is most recent should be used.

Lasting power of attorney (LPA) for health and welfare

An LPA for health and wellbeing is a person or people able to make decisions on behalf of an individual if the individual loses capacity to make the decisions themselves. The appointment of an LPA should be documented in a legal form. There are different types of LPA covering various aspects of a person's life but only 'Health and Welfare' can make decisions about people's medical care. Someone can appoint one or more people to make decisions. If there is more than one attorney, it should be stated whether they must make decisions 'jointly', meaning always together, or 'jointly and severally', meaning they can make decisions together and separately. If it is stated that someone has LPA, it is essential that you see the document and check it is for 'Health and Welfare', who the named LPAs are and whether they can make decisions 'jointly' or 'jointly and severally'. The LPA has the same level of authority as the person they are representing, including refusing lifesaving treatment. This only comes into action when the person no longer has capacity to make the decision.

Next-of-Kin or independent mental capacity advocate

A NOK does not have a legal right to make decisions on behalf of the individual but they are someone who will be part of discussions when trying to make 'best interest' decisions for a patient who lacks capacity. Ultimately, decisions should be made by the clinical team. An IMCA is an individual who is independent of health care services and tries to represent the individual when there is no NOK available. They have the same powers as the NOK when making 'best interest' decisions. It is a legal necessity that a person has either a NOK or an IMCA.

Reflection

Have there been any scenarios where the interpretation of documents has been particularly challenging? Why?

Are there any other legal aspects that you have come across that you are unsure about?

Document any thoughts or questions so you can discuss them at the live discussion session.

Complex Conversations

Health care is not a purely transactional process but a relational one and patients are often searching for a human connection with regards to the care that they receive. Effective communication is the backbone of the care that we provide. Done well, it improves patient and families' experience, clinical management plans, reduces complaints and increases job satisfaction.

Top tips

- If you need to have a discussion with a patient or their relatives, sit down.
- Much of what we communicate is non-verbal through body language. Look relaxed and open to discussion.
- Do not assume individuals' relationships to one another. It is helpful to clarify relationships and respect all potential relationship dynamics.
- Avoid euphemisms and jargon, for example, avoid saying 'deteriorating' if you mean dying. Be clear and do not be afraid to use the word dying.
- Acknowledge the burden of responsibility that relatives may be feeling.
- Let the person tell their story and don't interrupt with your own agenda. It may feel like it takes a long time but the person feels you have listened, they will trust you and it will be easier to make decisions moving forwards.
- It is okay to not have all the answers. Share your feelings of uncertainty and explain why.
- It is also okay to show your concern. Using phrases like "I'm worried that you are so unwell that you might die"
- Some direct questions may best be answered by saying 'What makes you ask that?'

What to do if the patient doesn't speak English

If a patient doesn't speak English the first step is to use the 'Language Line' service.

Phone number: 0800 169 2879. Pin code: 290000. Follow the instructions to get a translator. Once you have a translator, put the phone on speakerphone. Look at the patient, asking them the questions rather than the phone. Given unclear family dynamics and the importance of accurate translation during complex conversations, using family and friends or 'Google Translate' to translate should be avoided.

Breaking bad news

This is not an uncommon scenario to come across, particularly if an acute event has occurred. A helpful framework to have these conversations is the 'SPIKES model'. This can be used for most clinical communication scenarios. The model is described below but also click [here](#) for a video covering the topic. It is acknowledged that you are called to a variety of situations, and it may not always be possible to achieve all the points in the model. The aim is to work through each section in chronological order.

S - Setting

- Ensure the space is private where possible
- Ensure the right people are present. If the patient has capacity to have these discussions, ask them who they would like present. Something like "I would like to talk to you about what is going on at the moment and what we can do about it. Who would you like here whilst we have that conversation?". If the patient does not have capacity, ask about LPAs and who is the NOK and make sure they are present. If they cannot be physically present, perhaps get them on speakerphone.
- Perform appropriate introductions with the patient and family.
- Manage distractions (turn off or turn down phones/pager when possible).

- P - Perception
- Explore what the patient and/or family knows so far about the issues at hand. Something like “What do you understand about what is happening at the moment?”
 - Elicit their concerns. Like “what is worrying you the most at the moment”
 - Ensure to clarify any euphemisms they may use
 - If possible, remember the phrases they use here to pick the language you use when you deliver the bad news
- I - Invitation
- Ask the patient and/or family how much information they want to know. Are they someone who wants to know all the details, broad strokes or do not want to talk about it at all. Respect their wishes.
- K - Knowledge
- Give an obvious ‘warning shot’. Like “I’m afraid I have some bad news”
 - Deliver the information in easy-to-understand terms, ideally using their own phrases step-by-step and making sure, through questioning, that they have understood what you have said. Like “I appreciate that this is a lot to take in so could you explain back to me what I’ve just said?”
- E - Emotions
- Allow the patient and family to express their emotions freely. Give them time and space to do so before discussing next steps.
 - Identify the emotions that are being expressed by individuals and empathise with them. Something like “I can see this is really difficult”

It is after this point that you might need to discuss management options. During this part of the conversation, it is important to remember to give the patient or family different management options, including the practical steps and potential consequences of each option. Depending on who you are speaking to, e.g., the patient, NOK or LPA, they will have a different amount of power in deciding what the next steps are. Recognise this may be overwhelming for the person and they may find decision making difficult.

- S - Summary
- Summarise the conversation and the next steps
 - Ask the patient or family if they have any questions or whether they need any part of the conversation to be repeated.

Discussing treatment options with people

This can be particularly challenging in the acute situation but, when possible, it can be helpful to understand the patient’s wishes with regards to treatment. It often means that those tough decisions, we feel we must make as healthcare professionals, are a whole lot easier and we make the right decisions more frequently.

It is useful to start this conversation by explaining that we can manage this situation in several different ways. There is not a single right way but it is important to pick the best option for that person. Explain that, to a large extent, they are the boss and it is our role to try and inform them of their options and to facilitate the decisions they make. Before going into the detail of the different options, it is sometimes useful to ask a broad, open question like “With regards to the next steps what matters to you?”. This helps to focus the mind when talking in more detail about treatment options.

It can also sometimes be helpful to explain that treatment options tend to fall on a spectrum. At one end of the spectrum there is treatment aimed at prolonging life but acknowledging that this is likely to negatively impact a person’s comfort. At the other end of the spectrum there is treatment that aims entirely at comfort, dignity and symptom control but this may come at the cost of life being shorter than it otherwise could be. There are treatment options that sit across the spectrum, finding a balance between these two factors. You could then ask where they feel they fit on that spectrum. Again, this helps to focus the mind when talking about the specifics of treatment options. This idea can be demonstrated by the following section on the ResPECT form.

Prioritise extending life clinician signature	or	Balance extending life with comfort and valued outcomes clinician signature	or	Prioritise comfort clinician signature
--	----	---	----	---

Discuss the options with the individual including the potential consequences and together you will produce a personalised plan that is most appropriate. It is important to note and explain to the patient that the decisions that are made are not set in stone and if the clinical situation changes or they change their priorities, then that is okay and plans can be changed.

What if the patient lacks capacity to make treatment decisions?

The difference here is that you would need to consider the legal aspects of the decision-making process e.g., LPAs vs NOK, ADRTs and ACPs (Discussed in more depth [here](#) in the handbook). Ultimately, even if the family do not have any legal power to make decisions, discussing management options using the principals described above and identify what they feel their loved ones wishes would be is still an essential step to making management decisions.

Collusion

Collusion is when family or friends conspire to withhold information from or lie to the patient. Whilst often well intentioned, the patient ethically and legally has a right to this information.

You should:

- Explore the family or friend’s reasoning
 - Are they protecting themselves or the patient?
 - They may have valid concerns about the patient’s capabilities or previous disclosures
- Reassure and explain to the family or friends:
 - You will not force information on the patient
 - The patient has a right to information if requested and health care professionals must be honest
 - If a patient asks a direct question, their understanding and wishes will be explored first
- Offer a joint conversation with family and friends present

Patients may also ask to withhold information from their family. They have the right to do this. However, the principles remain to try to encourage an open dialogue and if appropriate offer to support the patient to talk to their loved ones.

Be aware of cultural variations in information sharing within families. If the patient is asking for information and decision making to be directed to another family member, then respect this. If something about the situation feels uncomfortable to you, call your senior clinical advisor.

Common questions with people who are dying

The following section covers common questions that patients and relatives have with regards to the dying process. The responses are to act as a guide however, it is entirely acceptable to say that you are unsure and direct them to someone who will be able to talk to them about it. When someone is thought to be dying the aim of treatment, ideally, should move from a focus of prolonging life to a focus of comfort, dignity and peacefulness. Bearing this in mind when answering these questions can be helpful.

Are they dehydrated? Do they need fluids?

When people are at the end of their life the drive to drink and the feeling of thirst usually reduces significantly. It is therefore unlikely that thirst is causing them discomfort. When people are this unwell their body becomes ineffective at keeping fluid in the right places, which means that fluid can leak out of blood vessels and into other spaces. Most commonly this will be under the skin and in the lungs. If we give fluid, it can end up in these places. This can cause people to have difficulty breathing and worsen respiratory secretions, making them more uncomfortable. A dying person often 'mouth breathes'. This gives them a dry mouth and can mistakenly give the message they are dehydrated. Empower the families to deliver mouth care to keep the dying person's mouth moist and comfortable. District nurses can provide mouth care packs.

Would oxygen help their breathlessness?

Breathlessness is caused by many things, low oxygen levels (hypoxia) being just one of them. If they are hypoxic, oxygen could help but it is not the only option and does come at a cost. Oxygen is very drying and can often cause nose bleeds and a dry mouth causing discomfort for the patient. The mask or nasal cannula can be uncomfortable to wear and prevent the family from being able to see the individual's face or interact with the patient as meaningfully. As they become less well patients often try and pull off masks or nasal cannula. Often, medication can be used to effectively control breathlessness without these kind of side effects and therefore is the primary focus of care.

