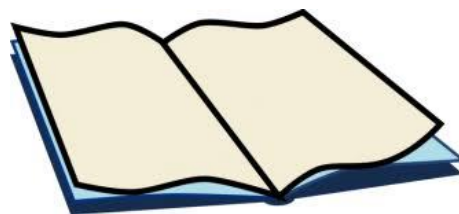


PALLIATIVE & END OF LIFE CARE RESOURCE BOOK



Written by: Mahe Mahadevanachari, EOLC Nurse
Edited by: Heather Boore, EOLC Nurse and Tania Perry, Claire Bunday & Jennie Turner, Palliative Care Nurses
Luton & Dunstable University Hospital, August 2020

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PALLIATIVE AND END OF LIFE CARE

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, 2002)

End of life care begins earlier than the point at which dying is diagnosed, and in most patients, is much longer than the last days of life. End of life care is an integral part of palliative care, but it is particularly focused on the final phase of life, which is often regarded as the final days to months of life. However, this will depend on the disease itself and how rapidly progressive it is in that particular patient. There is considerable overlap between these terms and concepts. Some people refer to this as the 'dying phase' - others use the term 'terminal care'.

The term End of life care is used in the Trust to define the care people receive in the last days of life. Palliative care also encompasses these last hours, and days, of life but is often delivered for many months and sometimes even years.

The Ambitions for End of Life Care National Framework was launched as it was recognised that care was available to all dying patients but the quality of the care was inequitable. The aim is to bring good quality care to *all* dying patients regardless of where they are and who they are. The emphasis is on local leadership rather than national directive.

Ambitions for End of Life Care National Framework 2015-2020

Each person seen as an individual

Each person gets fair access to care

Maximising comfort and wellbeing

Care coordinated

All staff prepared to care

Each community prepared to help

Recognising Dying

Learning Objectives:

- To understand the common signs indicating a person is entering dying phase
- Identify the Individual Plan of Care for the Dying Person and Blossom symbol used in the Trust
- Understand the frequency of assessment of a dying person



What would make you think a patient was entering the dying phase i.e has days or less to live?

The signs below may indicate the patient is entering the dying phase.

- no interest in, or not able to eat or drink
- withdrawing
- sleeping more / becoming drowsier
- breathing changes
- waxy / cold skin
- delirium
- weakness / fatigue
- bedbound

Clinical deterioration such as advanced progression of disease, poor / no response to treatment, poor blood / scan results, no reversible causes and poor vital signs can also be indicative of dying.

It is important to remember not everyone will present with these symptoms / signs.

The Individual Plan of Care for the Dying Person

To aid in providing excellent care for a dying patient, a care plan that addresses their individual needs is required. The care plan will address the patient's physical, spiritual and social needs through holistic assessment.

The Individual Plan of Care for the Dying Person (IPCDP) is initiated when it is recognised that a person is in the last hours to days of life. The care plan should be agreed by the medical and nursing teams and where possible, the patient & family / Next of Kin should be involved when initiating the plan. All documentation is recorded in the IPCDP once it has been commenced. Anyone involved in the patient's care can document in the IPCDP. *The nursing comfort sheet should be completed hourly.*

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Wards can collect the IPCDP from the Specialist Palliative Care Team (SPCT) based in the Macmillan Unit.

Booklet No:

LUTON & DUNSTABLE UNIVERSITY HOSPITAL

Individual Plan of Care for the Dying Person

MANAGEMENT PLAN

Aim to ensure maximum comfort, dignity, compassion and sensitive communication at all times.

