



End of Life Care Workbook for Support and Care Staff

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Welcome and Foreword

You may be reading this workbook with very mixed feelings. Many people worry when it comes to thinking about death, dying and the end of life. Whilst it may be something you are aware of within your setting, you might not have thought about the role that you may play.

Death is an inevitable part of life. We will all die and almost all of us will experience the death of someone close to us. Every year in England and Wales over 500,000 people die (ONS, 2017). A quarter of these deaths will be sudden, but that means three-quarters of the deaths might be expected and planned for.

Dying can be a process, and which may include a decline in functioning over a period of days, weeks or even years.

During this time, some people will receive a form of end of life care, designed to maximise their quality of life until the moment of their death (Hughes-Hallett et al 2011). This may include managing pain and other symptoms, along with providing psychological, social, spiritual and practical support.

This care extends not only to the people who are reaching the end of their lives but also to their families and carers.

But, not everyone experiences good quality end of life care. We know that the need will continue to grow as the population changes.

We also know from recent reports, including the End of Life Evidence Review (Age UK, 2013), that there is a need for more training and education for care and support staff.

If you think about the people you support, you may agree that they have many different health conditions, or problems with cognition (understanding), sight or hearing. The people you support may have pain which might not be recognised or well treated. But, by improving your knowledge and understanding, you can play a bigger role and improve the experience of the people you support.

The purpose of the workbook is to increase knowledge and awareness of good practice within end of life care.

This workbook has been compiled by the Kirklees and Calderdale End of Life Care Education Group, who lead on sharing best practice and training. It has been developed specifically for care and support staff, across nursing care, care homes or in the community. It helps you to recognise what good end of life care looks like, in order to make a difference to care.

This workbook provides information, practical tips and resources. It has been designed to act as a resource which can be accessed as and when required or used as part of training.

Through using the workbook, you can expect to:

- Feel more empowered to support people at the end of life
- Increase your knowledge on key topics and conditions
- Find ways in which you can improve care
- Access further resources and learning materials

We hope this workbook will prove to be useful.

*Kirklees and Calderdale End of Life Training and Education Group
2018*

How to use this Workbook

You can complete the workbook at your own pace; reading through each section and completing the tasks and questions. These are designed to make you consider your role and what you may do well at the moment, as well as what you might want to do differently. This includes practical tips and things you may want to discuss with your wider team. We would expect the workbook to be completed within six months.

Before you begin, complete the pre-assessment questions. You will return to these at the end of the workbook to see if there has been a difference in your confidence and understanding of key issues. We would recommend that your manager informs CQC that you have completed the workbook.

By completing this workbook, you will be in line with existing competencies. This has the potential to develop better outcomes for people in your care by improving your knowledge and understanding, as well as considering what you might do differently.

The content within this workbook is intended as a guide only. It is not intended to be a substitute for professional medical advice, diagnosis, or treatment. Professionals remain responsible for their own clinical advice and decision making.

Area	Scale (circle a number between 1 to 10, to show where you feel you are the moment for each question)									
	Not confident/ able at all					Extremely able/ confident				
	←—————→									
How confident do you feel in understanding symptoms and how these can be managed?	1	2	3	4	5	6	7	8	9	10
How able are you to understand non-malignant conditions in the end of life?	1	2	3	4	5	6	7	8	9	10
How well do you understand the importance of spirituality and how you can offer holistic, spiritual care at the end of life?	1	2	3	4	5	6	7	8	9	10
How confident do you feel in supporting someone through grief, loss and bereavement?	1	2	3	4	5	6	7	8	9	10

What is End of Life Care?



What is end of life care and why do we need it?

End of life care is care in the last year of life for people with an incurable illness. It helps all those with advanced, progressive illness to live as well as possible until they die.

End of life care is a proactive process. It aims to identify any problems early on and solve them as soon as possible. You cannot know exactly when someone will die, and even the most experienced doctor or nurse can find this hard to predict. However, there can be signs that a person is near the end of life, which are discussed within this workbook.

End of life care also includes care for families and friends, offering them support both before a person dies but also afterwards.

End of life care recognises that death is not just a physical reality, but social, emotional and spiritual too. Good end of life care aims to provide a compassionate approach which meets the needs (physical, emotional, social and spiritual) of both the dying person and their loved ones.

End of life is a time to plan with a person what care they need as their illness progresses and to talk about what they want to happen. It includes the management of pain and other symptoms.

It is also the time to have important conversations with loved ones, as they too need to know what is happening and what the dying person may want.

We know that many people will want to die in their place of residence, but they often end up in hospital instead. If you talk to people and find out what they want at the end of their life you can begin to plan care which means that have a better chance of their needs being understood and met.

Q1. Endings

Think of some of the endings that have happened in your life. Look at the endings in the box below and circle any that have happened to you. Add any other endings that have happened to you.

Leaving school

Leaving home

Children leaving home

Changing jobs

Death of a pet

Death of a loved one

Moving house

Separation

Divorce

Friends moving away

Emigrating

Relationship breakdown

Q2. End of life care

What do you think end of life care might involve? Spend some time reflecting and record your thoughts below. You can do this as a list of words or sentences.

You may choose to do this exercise with a group of colleagues.

Q3: Give 3 reasons why end of life care is important

Reason 1:

Reason 2:

Reason 3:

Glossary of Terms

There are a number of terms used within this workbook. These are included in the glossary below.

Terms relating to end of life care:

ACP - Advance Care Plan. Advance Care plans are used to identify a person's preferences and wishes at the end of life

ADRT – Advance Decision To Refuse Treatment. A decision made by the person to refuse specific medical treatment/care when they have capacity. This then becomes effective when the person loses capacity

Bereavement – a period of mourning after a loss, especially after a death

Best interests – any decision made on behalf of a person who lacks capacity and must be made in that person's best interests

Capacity - the power of receiving and retaining knowledge

Cheyne Stokes Breathing - abnormal pattern of breathing described as deeper and sometimes faster breathing, followed by a gradual decrease that results in a temporary stop in breathing

CPR – Cardio Pulmonary Resuscitation. This is an emergency procedure that combines chest compressions often with artificial ventilation in an effort to manually preserve intact brain function

DNACPR – Do Not Attempt Cardio Pulmonary Resuscitation. The purpose of a DNACPR decision is to provide immediate guidance to those present (mostly healthcare professionals) on the best action to take (or not take) should the person’s heart stop beating

DoLS – Deprivation of Liberty Safeguards - These safety measures are required if the restrictions and restraints being used to keep someone who lacks capacity, in their placement are actually depriving them of their independence/freedom

End of life care- care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die

Holistic care - means looking at all the needs and aspects of wellbeing of the person. This means that care considers the whole picture. It includes the person’s physical, emotional, social and spiritual needs. It includes all needs of the person and their family

LPA – Lasting Power of Attorney. This is a person who has authority to act on behalf of a person who lacks capacity

Metastatic- is cancer that spreads from its site of origin to another part of the body

Mourning - to feel or express sorrow or grief for the dead

Non- malignant - relates to other diseases that are not cancer

Palliative care - an approach that improves the quality of life of people and their families facing the problems associated with a life threatening illness. This is achieved through preventing and relieving distress by identifying, assessing and treating pain and other physical, psychological, social and spiritual problems

Supportive care - is for anyone who is ill, at any time. Supportive care is an umbrella term used both by generalist and specialist healthcare services. Supportive care helps people and their families cope with the illness and its treatment, from diagnosis to cure, recovery or death and bereavement. It involves a wide range of health and social care professionals.

Other terms used within the workbook:

Acknowledge – to recognise as real or true

Adjuvant – to help or assist (adjuvant drugs – additional medications)

ANP – Advance Nurse Practitioner. An advanced practice nurse who has more clinical independence and authority than some other types of nurses

Analgesics – painkillers

Anti-depressants – medication used to treat mood disorders

Anti-emetic – medication used to suppress nausea and vomiting

Anti-epileptic – medications used to control epilepsy

Anti-muscaric – medication used to control saliva production

Ascites – abnormal accumulation of fluid in the abdomen

Aspiration – inhalation of foreign material

Aspiration Pneumonia- an inflammatory condition of the lungs caused by inhaling foreign material or acidic vomitus

Benzodiazepine – medication that works in the central nervous system and make the nerves in the brain less sensitive to stimulation, which has a calming effect

Botox- medication administered by injection to treat muscle spasms and diseases

Candidiasis – fungal infection

Carotid Pulse - relating to the pulse in the two main arteries which carry blood to the head and neck, and their two main branches

Clarifying - make a statement or situation less confused and more understandable

Cognition - the act or process of knowing

Cognitive Impairment - there is clear evidence of problems with the way the person processes and uses knowledge.

Constipation- a condition of the digestive system characterised by hard faeces that are difficult to pass

Comorbidities - the presence of one or more additional diseases or disorders co-occurring with a primary disease or disorder

Competency – be able to make a decision

Competencies – skills, abilities and experience

Compassionate – having tender feelings, treating people with humanity

Coordinated - discuss with others in order to work together effectively

Court of Protection – make decisions on financial or welfare matters for people who can't make decisions at the time they need to be made (they 'lack mental capacity')

COPD – Chronic obstructive pulmonary disease. The name for a group of lung conditions that cause breathlessness

Cox 2 Inhibitors - is a form of non-steroidal anti-inflammatory drug

Delirium – delirium is a serious disturbance in mental abilities that results in confused thinking and reduced awareness of your environment creased confusion

Delusions - is a mistaken belief that is held with strong conviction even in the presence of superior evidence to the contrary

Dementia - dementia is the name for a group of symptoms caused by disorders that affect the brain

Depression - depression is a mood disorder that causes a persistent feeling of sadness and loss of interest

Disengagement – the act of detaching or withdrawing

Disorientation - the inability of a person to correctly determine his/her body position in space. To be disoriented is to feel lost or confused

Dopamine – dopamine is a chemical that plays several important roles in the brain and body

Dysarthria- this is a condition in which the muscles you use for speech are weak or you have difficulty controlling them

Dysphagia – swallowing difficulties

Dyspnoea – breathlessness

Echocardiogram – scan of the heart

Environmental – relating to the setting, surroundings and location

Empathy – the ability to recognise the felt experience of another person. To put oneself in their position and to see the world from their perspective

Empowered – to give power or authority to

Emphysema - is a long-term, progressive disease of the lungs that causes shortness of breath due to over-inflation of the air sacs in the lung

Ethical - relating to moral principles or the branch of knowledge dealing with these

Exhibit - demonstrates or displays

Expulsion – the action of forcing something out of the body

Dietician - an expert in human nutrition and the regulation of diet

Fatigue – the feeling of tiredness, exhaustion or lack of energy

Frailty - frailty is related to getting older. It describes how our bodies gradually lose their in-built reserves, leaving us vulnerable to dramatic, sudden changes in health triggered by seemingly small events such as a minor infection or a change in medication or environment

Fundamental - essential

Genetic- inherited

Hallucinations - where someone sees, hears, smells, tastes or feels things that don't exist outside their mind

Holistic care – the whole person approach

Hyperventilation – over breathing

IMCA – Independent Mental Capacity Advocate. The IMCA role is to support and represent the person in the decision-making process

Improvise- to deliver without previous preparation

Incompetent – not having or showing the necessary skills to do something successfully

Insomnia - sleeplessness

Interventions – action taken to improve a medical disorder

Instigated - started

Intermittently - at irregular intervals; not continuously or steadily

IV – Intravenous. Administered into, a vein or veins

Laxative- substances that loosen stools and increase bowel movements

Legalities - observance of law

MND – Motor Neurone Disease is a disease that progressively damages parts of the nervous system

MS/ Multiple Sclerosis- is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body

Occupational Therapy - helps people overcome difficulties caused by physical or mental illness, accidents or ageing

Namaste - a way of connecting with people in end stage of dementia through comfort, sensory stimulation, and often, just “being present” or “in the moment”

Negotiation - discussion aimed at reaching an agreement

NIPPV – Non-Invasive Positive Pressure Ventilator. A device that pushes air into the lungs via a mask

NIV /Non Invasive Ventilation - this is the use of airway support administered through a face (nasal) mask instead of an endotracheal tube

Non Opioid- medications that control mild to moderate pain

Nutritional Support - is treatment for people who cannot get enough nourishment by eating or drinking

NSAIDs – Non steroidal anti-inflammatory drugs. Drugs used to control inflammation/swelling

Oedema - swelling caused by fluid in the body’s tissues

Opioids - are narcotic medications that act on opioid receptors to produce morphine-like effects. They are used for pain relief

Paraphrasing - restating or rewording

Parenteral - delivered by some route other than through the alimentary canal, such as by subcutaneous, intramuscular, or intravenous injection

Peripheral - to the outside or extreme edge of the body

PEG / Percutaneous endoscopic gastrostomy – this is a tube which is passed into the person’s stomach through the abdominal wall, most commonly to provide a means of feeding when oral intake is not adequate

Physiotherapy - the treatment of disease or injury by physical methods such as massage, heat treatment, and exercise rather than by drugs or surgery

Pharmacological - relating to the branch of medicine concerned with the uses, effects, and modes of drug actions

Pleural effusion - is a buildup of fluid in the pleural space, an area between the layers of tissue that line the lungs and the chest cavity

Premature - early

Principles - basic idea or rule that explains or controls how something happens or works

Proactive – be prepared, ahead of time

Prognosis- the likely course of a medical condition

Psychological – relating to the mind

Pulmonary – relating to the lungs

Reflection - learning from experience, in that time is taken to think about what happened, and decide from that what you would do differently next time

Reflux - (of a fluid) flow backwards through a valve in the body.