Are they hungry? Should we be trying to feed them?

The drive to eat and the feeling of hunger reduces significantly as someone becomes less well and is usually absent in the dying phase. If the individual shows signs of wanting to eat and their swallow is safe, then helping them to eat is okay. If they are not showing a drive to eat then forcing oral intake is not encouraged, as it is unlikely to have a positive impact on their comfort and is not expected to prolong the person's life. Artificial nutrition with a nasogastric (NG) tube is also problematic for several reasons. Placing the NG tube is likely to be distressing to the individual, the individual is at significant risk of aspirating the feed, worsening symptoms like breathlessness and upper respiratory secretions. This would also require a hospital setting which may directly contravene the individual's wishes. The evidence shows that once someone has started dying, they do not live any longer if receiving artificial nutrition but they are more likely to have a lower quality of life. National guidelines advise against giving someone with advanced dementia artificial nutrition.

Are they suffering?

No matter how unwell someone is they are often able to communicate, in some way, their discomfort. Sometimes these signs are subtle like, groaning, frowning or wincing. Those closest to the individual are often the most sensitive to signs of discomfort so take their concerns seriously. If they feel that the individual seems comfortable then it is appropriate to reassure them that we think the individual is comfortable.

Can they hear me?

Two pieces of evidence support the idea that people can hear things around them at the end of life. One is people who are heavily sedated in the intensive care unit who, after their illness, can recall conversations. The second is seeing people who are dying and distressed being visibly comforted by a familiar voice. The individual might not be able to process every word but it can certainly be of benefit not only for them but for their loved ones as well. Please encourage loved ones to say things they want to say, for example, “I love you” or “I forgive you”.

Prognosis?

This question can be asked in lots of different ways. When answering, it is helpful to first identify what the person asking the question thinks. This can guide how you respond. If they say what you feel is a realistic reflection of the situation it may be enough to nod and say “yes, I’m worried this is the case”. Often, we speak of units of time whether that be hours, days, weeks or months. The rate of decline in the recent past can be a predictor for the future i.e., if the person seems to be getting more unwell from week-to-week, day-to-day or hour-to-hour then this is the unit of time that would be most appropriate to use going forwards. It is also okay to be honest and say you do not know. Explain that it is impossible to know for sure and sometimes we can be surprised one way and the other.

Reflection

What questions from family members have you been asked and were unsure how to answer them? Are there any particular communication scenarios you find challenging? Document any thoughts or questions so you can discuss them at the live discussion session.

Use of Just-in-Case Medications

Also termed anticipatory medications or ‘PRNs’, these medications should be prescribed for people who are at the end of their lives and are often essential to maintain comfort. They are given subcutaneously (SC) because often swallowing becomes difficult at the end-of-life and SC administration is the least painful approach. Click [here](#) to watch a video demonstrating how to give SC medications.

There are five symptoms that may develop in the last hours or days of life. They are discussed in more detail in the [‘symptom control’](#) but are listed below:

- Pain
- Agitation
- Respiratory tract secretions
- Nausea and vomiting
- Breathlessness

Drugs commonly used to treat these symptoms are below. If you are unsure of local guidelines or which drug or dose to use, contact someone for advice using the Midos or service finder apps.

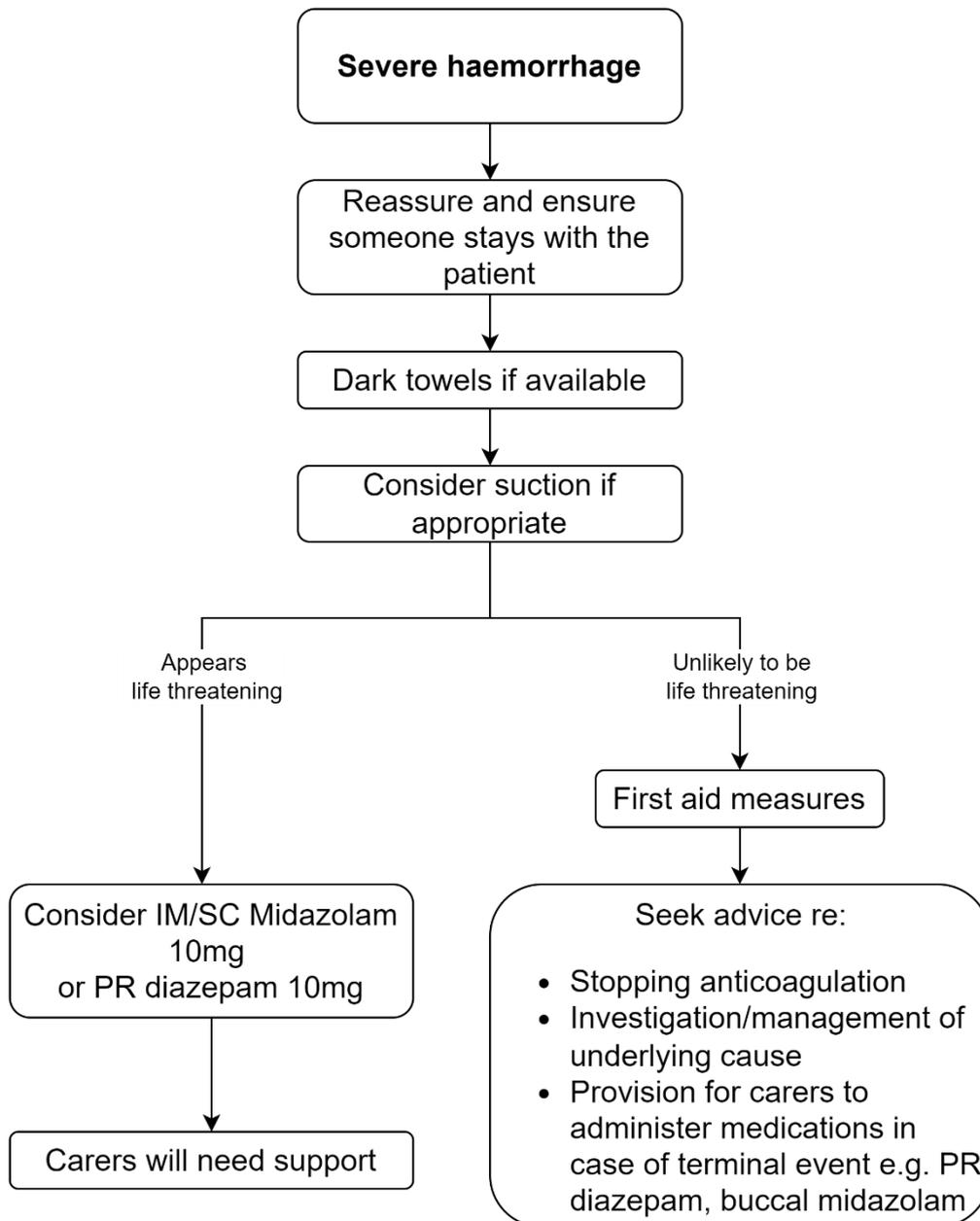
Symptom	Medication PRN SC	Notes
Pain	Morphine sulfate 1-5mg if opioid naïve Oxycodone 1-2.5mg if opioid naïve	If previously taking oxycodone use that Caution in renal and liver failure
Agitation	Midazolam 2.5-5mg	If frank delirium can use haloperidol
Respiratory tract secretions	Hyoscine butylbromide 20mg (max 120mg in 24hrs) Glycopyrronium 200-400mcg (max 1.2mg in 24 hrs)	Not everyone responds to these medications; non-drug measures are key It is better to give it sooner rather than later
Nausea and vomiting	Haloperidol 0.5-3mg (max 10mg in 24hr) Levomepromazine 6.25- 12.5mg (max 25mg in 24hr) or Cyclizine 25-50mg (max 150mg in 24hr)	Continue the patient's regular antiemetic if symptoms are well controlled
Breathlessness	Morphine sulfate 1-2.5mg	Increase as appropriate If previously taking oxycodone use that Caution in renal and liver failure

Palliative and Oncological Emergencies

Bleeding

Causes include:

- Tumour invasion
- Blood clotting disorders
- Infection e.g. fungating wounds
- Anticoagulants
- Peptic ulcers



Advice for management may include:

- Stopping or holding anticoagulants
- Tranexamic acid
- Site specific interventions e.g., cautery, radiotherapy, medicated dressings, mouthwashes for oral lesions, treatment of related infections
- GI bleeding – PPIs, rectal steroids

Diabetes care

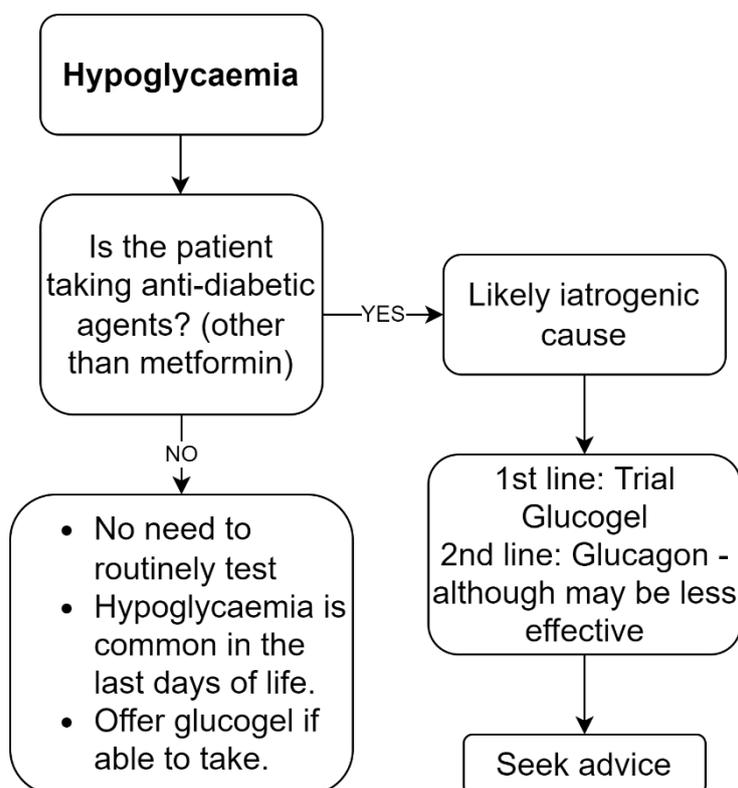
This section briefly outlines management of diabetes in patients with palliative needs. For more information on this topic, [click here](#) to see the excellent Diabetes UK guidelines. Particularly helpful are the flowcharts towards the bottom of the document.