Date: _____ Time: _____ Ward: _____

Care plan initiated by: _____

Job title: _____

Signature: _____

Patient Label

HEALTH RECORDS FILE SECTION - INPATIENT INFORMATION

Senior responsible clinician:	Name	Grade
You MUST refer to the EOLC Nurse - Bleep 260		Completed
Reasons patient is thought to be dying in the next few hours or days:		
Agree with (names of relevant MDT members):		
Is the patient aware that this care plan is being initiated? Yes No		
Does the patient have capacity? Yes <input type="checkbox"/> No <input type="checkbox"/>		
If no, state reason:		
Ensure DNACPR form has been completed and discussed with the patient and/or those important to them.		
Review TEP <input type="checkbox"/>		
Does the patient have an advance care plan (ACP)? Yes No		
Patient's preferred place of death		
If PPD is in the community setting i.e. home, nursing home, hospice, then contact Integrated Discharge Team on Bleep 167		
Is there a Lasting Power of Attorney for health? Yes <input type="checkbox"/> No <input type="checkbox"/>		
If yes hold by		
If yes, ask to see the document to establish validity and applicability and ensure that the person with power of attorney has been contacted		
Person to contact for discussions (nominated by the patient)		
Name	Relationship	
Contact details		
Is this person aware that this care plan is being initiated? Yes <input type="checkbox"/> No <input type="checkbox"/>		
Document details of all discussions on final page of assessment		
If you require any further information please contact the Palliative Care Team on: Bleep 492/269 or Ext 7522 Out of hours advice line 24 hours a day: 0205 160 7788		

PF-002133-116 v10.0 - Plan of Care for the Dying Person - 0_0507 - page 1 of 20

It is important to consider the following:

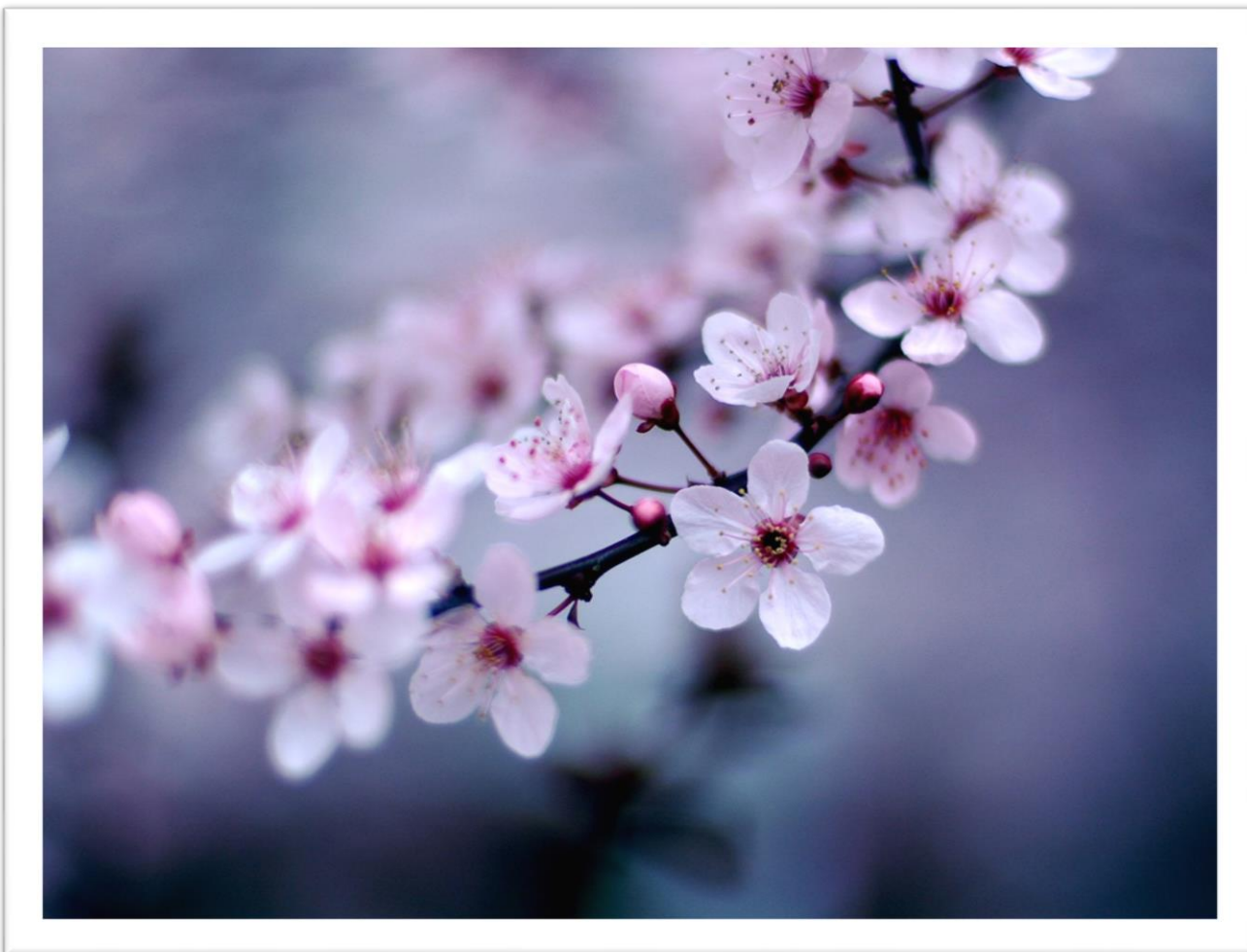
- Don't document you have visited hourly if you haven't!
- Document if you have acted on, or treated any symptoms
- Document if you have spoken to the family
- Document if your patient dies
- Document care after death