Regurgitation - the action of bringing swallowed food up again to the mouth

Resuscitation - the action or process of reviving someone from unconsciousness or apparent death

Relapse – periods when symptoms get worse

Remission – periods when symptoms improve or disappear

RIG- Radiologically Inserted Gastrostomy - inserted using X-ray guidance after having barium placed inside the stomach

Revoke – cancel or withdraw

SALT- Speech and Language Therapy. Specializes in the evaluation, diagnosis, and treatment of communication, cognition, voice and swallowing disorders

Sepsis- is a life-threatening condition that arises when the body's response to infection causes injury to its own tissues and organs

Spasticity - unusual tightness, stiffness, or pull of muscles

Spiritual – relating to the spirit/soul – may include interests, outlook, attitude and religion

S/C - Subcutaneous - situated or lying under the skin

Susceptible - likely or liable to be influenced or harmed by a particular thing

Summarising - involves taking the main ideas from the conversation and rewording/shortening to feedback

Stimulant Laxative- preparation used to ease constipation by inducing a bowel movement

Stridor - is a high-pitched, wheezing sound caused by disrupted airflow

Substantia Nigra - is a brain structure located in the midbrain that plays an important role in reward, addiction, and movement

Symptom –sign (of disease or sickness) which might occur now and again or become worse

Tracheostomy - is a procedure used to create an opening in the neck to bypass an obstructed airway to more easily deliver oxygen to the lungs

Unconscious - not awake and aware of and responding to one's environment.

Ventilation- the supply of air to the lungs, especially by artificial means

Voluntariness – to do something using your free own free will, to not be forced

Important documents used within End of Life Care

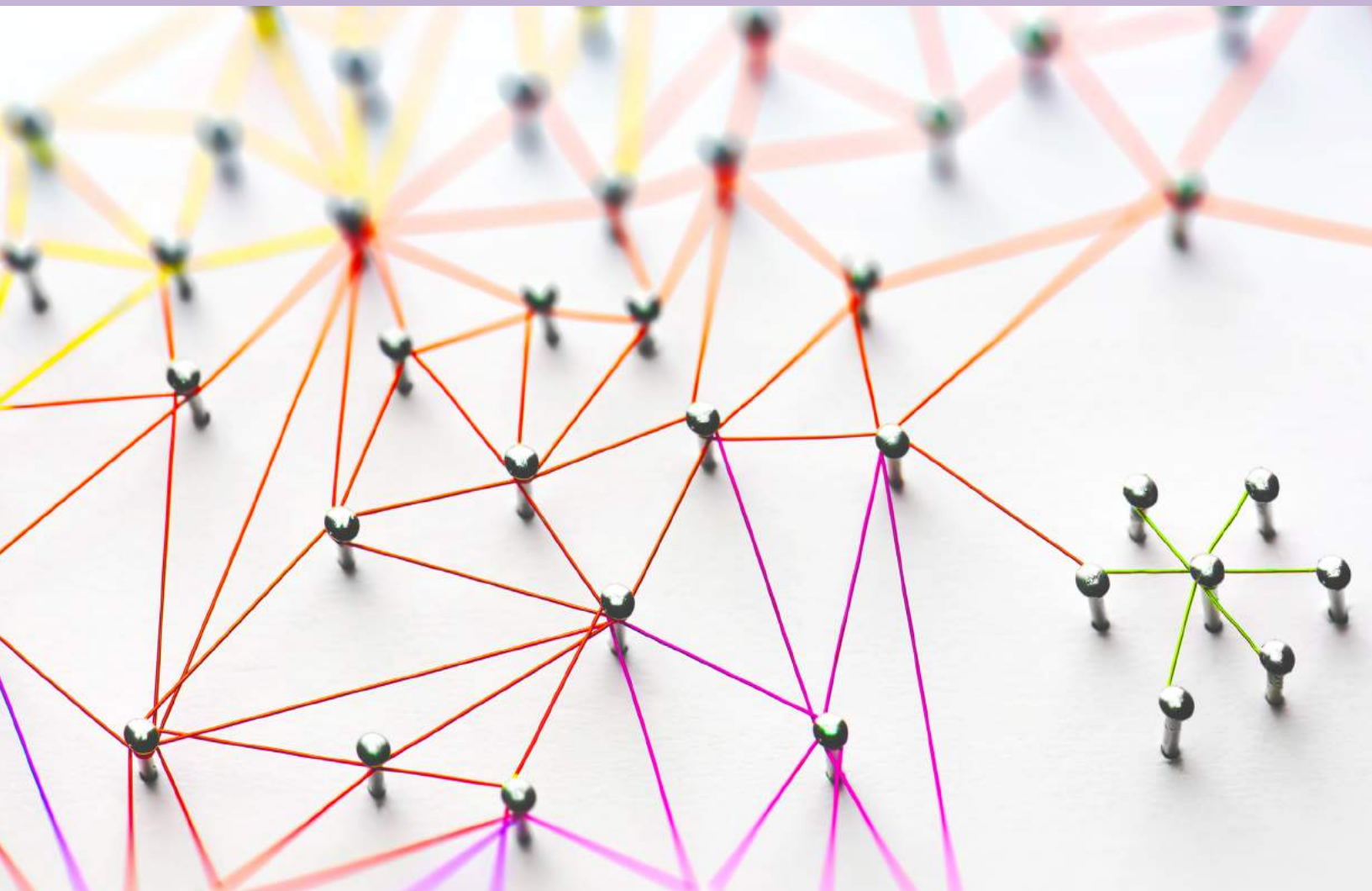
Individualised Care of the dying document (ICODD)

This care plan is a document that helps clinical staff who are caring for people who are dying and in the last hours or days of their lives. It guides them in delivering the best care that they can, in order to meet the needs of the person and their families. This is a way of recording the special care that the dying person needs. It is important that people and their families get the chance to have a clear discussion. Anyone caring for the person can fill in the document.

When should the ICODD be used?

This care plan should be used when the doctors and nurses caring for a person believe that he or she is dying from an irreversible condition, and a decision has been made that the focus of care is now on quality and comfort. You can find a copy of the document within the online resources.

Communication Skills



Communication

Communication lies at the heart of all health and social care delivery. It should be a two-way process, involving listening as much as telling. Done well, it can help to reduce anxiety and distress, but done badly it can affect the person's experience of even the best care.

How do we communicate with people and families?

Think about this and write your answers below:

Why do we communicate with people and families?

Think about this and write your answers below:

Principles of good communication - some key points to remember are as follows:

- When meeting people start from where they are and their level of understanding- so you have to start by asking and listening, NOT telling them things
- Use phrases and language that are right for them
- Keep sentences simple, not asking too many questions at once.
- State why you have come and how long you can stay
- Demonstrate empathy and genuineness
- Ask for clarification if you do not understand
- Demonstrate respect and be non-judgemental
- Pay attention to both the things said and the unspoken

- Allow silence to give people time to think and reflect
- Observe body language
- Respond using verbal and non-verbal prompts
- Expect and allow lots of repetition
- Believe what you are told
- Keep your own personal information out of the session
- Encourage some expression of emotions, but not as you leave and only if appropriate
- Don't push people to talk if they don't want to
- Be mindful that someone may be tired - choose the right time and observe for signs that they are disengaging.

Generally, when people are unwell, they find it more difficult to receive and provide information. Their verbal and non-verbal communication may also differ compared to when they are feeling well.

**Think back to a time when you felt ill:
How did it affect your ability or desire to communicate?**

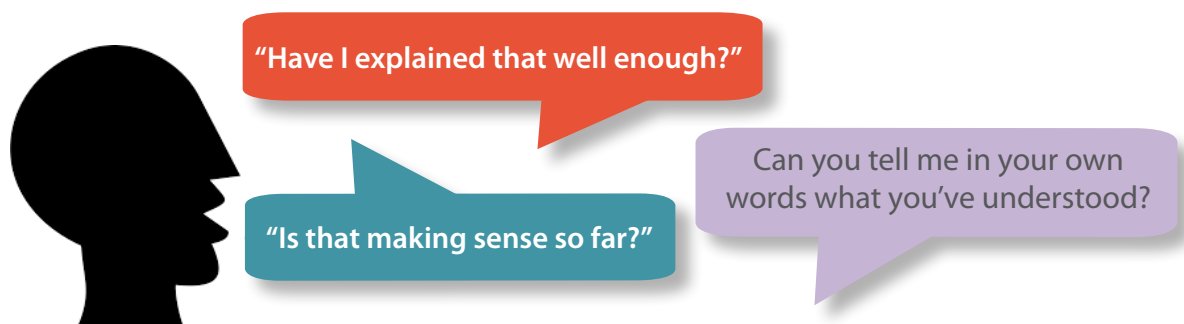
What was the main thing in your mind at the time?

How might others have realised that you were struggling?

What could others have done differently that might have helped you?

How did you feel if others kept on trying to have a conversation with you?

Reflecting on your own past experiences may help you to understand how a person may be feeling and how to respond more effectively.



- Even if the person says they do understand, look for non-verbal cues that may suggest otherwise (e.g. they are looking puzzled).
- Several short visits are much more effective when meeting ill people in end of life care.

Apart from illness related factors, what other factors can make communication difficult for people in end of life care?

List two or more factors that you think can make communication difficult. Write your answers below

TOP TIP

You can get it right in 10 minutes and spend two hours getting it wrong...

Reflective exercise

What things might be most important towards the end of life?

For the person approaching end of life?

For you the health or social care professional?

For families?

Why might people and families find it difficult to tell us what matters to them?

Timing

Finding the right time to start end of life care discussions is critical. The earlier this is done, the better. For example, a person in a care home with dementia may lack capacity to make decisions when their condition advances. But, by speaking to them in the earlier stages of the disease, they can record their preferences for future care which can then be used as capacity is lost.

When do you think discussions about end of life care should begin?

- Is it when a person receives a diagnosis of a life-limiting or life-threatening condition?
- Is it when a medical crisis occurs?
- What other triggers might lead to people considering end of life care preferences?

Triggers could be admission to a care home or the death of a loved one.

Key worries that people and carers might have at the end of life			
Relationships Why Me?	Am I still needed as a partner/parent/friend?	Concerns/ Spiritual	Why now? What have I done to deserve this?
Physical Symptoms	Will I be in pain or experience any other physical symptoms such as incontinence or weight loss? Will I lose control of my bodily functions?	Psychological	Will it change how people view me? Will I be an outcast/avoided? Should I tell people? How? Will I lose control of my mind? Will I lose control of my world?
Treatment	Will it cause any unpleasant side effects? Will it prolong my life? Will I be able to cope? What if it doesn't work?	Practical	What financial arrangements do I need? Who will look after the children, pets, parents, relatives? Will I be able to stay here?
Social/ Support	Who will look after me? What extra help is there?	Dying	How long? How ill will I become? What will it be like?

When the person is dying

- What things could you do in your professional role to help when someone is dying?
- How could you help them?
- How could you help their family?
- How could you help your colleagues?
- If you have been through the experience of someone dying, you can note those things which helped and which could have been done differently.

What could I do to help?	Things which could be different

Somebody asks you, “Why does God allow suffering?”

How should you respond to this question?

Select one option from the list below.

1. “That’s a difficult question to answer. I can talk about how I feel about it.”
2. “I think it would be best if I asked the chaplain to come by and see you.”
3. “That’s a good question. What’s put that in your mind? What have you been thinking about?”
4. “I think its best that we talk about something else. Thinking about questions like that might make your pain worse.”

When assessing and communicating with the withdrawn person...

Select true or false for each of the following statements. You might like to do this exercise with a group of colleagues.

1. A person is more likely to share something they are worried about if they trust you.

True False

2. It's better to ask someone who doesn't feel like talking 'yes' or 'no' questions so they don't have to talk too much.

True False

3. Someone who is withdrawn might start to engage if you focus on their body language.

True False

4. If a person is quiet or withdrawn, it's easier to pass on information.

True False

5. It's important to look at signs and signals.

True False

But I don't give bad news do I?

"I'm really sorry but"

"We're worried about the symptoms"

"Your wife's not so well today"

"Your daughter can't visit today she's ill"

"He's going to have to have to go into hospital"

"We haven't been able to get the care package together in time to get you home today"

What would you want from someone you could trust?

What would you want from a person with who you could be yourself?

Empathy is: The ability to recognise the felt experience of another person. To put oneself in their position and to see the world from their perspective.

Empathy is not: Feeling the same, or how you would feel in that situation.

Reflection: Some people would say that in order to feel compassion you first have to be able to empathise – to see the situation from the other person’s point of view.

What do you think?

“Special people” and you

Most of us can identify particular people or carers who for one reason or another we became more attached to than usual or who have affected us deeply.

Think of a particular person with whom you have worked.

Perhaps there was something very special about him or her.

“Special people” and you

Perhaps something about the circumstances that reminded you of your own.
 Perhaps the illness or death was especially tragic or traumatic.
 What was it about this person that affected you?
 How did you cope? (What helped? What hindered?)
 What else did you need? (Perhaps from colleagues or managers?)