Aims at end of life:

- Blood sugar 8 – 20mmol/L
- Asymptomatic
- No hypoglycaemia, Diabetic ketoacidosis or Hyperglycaemic Hyperosmolar State
- Avoid unnecessary injections / testing

Hypoglycaemia

- Please always seek advice for managing people with Type I diabetes.
- Towards the end of life, people with diabetes are likely to eat less and therefore do not need as much insulin or oral hypoglycaemics.
- Insulin can be converted into a once daily long-acting regime.
- Some people may not need any medications



Hyperglycaemia

- Please always seek advice for managing people with Type I diabetes.
- Steroids can increase blood sugars significantly in people with or without diabetes.
- 'Osmotic symptoms' i.e. increased thirst, increased urination (polyuria) are common if blood sugars are >20
- Specialist Diabetes Team / Specialist palliative care team can advise

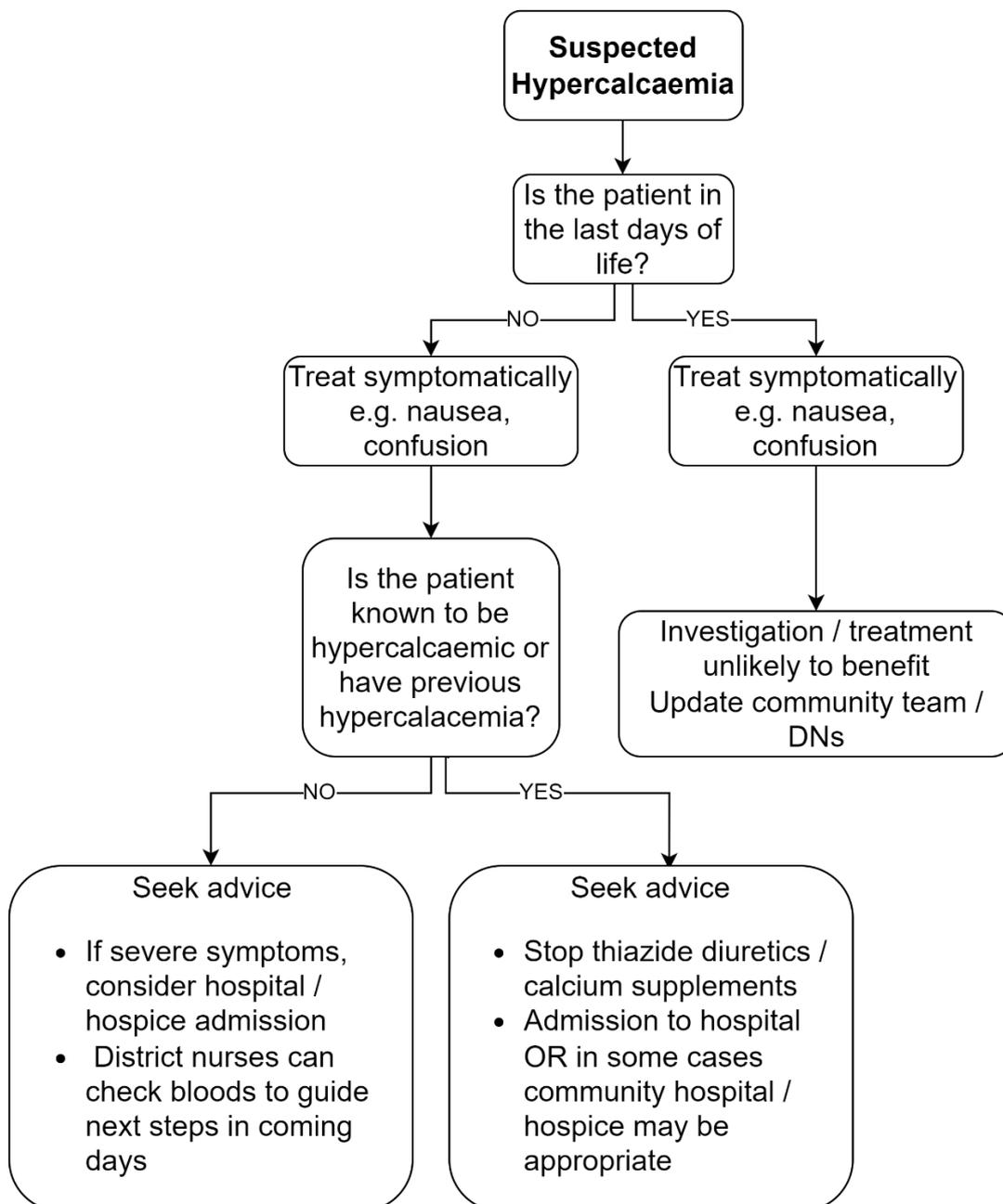
Hypercalcaemia

Hypercalcaemia is a known complication of malignancy. It is more common if patients have bone metastases and especially if they have had a previous episode of hypercalcaemia. Hypercalcaemia is defined as adjusted serum calcium $>2.7\text{mmol/l}$ and can be fatal at $>4\text{mmol/l}$. Symptoms include;

- Nausea
- Confusion and mood changes
- Fatigue
- Thirst, polyuria
- Abdominal pain and constipation

The mainstay of treatment is with IV rehydration. IV bisphosphonates are sometimes given but can take up to 72 hours to be effective. Helpfully, the impact of it should last several weeks.

Hypercalcaemia, especially recurrent hypercalcaemia, is a poor prognostic sign.

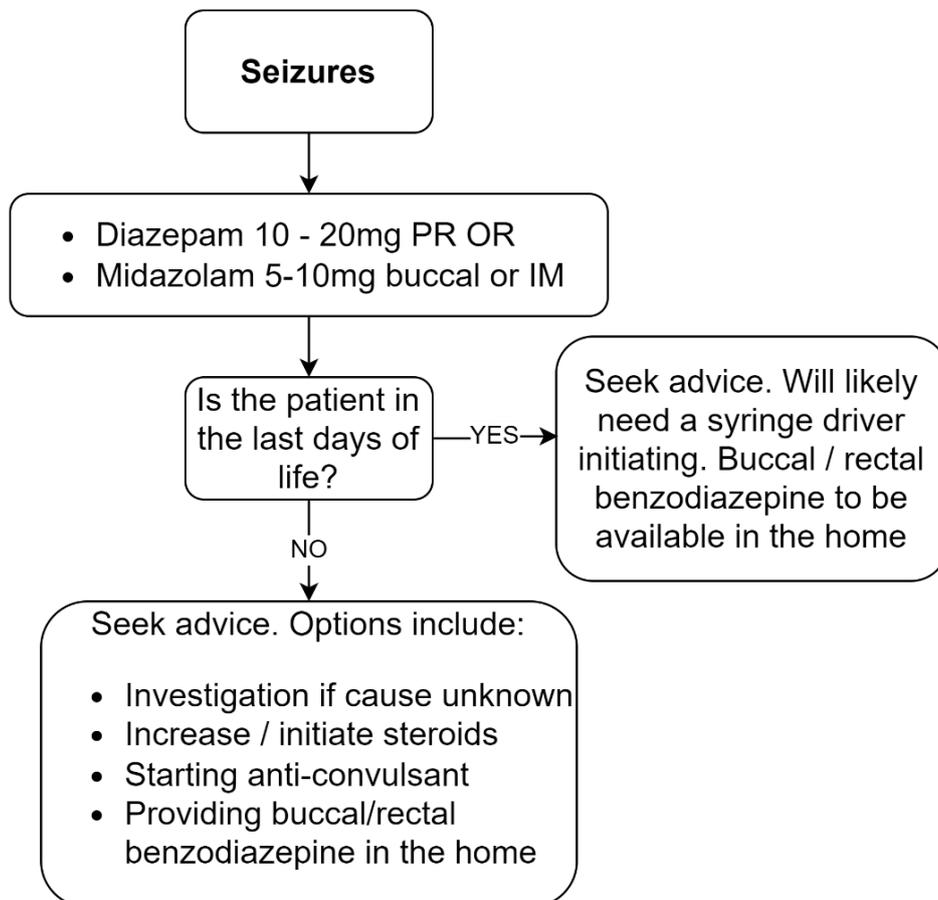


Seizures

The first step is to assess whether this is a seizure or something which may mimic a seizure like a syncopal attack, arrhythmia or transient ischaemic attack (TIA). A seizure does not automatically require conveyance to hospital. It can often be managed in the community. In these circumstances, please seek help with decision making and providing appropriate community support to the individual and their family. The first people to call would be the local palliative care services and GPs.