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The Blossom Project

The blossom symbol is used in the Trust to highlight the patients on the IPCDP to enable staff to easily recognise and locate them in their area of work.



The Blossom Project is aimed to consolidate the measures that have been put in place to improve the quality of care received by dying patients and their loved ones. Each ward has a '*Blossom resource pack*' which contains resources to enable staff to achieve this aim.

Please see *Blossom resource pack* located in your area for further information.

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Symptom Management

Learning Objectives:

- Discuss symptoms that commonly arise in the last days to hours of life
- Describe how to address the dying person's comfort
- Understand the term 'anticipatory medications' and where you can find the Trust's guidelines
- Understand the importance of anticipatory medications prescribed for dying patients
- Identify common anticipatory medications, dosage, frequency and route used in the Trust

Palliative and End of Life care includes the management of pain and other symptoms as well as the provision of psychological, social, spiritual and practical support. It is the prevention and relief of suffering by means of early identification and impeccable assessment and treatment. If a patient is unconscious or non-communicative then the nurse must use non-verbal cues to assess for pain or other symptoms.



What are the 5 most common symptoms that the dying patient can experience?

1. Pain
2. Agitation / Delirium
3. Nausea & Vomiting
4. Breathlessness
5. Noisy secretions

Anticipatory Medications

One way to manage these symptoms is with medication. All dying patients are prescribed a group of drugs called anticipatory medications. They are called this as they are prescribed in anticipation of a common symptom developing and therefore can be administered immediately rather than waiting for the symptom to be present and then having to wait for the medication to be prescribed. This prevents delays in the patient receiving appropriate medication and therefore ensures better care. It is best practice to first administer the lowest dose of the anticipatory medication when a symptom develops. Large doses can be given if symptoms remain uncontrolled or advised by SPCT. Anticipatory medications are given by subcutaneous injection. This is due to several reasons; the patient can no longer take oral medications or the patient may not be absorbing effectively. IV cannulas should be removed once a patient is recognised as dying in order to 'de-medicalise' them as much as possible, therefore subcutaneous injection is used as it is the least invasive.

The anticipatory medications or '*Medicines required for Palliative patients*' can be located on the Trust's intranet, in ward / department Palliative care resource boxes and on laminated posters in some areas.

Symptom	Anticipatory Medications	Dose
Pain & Breathlessness	Morphine or Diamorphine	2.5 - 5mg S/C Hourly
	Or Oxycodone if AKI	2.5 – 5mg S/C Hourly
Agitation, Breathlessness, Delirium & Jerking	Midazolam	2.5 - 5mg S/C Every 20 mins
Nausea & Vomiting	Cyclizine	50mg S/C TDS Max 150 mg in 24 hours
	and/or Haloperidol	1.5 - 3mg S/C BD
Respiratory secretion	Glycopyrronium or Hyoscine Hydrobromide	200 mcg S/C 4 hourly, Max 1.2 mg in 24 hours 400mcg S/C Max 2.4mg in 24 hours

Syringe Drivers



Learning Objectives:

- Identify indications for the use of a syringe driver
- Understand the equipment needed to set up a syringe driver
- Dispel some myths and assumptions about the use of syringe drivers

If a patient requires several doses of anticipatory medications then a Continuous Subcutaneous Infusion (CSCI) is preferable to repeated subcutaneous injections. The T34 syringe pump (driver) is used to administer anticipatory medicines via CSCI. It is important to note:

- **Not all dying patients require a syringe driver.**
- **Equally having a syringe driver does not always mean a patient is dying.**
- **A syringe driver may be used if requiring two or more doses of anticipatory medication or if advised by the Specialist Palliative Care Team.**
- **The medicines in the syringe driver will take a minimum of 4 to 6 hours to reach a steady level in the body.**
- **A syringe driver is NOT a replacement for anticipatory medications. It works in the background, while anticipatory medications are administered to treat any breakthrough symptoms.**
- **If an opioid is in the syringe driver, the PRN opioid should be the SAME medication**

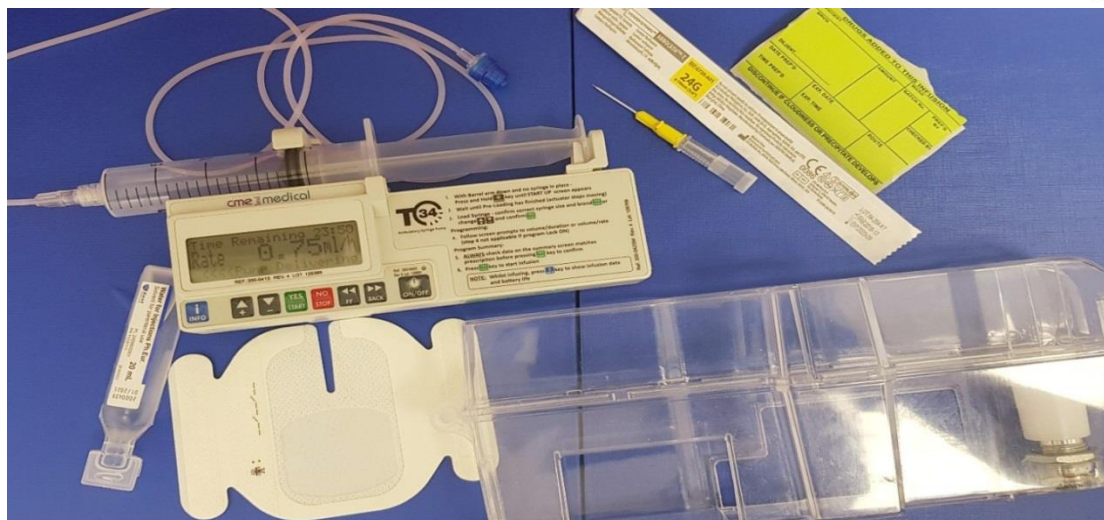
There are many myths and misconceptions regarding the use of a syringe driver in palliative care. Sometimes, patients or relatives fear that the use of a syringe driver accelerates death.

Open and sensitive communication needs to take place to explain that a syringe driver is used at this point purely as an alternative method of delivering medication.

It allows a constant, steady administration of medication rather than the peaks and troughs that come with injections or oral medications. Generally, the dose of opioid used in a syringe driver will be equivalent to the oral dose the patient was previously on. Daily assessment is imperative as a change in symptoms may require a change in the syringe driver prescription.

Equipment needed for setting a syringe driver up:

- Syringe driver & battery
- 20 or 30 mls BD plastipak leur lock syringe
- 24 gauge needle
- Subcutaneous infusion set (blue tip)
- Medications
- Water for injection
- Medicine Additive Label for syringe
- Transparent dressing
- Sani-cloth
- Syringe driver documentation chart (can be printed from Evolve)



Syringe drivers in the Trust can be obtained from Clinical Engineering Ext: 2480 or via Porters Ext: 7191 or Bleep 552. For further training on assembling a syringe driver, contact Sam Gilmore in Clinical Engineering Ext: 7495

Non-medical interventions for symptom management

Learning Objectives:

- Describe a range of non-pharmacological interventions that can be used as part of an integrated symptom management approach in end of life care

Medication is only one way to manage symptoms. There are many other tools that can be utilised to settle a patient. When a patient develops a symptom, think about what might be the cause, particularly if they don't respond to medication.

Agitation can have many causes; discomfort, anxiety, a full bladder, pain, feeling hot, feeling cold, breathlessness, nausea, fear. These are just some of the reasons a patient may display agitation. Excellent assessment and action can ease the agitation.

- Repositioning
- Contenance care
- Catheterisation for urinary retention
- Family visit
- Chaplaincy for spiritual support
- A cold compress

Breathlessness can often cause a great deal of fear in a patient, which in turn can exacerbate the breathlessness. While medication can be very effective in managing breathlessness, often non-medical intervention can be equally as useful.