Listening Skills



TOP TIP

We were born with two ears and one mouth – an indication that we should listen twice as much as we speak.

Think about what the skills below communicate to the person.

Skill	What does this communicate to the person?
Eye contact and attention	
Minimal prompts: “yes, go on”	
Acknowledging/reflection: “you had a rotten time by the sound of it” “you look/sound upset”	
Paraphrasing: “being ill has been really distressing”	
Open question: “How are you feeling?”	

Skill	What does this communicate to the person?
Open directive questions: "What's most important to you right now?" "How did it feel when you heard...?"	
Educated guesses: "I imagine that news came as quite a shock"	
Negotiation: "Are you able to say what is worrying you?"	
Clarifying: "What were the things about being ill that upset you?"	
Summarising: "So what's most important is..." (list what was said)	

Answers on page 38.

Communication Breakdown

Question: What prevents people, including carers or staff, from sharing worries and needs?

Fears

- strong emotions coming out
- making things worse
- facing difficult questions
- taking up too much time
- facing our own failure
- being shamed
- not being able to find the words

Beliefs

- Problems are a normal part of illness so staff should know they are coming
- Feeling like a problem can't be fixed
- Professional people are only interested in certain types of problems
- This is not the "right" professional person to talk to

Communication Challenges

- It's hard to find the right words
- The right questions weren't asked by the professional
- Problems hinted at but not picked up by professional
- Not communicating in first language
- Cognitive impairment

Workplace

- Lack of support from colleagues or managers
- Lack of privacy
- Time constraints
- Noise/distractions
- Nowhere to refer for psychological support
- No training or supervision in communication skills

These are all some examples of barriers to communication.

Question: How many do you recognise for yourself and in your workplace?

Question: Why do professional staff struggle to talk about dying?

The conversations I find most difficult are:

I find these conversations difficult because:

Some ways in which we **STOP** people from telling us about their needs and concerns

Person says "I was upset about being ill"

Overt blocking
Complete change of topic

How's your family?

Distancing
More subtle change of focus

Are you upset now? (change of time frame)
Was your wife upset? (change of person)
How long were you ill? (removal of emotion)

Blocking - Questions!	
Physical	"Did you have a lot of symptoms?"
Closed	"Did you tell anyone?"
Multiple	"How are you, is the pain any better?"
Leading	"You'll feel better in a minute won't you?"
Defending/justifying	"I'm sure the doctor didn't mean to upset you."
Premature reassurance	"You'll feel better after you've seen the doctor."
Premature advice	"You need to ..."
Normalising	"Everyone gets upset when they're ill."
Reducing	"It won't be as bad as you think."
Jolly along	"Come on you have to stay positive."

Tips and Tricks for Communication

Words to mentally prepare you...

The use of the acronym **PREPARED** may help with end of life care discussions

P repare for discussion – confirm diagnosis before discussion, ensure privacy

R apport – relate to person, show empathy, care and compassion

E xpectations – clarify the person and their family's understanding and wishes

P rovide information – tailored to the need of the person and their family

A cknowledge – their fears and concerns

R ealistic hope – be honest without being blunt, giving reassurance and facilitate realistic goals

E ncourage – questions and further discussions, checking their understanding

D ocument – summarise what has been discussed

“ Kindness – Curiosity- Honesty “

Tips and Tricks for Communication

Staff introducing the subject:

- “Do you like to plan your life or are you someone who likes to improvise?”
- “Thinking about your future care, where would you like to be cared for?”

Person / carer introducing the subject:

- “I am happy to answer that, but do you mind telling me what made you ask that question?”

Clarifies a person’s fears:

- “What worries you most?”
- “What is your biggest concern?”
- “What frightens you at the moment?”

Maintaining Hope:

- “What do you hope for the future?”
- “What are the things you most want to invest time and energy in?”
- “Have you any unfinished business?”
- “We can prepare for the worst while hoping for the best.”
- “The aim of this treatment is changing more towards making the most of your function and comfort.”

Family conflict:

- “If he/she were able to talk to us, what do you think he/she would want us to know?”

Dealing with denial or expectations not consistent with clinical evidence:

- “What is your understanding of what is likely to happen with your illness/ treatment options?”
- “I wish too that this disease would get better. If we can’t make that happen, what other shorter- term things would you like to achieve?”
- “Have you thought about what might happen if things don’t go as you wish?”
- “Sometimes having a plan that prepares you for the worst makes it easier to focus on what you hope for most?”

Requests by family to withhold end of life care Information:

- “What is it that you think will happen if we have this conversation?”
- “What do you think will happen if we don’t tellwhat is happening at the moment?”

- “Do you think knows that all is not right at the moment? What must that be like for to suspect but not know?”
- “By not acknowledging what is happening we are blocking ability to have some really important conversations”

Discussing the process of death and dying:

- “Have you thought about where you would like to be when you get sicker with this illness – where you would like to be cared for?”
- “IV fluids are unlikely to alter the course of this disease and at this time they may pool in the lungs and make breathing more difficult”
- “Hospitalisation is unlikely to alter the course of this disease and at this time has already expressed a wish to remain in the care home”

DNACPR orders:

- “We need to focus the care on ways that can make a difference for the better.”
- “We need to ensure they do not suffer unnecessarily and are allowed to die in peace and comfort”
- “CPR would not be helpful, it would not prevent the person’s death and may prolong their dying and cause more distress”

Advance Care Planning:

- “Have you thought about the type of care you would like to have if you ever become too sick to speak for yourself?”
- “Have you spoken to someone who will make decisions for you?”
- “Would you like to include them in these discussions?”
- “It’s often easier to talk through tough decisions when there isn’t a crisis”

Introducing Specialist Palliative care services:

- “What does the term Palliative mean to you?”
- “Palliative care team includes a whole range of health care professionals who can help support you and your family at this time”

Stopping disease specific treatments:

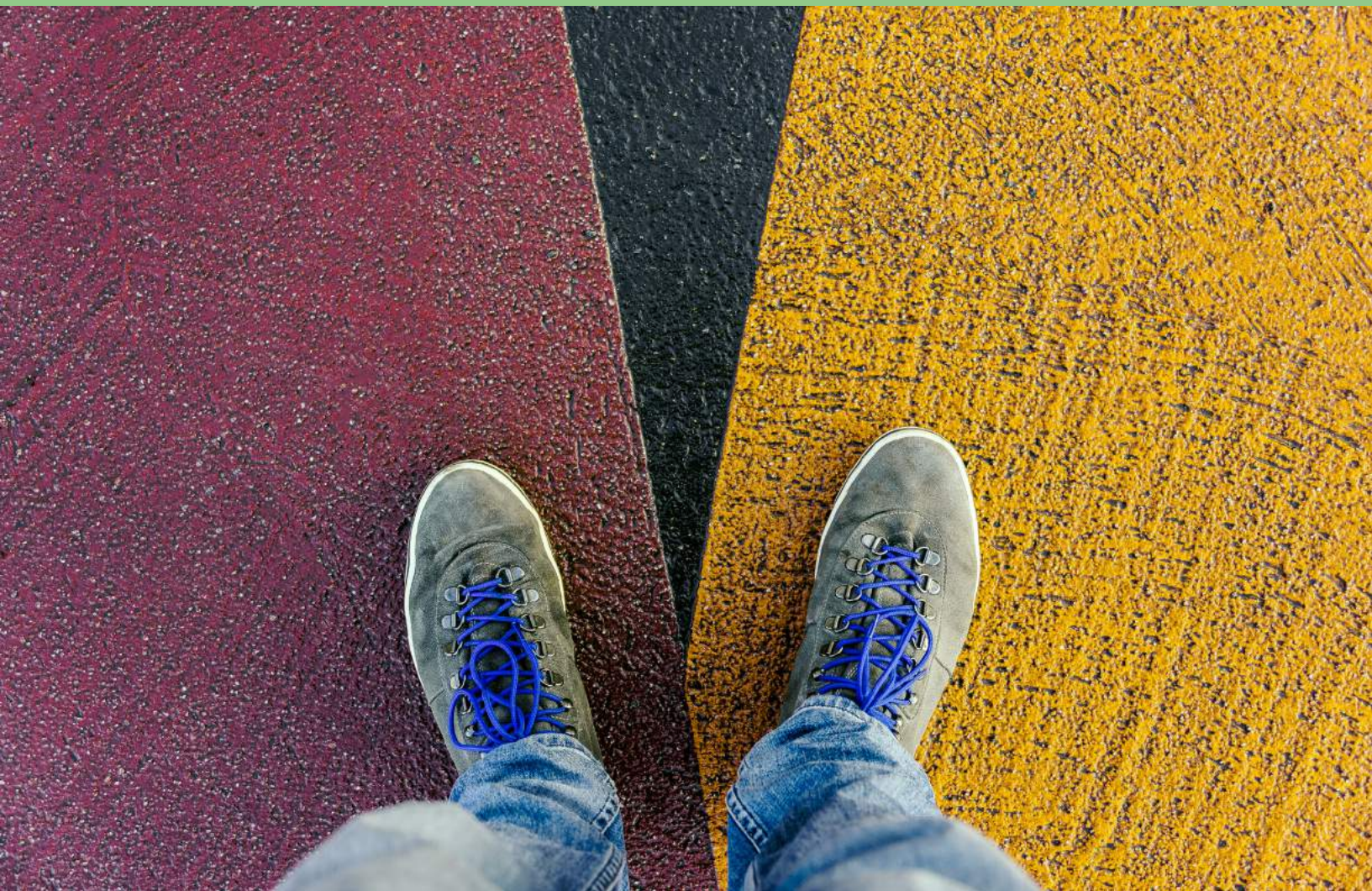
- “The aim of treatment is now changing from trying to control the disease to reducing the symptoms you may get”

Discussing end of life care Issues:

- “To make sure we are on the same wavelength, I want to check your understanding of what we have discussed”

Skill	Communicates
Eye contact and attention	"You are important"
Minimal prompts: "yes, go on"	"I'm still listening"
Acknowledging/reflection: "you had a rotten time by the sound of it" "you look/sound upset"	"How you feel matters" "I can see you're upset, it's OK to tell me about it and I want to help"
Paraphrasing: "being ill has been really distressing"	"I want you to know I've heard you and also to check that I've got it right"
Open question: "How are you feeling?"	"I'm interested/concerned"
Open directive questions: "What's most important to you right now?" "How did it feel when you heard...?"	"I think you might have concerns or needs and I want to help"
Educated guesses: "I imagine that news came as quite a shock"	"I have an idea about how you may be feeling. Do you want to tell me?"
Negotiation: "are you able to say what is worrying you"	"I'm willing to listen but I can see it's hard and I don't want to pry"
Clarifying: "what were the things about being ill that upset you?"	"I'd like to understand exactly what the problem is?"
Summarising: "So what's most important is..." (list what was said)	"I've heard you, have I got it right, have I missed anything?"

Advance Care Planning



Advance Care Planning

Advance Care Planning should be about enabling people to live well until they die.

At some time in a person's life, they may want to think about the consequences of becoming seriously ill or disabled. They may wish to discuss their feelings, and consider recording their wishes and preferences.

Advance Care Planning (ACP) is a voluntary process of a discussion about future care between a person and those who provide care for them, for example a nurse doctor, care home manager, carer or a family member.

The discussions between the person and the health/social care providers are the foundation for documentation.

The plan makes clear what a person's wishes are, recognising that they may deteriorate and not be able to communicate their wishes to other or have capacity to make decisions as their illness progresses.

It includes important information about concerns, values and preferences. ACP's should be documented and communicated to all those involved in the care plan, including family and friends if the person wishes it.

An ACP is not legally binding; however it must be taken into account when acting in a person's best interests. A signature is not a requirement, but its presence makes clear whose views are documented. The ACP makes the multidisciplinary team aware of the person's wishes and preferences in the event that the person loses capacity.

Sometimes the person provides a signal to open up discussions. However you have to remember that the Advance Care Plan process is not a one-off conversation. It might require a number of discussions with the person and their family.

What is an Advance Care Plan (ACP)?

Advance Care Plans are used to identify a person's preferences and wishes at the end of life. The document which is held by the person can be taken with them if they receive care in different places. It has space for the person's thoughts about their care and the choices they would like to make, including saying where they would like to be when they die.

Information about choices and who might be involved in their care can also be recorded so any care staff can read about what matters to the person, which ensures continuity of care. If anything changes, this can be written in to the plan so everything stays up to date.

Key elements:

- A document held by the person concerned and should accompany that person when transferring out of the usual care setting
- If a person chooses they can share information in their ACP with their family and professional carers.
- The document can tell staff who the person's Lasting Power of Attorney (LPA) is. Appointing a LPA is a legal process and has to be done separately in addition to an ACP.
- The ACP process is voluntary and should not be as a result of external pressure.
- An ACP discussion should be offered to everyone with mental capacity to have the discussion unless they have clearly stated they do not want to talk about their future health care.
- The result of the ACP process may be a statement of a person's wishes, preferences, beliefs and values. This may include a choice for a preferred place of care.

All health and social care staff should be open to any ACP discussion which person may try to start talking about.