Causes / risk factors:

- Epilepsy, brain tumours, brain metastases, surgery/trauma
- Some drugs can increase the likelihood of a seizure or reduce the effectiveness of anti-seizure medication. This is particularly important to consider if the person has started a new medication
- Drug withdrawal, e.g., alcohol
- Metabolic, e.g., hypoxia, hypoglycaemia, hyponatraemia

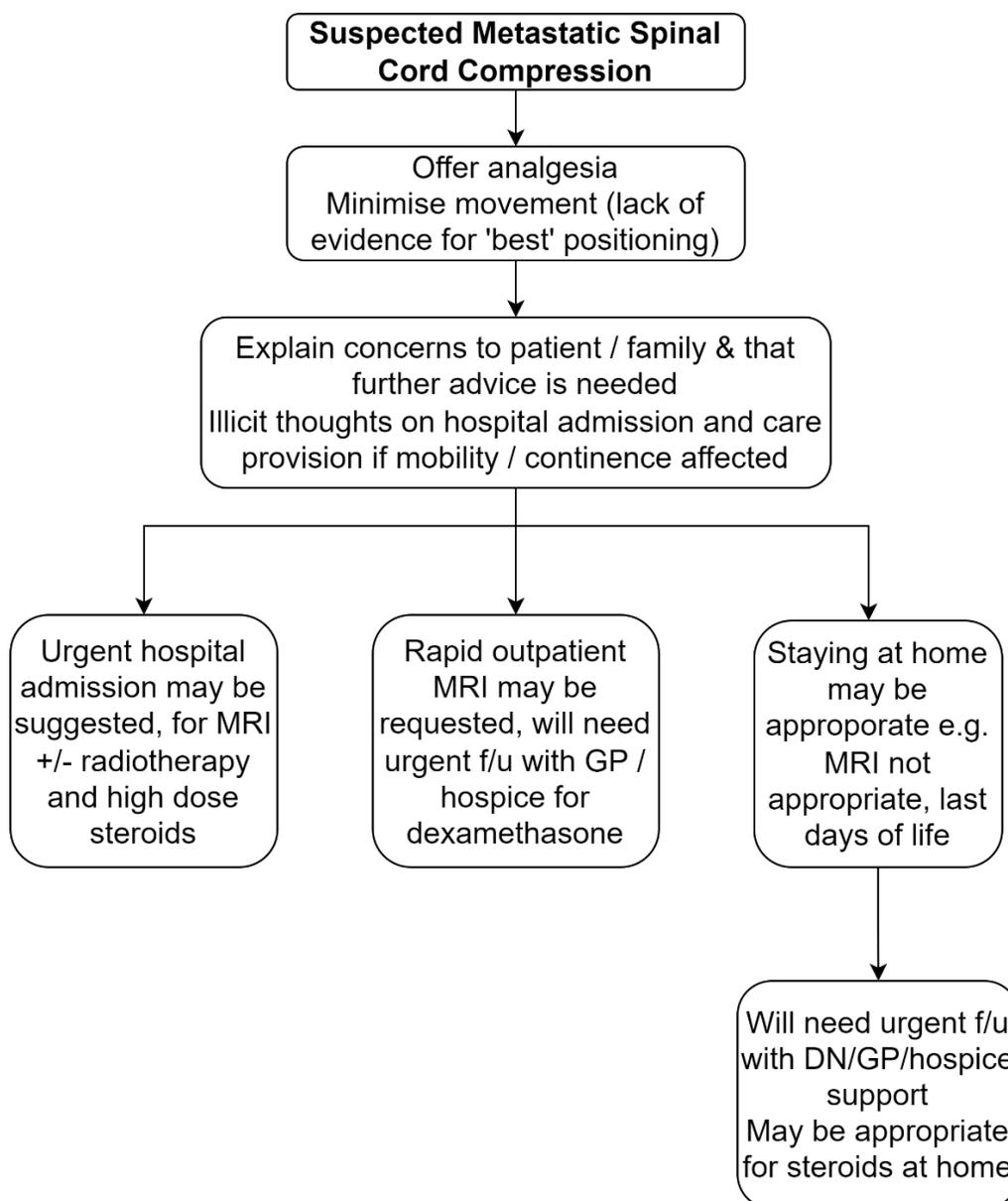


Malignant spinal cord compression (MSCC)

Occurs in 5-10% of patients with advanced cancer. As the name suggests this is when the spinal cord is being squashed. This is caused either directly from a cancerous tumour or damage to vertebral bones by the invading cancerous tumour causing the bones to press on the spinal cord. Early diagnosis and urgent treatment are vital for improved outcome, mobility and continence. Signs can be subtle e.g. heaviness in legs, but can include;

- Back pain, with or without radiation in the territory of a nerve root
 - Classically 'band-like' pain around torso/abdomen
 - Sensory changes
 - Bladder/bowel disturbance
 - Leg weakness
- } These are late signs

If you are suspecting MSCC – SEEK ADVICE. Cases should be discussed with the local Acute Oncology Service. It may be appropriate to speak to the community palliative care team first if admission to hospital is not in line with the patient's wishes or seems clinically inappropriate.



A patient with paralysis from MSCC will need pain management, pressure area care, catheterisation, bowel regulation, OT/PT support and psychological support. As ambulance clinicians you would not be responsible for carrying this out but these are points worth considering when assessing someone with MSCC and flagging the individual to the right services if you feel something is missing.

Neutropenic sepsis

- Neutropenia is where the number of white cells (cells that fight infection) in someone's blood decreases, making the body less able to fight infections.
- Patients who are undergoing chemotherapy may be neutropenic.
- Most commonly levels are at their lowest between days 7 – 12 post-treatment but in some patients it might be longer.
- Neutropenic sepsis is a life-threatening medical emergency and patients can deteriorate rapidly.
- Symptoms are often non-specific but can include;
 - Temp >37.5 or <36
 - Feeling generally unwell
 - Shivering episodes
 - Raised RR / tachycardia / hypotension
 - GI symptoms eg vomiting, diarrhoea
 - Symptoms of local infection eg cough, dysuria etc.
- Review the patient's 'Alert Card' for advice – this will likely involve calling the local Acute Oncology Service.

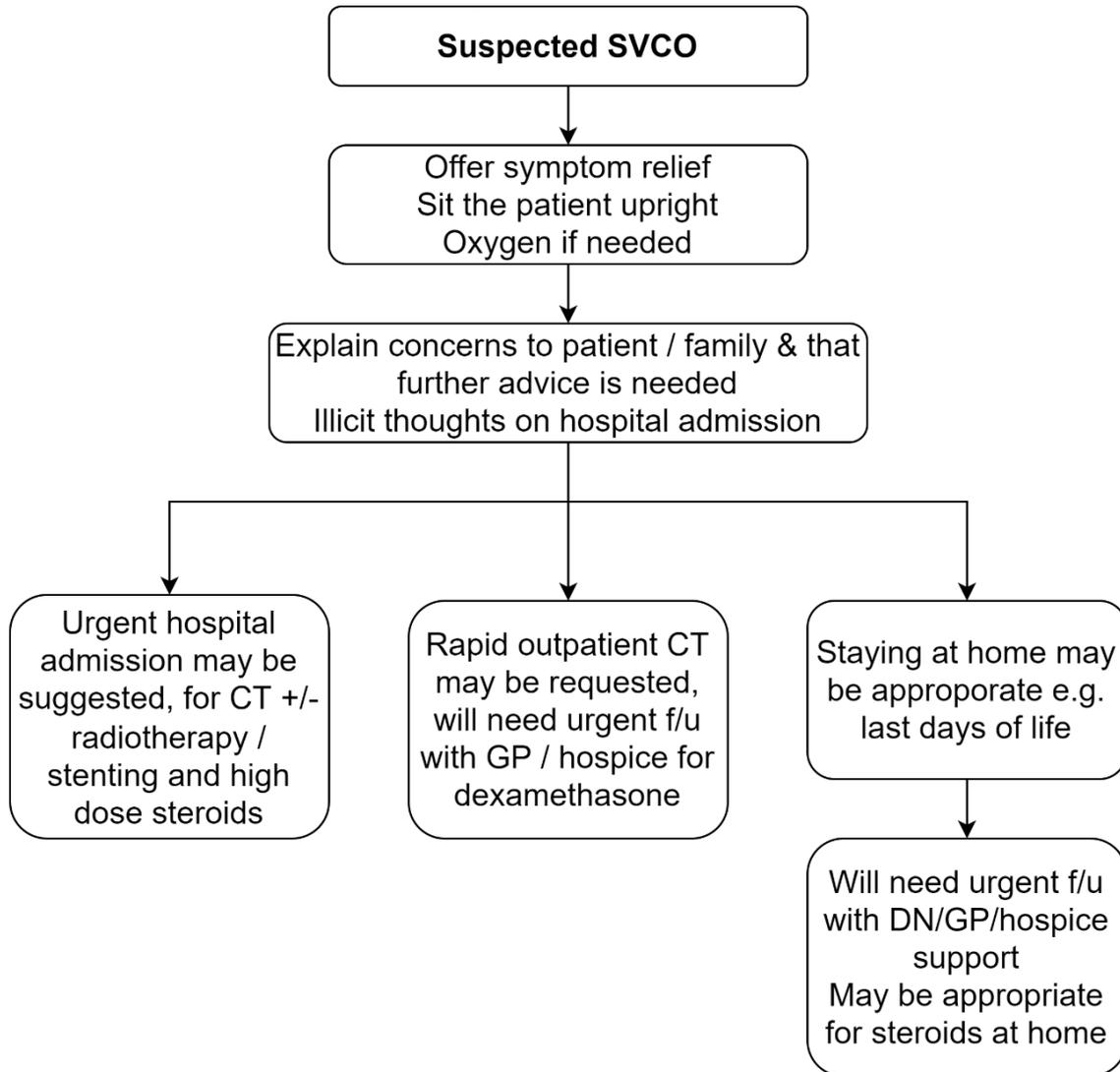
Superior vena cava obstruction (SVCO)

This occurs when there is an obstruction of the superior vena cava, caused by a tumour or lymph nodal disease. Cancers which more commonly cause SVCO include breast, colon, oesophageal, lymphoma and lung.

