Priorities of care for the dying

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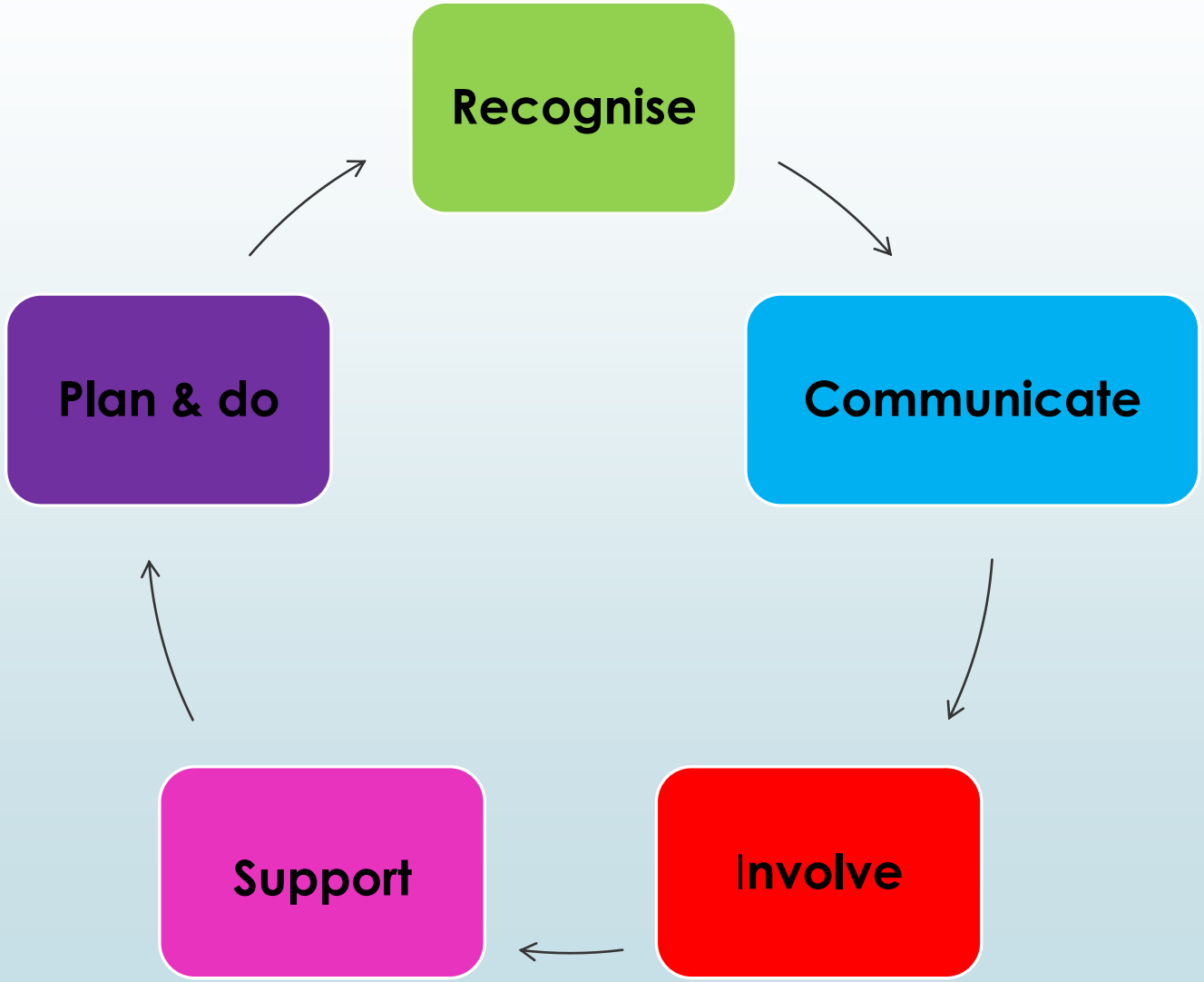
Learning objectives

- By the end of this session you should be able to:
- Understand the 5 priorities of care for the dying
- Speak about death and dying
- Plan care for someone who is dying
- Provide support for families and loved ones

Why is it so important to ensure someone has a “good death”?