- Staff will require the appropriate training to enable them to communicate effectively and understand any legal or ethical issues involved.
- Discussions focus on the views of the person although they may make a request for a carer, friend, partner or relative to be involved.
- ACP requires that the person has the capacity to discuss and understand the options available to them and agree what is then planned.
- Should a person wish to make an advance decision to refuse treatment (ADRT) this should be completed following the appropriate guidance.
- The wishes expressed during ACP are not legally binding but should be taken into account when professionals are required to make a decision on a person's behalf.
- If there is no record of ADRT then decisions will be made in a person's Best Interests. ACP can help in making best interest decisions.
- Document any ACP discussions even if they decline to complete an Advance Care Plan- this is vital information that the person has had the courage to tell you, and they need professionals to know about it even if they don't want to keep a written copy of it themselves.

Triggers that an ACP discussion may be required

Both you and the person you support might start thinking about an Advance Care Plan following a trigger. Examples of a trigger could be:

- If the person asks to discuss advance care planning
- The death of a spouse or a close friend
- A new diagnosis of a life limiting disease
- A change in progress of an existing illness
- New treatment options to consider
- A need to consider a different care setting, admission to the care home
- A change in personal circumstances, for example retirement
- Changes within the family dynamics

If a trigger is identified; it is important to discuss with the person in a sensitive and open manner and pass the information on to a senior member of staff when the person has agreed for you to do so. It is appropriate to document in the person's plan of care what has been mentioned.

An ACP form can then be discussed and completed for the person by the appropriate health/social care professional.

Consent

People have a fundamental legal and ethical right to determine what happens to their own bodies.

Valid consent to treatment is central in all forms of healthcare, from providing personal care to undertaking major surgery.

Seeking consent is also a matter of common courtesy between health/social care professionals and the people under their care.

Competent adults are entitled to refuse consent; the only exception to this rule is for people detained under the Mental Health Act 1983.

BUT, people do not have the right to demand a treatment that would not help.

People may indicate consent in the following ways:

- Non-verbally/IMPLIED (for example by presenting their arm for their pulse to be taken)
- Verbally
- In writing

English Common Law identifies three components of a valid consent:

- Competency – be competent to make the decision
- Information – have received sufficient information to make it
- Voluntariness – not be acting under duress

Competency

The competency or capacity of a person to give their consent should be considered in all situations. It should never be assumed that an adult or child is either competent or incompetent without a full assessment of that person.

Where an adult lacks the mental capacity (either temporarily or permanently) to give or withhold consent for himself or herself, no one else can give consent on their behalf. However, treatment may be given if it is in their best interests, as long as it has not been refused in advance in a valid and applicable advance directive.

The standard consent forms should never be used for people over the age of 18 unable to consent for themselves. For more minor interventions, this information should be entered in the person's documentation.

A person's capacity to make decisions must be identified using the Mental Capacity Act 2005. The following principles apply when assessing capacity.

Principles for capacity to make decisions.

Presume capacity.

Help and encourage people to have capacity.

People are entitled to make unwise decisions.

Decisions for person without capacity: best interests.

Someone making a decision or acting on behalf of a person who lacks capacity must consider whether it is possible to decide or act in a way that would interfere less with the person's rights and freedoms of action, or whether there is a need to decide or act at all.

Assessment of Capacity

Definition and two step test of incapacity.

1. Is there an impairment of, or disturbance in, the functioning of the person's mind or brain?
2. Does the impairment make the person unable to make the decision?

Can the person:-

- Understand the information relevant to that decision?
- Retain that information?
- Use or weigh that information as part of the process of making the decision?
- Communicate their decision?

Try different ways of communicating and consider using professionals with specialist skills in verbal and non-verbal communication.

The standard is whether it is more likely than not that the person lacks capacity.

Assessing capacity

Suitably trained health and social care professionals make the assessment for capacity following specific criteria.

- Assess the person's capacity to make a decision.
- Make a record of assessment.
- Don't rush.
- Decision specific.
- Don't push through decisions when capacity is lowest.
- A strange or unwise decision does not necessarily mean lack of capacity.

Lacking capacity

If a person does not have capacity:

- Does the decision need to be made without delay?
- Will the person regain capacity?
- Is it possible to wait until the person does have capacity?

Consulting others

If appropriate consult other people such as:

- Carers, close relatives, friends.
- Attorney under a Lasting Power of Attorney (LPA).
- Any deputy appointed by Court Of Protection.

Should an Independent Mental Capacity Advocate (IMCA) be instructed?

Must do so if there is no-one else appropriate to consult with over best interests and, the decision concerns serious medical treatment or the provision of longer term accommodation.

Lasting Power of Attorney (LPA)

Someone with a Lasting Power of Attorney (LPA) has the authority to make decisions on behalf of a person who lacks capacity. The LPA must be registered by the Office of the Public Guardian for it to be valid. There are two types of LPA:

Lasting Power of Attorney (LPA) for Health and Welfare

Lasting Power of Attorney (LPA) for Property and Finance

When involved in discussions and making decisions about a person's health, treatment, welfare and future care, the decision maker must have an LPA for Health and Welfare.

The two types of LPA are not interchangeable.

Best Interests

Any decision made on behalf of a person who lacks capacity must be made in that person's best interest. (As defined by the Mental Capacity Act 2005)

This applies regardless of who is making the decision or what the decision applies to.

Consider anything relevant and in particular:

- Past and present wishes and feelings of the person.
- Any beliefs and values of the person that may influence the decision.
- Has a written statement of wishes and feelings been made?
- Has a valid and applicable advance decision to refuse treatment been made?
- Is the act or decision the less restrictive of basic rights and freedoms?

After carefully considering the above, it is good practice to clearly document what the decision under discussion was, who was consulted, what the outcome of the discussion was and the action taken.

Deprivation of Liberty Safeguard (DoLS)

- These safeguards are required if the restrictions and restraint being used to keep someone, who lacks capacity, in their placement are actually depriving them of their liberty.
- DoLS can only be used in a hospital or care home and cannot be used in other settings (such as supported living) as the Court of Protection must authorise a deprivation in these situations.
- Care homes and hospitals (managing authorities) must ask the local authority (supervisory body) for permission to deprive someone of their liberty although hospitals and care homes can authorise themselves for the first seven days if the need is thought to be urgent.
- These safeguards are overseen by independent professionals who ensure that people are not deprived of their liberty arbitrarily, without due process and that they have the same rights as everyone else under the Human Rights Act.

The acid test states that if someone lacks the capacity to consent to their residence, is under “continuous supervision and control of movement and not free to leave”, then they require a DoLS.

Advance Decisions to Refuse Treatment (ADRT).

An Advance Decision to Refuse Treatment ADRT (previously known as a living will or advance directive) is a decision that can be made in order to refuse a specific medical treatment in whatever circumstances that are stated. This can include the choice to refuse treatment even if doing so might put an individual's life at risk. The ADRT will not be used if an individual can make their own choices at the time the treatment is needed and offered. The ADRT will only become effective if the person loses capacity to make decisions about their future treatment.

The ADRT is legally binding if assessed as complying with the Mental Capacity Act 2005 and is valid and applicable. If it is binding it takes the place of best interests decisions about the treatment. If the ADRT is valid and applicable to current circumstances it provides legal and clinical instruction to multidisciplinary teams. For the refusal of life sustaining treatment, the ADRT must be written, signed and witnessed and contain a statement that it applies even if the person's life is at risk.

The individual can revoke decisions at any time.

Advance Decisions to Refuse Treatment (ADRT)

Key elements:

- Making an advance decision is entirely voluntary and should not be made as a result of external pressure
- An advance decision can only be made by someone over 18 years of age
- The person making an advance decision must have the capacity to do so
- The advance decision should specify the treatment which is to be refused and the circumstances in which the refusal applies
- The decision must be valid
- The decision must be applicable to specific circumstances
- If the advance decision is to apply even if the person's life is at risk, it must be in writing, signed and witnessed and it must say that the decision applies even if it means the person's life is at risk
- An advance decision can only be used to refuse treatment not to demand treatment or to request procedures which are against the law e.g. assisted suicide
- A copy should be retained by the person and (with consent) be retained in all relevant care records

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

DNACPR is an order stating that a decision has been made either by the person or the Medical Officer/Specialist Nurse/Advanced Nurse Practitioner (ANP) in charge of their care that CPR would have no clinical benefit or be wished for in this situation.

It does not mean that treatment will be withheld, e.g. antibiotics, analgesia, feeding, hydration, suction, treatment for choking etc.

If the person is choking it is advisable to ring 999 for the ambulance crew to attend to manage the situation.

A decision **not to attempt** CPR applies only to CPR. It must be made clear to person/people close to that person and members of the healthcare team that it does not apply to any other aspect of treatment and that all treatment and care that are appropriate for the person will continue. To avoid confusion, the phrase '**Do Not Attempt Cardiopulmonary Resuscitation**' should be used to record DNACPR.

Key elements:

- The Senior Clinician/Specialist Nurse/ANP will have the DNACPR discussion with the person and with their consent also with the family
- Full information including risk factors will be given
- DNACPR form will be completed, signed and dated by the professional, NOT the person or their carer
- The original copy remains with the person wherever they receive care and when care is transferred to other settings
- A DNACPR decision does not influence the decisions of the healthcare professionals looking after the person regarding any other treatments or medications they think would be right for them
- A DNACPR decision is about CPR only. The person will still receive the best possible treatment and care for their illness even if they or the team looking after them, have decided against CPR
- The DNACPR form is not legally binding, but an ADRT refusing CPR is legally binding if it is valid and applicable

Answer the questions from the information provided in this section

Explain what an Advance Care Plan is.

When should the discussions take place?

Why might a person begin to make an advance care plan?

What is informed consent?

Explain the legalities of an advance decision to refuse treatment.

What is a DoLS?

When would someone require a DoLS?

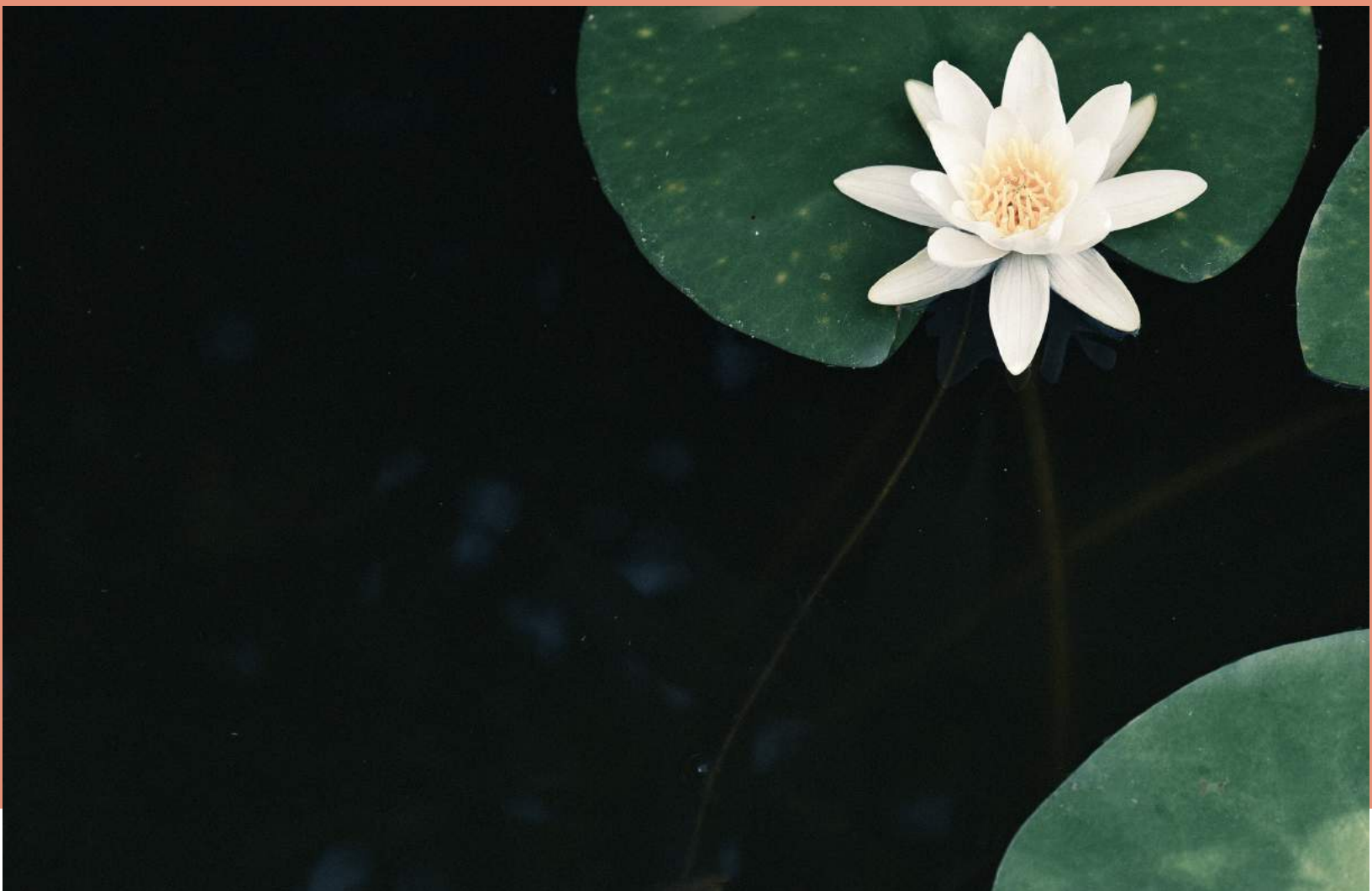
What do the initials DNACPR stand for?