Signs and symptoms:

- Venous distention in the chest and/or neck
- Facial and neck oedema, can also affect the arms
- Dilatation of superficial blood vessels. This can make the person look flushed, known as plethora
- Shortness of breath, stridor
- Headache, head fullness, nasal congestion
- Hoarse or whispery voice

Symptoms may be mild, especially if it has developed slowly, but SVCO can be life-threatening if it occurs quickly. SEEK ADVICE. Management can involve a CT to diagnose, high dose steroids, radiotherapy +/- chemotherapy. Stenting may also be possible. This can also be managed at home and will require a conversation with the patient and their loved ones with support from the local palliative care team.



Reflection

Have you had any cases with one of these presentations? Did it go well and what could have gone better?

Any real-world problems that might occur whilst using these guides?

Document any thoughts or questions so you can discuss them at the live discussion session.

Symptom Control

Golden rules of symptom control

There are some key principles or 'Golden Rules' which underpin symptom management in palliative and end-of-life care. These include:

- Aim to assess and diagnose the underlying cause of symptoms, before planning symptom management.
- Treat potentially reversible causes, where appropriate.
- Always consider non-drug approaches as they can be as important as the use of drugs
- Management plan is influenced by prognosis and patient choice and depends on the therapeutic goal. Remember, the goal may not be to prolong life.
- Assessing the impact of treatment is paramount. This may not be done by you but make sure that there is appropriate follow-up.

Nausea and vomiting

Common Causes and Their Presentations:

Raised intracranial pressure → Likely to occur in patients with cancer due to a brain metastasis. Worse in the morning, may be associated with headache and drowsiness.

Medication induced → Normally coincides with starting a new medication.

Metabolic causes → This can occur in people with cancer due to hypercalcaemia, other causes could be due to renal or liver failure. People feel nauseous most of the time and may vomit intermittently.

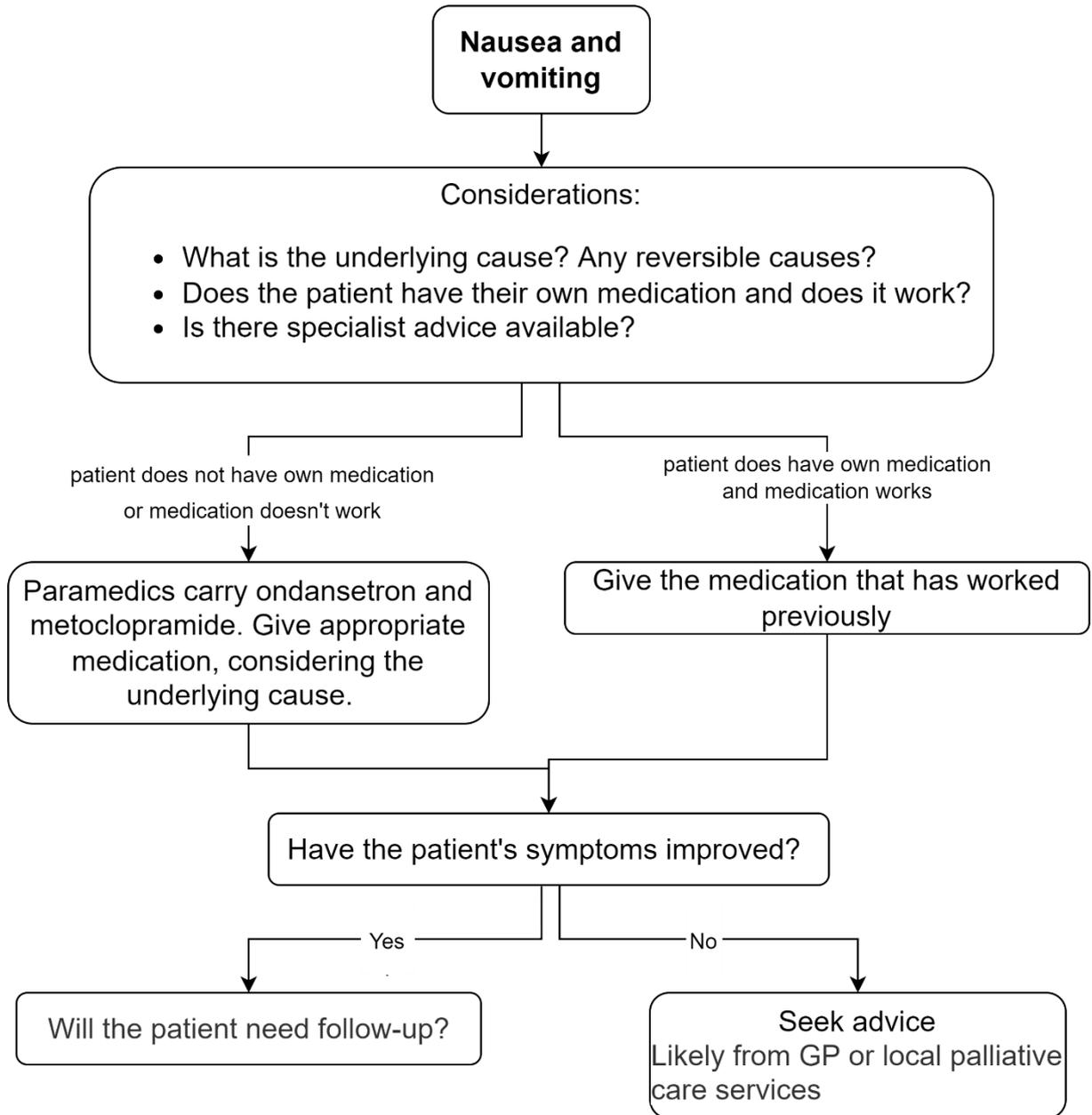
Chemotherapy related → Worsen at times of treatment.

Gastric stasis → Feel full quickly when eating. Nausea and vomiting worse just after eating.

Constipation → Reduced frequency of bowel motions and hard stool.

Below is a table of the common anti-sickness medications used, the underlying cause they tend to help with and their main side effects.

Medication	Underlying cause of sickness	Common side effects
Haloperidol	Metabolic causes	Drowsiness at high doses
Cyclizine	Raised intracranial pressure	Agitation
Metoclopramide	Gastric stasis	Dystonia, restlessness Contraindicated in bowel obstruction
Levomepromazine	Broad spectrum	Drowsiness
Ondansetron	Chemotherapy related sickness	Constipation

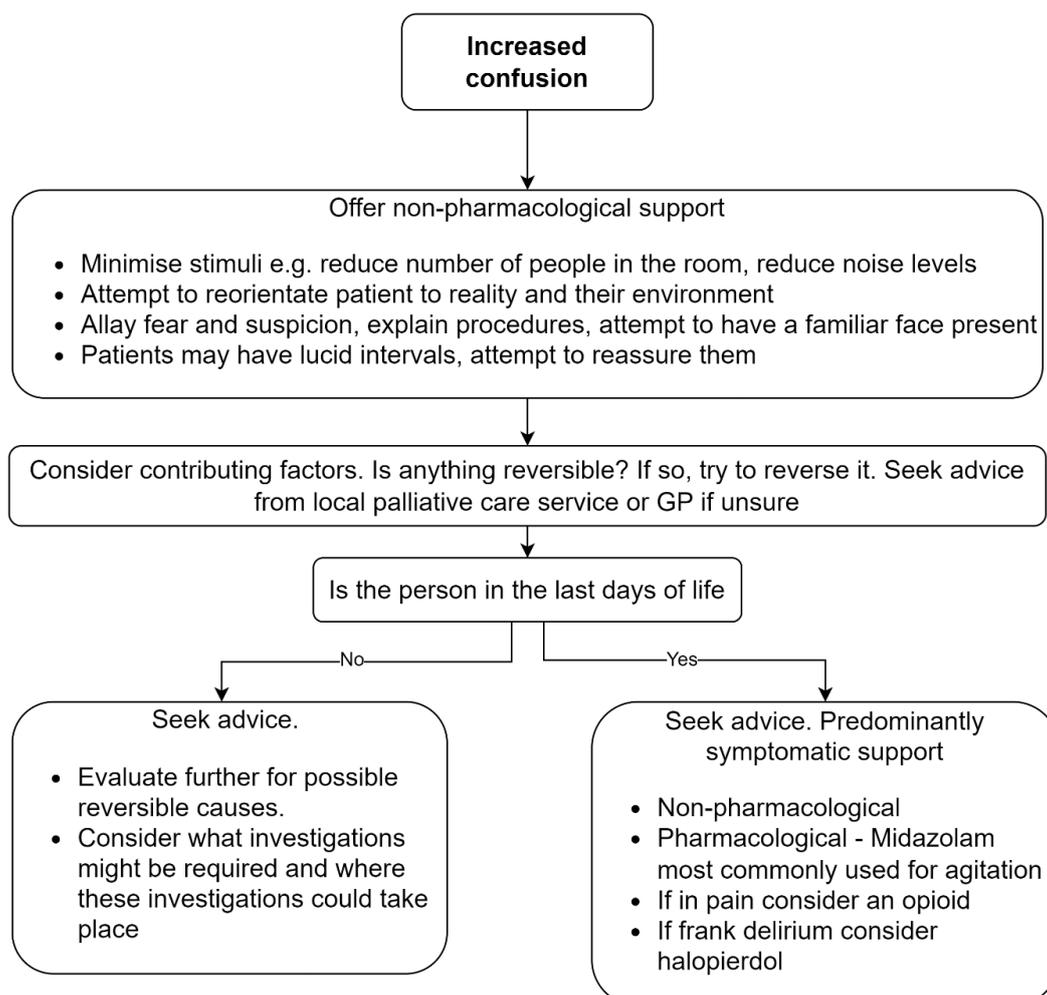


Confusion/Delirium/Agitation

This can be a challenging symptom and the aim should be to treat any reversible causes and reduce the distress and agitation for the patient and their carers using both pharmacological and non-pharmacological treatments