- Oscillating fan
- Open window
- Repositioning
- Music therapy
- Mindfulness

Respiratory secretions can be noisy and distressing for family members. They rarely cause a patient discomfort so it is important to reassure loved ones of this. Giving an explanation of the cause of the secretions can help families understand the sound. Non-medical interventions are often more effective in managing this symptom, such as:

- Repositioning
- VERY gentle suctioning in the front of the mouth

Pain can be well managed with medication however; non-medical interventions are often very effective also. Some patients prefer not to have opioids, so offering alternative options is important.

- Repositioning
- Pressure area care
- Hot or cold compress
- Music therapy
- Aromatherapy
- Distraction therapy

Nausea and Vomiting can be difficult to manage with medication. Non-medical interventions may not resolve the symptoms but can offer great comfort to patients, such as:

- Cold compress
- Oscillating fan
- Sips of water or fizzy drinks
- Ice lolly
- Repositioning
- Loose clothing

Communication

Learning Objectives:

- Identify why good communication is important to patients and their families in end of life care
- Explain why good communication is important for those working with patients and their families in an end of life care setting
- Understand who to contact for further support in regards to discharging a dying person

Provide the dying person, and those important to them, with:

- accurate information about their prognosis (unless they do not wish to be informed), explaining any uncertainty and how this will be managed, but avoiding false optimism
- an opportunity to talk about any fears and anxieties, and to ask questions about their care in the last days of life, preferred place of care / death
- information about how to contact members of their care team for further support

Care of dying adults in the last days of life, NICE (2015)

- **Don't assume that the patient is aware they are dying**
- **Avoid using medical jargon. Use the word DYING when communicating with patient & family about initiating the IPCDP**

If a patient wishes to die at home or requires another placement for end of life care, fast track paperwork must be completed and the District Nurse Liaison Team should be contacted to facilitate discharge. Ward nurses are expected to refer the patients to Community nurses for End of life care support according to their discharge destination. The SPCT should be contacted if a hospice referral is required.



Other points to remember:

Learning Objectives:

- Dispel some myths and assumptions about hydration, nutrition and weaning off oxygen when someone is dying
- Explain how you can provide good mouth care in EOLC

Hydration & Nutrition

Towards the end of life patients often have a reduced appetite and may not be able to digest food and drink properly or comfortably in order to maintain a good diet. A sensible approach would be to offer food that they enjoy and that is easy to swallow rather than foods that provide essential nutrients. Artificial feeding and hydration are rarely recommended in the dying phase as they seldom improve the patient's comfort and can actually cause more symptoms. No patient should be nil by mouth when end of life even if they have a compromised swallow. Patients should have risk feeding and the consequences explained to them and their loved ones so they are able to make an informed choice on eating for pleasure.

Oxygen

Oxygen therapy in the dying patient is generally not recommended as the focus of care at end of life is comfort. Oxygen masks can cause discomfort to the face and ears and the oxygen causes drying of the mouth and nose. For the majority of breathless patients, medications in a syringe driver are a more effective way to manage the symptom.

Mouth care

Poor mouth care can have a negative impact on quality of life, both physically and emotionally. Mouth care should be part of the hourly routine care for all dying patients as a dry mouth can develop a thick coating over the tongue and lining of the mouth.

There are many things you can do to help someone with a dry or coated mouth:

- Offer small and frequent drinks throughout the day if the patient is able.
- Wetting mouth care sponges / swabs in the patient's favourite drink to provide oral care
- Saliva replacements or oral gel can be used to keep the mouth moist.
- Paraffin ointment for lips
- Gently remove coating and debris from the lips, tongue and lining of the mouth using a mouth swab or a soft toothbrush.
- Use prescribed medicines for any infection in mouth

BEFORE



AFTER



Care After Death

Learning Objectives:

- List the signs that indicate when a patient has died
- Evaluate how well personal care after death is carried out in your own clinical area

There are several signs that indicate death has occurred. In the hospital setting a doctor is required to certify death however it is important to be familiar with the signs.