Give a brief explanation for DNACPR.

Who is responsible for making the decisions vs. following the decisions made in an ACP?

If you identified a 'trigger', what would you do about it?

Recognising Dying



Recognising the last hours and days of life

A person who is dying needs a care plan tailored to their individual needs. This should include attention to physical, spiritual, social and psychological needs that are identified by a holistic assessment. This is when the Individualized Care Of the Dying Documentation (ICODD) is used.

Five priorities for care of the dying person are identified in the report “**One Chance to Get it Right**”. (2015) This sets out the approach to caring for dying people that staff should adopt:

Priority 1 – Recognise – the possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Priority 2 – Communication – sensitive communications takes place between staff and the dying person, and those identified as important to them.

Priority 3 – Involve – the dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

Priority 4 – Support – the needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

Priority 5 – Plan & Do – an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

One of the most important elements of end of life care is to be able to identify when a person reaches the point where they are actually dying. It is never easy to decide when this is. It is important to look for reversible causes of deterioration and for a decision to have been made about whether or not treating this is possible, beneficial and/or in keeping with the person’s wishes.

Although it is impossible to predict the exact time of death, there are signs when it might be near, but each person will change in different ways.

Here are some of the clues that will help you identify that dying is imminent. You will need interventions at each stage both for the person, their family and loved ones.

Circulatory changes in the hours and days before death - peripheral circulation decreases and blood pressure gradually lowers. The person's extremities feel cold and the skin colour may change from pale to purplish in the extremities. This change is something that experienced staff will see as a key sign of imminent death. Kidneys retain more water when the person stops drinking resulting in decreased urine production.

Increasing frailty - with progressive illness comes an increasing symptom burden and reduced appetite. The person becomes less mobile, weak, frail and ultimately bedbound.

Loss of interest and withdrawal - as the person becomes weaker they lose interest in their environment and may withdraw from the people around them. Restlessness and confusion are quite common in the last days of life. There is a gradual increase in the length of time the person sleeps leading to periods when it is difficult to rouse them, until finally it leads to unconsciousness for most people in the last hours of life. It is important to still talk to and explain things to the person.

Difficulty swallowing - in the last few hours or days, swallowing becomes difficult, making eating or drinking difficult or impossible and increasing the risk of aspiration and choking.

This can increase distress, as the person's mouth may become dry and uncomfortable. It may be no longer practical to administer oral medication, so an alternative route must be used. Good mouth care is essential.

Changes in breathing - when a person is close to death, their breathing often changes from normal rate and rhythm to a new pattern. They may stop breathing for a few seconds or even as long as a minute before starting to breathe again. The depth of each breath can also vary. This is called Cheyne-Stokes breathing. Coughing and 'rattling' can also be common. This breathing is sometimes known as the 'death rattle' and can be upsetting to care givers but is not an indication of distress.

The final moments of life are often very peaceful. Breathing becomes irregular and slows down dramatically. The stomach muscles rather than the chest muscles may control the person's breathing, and you will see it rise and fall with every breath they take.

Once a person has got to this stage, it could be just a matter of minutes or maybe even a few hours before they take their last breath. Everyone is different. It is important that someone is with the person during this time, because even though they are dying they may still sense your presence, which will be comforting to them.

Other people may also wish to say their goodbyes at this time. So consider their needs too and allow them time with the dying person if it is felt appropriate. Families should not feel under pressure to stay with the person if they do not want to be there at the time of death.

A sudden event leading to death

It is not uncommon during this period for a sudden event to take place even when we are expecting a person to die. This includes events such as a pulmonary embolism (blood clot in the lung) a heart attack or stroke. This can be very distressing for the family. Although you may not be certain about the actual cause of sudden death, make sure that the family and loved ones have careful, empathetic explanation and reassurance given to them.

Most people die peacefully and gradually, so when you're asked how someone will die it is right to say that it is likely to be peaceful, not dramatic, and that only occasionally there may be a sudden change.

The person becomes more deeply unconscious just before death occurs. Their breathing pattern changes, their extremities become cooler. When this happens families will often recognise that death is near. For some families, this will be their first experience of death and dying, so it is important to make sure that they realise that death is imminent. This will give them the opportunity to make any specific preparation they wish to remain with the person and to summon others.

Although as a care worker you are unable to verify expected death and will have to contact a doctor/ or nurse who has undergone the training to do this, there are signs and symptoms that are commonly used to tell that a person has died.

The person may be very pale, have bluish discolouration of the skin due to lack of oxygen in the blood and will not respond to touch, voice or painful stimulus.

The following signs are commonly recognised clinical signs used when verifying death:

- Absence of carotid pulse over one minute
- Absence of heart sounds over two minutes
- Absence of respiratory movements and breath sounds over two minutes
- Fixed, dilated pupils (unresponsive to bright lights)

Supporting someone who is deteriorating

Content adapted from the 'Doing It My Way', a comprehensive guide to end of life care for people with learning disabilities, reproduced with permission from St Anne's Community service. A link to the guide can be found within the resources section online.

Once a person is approaching the end of their life, there are a number of things to be discussed by health care professionals who support the person. It is important for you to be aware of these as they will impact on your day to day care.

This includes:

- Symptom control (see Symptom Management section)
- Resuscitation status (see Advance Care Planning section)
- Reduced trips to hospital
- Out of hours continuity
- As and when required medication and 'just in case' or Anticipatory Medication (see Advance Care Planning section)
- Supporting relatives
- End of life support

Resuscitation status

Once a person's health starts to deteriorate, it is time to think about a DNA CPR order, if one isn't already in place. Once this has been put into place, it is important that all staff members who work with the person are made aware. The DNA CPR is a legal document which must be followed by all staff, and so it is important that all staff are aware of this.

Reduced trips to hospital

Once a person is known to be coming towards the end of their life, it can be worrying for staff when their health takes an unexpected turn. This may mean the person gets taken to hospital more often than usual – and sometimes for things which can be treated in the home.

Once a person has been diagnosed to be at the end of life, there is often very little the healthcare professionals in a hospital can do to help. The medication alone will often be making the person as comfortable as possible in their final days. It is important to let the person you support have as dignified a death as possible. Sometimes going into hospital and having tests done may prevent this from happening.

It can also be distressing or tiring for the person to be taken to hospital, and it could make them more susceptible to other health problems, such as infections. As long as their pain and other symptoms are being managed effectively, and they have access to all the medication they need, a trip to hospital can often be avoided.

Asking for advice

By this stage you should have regular contact with the person's GP or palliative care nurse, and they will be able to advise about any concerns regarding the person's health. It's a good idea to put plans into place so that staff know at what point they need to contact the out of hours team. This might be if a person appears to be in pain or if they are struggling to swallow food or fluids.

The out of hours team will be able to determine whether or not a trip to hospital for the person is needed. Both hospices in Kirklees and Calderdale have 24 hour advice lines which can be used even if the person is not already known to the palliative care team.

Kirkwood Hospice Advice Line number: 01484 557910

Overgate Hospice Advice Line number: 01422 379151 (for out of hours, select option 1)

Out of hours continuity

It is important that all services are aware of a person's needs, including out of hours services. This is where completion of the palliative care handover form can help. This could be discussed with the GP/ ANP, district nurse, specialist nurse or community matron.

If one of the people you support is admitted to hospital, it is important to ensure good communication with the ward. Due to staffing issues or costs, it may not be possible for a member of staff to be with the person at all times. However, it is important to know the progress of the person whilst they are in hospital so you should instruct one or two members of staff to make regular contact with the hospital, to gather information on the health of the person. This information should be documented and kept in the person's file, and can be used to update families about the condition of their relative. Ideally, family members should get their information from the team treating the person at that time, but they may want to talk to you in general.

Keeping regular contact with the staff on the ward will also be beneficial to the person, as you will be able to give them advice on their needs and support plans. They will also be able to ask for things the person needs, such as pyjamas, incontinence pads or toiletries.

Supporting Relatives

Supporting the family members of a person living their final days is an important part of End of Life care. Practical advice should be offered as well as informed answers to any of their questions or concerns. Naturally this is a difficult time for relatives, especially if they were close to their loved one, and you and your staff team will need to be prepared for this. The level of support required varies from family to family, but you should try your best to offer as much support as they need. Further details are included within the bereavement section and communication sections of this workbook.

Involving family and friends

Involving relatives and friends in the various aspects of their loved one's final days can often be a comfort.

For example, this could include them being invited to meetings with doctors or community nurse teams.

If a person's family speaks a different language, it is important to use an interpreter so

there is no breakdown or confusion in communication. It also puts unfair pressure on family members who may be asked to translate bad news, which means they might not translate the message you would want to get across.

Details of local counselling services or help lines may also be helpful to grieving families. You can find further information in the online resources.

It's never easy to determine exactly when a person is approaching their final days. However, there are a number of symptoms and side effects that may indicate death is not too far away. Remember, every person is different and not all these symptoms will necessarily be present, nor indicate that death is close.

Some of the common signs are listed below:

- Sleepiness – to combat this try to plan visits and activities when the person is most alert.
- Unable to swallow well or having no interest in food or drink – let the person choose when and if they want to eat or drink. Ice chips, water or juice may be refreshing if the person can swallow. At this stage, it will not harm the person if they don't eat.
- Loss of control of bladder or bowel – keep the person as clean, dry and comfortable as possible. Place disposable pads on the bed beneath them and remove when they become soiled.
- Changes in breathing pattern or heavy breathing – breathing may be easier if the person is turned to the side and pillows are placed beneath their head and behind their back. A fan directed at the face may help.
- Cold feet, hands, arms or legs – warm the person with blankets but avoid electric blankets or heating pads as these may cause burns.
- Complete loss of consciousness – many people are still able to hear after they are no longer able to speak, and some experts think that hearing is one of the last senses to go. Encourage both staff and family members to continue talking to them.
- Disorientation or confusion – speak calmly to help keep the person relaxed. Let them know when you enter the room, who else is also there, and talk about what is happening around them. Keep the information brief and simple so as not to overwhelm the person.

Informing family and friends

It can be very difficult to watch a person go through these changes. However they are natural symptoms of dying and by this stage you'll have regular contact with qualified nurses and palliative care nurses who will be able to help you determine if they have reached their final stages of life. When this occurs, it's time to inform family members or next of kin so that they have the opportunity to be with their loved one in the final days.

At this point, you should assess care plans, (including Advance Care Plans) and, if necessary, put new ones into place to ensure that the person's needs continue to be met. This may include changes to manual handling or bathing. You should also have regular contact with their GP who can assess the effectiveness of symptom control medication and make changes if needs be. For instance, this may include changing the route of medication, and stopping nonessential medications.

During a person's final days, you may feel that nothing you do is right and that you are not helping them. However just being with them and making them as comfortable as possible is the best thing you can do.

Keeping the person informed and being open and honest will maintain the relationship and trust they may have built with you over the years. Spend time with them doing things they enjoy, such as listening to music or watching TV. This will make them feel safe and secure and provide a good deal of comfort for all concerned.

Symptom Management



Symptom management

There are many things we can do to make someone more comfortable and keep them feeling well. This section gives you more information about symptoms to look for and how to treat them. A symptom is an unusual feeling or sensation which a person may experience. It may occur now and again or may become progressively worse. A person may experience several symptoms at the same time. The symptom, including how bad it is, is something only the person can truly know so it is crucial to listen to their report of it.

If care home staff are concerned about symptom management, they can contact the Care Home Support Team (South Kirklees), Quest Matrons (Calderdale), GP/District nurses/ Community Specialist Palliative Care Teams or 111 if out of hours.

This section covers:

- Nausea and vomiting
- Hydration and nutrition
- Weakness and fatigue
- Confusion and delirium
- Depression
- Breathlessness
- Bowel management
- Pain
- Medications in the last few days of life

Nausea and Vomiting

Nausea is the feeling of wanting to be sick. It's very unpleasant and is often associated with other symptoms, such as being pale, having a cold sweat or diarrhoea. If you have ever felt sick without being sick, you will understand how awful nausea feels, it can feel worse than being sick.

Retching is when the stomach cramps as if someone is going to be sick. It is very tiring and can be very painful.

Vomiting is actually being sick - the forceful expulsion of the stomach contents through the mouth.

Nausea and vomiting can be symptoms of advanced disease. They can also be caused by treatment of the disease, such as medication or surgery.

Nausea and vomiting can also be caused by something which is unrelated to the disease, such as an upset stomach. Both can also be triggered by extreme coughing or breathlessness or an unpleasant thought or memory.

What you can do to help:

- Don't wear strong perfume as it can increase nausea
- Make sure the person is in a calm environment, away from the sight and smell of food. The smell of food can make nausea worse
- If they get hungry, offer small snacks not big meals
- Try and offer foods you know that they like
- Make sure good mouth care is maintained
- Ensure they are in a comfortable position
- Have vomit bowls to hand
- The registered nurse may need to give medication to help control nausea and vomiting

Why might a person experience nausea and vomiting?

Give an example of how nausea and vomiting might be cared for?

How can good oral hygiene assist a person with nausea and vomiting?

Hydration and Nutrition

Eating is one of the key social things people do and is important for more than nutrition.

Weight loss is common in people with advanced illnesses and many people find that they want to eat less. As someone's illness progresses, people can have less energy because of the disease, even if they eat normally.