Contributing factors:

- Age and pre-existing cognitive deficit
- Drugs – any sedating drug. e.g., opioid, baclofen, levomepromazine
- Opioid toxicity exacerbated by renal failure, dehydration or infection can cause confusion and hallucinations (look for constricted pupils, muscle jerks, and reduced respiratory rate)
- Poor symptom control e.g., pain, constipation, urinary retention
- Infection, respiratory and urinary tracts
- Biochemical/ metabolic abnormalities
 - Uraemia (in renal dysfunction), especially if on opioids
 - Hyper/hypoglycaemia
 - Hypercalcaemia
 - Hyponatraemia
 - Liver dysfunction
 - Hypoxaemia
- Intracerebral causes – space occupying lesions, stroke
- Environment- unfamiliar stimuli or surroundings, a room full of heightened emotions
- Alcohol or drug withdrawal, including nicotine



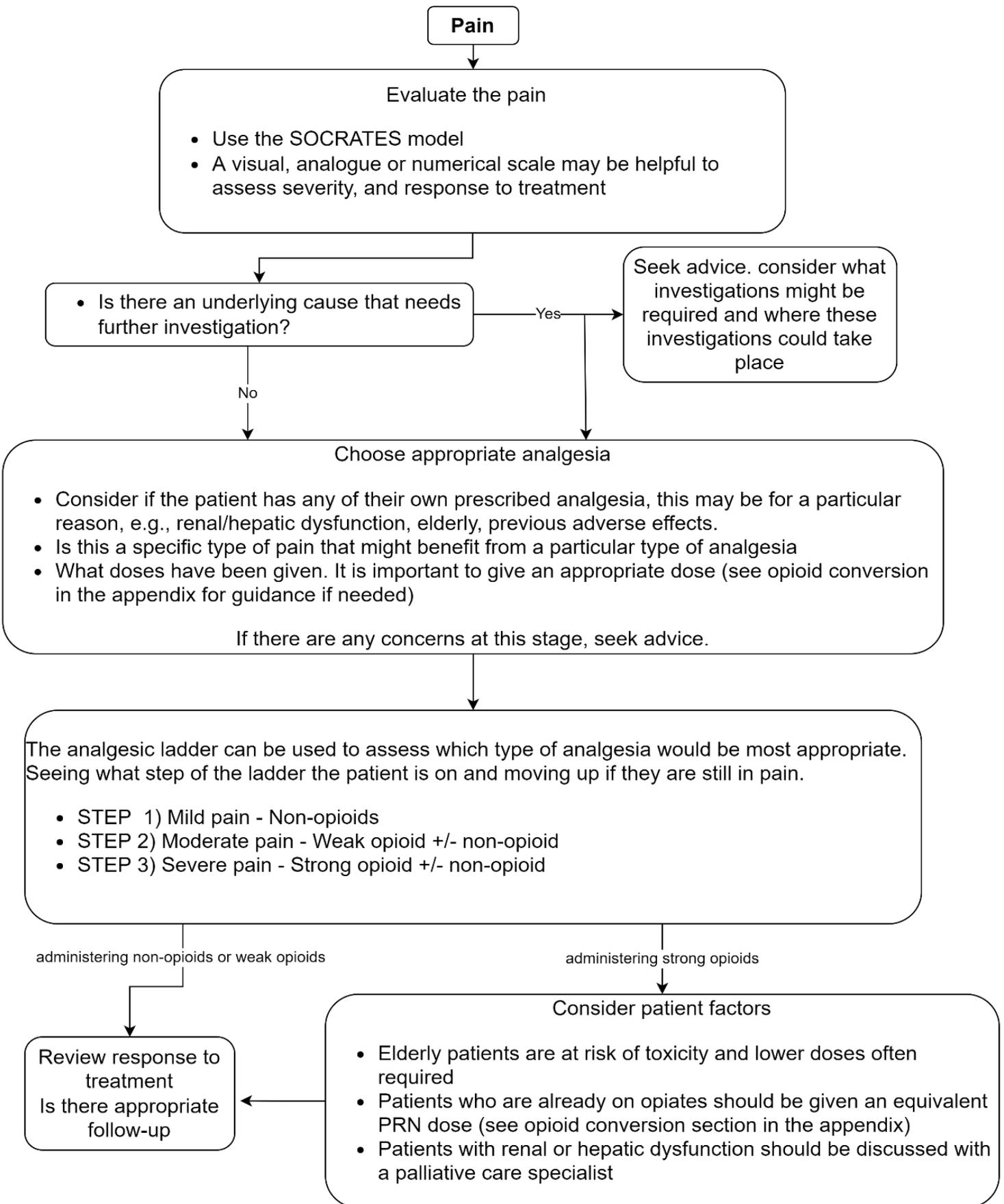
Pain

It is crucial to obtain a clear understanding of someone's pain to make the best management plan. A useful acronym to aid a comprehensive pain history is SOCRATES:

S	- Site	- Where is the pain?
O	- Onset	- When did the pain start?
C	- Character	- What does the pain feel like? e.g., Sharp, dull, burning, etc.
R	- Radiation	- Does the pain spread anywhere else?
A	- Alleviation	- Does anything make the pain better?
T	- Timing	- Does the pain come and go? If so, over what time period?
E	- Exacerbation	- Does anything make the pain worse?
S	- Symptoms	- Are there any associated symptoms? E.g., nausea, constipation etc.

There are a few specific pains in palliative care that is helpful to know. You would not be expected to manage these problems alone and you should seek advice and follow-up. If you present the information gleaned using SOCRATES, the specialist will often be able to give you specific and successful advice:

- Liver capsule pain
 - Often associated with liver metastases.
 - Sharp stabbing pain in right upper quadrant of the abdomen or shoulder tip.
 - Can respond well to non-steroidal anti-inflammatory (NSAID) medications.
- Bone pain
 - Common in bony metastatic disease or haematological malignancy.
 - Can be a sign of pathological fractures. Does not need to be traumatic, e.g., a person can fracture their femur rolling over in bed.
 - If suspected pathological fracture conveyance to hospital is usually required.
 - If the patient does not wish to attend hospital, this can be managed in the community; please contact your local palliative care team via Midos or Service Finder.
 - Can respond well to NSAIDs.
- Total pain
 - Pain over large parts of the body without a clear physical cause.
 - Pain often gets worse when the individual is anxious or at night.



Breathlessness

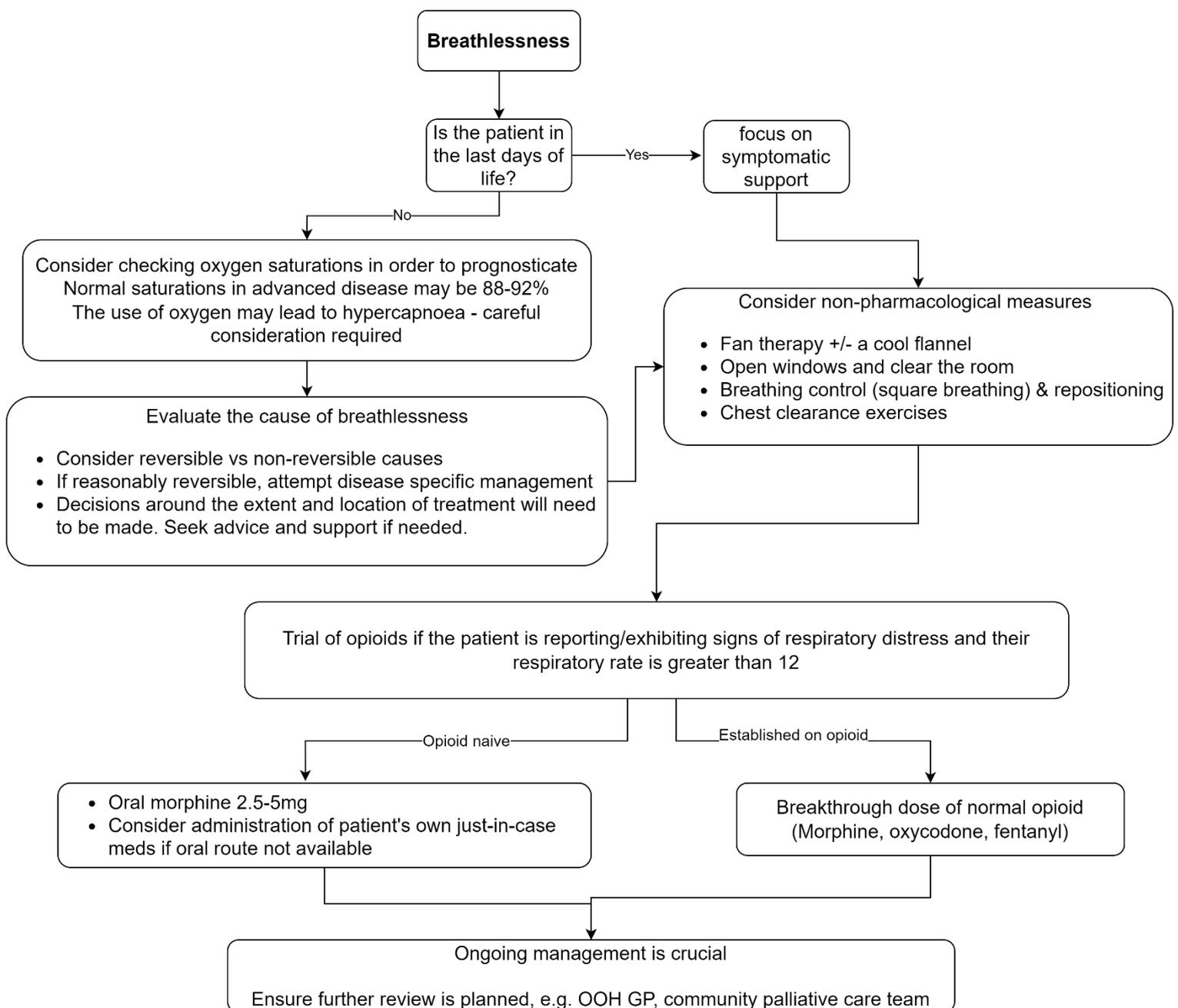
Breathlessness is one of the most common presentations in patients with palliative needs and the fear and feeling of uncontrolled crisis that is associated with the symptom means that often patients or their family call emergency services for help.