- There is only one chance to get it right
- Alleviate suffering
- Promote dignity
- The nature of the person’s death and the events leading up to it can have positive or negative effect on loved one’s grieving process

5 Priorities of care for the dying



The HCP's role in caring for the dying person

ASSESSOR

FACILITATOR

ADVOCATE

Recognise

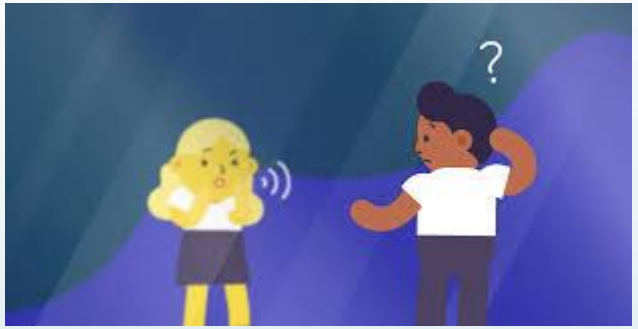
How do we recognise somebody is dying?

- Decreased functional ability
- Reduced oral intake
- Sleeping for longer periods
- Increase in symptoms (possible)
- Loss of bladder/bowel control
- Changes in communication
- Changes in breathing
- Skin changes


COMMUNICATION

Are we scared to talk about death?

Barriers to talking about death and dying



- **Lack of experience**
- ***"It's not my place to say"***
- **Fear of "getting it wrong"**
- **HCP own fear of death and dying**
- **Cultural issues**
- ***"If I talk about it, it might happen/the patient will give up hope"***

Breaking bad news: starting the conversation

- **Prepare**
- **Consider the environment**
- **Have a colleague present if possible**
- **Introduce yourself, gain consent for the conversation**
- **What do they understand?**

- ***Read the notes, ensure the patient is comfortable***
- ***Is it suitable?***
- ***A colleague can support you and the patient***
- ***Hi I'm Laura, I am the nurse looking after you today, is it OK if we discuss your care?***
- ***Can you tell me what's been going on?***

BBN: picking up on cues

- **Pick up on cues**
- **Gain clarity**
- **Give a warning shot**

- ***I hear that you are telling me you are spending most of your time in bed as you feel very weak.***
- ***Does that sound right to you?***
- ***I'm afraid this isn't a good sign/I'm afraid I have bad news***

BBN: Delivering the bad news

Deliver the bad news	***I am sorry to tell you that (insert name) is dying……***
PAUSE	***Breathe, allow for the information to be absorbed***
Show empathy	***I am aware how hard this is to hear…….***
Do not give false hope	***but it is important I am honest with you so we can discuss how and where you wish to be cared for when you are ready***

Language, tone & silence

- Communicate sensitively with the patient & loved ones
- Avoid using euphemisms
- Allow for silence
- Do not give false hope
- Actively listen

Words and phrases to avoid

“You just need to build yourself up”

“Getting better”

“Things are moving on”

“Disease progression”

“We can’t do anymore right now”

“Let’s see how you do”

To summarise

- Gain consent
- Give the information in stages
- Use suitable language
- Pause
- Do not offer false hope
- Show empathy
- Discuss the plan of care
- Involve
- Summarise key points

Mary Jones

70 year old with metastatic pancreatic cancer

Discharged from local oncology team 6 weeks ago

Known to hospice community palliative care team and district nurses. Takes 5mg Oramorph PRN for abdominal pain.

DNACPR in place

PPC: Home

PPD: Hospice or home

Social history: Widowed. Has 2 daughters Anna & Claire. Lives with daughter Anna.

In the last week Mary has become bed-bound. She no longer wants to eat. Daughter Anna called the hospice concerned with how sleepy her mother is. A consultant from the hospice arrives at the home and reviews Mary.