Some people need lots of reassurance so that they do not worry about their weight loss. Good assessment skills help to find out if lack of eating is a problem.

Talk to the person and ask them how they are feeling and listen to their response.

Reassure them that a loss of appetite is quite common. Tell them it is fine to eat less.

Do not talk about food all the time; if a person has no appetite they may not fancy anything. Towards the end of life, not eating does not harm the person, because their metabolism has changed and they cannot use nutrients effectively, even if they do eat.

Consider barriers to eating:

- Medications causing a metallic taste in the mouth
- Oral hygiene
- Mouth ulcers
- Thrush
- Ill-fitting dentures
- Depression
- Too much food being offered

Tips:

- Offer small portions
- Make the food look nice
- Encourage them to eat what they can manage
- Help with cutting up food when needed
- Use non-slip mats
- Sit the person in a position where they can eat
- Sometimes an alcoholic drink can help stimulate the appetite
- If they have enjoyed alcohol before, a drink may reduce stress and give them extra calories. Help their families to understand that a drink of alcohol and small amounts of food may be all their loved one needs.

At the very end of life or when a person is imminently dying, the prognosis will not be altered by providing hydration and nutrition.

If the person wants to eat or drink but there is risk in doing so please support the person in eating and drinking if they are deemed to have mental capacity to make an informed decision.

If mental capacity is lacking follow 'best interest' procedures. Reassess the person regularly with a view to eating and drinking and document. Ensuring regular mouth care is maintained which is also covered in this workbook.

Avoid pushing food and drink as this can worsen symptoms such as nausea and vomiting. If the person is prescribed supplements, offer these but respect the person's decision if they do not choose to drink these.

Case Study

Mr Ahmed has advanced lung cancer. He hasn't eaten for the last few days. When asked he says he's just not hungry, what could you say to help?

Choose from the following options which you might choose to say:

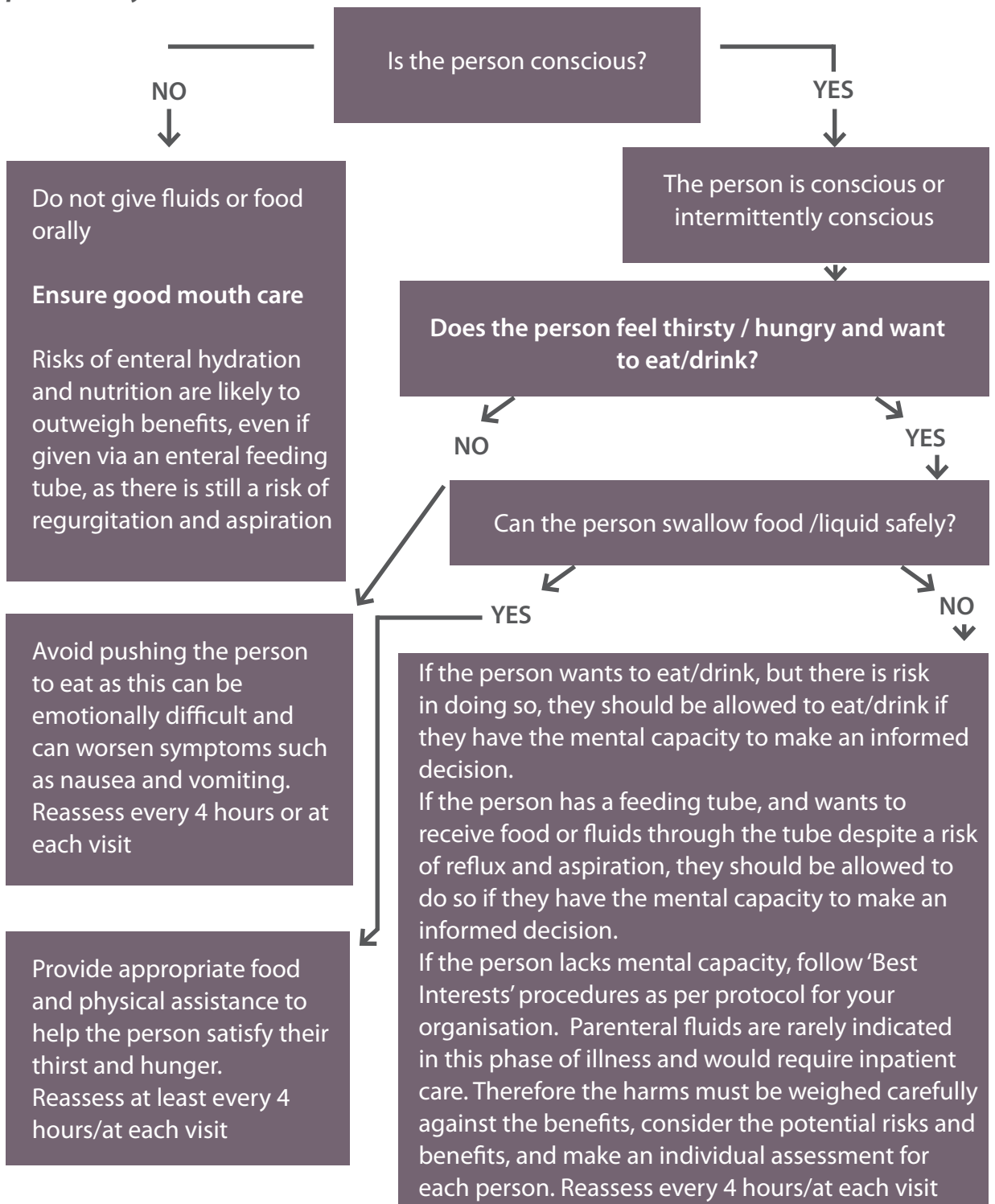
- Is your mouth sore?
- Come on, you've got to keep your strength up
- They're serving yummy roast beef with all the trimmings today
- Can you tell me a little bit about how you are feeling?
- I could bring you some of your favourite food and leave it on the side until you feel like it

Do's & Don'ts

- **Do find out if there is a problem with his eating**
- **Don't nag him, reassure his family too**
- **Don't talk too much about food if he's not hungry**
- **Do offer small portions of food he likes**

Hydration/Nutrition (Taken from the ICODD)

This guidance is for use when it is thought that the person is in the last days or hours of life, and reversible causes for the deterioration have been considered. **At this stage of an illness, the prognosis will not be altered by providing hydration and nutrition, orally or parenterally.**



Weakness and Fatigue

Weakness is when your arms and legs feel too weak to do normal daily activities. Fatigue is a feeling of tiredness, exhaustion or lack of energy. A good night's sleep is not enough to make someone feel better when they are experiencing weakness and fatigue that is due to a life-limiting illness.

Causes:

- The disease or the treatment
- Other health problems
- Common in depression
- Increasing weakness and fatigue are common at the end of life

As weakness and fatigue can have a number of causes, an assessment is needed to work out what treatment is most likely to help. People can feel very frustrated and helpless, as weakness and fatigue aren't always seen as symptoms. So first of all, you can tell them the symptoms are real and caused by health issues.

They need to be realistic about what they can actually do at the current time. Help them to plan rest periods during the day, but encourage them to keep up some activity but make sure they leave the less important tasks until they have more energy. Ensure they have as good a night's sleep as they can. Invite the person to share how they are feeling and ask questions if they want to.

Case Study

Mr Kozial has widespread metastatic cancer and came back from hospital three days ago after a minor operation. He hasn't got out of bed since. He says he's a sad old fool, but he just doesn't have the energy to get out of bed. What could you say to help?

Choose from the following options:

- Come on now, you don't want to get bed sores
- It's quite normal to feel a bit weak after an operation
- I'm sure you'll be up and about in no time
- How about just coming down for lunch today?
- Feeling a bit weak is expected, but is there anything else worrying you?

Do's & Don'ts

- Don't worry him and make him feel worse than he already is
- Do reassure him that this is a normal symptom after an operation
- Don't be unrealistic
- Do encourage a little activity
- Do talk to him and find out if anything else is wrong

Confusion and Delirium

As we age it is common to have a few memory problems, such as forgetting a name or taking a while to remember a word. Confusion and delirium (extreme confusion) are sudden changes in mental function. For example someone with delirium may forget the names of their children or forget the way to the bathroom, or they may just be a bit slower at finding their words.

It is important to recognise confusion and delirium as symptoms, because they can often be treated and the symptoms reduced. People with dementia may often be confused but this is a gradual and steady worsening, whereas delirium fluctuates and can change suddenly.

Confusion and delirium can be caused by an existing disease such as dementia. Or they may be caused by a new medical problem such as an infection or kidney failure. Confusion or delirium can also be caused by withdrawal from alcohol or drugs.

At all stages, we should try non-medical interventions before using drugs. Before someone reaches the dying phase, the aim is to treat the underlying problem that is causing the delirium (e.g. treating an infection).

However, terminal restlessness is delirium in the last days of life. It often happens as major organs shut down and cannot be reversed. It may be made worse by a person's emotional or spiritual distress. At this stage, drug and other medical treatment is normal to reduce the agitation as it is distressing for the person and their family. Listening to and discussing fears, anger or guilt can also help.

Q3: Words

Look at the words below and circle the words that apply to confusion and delirium:

Sudden	Dementia	Infection
Hunger	Change	Dehydration
Confusion	Distracted	Rambling
Urine Infection	Forgetful	Pain
Weary	Quiet	Fever
Chills	Aggression	Tearfulness

How can you tell confusion and delirium from the forgetfulness of old age or from dementia? There are some signs to watch out for.

In general look for sudden and unusual confusion:

- The confusion happens suddenly, over a few hours or days
- The person shows a lack of attention and are easily distracted
- Their conversation is rambling or pointless
- They don't know the time, where they are or who they are
- They cannot remember anything new
- They may be agitated and hallucinating (seeing things that aren't there)
- They may be unusually weary or quiet

There may also be physical signs like fever, chills or urinary problems. (Please refer to a senior health care professional if you have concerns about the person).

With confusion and delirium, the things you can do to help are:

- Look after the person in a calm, well-lit place
- Keep up the person's liquid intake - dehydration makes it worse- but this might not be possible in the dying phase
- When the person has clear moments, talk to them and reassure them
- Talk to the person in a clear, simple way
- Request a medical review from your local care home support team, community matron or GP

Why do you think a person might experience confusion and how would you recognise it? What support could you offer?

Why do you think a person might experience delirium and how would you recognise it? What support could you offer?

Why do you think a person might experience anxiety and how would you recognise it? What support could you offer?

Depression

Depression is more than feeling a bit low. It is feeling very low and sad for a long time. It is a serious illness and something to watch out for. Depression is very common in older people. Although the symptoms are the same as for younger people, older people are less likely to talk about unhappy feelings. People may use different ways to describe depression such as feeling down, being blue, feeling a bit low or feeling down in the dumps.

There are many different factors that can trigger depression. Sometimes it is a reaction to an event. In other cases, depression does not have an obvious cause. A stressful life event such as bereavement or terminal illness can cause a constant low mood and feelings of hopelessness about the future. Depression can also be caused by changes in levels of chemicals in the brain. For example, mood can change as hormone levels go up and down. There can also be a social cause, doing fewer activities or having fewer interests can cause depression.

If you are concerned about someone being depressed, talk to them about their mood and whether they are feeling down.

Here is an example of a depression screening tool:

NAME _____ AGE _____ SEX _____ DATE _____

Cornell Scale for Depression in Dementia

Ratings should be based on symptoms and signs occurring during the week before interview. No score should be given if symptoms result from physical disability or illness.

SCORING SYSTEM

a = Unable to evaluate	0 = Absent	Score greater than 12 = Probable Depression	
1 = Mild to Intermittent	2 = Severe		

A. MOOD-RELATED SIGNS

1. Anxiety; anxious expression, rumination, worrying	a	0	1	2
	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
2. Sadness; sad expression, sad voice, tearfulness	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
3. Lack of reaction to pleasant events	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
4. Irritability; annoyed, short tempered	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

B. BEHAVIORAL DISTURBANCE

5. Agitation; restlessness, hand wringing, hair pulling	a	0	1	2
	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
6. Retardation; slow movements, slow speech, slow reactions	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
7. Multiple physical complaints (score 0 if gastrointestinal symptoms only)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
8. Loss of interest; less involved in usual activities (score 0 only if change occurred acutely, i.e., in less than one month)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

C. PHYSICAL SIGNS

9. Appetite loss; eating less than usual	a	0	1	2
	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
10. Weight loss (score 2 if greater than 5 pounds in one month)	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
11. Lack of energy; fatigues easily, unable to sustain activities	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

D. CYCLIC FUNCTIONS

12. Diurnal variation of mood; symptoms worse in the morning	a	0	1	2
	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
13. Difficulty falling asleep; later than usual for this individual	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
14. Multiple awakenings during sleep	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
15. Early morning awakening; earlier than usual for this individual	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

E. IDEATIONAL DISTURBANCE

16. Suicidal; feels life is not worth living	a	0	1	2
	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
17. Poor self-esteem; self-blame, self-depreciation, feelings of failure	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
18. Pessimism; anticipation of the worst	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
19. Mood congruent delusions; delusions of poverty, illness or loss	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

NOTES/CURRENT MEDICATIONS:

ASSESSOR: _____

Score

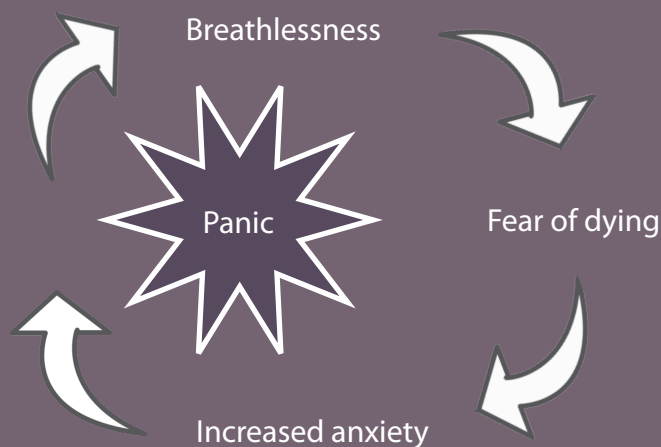
Alexopoulos, Abrams, Young, Shamoian (1998).