A helpful distinction when thinking about breathlessness is whether the cause is usually reversible or not:

Often reversible – Anaemia, Pulmonary oedema, bronchospasm, pleural effusion

Irreversible – lung fibrosis, malignant infiltration of lungs

It is important to consider the overall condition of the patient as reversibility may be of limited benefit.



Please see the '[would oxygen help their breathlessness](#)' section for use of oxygen in palliative care

Secretions

Upper airway secretions are a common symptom at the end of life and a strong predictor of death. Commonly the patient is not distressed by this symptom but the family may be and may believe the patient is. The best management is repositioning and explaining to family that we do not think the patient is suffering. Pharmacological treatments include glycopyrronium bromide and hyoscine butylbromide (also known as buscopan). See '[Just in case medications](#)' for more detail.

Reflection

Any particular cases where a symptom has been difficult to manage?

What barriers do you feel there are to giving just-in-case medication?

Document any thoughts or questions so you can discuss them at the live discussion session.

Implantable cardiac defibrillators (ICDs) and pacemakers

ICD and pacemaker implantation is increasing in the UK and it is important to know how to manage this cohort at the end of life, ideally with planned and timely deactivation of ICDs. Inappropriate cardioversion at the end of life can be distressing and painful for the patient and family.

Important principals to remember when considering what to do include:

- Whenever possible, discussion regarding deactivation should involve the patient and/or the NOK.
- Clarify what type of device the person has.
 - ICD – this will shock someone and needs to be deactivated
 - Pacemaker – most pacemakers do not need to be deactivated however CRT-D pacemakers do have the ability to shock and should be deactivated.
- A DNACPR decision does not automatically warrant ICD deactivation and vice versa so is important to clarify.

Non-emergency situation

If the person is not felt to be imminently dying it would not be expected of the ambulance service to have the conversation about device deactivation. Ideally, this is a conversation had by clinical specialists, including Cardiologists, Palliative care practitioners and the patient's GP. What would be expected is to identify that this might be an issue soon, briefly mention it to the patient, if felt appropriate, and raise the issue with an appropriate health care clinician.

Emergency situation

There will be instances where advanced decisions around deactivation have not been discussed and it is vital that this is addressed in people who are actively dying. The primary question here is whether the person has a cause of illness that cardioversion would potentially reverse or whether the illness trajectory would not be altered by cardioversion and would be preventing a natural and peaceful death. Sometimes, this can be a challenging decision. Do not hesitate to call for help if you need it. The best people to call would be the senior clinical advisor in SWASFT, the patient's GP if in hours or the palliative care specialists.

If it is decided that deactivation is appropriate but formal deactivation is not possible, tape a ring magnet on the patient's chest over the device. Ring magnets should be available in every vehicle. Write the date and time on the tape because the magnet will need to be removed and replaced every 7 hours. Click [here](#) for a video demonstration of how to apply the magnet.

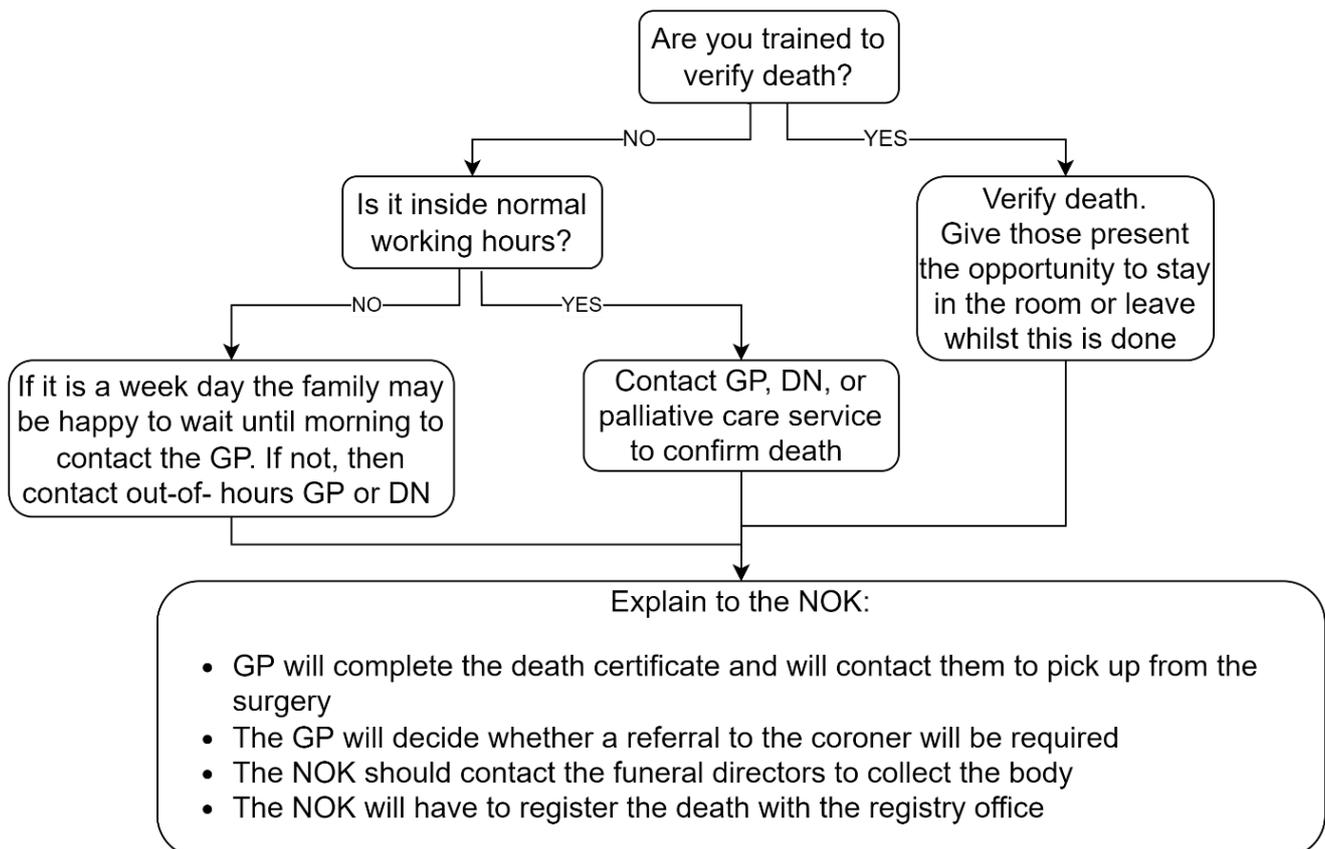
After death

ICDs and CRT-D pacemakers that have not been formally deactivated will not shock someone once they have died and it is safe to remove the magnet from the chest wall. It is, however, important to get the device deactivated as soon as possible. To do this, check care plans and patient notes for local services or use MIDOS or Service finder Apps to find the local cardiac physiologists. It is likely that funeral directors will not accept the body until the device has been deactivated.

After Death Care

Verifying an expected death and next steps

Confirming or verifying a death is the same thing. It is the examination that takes place to confirm that a patient has died. Certifying a death is a different thing. This is where someone, normally a doctor, will write the death certificate. Below is a flow chart briefly outlining procedures around verification and certification of death. For more information go to the 'recognition of life extinct' section in the SWASFT cardiac arrest guidance in the JRCALC app.



Personal care

- Check for any Advance Care Plan and talk to relatives about any spiritual, religious or cultural wishes or practices after death.
- Wear appropriate PPE before touching the patient. Under normal circumstances this will be gloves, a gown and a face mask but if there are any doubts, please discuss them with your senior clinical advisor.
- Lay the patient flat on their back. Straighten their arms and legs and place their arms by their side.
- Place one pillow underneath their head.
- Try to close their eyes by pressing down lightly on their eyelids for 30 seconds. If this does not work leave them and explain to the family that the funeral director will be able to help with this.
- Clean the mouth and teeth. Unless asked to by the family, do not take dentures out of the mouth as you may not be able to replace them. If dentures cannot be put back in explain that the funeral directors will be able to help with this.
- Tidy their hair, wash, and re-dress them if appropriate.
- Shaving a patient can cause them to become bruised. If family members ask about this, sensitively explain the consequences of doing so. Explain that the funeral directors may be able to help with this.
- Ask family members about personal belongings and jewellery. If required, remove the jewellery in the presence of another person.
- In general, keep medical equipment attached to the patient. Catheters, IV lines and SC lines can be clamped. Cover stomas with a clean bag. Cover wounds with an absorbent dressing and secure with an occlusive dressing.
- Switch syringe pumps off. This is done in three simple steps:
 - Hold down the blue info button until the pump bleeps
 - Press the red stop button
 - Hold down the black on/off button until the pump bleeps

Click [here](#) to watch a video demonstrating the correct procedure when caring for a person after death.

Family care

Every death is unique and people react in different ways and demonstrate a wide variety of emotions. It is important to be respectful of the needs of anyone close to the patient that has died. They might want you to take the lead or prefer that you are in the background. Allow them time to process what has happened and be prepared to listen rather than speak.