involve

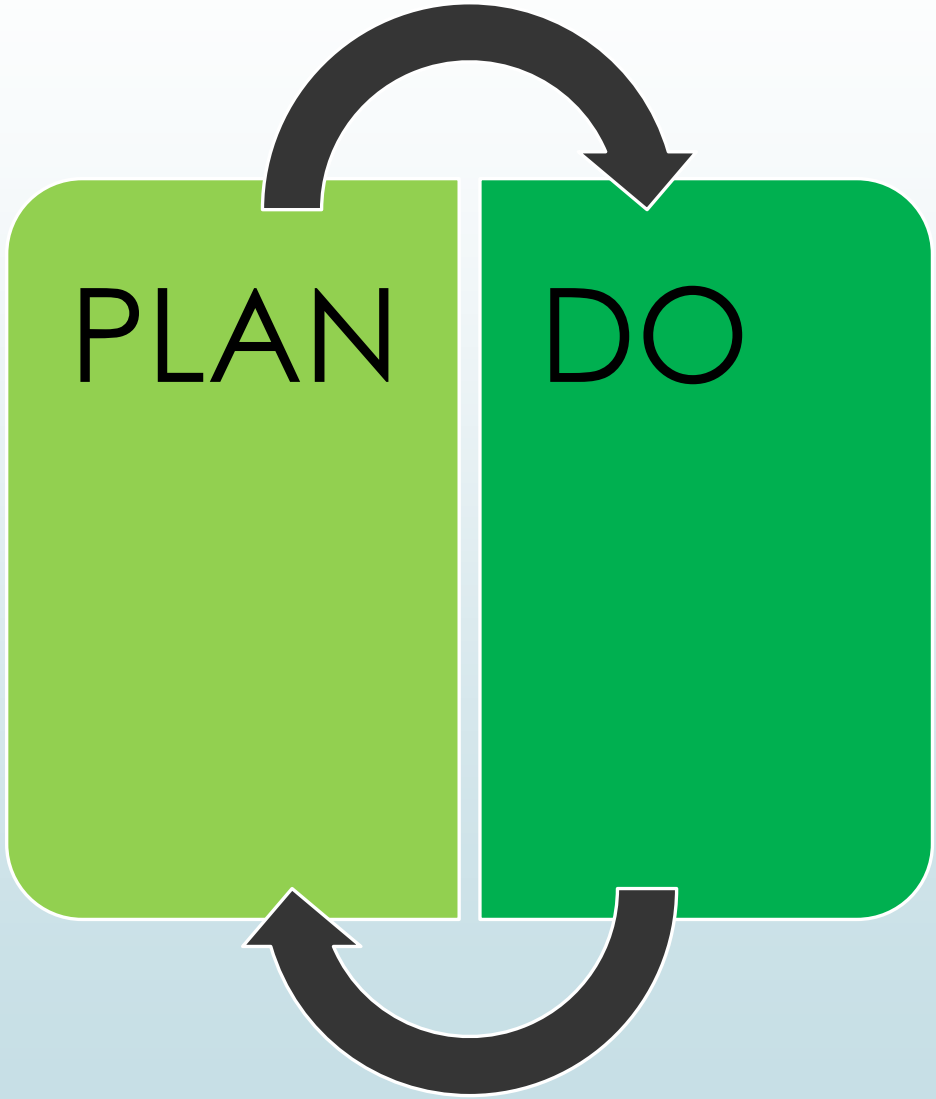
Involve

- Involve the patient, family and loved ones
- "What's important to you?"
- Involve GP/hospice/allied healthcare professionals/hospital team
- What are the patient's wishes for their future care?
- Involve the patient and family in important decisions, including DNACPR, PPC/PPD


SUPPORT

Support

- Be the patient's advocate
- Support them with informed decision-making
- Practical
- Emotional
- Psycho-social
- Spiritual


PLAN
DO

Plan & do

- Create an individualised care plan (include ACP)
- Include symptom control interventions
- Support for eating and drinking as long as the person wishes to
- Address current issues
- Review regularly
- Create a CMC record recording their wishes

coordinate my care

Caring for adults in the last days of life

Learning objectives

- **By the end of this session you should:**

- **Have an understanding of the last days of life**
- **Be able to care for patients and their loved ones**
- **Have an awareness of cultural, spiritual and religious needs at the end of life**
- **Consider your own mental well-being**

Final hours

Terminal phase

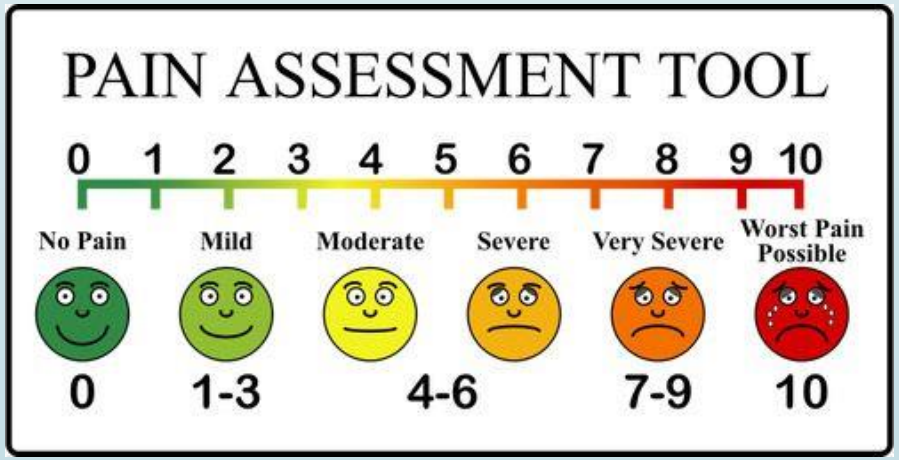
Actively dying

Care needs

- Pain management
- Symptom management
- Nutrition and fluids
- Pressure area care
- Mouth care
- Continence care
- Rationalise medications
- ACP is reviewed & up to date

Pain assessment

- Does the patient appear in pain?
- Can they can communicate they are in pain?
- Use an appropriate assessment tool
- Do they have analgesia prescribed?