Why do you think a person might experience depression and how would you recognise it? What support could you offer?

Breathlessness

Breathlessness (sometimes called Dyspnoea) is feeling short of breath. Feeling breathless without doing anything active is common when people are at the end of their lives. Rarely you may hear stridor, which is a noise when the person breathes in and has a narrowed upper airway. Breathlessness may be distressing for the family or carers, rather than the person, and can be more frightening when the sound is loud or unusual.

Cycle of increasing panic and breathlessness



Davis. C (1998)

Respiratory or breathing problems are common in people with advanced incurable disease, especially when the disease is in the lungs or the heart. Breathlessness may also be caused by another medical problem, such as a chest infection, which can be treated. A detailed assessment will be needed.

Anxiety, panic attacks and hyperventilation (breathing too quickly) are common which make the breathlessness worse. If breathlessness is getting worse, even when they are doing nothing, it can mean they are getting close to the end of life but it's still important to check for something reversible, like a pleural effusion (fluid around the lungs) in case it can be drained.

Medication can reduce the stress for both them and their relatives by treating the symptoms of severe breathlessness. As breathlessness can be frightening and very distressing, you can help by asking them about their fears and reassuring them that it is quite common.

Oxygen is not usually considered helpful for the dying person unless they have previously been prescribed it.

Ways to help:

- Simple breathing exercises
- Relaxation techniques
- A fan
- An open window
- Good posture or position
- Making sure the room is well aired
- Relaxing gentle music
- Walking aids

Sometimes they will need a referral to a specialist breathlessness service for breathing equipment or drug treatment.

Death rattle

A person may make a distinctive 'rattling' noise at the back of the throat which is also known as the 'death rattle'. This is a sound that a person may make as they are coming to the end of their life and may no longer be able to swallow or cough effectively enough to clear their saliva. People with the 'rattle' are often NOT breathless.

No evidence currently suggests that a death rattle is painful, distracting, or distressing to the dying person. However, the sound can be distressing or concerning to family members and loved ones and it is important to reassure them that these noises are not causing the person pain, anxiety or distress.

Give 3 examples of non-medical ways of improving symptoms of breathlessness

- 1.
- 2.
- 3.

Bowel Management

Bowel management should form part of any good palliative care, to prevent distress at the end of life.

Bowel movements can be a source of discomfort or very painful when they are not normal. So an understanding of the person's normal accepted bowel habit is essential for assessment.

To keep up a healthy bowel movement, it is important to make sure people have a healthy, varied diet (this might not be possible at the very end of life). You can make sure the person has dignity by, when appropriate, offering use of a commode and giving them privacy.

Bowel Management

People may use the term diarrhoea when they go to the toilet often, or when their motions are loose and watery. It is important to find out more to diagnose the cause. Diarrhoea can be caused by a number of things. It may be caused by medication such as antibiotics. It may follow an operation. It may be caused by an infection or a bug. It can be caused by constipation, if there are hard faeces in the rectum, the soft faeces may 'overflow'. Or, it may be a symptom of a more serious medical problem. It is important to get much history as you can from the person.

Constipation is not being able to go to the toilet. Again, there are a number of causes and an understanding of their normal, accepted bowel habit is essential. Many drugs and treatments can cause constipation. It is important for you to monitor and report if a person has not opened their bowel for several days, in case the person has a bowel obstruction.

If a person has been prescribed opioids a laxative should also be prescribed, and they should be assessed on a daily basis.

Constipation

Adapted from the Yorkshire Cancer Network and North East Yorkshire and Humber Clinical Alliance - A guide to symptom management in palliative care (2016)

Constipation is very common in people requiring palliative care, due to a combination of factors including immobility, reduced food and fluid intake, drugs, bowel pathology and sometimes hypercalcaemia. Diagnosis is usually made on the basis of history and examination and abdominal X-ray is rarely required.

Some of the things you might wish to consider are educating the person and their family about the causes of constipation. Increasing fluid intake and making appropriate dietary changes may help improve symptoms.

Guidelines on the use of laxatives in constipation

- A combination of stool softener and stimulant laxative is usually required.

Examples of stool softeners include:

- Docusate
- Poloxamer
- Lactulose
- Movicol®
- Magnesium salts

Examples of stimulant laxatives include:

- Senna
- Dantron
- Bisacodyl
- Sodium picosulphate

Examples of combination preparations include:

- Codanthramer (poloxamer and dantron)
- Codanthrusate (docusate and dantron)

Assessment**An assessment of normal bowel habit should include questions about:**

- Normal frequency of stool
- Current frequency of stool
- Stool consistency
- Stool size and volume
- Any blood or mucus in stool
- Ease of passage

The Bristol Stool Chart would aid this assessment.

- Give 2 examples of why a person might be constipated or have diarrhoea?

2. What action should you take if you notice a change in a person's bowel habits?

3. How can you support a person with constipation/diarrhoea?

Mouth Care

Mouth care is very important for comfort and wellbeing. Keeping the persons mouth healthy means they can eat and drink, take medication and avoid a lot of discomfort.

If they are well enough give them this routine to follow. If they are too weak, you can do it for them, to keep the mouth healthy.

Mouth care assessment

- Check mouth at least daily for changes or more frequently if problems are observed
- Clean teeth using a soft toothbrush, (e.g. a baby's toothbrush) toothpaste and water

- If the person is unconscious or finds a toothbrush too painful, try a softer toothbrush or use the mouth-ease tool. Check the method your organisation uses.

If the person's mouth is dry, coated or sore:

- Check if this is a side effect of their medication
- Follow routine for healthy mouth care
- Offer them regular unsweetened drinks
- Offer them ice to suck or sugar free chewing gum, or sugar free mints or sweets, ensuring they are safe to chew gum and there is no risk of choking. Once a person has become drowsy or unresponsive, it is not safe or appropriate to offer ice, gum, mints or sweets.
- Apply a non- perfumed, non-petroleum based moisturiser to cracked dry lips. Make sure that petroleum based lip balms are not used at all.
- Obtain advice from your District Nurse or GP

Observe for candidiasis commonly referred to as thrush. Signs are white, cream-coloured or yellow spots in the mouth. White spots may not always be thrush- it could be food debris. Thrush usually makes the mouth sore and red. If you see this refer to the GP so the person can get treatment. Keep an eye out for mouth ulcers which may require treatment depending on the cause.

Remember treating any dentures to prevent reinfection is very important

How can good oral hygiene assist with comfort?

Pain

We mostly think of pain as something we feel in the body. However there are four ways in which a person can suffer from pain. These four ways are physical (how we feel in our body) as well as social, spiritual and psychological (how we feel in our minds). Pain in one area often affects another.

Diseases often cause physical pain. Infection caused by the disease can cause pain. Some drugs and treatments may have painful side effects; however it is important to reassure people to take certain medicines such as analgesics that may help with reducing pain.

People can also have social pain - they might be worried about their family or they might be sad because they don't often see their families and friends.

Physical Pain

- Other symptoms
- Adverse effects of treatment

Anger

- Delays in diagnosis
- Unavailable healthcare professionals
- Health care professionals who do not communicate
- Failure of therapy

Total Pain

Depression

- Loss of social position
- Loss of job prestige and income
- Loss of role in family
- Insomnia and chronic fatigue
- Sense of helplessness
- Disfigurement

Anxiety

- Fear of hospital or nursing home
- Fear of pain
- Worry about family and finances
- Fear of death
- Spiritual unrest, uncertainty about future

When someone is near the end of their life they may have strong spiritual feelings. They may want to ask questions like:

- Is there any meaning or purpose in life?
- Will I be forgiven for the things I have done wrong?

Some people may suffer psychological pain. This means the pain comes from emotional distress rather than a physical problem, but is real pain all the same. Some may be afraid of pain. Some may be afraid of dying. Others may feel embarrassed because they need help in their personal care.

If you can assess pain, you can help people feel more comfortable. It can be difficult for someone to describe the pain they are in. It is more difficult if they cannot speak because of their illness.

There are many pain assessment tools including Abbey Pain Score for cognitively impaired people, with further information included within the online resources.

There are a few questions you can ask to find out more about the pain:

- What makes the pain better?
- What makes the pain worse?
- Is this your normal pain or a new pain?
- On a scale of 1 to 10 how bad is the pain? (There are different tools available for people with learning difficulties, dementia etc.)
- Are there any other symptoms?

Other symptoms might include nausea, feeling faint and tingling often called pins and needles.

Explain to them that anything they can tell you might help in deciding how they are treated. Ask them to describe what type of pain they are feeling. They might use other words to describe their pain such as saying it is: aching, burning, cramping, dull, electric shock, radiating, shooting, stabbing or throbbing.

You can then tell the doctor or nurse the type of pain they are in. Find out how frequently they get the pain, is it always there or does it come and then go away again? If it comes and goes is it starting to come more often? Or do they feel the pain only occasionally?

There are other ways to look for pain. Look at their body language:

- Is the face showing/expressing signs of pain?
- Are they moving more slowly?
- Do they tell you they are fine, but then grit their teeth when they think you are not watching?

You should also ask yourself some questions:

- What are they like on a normal day?
- Has something changed in the way they are behaving?
- Are they more confused or upset than you expected?

Q5: Pain

Look at the following scenarios do you think these people are in pain?

Scenario 1:

Mr Lee is an elderly man who has arthritis and the medication he is taking are making him feel sick and causing mouth ulcers. He is finding eating uncomfortable.

- Do you think he is in pain?
- What type of pain do you think this is?
- How can you help?

Scenario 2:

Miss Barker is an elderly lady who has terminal cancer. She is a Catholic, but feels that God has abandoned her. Why is she being punished when she tried to lead a good life?

- Do you think she is in pain?
- What type of pain do you think this is?
- How can you help?

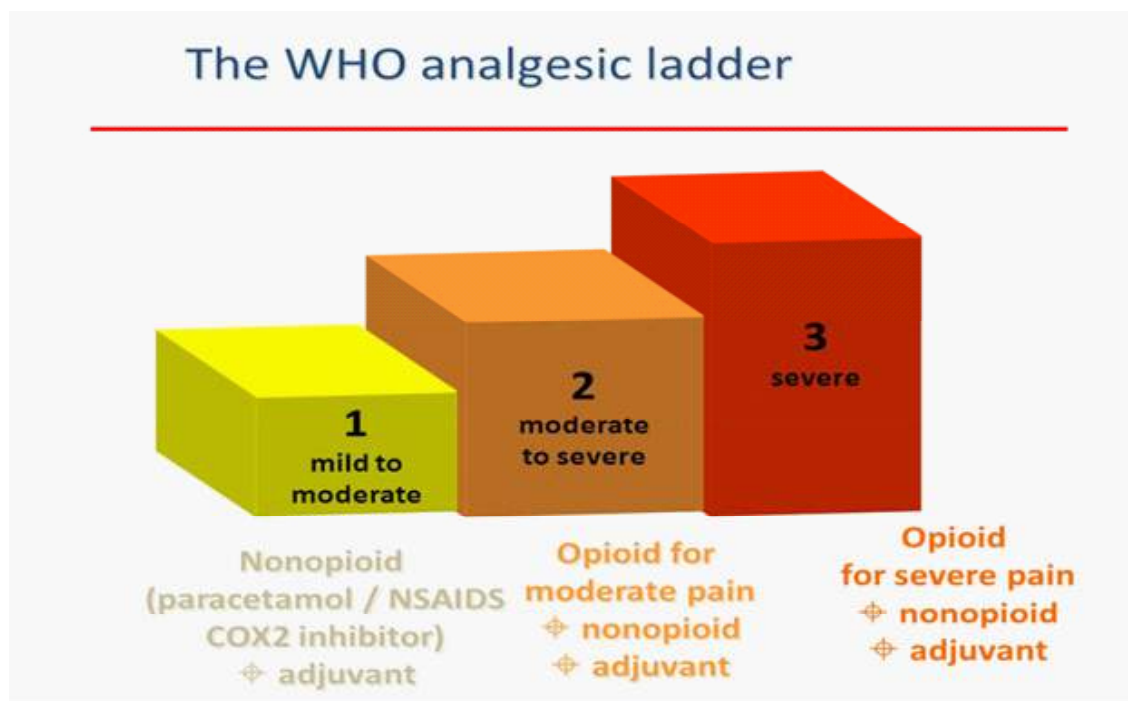
Scenario 3:

Mr Harland is an elderly man; he was a very successful businessman. He is a proud and independent man and hates the loss of dignity now that he has to rely on other people for personal care.