Be aware of anyone in the household who may need extra bereavement support. This might include children, adults with learning disabilities, mental health illnesses or vulnerable adults. If this is the case, contact GPs, district nurses or community palliative care services to inform them of your concerns.

Reflection

Any issues that have arisen after the death of a patient that you have been unsure how to manage? Any questions that were asked by family members, after a relative had died, that you found difficult to answer?

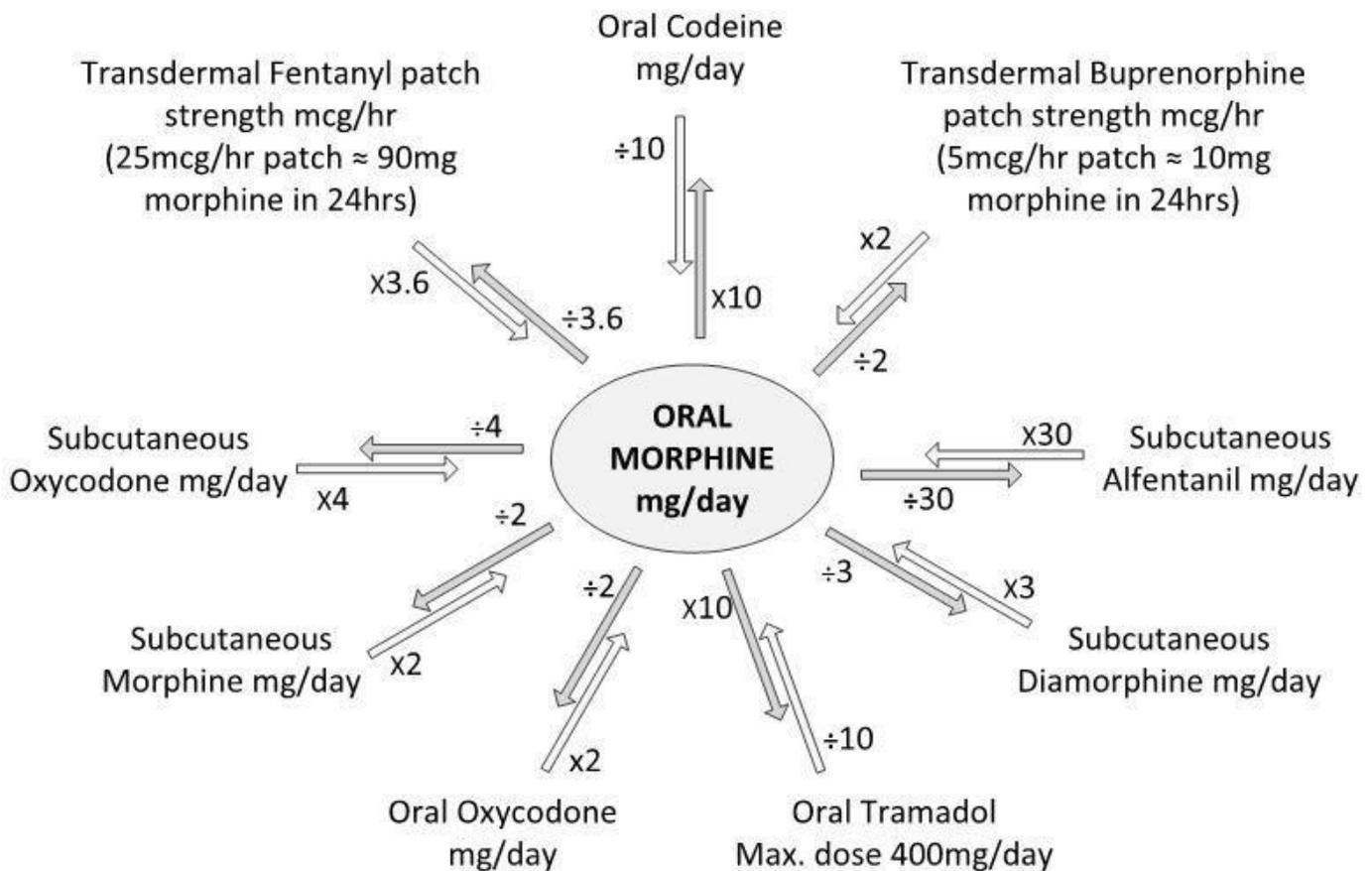
Document any thoughts or questions so you can discuss them at the live discussion session.

Appendix

Opioid conversion

This can be helpful if faced with a situation where medication administration records (MARs) charts offer a range of PRN opioid doses and you must decide how much to give. Remember that PRN opioid dosing is relative to the regular dose that people are already taking. 1/6 of the 24-hour dose of regular opioid should be given. Giving 2.5mg of immediate-release morphine to someone who is opioid naïve is reasonable but giving that same dose to someone who normally takes 60mg modified-release morphine twice a day is not going to offer any benefit.

Below are two conversion charts to help work out someone's total 24-hour dose of opioid. The trick is to convert everything to oral morphine and then convert to the relevant medication afterwards.



Opioid Conversion Chart

"Strong" opioids												Patches		"Weak opioids"			
Morphine					Oxycodone					Diamorphine		Alfentanil		Fentanyl	Buprenorphine	Tramadol	Codeine Phosphate
Oral (mg)			Subcutaneous (mg)		Oral (mg)			Subcutaneous ¹ (mg)		Subcutaneous (mg)		Subcutaneous ² (mg)		Transdermal Patch (mcg/hr) <i>Stable pain only</i>	Transdermal patch (mcg/hr) <i>Stable pain only</i>	Oral (mg)	Oral (mg)
4 hr dose (IR)	12 hr dose (MR)	24 hr total dose	4 hr dose	24 hr total dose	4 hr Dose (IR)	12 hr Dose (MR)	24 hr total dose	4 hr dose	24 hr total dose	4 hr dose	24 hr total dose	4 hr dose	24 hr total dose	Change every 72 hours	Change at intervals indicated	24 hr total dose	24 hr total dose
1.25		10													5 <i>7 days</i>	100	120
2.5	10	20	1.25	10	1.25	5	10	1.25	5	1.25	5	0.125	0.5		10 <i>7 days</i>	200	240
5	15	30	2.5	15	2.5	10	20	1.25	10	1.25	10	0.125	1	6-12	15 <i>7 days</i>	300	
7.5	20	40	5	20	5	10	20	2.5	10	2.5	15	0.25	1.5	12	20 <i>7 days</i>	400	
10	30	60	5	30	5	15	30	2.5	15	2.5	20	0.25	2	12-25	35 <i>72 hrs</i>		
15	45	90	7.5	45	7.5	25	45	3.75	25	5	30	0.5	3	25-37	52.5 <i>72 hrs</i>		
20	60	120	10	60	10	30	60	5	30	7.5	40	0.75	4	37-50	70 <i>72 hrs</i>		
30	90	180	15	90	15	45	90	7.5	45	10	60	1	6	50-75			

¹Some units recommend a 1:1 conversion from CSCI morphine to CSCI oxycodone* rather than the 2:1 conversion in the table above.

²Some units recommend an 18:1 conversion from PO morphine to CSCI alfentanil* rather than the 30:1 conversion in the table above.

*Seek specialist advice when doses are greater than the equivalent of 180mg PO morphine in 24 hours

Consider reducing the equianalgesic dose by 25-33% if converting from a less sedating opioid, e.g. fentanyl to morphine, oxycodone or diamorphine, as sedative actions may be greater for an equianalgesic dose.

Opioid side effects

Side effect	Notes	Suggested management
Constipation	Virtually inevitable	<ul style="list-style-type: none"> • Proactive prescribing of softening & stimulant laxatives
Nausea	Usually settles after a few days Less likely with slow titration	Consider <ul style="list-style-type: none"> • Haloperidol 0.5-1.5mg nocte PO • Domperidone 10mg tds PO • Metoclopramide 10mg tds
Dry mouth, Hiccups, sweating		<ul style="list-style-type: none"> • Manage symptomatically • Consider opioid switch if severe
Toxicity myoclonus (twitching of muscles), hallucinations, delirium, sedation	May be precipitated by rapid dose escalation, accumulation (particularly methadone, and fentanyl patches), renal or hepatic impairment, dehydration or infection	Seek specialist advice <ul style="list-style-type: none"> • Reduce dose • Monitor respiratory rate
Respiratory depression Respiratory Rate <8 breaths per minute	Sign of severe toxicity	Seek specialist advice <ul style="list-style-type: none"> • Stop regular opioid • Remember to remove patches • Use naloxone (20-100mcg IV and repeat every 2 minutes depending on respiratory rate) only if severe as will cause reversal of analgesia with sudden severe pain • Consider the cause e.g. change in renal function • Consider urgent bloods and give IV or SC fluids if dehydrated to aid opioid clearance
Opioid-induced hyperalgesia (OIH) Widespread and worsening pain, myoclonus, delirium, sedation +/- fits	Pain can be increased paradoxically as a result of taking an opioid. The pain also can spread beyond the original site. It can occur at any dose and with any opioid.	Seek specialist advice Failure to recognise OIH can result in an escalating dose of opioid and a risk of increasing toxicity.

Abbreviations

ANDO- Allow Natural Death Order
 ACP- Advance Care Plan
 ADRT- Advanced Decision to Refuse Treatment
 GP- General Practitioner
 ICD- Implantable Cardiac defibrillator
 LPA- Lasting Power of Attorney
 NG- Nasogastric
 NOK- Next-of-Kin
 NSAID- Non-steroidal anti-inflammatory
 OIH- Opioid induced hyperalgesia
 SC- Subcutaneously
 TIA- Transient ischaemic attack
 TEP- Treatment Escalation Plan