Pain Assessment Model

S	Site	Where exactly is the pain?
O	Onset	What were they doing when the pain started?
C	Character	What does the pain feel like?
R	Radiates	Does the pain go anywhere else?
A	Associated symptoms	e.g. nausea/vomiting
T	Time/duration	How long have they had the pain?
E	Exacerbating/ relieving factors	Does anything make the pain better or worse?
S	Severity	Obtain an initial pain score

Pain management

- Oral analgesics may no longer be tolerated
- Consider alternative routes such as subcutaneous
- Transdermal patches may not be appropriate if prognosis is days
- If on long acting opioids, this should be converted to a subcutaneous syringe pump
- Repositioning may help
- Gentle touch if appropriate
- Heat pads/creams

Breathing in the last days of life

- **Breathing is likely to become laboured**
- **Breathing likely to be shallow & irregular, with pauses- *this is known as cheyne-stoking***
- **Loose respiratory secretions may present**
- **These can be audible, noisy**
- ***sometimes referred to as "death rattle"***
- **Can be very distressing for the family & loved ones to hear**

Managing breathlessness & secretions

- **Small dose opioid may help breathlessness (needs to be prescribed)**
- **Fan therapy not recommended in suspected or positive COVID-19 patients**
- **Re-positioning if possible**
- **Oral suctioning if available**

- **Explain to loved ones that audible secretions are not causing any pain or discomfort *"Although upsetting to hear, this is not causing pain or distress. (Insert name) is no longer able to swallow their saliva, so the noise you hear is a trickle of saliva going down their throat"***

- ***"Like snoring, it is more distressing for the people around the person hearing it, it is not causing the patient harm"***

Terminal Agitation

- **Establish the cause & treat these if possible**
- ***In Pain?***
- ***Constipated?***
- ***Urinary retention?***

- **Remember to communicate clearly, not too much information at once**

  Explain who you are, why you are there and how you are going to help

- **Consider repositioning**
- **Calm environment, music**
- **Consider gentle touch**
- **Medications may help, analgesics, benzodiazepines**

Nutrition & hydration in the last days

- Oral intake likely to reduce
- Swallow may become impaired
- Coughing and choking on food and fluids- potential to aspirate
- Family may ask for artificial supplementation
- Oral and tracheal secretions may become a problem

Nutrition & Hydration management

- Patient may not wish to eat much
- Ensure patient is sat upright and alert if they wish to eat or drink
- Coughing is a sign of aspiration, caution is needed
- If diabetic, medication should be reviewed and rationalised
- Sips of cool fluid/lollies/ice chips may help with dry mouth
- Offer smaller portions & plain foods if nausea an issue and if they can manage food

Gastrointestinal symptoms

- Assess for GI symptoms
- Nausea & vomiting
- Constipation, diarrhoea, bowel obstruction
- Colic
- Early satiety
- Treat appropriately
- NG tubes maybe considered for comfort, however often not appropriate for dying patients

Ethical issues to consider

The family may ask questions such as….

- ***Why doesn't my loved one have a drip?***
- ***Why aren't you artificially feeding them?***
- ***I do not want them to die of dehydration***

Communication is Key

- **Acknowledge their concerns**
- *"I understand your concerns given that your loved one can no longer swallow oral fluids, it must be very upsetting"*
- **Explain why this is happening**

"As (name) becomes weaker, they lose the ability to swallow. If we were to try and give them oral fluids, they are likely to choke. If fluid were to go down the airways instead of the food pipe it could cause a chest infection"

- **Reassure the family**

"It is common for patients to lose the ability to swallow at the end of life. It is part of the natural process of dying. We are ensuring we are keeping their mouth clean and moist."

- **Include loved ones in care**

"If you wish to, you can offer the mouth care to (name) to keep their mouth moist. You can use water or juice if they would prefer".