- No response to voice / touch
- No respiratory movements / breath sound
- Fixed and dilated pupils
- Heart stops beating

Nurses, healthcare assistants and porters have a key role in ensuring that care after death is carried out respectfully, in line with Trust policy and in a way that preserves the deceased person's dignity. How care after death is delivered has a lasting impact on bereaved family members and caregivers. Remember that mortuary staff and bereavement officers can be a useful source of advice in seeking to address any concerns or issues.

Bereavement Team Ext No: 2818. Bleep: 299

Further Learning:

End of Life Care for All (e-ELCA) is a national e-learning programme developed by Health Education England's e-learning for Healthcare (e-LfH). It is aimed at enhancing the training and education of all those involved in caring for people in the last year of life.

The SPCT recommends the nurses and other health care professionals in the Trust to complete these e-learning sessions on ESR to increase their knowledge in End of life care.

1. Via ESR staff login, you can access the following training:

- **e-ELCA 0.0** End of Life Care: Introduction
- **e-ELCA 3.0** Communication Skills: Principles
- **E-ELCA 4.5** Symptom Management: Last Days of Life
- **E-ELCA 5.4** Integrating Learning: Care after Death



2. External training (free!) for any person, particularly those who do not have ESR login can be accessed via:

https://portal.e-lfh.org.uk/Catalogue/Index?HierarchyId=0_39701&programmeld=39701

We would recommend the following sessions following the link above:

- 00_01** Introduction to e-learning for End of Life Care
- 00_02** Relationship between palliative care and end of life care
- 04_01** General approach to assessment of symptoms

3. However if you have a work email you can register to access further sessions such as:

- 04_23B** Symptom Management for the Dying Adult

Specialist Palliative Care Team Contact

Palliative Care Consultant

(Dr Nicholas Herodotou)

Monday to Friday 9am - 5pm

via switchboard / 07970 689197 / ICE

Palliative Care CNS – 492

(Tania Perry, Claire Bunday, Jennie Turner)

End of Life Care Nurse – 269

(Heather Boore, Mahe Mahadevanachari)

Office extension: 7522

7 days a week 8am – 6pm

E-mail - Please use the address search within Trust email to find us...

‘Specialist Palliative Care Team’

Out of Hours - **My Care Co-ordination Team**

24 hour advice line for all palliative patients

0808 180 77 88

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Luton & Dunstable University Hospital, August 2020





1. Explain the differences and similarities between palliative care and end of life care.
2. What would make you suspect a patient was entering the dying phase i.e has days or less to live?
3. Do all dying patients display the same signs and symptoms? Explain your answer.
4. Where can staff find the Individual Plan of Care for the Dying Person?
5. Only nurses and doctors are allowed to record in the IPCDP. **True or False**
6. What is the recommended frequency of assessment of comfort for the dying patient?
7. What symbol represents End of Life Care in the Trust?
8. What are the 5 most common symptoms that a dying patient may experience?

9. What are the medicines that are used for symptom management at End of Life called?

10. Where can you find the guidelines for these medicines in the Trust?

11. Which medications and dosage are recommended for managing the symptoms of pain and breathlessness?

12. All dying patients need a syringe driver. **True or false**

13. Syringe drivers hasten death. **True or false**

14. Which extension set should be used with the T34 Syringe driver?

15. Which analgesic is recommended for managing pain in a patient with symptoms of AKI?

16. The larger dose of opioid is only to be administered if smaller dose is not effective
True or false

17. Your patient shows signs of pain but is not able to communicate.
Are you allowed to administer an opioid? Explain your answer.

18. A patient does not need any PRN analgesic if he/she is on a syringe driver.
True or false

19. Non-medical interventions like a cold compress, an oscillating fan, sips of water or fizzy drinks and an ice lolly are recommended for which common symptom?
20. My patient is agitated due to urinary retention. Can I still catheterise the patient?
Yes or No
21. Who should you contact if the patient wants to go home or to a nursing home for End of Life Care?
22. Who should be contacted if the patient's preferred place of death is Hospice?
23. The patient has not been awake enough to eat or drink for days. Is he/she suffering?
24. Enteral feeding and intravenous fluids are not recommended for a dying patient as they can cause more harm than benefit. **True or false**
25. The patient has some difficulty in swallowing. Should they be nil by mouth when they are dying **Yes or No**? Explain your answer.
26. Can I use juice or tea to provide mouth care?
27. How can you access palliative care advice in the middle of the night?