Mouth care

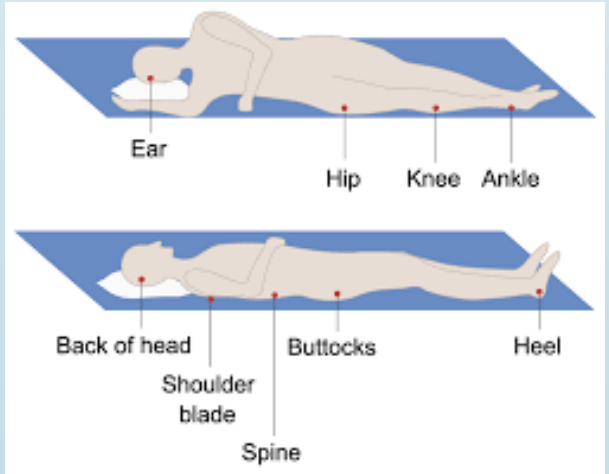
- Should be performed at regular intervals
- Can include family members/loved ones should they wish
- Inspect oral cavity
- Remove dentures if loose and clean- if patient unconscious leave dentures out-put in a labelled container and document where they are kept
- Follow local guidance to clean oral cavity
- Apply lip balm/vaseline to lips if oxygen not in use
- Note any oral thrush/redness/ulcers
- Document in notes

Skin changes in last days of life

- Skin may change in appearance, peripheral and central cyanosis maybe present – Blue tinge to lips/hands/feet
- Peripheral oedema may accumulate – swollen feet/legs/hands
- Skin may feel cool
- This is due to the cardiovascular system failing
- Pressure ulcers are sometimes unavoidable

Skin assessment

- **Document:**
- **Appearance:** ***dry, dehydrated, tissue paper***
- **Wounds:** ***pressure ulcers, moisture lesions, surgical wounds, drains***
- **Known conditions-** ***eczema, psoriasis***
- **Interventions in place-** ***repositioning chart, pressure relieving equipment, emollients/barrier creams/dressings used***
- **Ensure waterlow score is correct & reviewed as per local policy**



Continence care

- Loss of bladder and bowel function will occur as the patient becomes more weak
- Urine output may decrease due to dehydration, impaired kidney function
- Urinary retention may occur- sometimes due to side effects of certain medication
- Skin may become sore from incontinence
- Constipation may be an issue
- If not managed properly it can cause the patient to become agitated

Continence care

- Ensure hygiene needs are met
- Use of continence products such as pads, inco sheets, convene to be assessed for and used appropriately
- Assess need for barrier creams
- Consider catheterisation if in urinary retention- adhere to local policy guidelines
- Monitor bowel function, may require rectal suppositories

Managing anxiety

- **COMMUNICATION, COMMUNICATION, COMMUNICATION**
- **open, honest, factual**
- **Calm manner, reassurance**
- **Include the patient & family in care**
- **Suggest playing their favourite music as distraction**
- **Creature comforts from home- favourite pillow, blanket, etc.**
- **Aromatherapy- lavender oil known to have calming properties**
- **Ensure spiritual needs are met**

Spiritual assessment

- Are there any religious or cultural needs?
- Spiritual needs are not just about religion or culture
- It is about the patient as an individual

  What makes them who they are

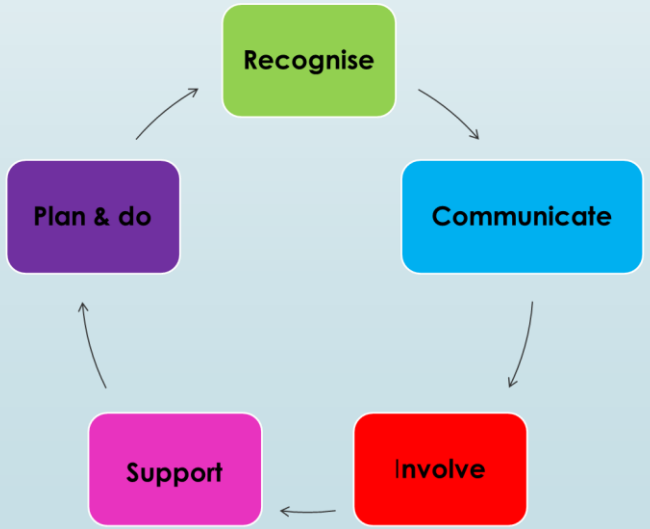
- **What is important to them?**

Medications/ACP

- GP should be made aware the patient is actively dying
- Review in person if required
- Oral medications rationalised
- ACP including resuscitation status reviewed & updated
- Ensure NOK/family aware of what is happening

Remember…..

- It is important loved ones are aware of what is happening
- Ask if there anybody who the patient wishes to visit
- Inform the GP
- Review care regularly
- Ensure urgent care records are up to date



Finally….

- Although a great privilege, caring for dying patients can be highly emotive
- Self-care is important
- Take your allocated breaks
- Ask for help!
- Find something to help you switch off from work
- De-brief with colleagues