- Do you think he is in pain?
- What type of pain do you think this is?
- How can you help?

Not all pain is caused by disease. The more you find out about the pain, the better it can be treated. Only a qualified professional can prescribe medication, but there are a number of things you can do to help reduce the pain. If it looks like someone is in pain, take time to talk to them and show them you are really listening. They will then be more relaxed about talking to you. They may tell you about problems that they don't want to bother the doctor about.

Medicine is not the only way to relieve pain. A massage or a warm bath can sometimes relieve pain and stress. A lavender scented pillow can also aid sleep. If you can assess pain you can help them. As their carer you are the best person to do this. There are a lot of options for medication to relieve pain.



You may already know the names of the most common painkillers, which are known as analgesics. According to the level of pain, these are some of the painkillers that can be used:

- Mild pain – paracetamol and non-steroidal anti-inflammatory drugs or NSAIDs (includes Diclofenac and Ibuprofen).
- Moderate pain – weak opioids (includes Co-Codamol and Codeine).
- Severe pain – strong opioids (includes Morphine and Fentanyl).

There are other drugs which can be taken to help increase pain relief, such as anti-depressants, anti-epileptic drugs and muscle relaxants.

There are also different methods for giving people drugs. These include:

- Tablets to swallow
- Suspensions – liquid medication
- Given in the mouth to be dissolved and absorbed through the mouth
- Patches which allow the medicine to be absorbed through the skin
- Suppositories
- Directly into the bloodstream via intravenous injection (IV)
- Subcutaneous (under the skin) infusion

Reviewing medications in the last few days of life

The focus of medicines management in the last days of life is on good control of pain, agitation and other symptoms. In the weeks prior to death, medications whose main role is prevention of long-term conditions including stroke, angina, high blood pressure etc. may have been reduced or discontinued. Once people begin to struggle taking their medicines orally, and/or become unconscious further changes are needed. The ICODD offers health care professionals guidance on which medicines are safe to stop and others which are not.

Oral pain medication can be changed to sub cutaneous medicines if appropriate.

McKinley T34 Syringe Pump (commonly known as a Syringe Driver)

Many people may be familiar with a syringe to give injections. A syringe pump is simply a syringe with a small battery operated pump. The pump means medication can be constantly pumped 24 hours a day. It stops the need for constant injections all the time. A syringe pump is not a tool to help someone die, but is often used in the final days and hours of someone's life to ensure they are pain free. A syringe pump is a good way to give people medication when they are dying and are unable to swallow. It can deliver drugs to control pain, sickness, secretions, restlessness and confusion if the person wants or needs them.

It can also help manage symptoms for those people who have a longer prognosis and are experiencing difficult to manage symptoms.



- When someone is unable to swallow
- Is unable to absorb drugs due to vomiting
- Is too weak or ill to take medicines by mouth
- Cannot take medication by another route, such as rectally

For example, if someone is vomiting, their medication is likely to come back up again and not be absorbed by the body. They may not even be able to keep down an anti-emetic to stop them being sick. A syringe pump is a way to get an anti-emetic into their system, as well as any other medication to reduce their pain.

Whenever a decision is made to start treating symptoms with a syringe pump, this must be done in discussion with the person and/or their relatives and a full explanation given as to why the pump is needed and what drugs are being used and why.

Whilst you won't decide if a syringe pump is the best way to give medication or which drugs to use, you may need to keep a check on the equipment and inform the district nurse or registered nurse.

Things to look for include:

- The skin where the needle goes in -is it red or sore?
- The light on the pump is not flashing- which it should do every 32 seconds whilst the pump is in use.
- The pump is not working or gets wet
- There is blood or drug crystals near the syringes or in the tube- would a hca understand this?
- The tube is blocked or there is a kink in it
- It does not improve the person's symptoms, so they still have pain or feel sick
- If you see any of these things contact the district nurse or registered nurse.

Anticipatory (Just In Case) Medicines

Anticipatory medicines are prescribed by the GP/ Advanced Practitioner for people nearing the end of life. They are there to help with the common symptoms that can occur in the last days of life.

Anticipatory medicines need to be given by a Registered Nurse and they are all administered by s/c (subcutaneous) injection.

The anticipatory medicines that are normally prescribed are:

- Diamorphine for pain and breathlessness
- Buscopan for noisy breathing or a noise described as a "death rattle"
- Midazolam for agitation, distress or breathlessness
- Haloperidol for sickness and hallucinations

If you feel the person you are caring for is nearing the end of life and showing any symptoms please report to the district nurses or a registered nurse who will be able to administer the anticipatory medicine if needed.

Non-Malignant Conditions



Non-malignant conditions

This section gives an introduction to conditions which are life limiting, other than cancer. These are often referred to as 'non-malignant conditions'.

We have included a brief overview of each condition, along with some practical tips for you to consider when supporting a person at the end of life.

- COPD
- Parkinson's disease
- Motor Neurone Disease (MND)
- Dementia
- Chronic heart failure
- Multiple Sclerosis

COPD

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions that cause breathing difficulties.

It includes:

- emphysema – damage to the air sacs in the lungs
- chronic bronchitis – long-term inflammation of the airways

COPD occurs when the lungs become inflamed, damaged and narrowed. The main cause is smoking, although the condition can occasionally affect people who have never smoked.

The damage to the lungs caused by COPD is permanent, but treatment can help slow down the progression of the condition.

Treatment

Treatments include:

- stopping smoking
- inhalers and medications – to help make breathing easier
- pulmonary rehabilitation – a specialised programme of exercise and education
- surgery or a lung transplant – although this is only an option for a very small number of people

Outlook

The outlook for COPD varies from person to person as the condition can't be cured or reversed.

But in some people COPD may continue to get worse despite treatment, eventually having a significant impact on their quality of life and leading to life-threatening problems.

Tips

- Pulmonary rehabilitation can be useful in those people who are well enough to complete the course. In addition to benefits from exercise it teaches people that breathlessness on exertion is manageable and what their individual limitations are
- Position and posture can relieve breathlessness
- Fans are useful- position so that air flows across the mouth and nose
- Set priorities with the person- what is important to them?
- Plan ahead – balance energy with time
- At end of life, medicines can be used to help control breathing rate, e.g. morphine like medicines

Parkinson's disease

Parkinson's disease is a condition in which parts of the brain become progressively damaged over many years due to lack of a particular chemical (dopamine) in the brain.

The three main symptoms of Parkinson's disease are:

- involuntary shaking of particular parts of the body (tremor)
- slow movement
- stiff and inflexible muscles

A person with Parkinson's disease can also experience a wide range of other physical and psychological symptoms, including:

- depression and anxiety
- balance problems – this may increase the chance of a fall
- loss of sense of smell
- problems sleeping
- memory problems

Causes of Parkinson's disease

Parkinson's disease is caused by a loss of nerve cells in part of the brain called the substantia nigra. This leads to a reduction in a chemical called dopamine in the brain. Dopamine plays a vital role in regulating the movement of the body. A reduction in dopamine is responsible for many of the symptoms of Parkinson's disease. Exactly what causes the loss of nerve cells is unclear. Most experts think that a combination of genetic and environmental factors is responsible.

Treatment

Parkinson's disease is a progressive condition. This means it will get worse over time. It's difficult to predict at what speed a person will progress because the condition is different for everyone.

Most of the current treatments involve managing the main movement symptoms of Parkinson's disease, which are tremor, rigidity and slowness of movement. Over time, these can affect everyday activities, such as walking, talking, swallowing and eating. As well as problems with movement, people may experience symptoms such as tiredness, pain, depression and constipation. These symptoms can also often be managed with treatments and therapies.

Some people also find they experience changes in how their mind works. This may be a result of the disease itself or a side effect of some Parkinson's medication that can include difficulties with memory, concentration, hallucinations, delusions, anxiety and depression.

Outlook

As the condition progresses, the symptoms of Parkinson's disease can get worse and it can become increasingly difficult to carry out everyday activities without assistance. Many people respond well to treatment and only experience mild to moderate disability, whereas the minority may not respond as well and can, in time, become more severely disabled.

As Parkinson's disease becomes more advanced, it leads to a chance of developing other complications such as chest infections and pressure sores.

Signs of deterioration (taken from Gold Standards Framework guidance)

- Drug treatment less effective or increasingly complex regime of drug treatments
- Reduced independence
- Condition less well controlled
- Mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)

Motor Neurone Disease (MND)

MND is a neurodegenerative disorder that causes progressive muscle weakness of limbs, chest and abdominal muscles, resulting in premature death, usually from respiratory failure. Around 5000 people in the UK are living with MND every year. The average survival from symptom onset is three years but one third of people will die within the first year of diagnosis.

There are four types of MND:

- Amyotrophic Lateral Sclerosis- ALS. Life expectancy may be six months to 3 years.
- Progressive muscular atrophy –PMA. Life expectancy may be five years or more.
- Progressive Bulbar Palsy- PBP. Life expectancy may be five years or more.
- Primary Lateral Sclerosis, PLS- can have near normal expectancy

Tests can help the clinical diagnosis but there is not one single test that shows whether or not someone has MND. These tests include MRI and CT scans, blood tests, nerve conduction tests, lumbar puncture and muscle biopsy.

Only one drug, Riluzole, is currently licensed in for use in MND. It is not a cure and will not reverse symptoms, but if used early enough, can improve life expectancy for two to four months.

As MND advances it causes progressive muscle weakness that often leads to breathlessness, swallowing problems, drooling, communication problems, loss of capacity and increasing dependency. These are discussed in detail on the next pages.

Dyspnoea (breathlessness)

This can be caused by weakened respiratory muscles, particularly the diaphragm. People often wake with morning headaches because they are not getting enough oxygen into their lungs during sleep and retain carbon dioxide. Some people may choose to use a Non-Invasive Positive Pressure Ventilator (NIPPV), a device that pushes air into the person's lungs via a mask. NIPPV can improve quality of life, but they can be noisy, difficult to fit well, especially as the person loses weight and can cause facial pressure ulcers. Good skin care and prompting mask adjustments may help to prevent these developing. Some people choose to have a permanent tracheostomy fitted which again, may improve life expectancy and quality of life, but the care for tracheostomy and a ventilator can be very hard to get out of hospital.

Acute episodes of dyspnoea and panic can be managed with very cautious use of benzodiazepines such as Lorazepam and Midazolam, or with opioid drugs such as Morphine and Oxycodone.

Dysphagia (swallowing difficulties)

Many people with MND struggle to swallow food, fluid and saliva as their disease progresses. The sensation of choking is very frightening, and people fear that they will choke to death, although this is rare. Some choose to have a feeding tube inserted directly into their stomachs, commonly known as PEGs or RIGs. These must be placed in the early stages of the disease as the person may not be fit enough for the procedure as their disease progress. Good oral hygiene and positioning the person in an upright position will help to reduce the risk of aspiration pneumonia. Ongoing input from speech and language therapists (SALT) is also essential, to ensure swallowing is managed as safely as possible.

Weakness/paralysis

MND is debilitating and its effects can be rapid. Ongoing physiotherapy and occupational therapy is essential for people to be able to live as independently as a possible for as long as possible. There are many aids and adaptations available as a person's mobility and dexterity reduces as well as sophisticated wheelchairs and communication aids. Regular, gentle and passive exercises will help prevent limb spasticity as will drugs such as Baclofen.

Sialorrhea (drooling)

If there are swallowing difficulties, some people cannot swallow saliva effectively which can lead to skin and mouth infections and worsen communication problems. People sometimes feel like they are choking on their own saliva and constant drooling can be very embarrassing and lead to social isolation. Barrier creams and moisturisers will help protect the skin and ensuring they have access to tissues or wipes will help protect their dignity. Positioning someone in an upright position and teaching them ways to manipulate saliva to the back of their throats before a controlled swallow can be helpful. By encouraging them to drop their chins down as they swallow, this can help protect the airway. Suction and cough assist machines can also be of benefit, but sometimes medication can be effective in drying the saliva.

Interventions such as Botox injections into the salivary glands can improve symptoms for up to four months but may thicken saliva too much and make the person too dry. Drugs that reduce saliva production can be very helpful but occasionally cause unwanted side effects such as rapid heart rate, palpitations, constipation and central nervous system disturbance.

Dysarthria (a motor problem with forming the words the person wants to say)

As face, tongue and neck muscles deteriorate, many people with MND will lose their ability to speak clearly and this can be extremely frustrating and distressing for both the person and for those caring for them. There are a variety of communication aids available including eye writers and picture boards. Patiently starting with open questions first which require one or two-word answers can help reduce the person's anxiety, and you can move to using closed questions if the person can't speak normally, given that not everyone loses their speech.

End of life care

For people with MND, death is often due to respiratory failure. Some people who are dependent on NIV choose to withdraw from ventilation even though it will mean that they die of MND sooner than they would if they had continued ventilation. This needs specialist management.

It is important that drugs are prescribed to manage dyspnoea, pain, nausea, secretions and agitation. Prompt and effective management of these symptoms will help to ensure the person's death is as peaceful as possible.

Dementia

This summary aims to provide some guidance and advice on how to support a person with dementia in the advanced stages of the disease and the approaches that allow a person with dementia to die in comfort and dignity.

Dementia is caused by diseases of the brain and is a life limiting, progressive condition. Symptoms of dementia will get worse however the speed of progression depends on the person and the type of dementia they have (Alzheimer's Society).

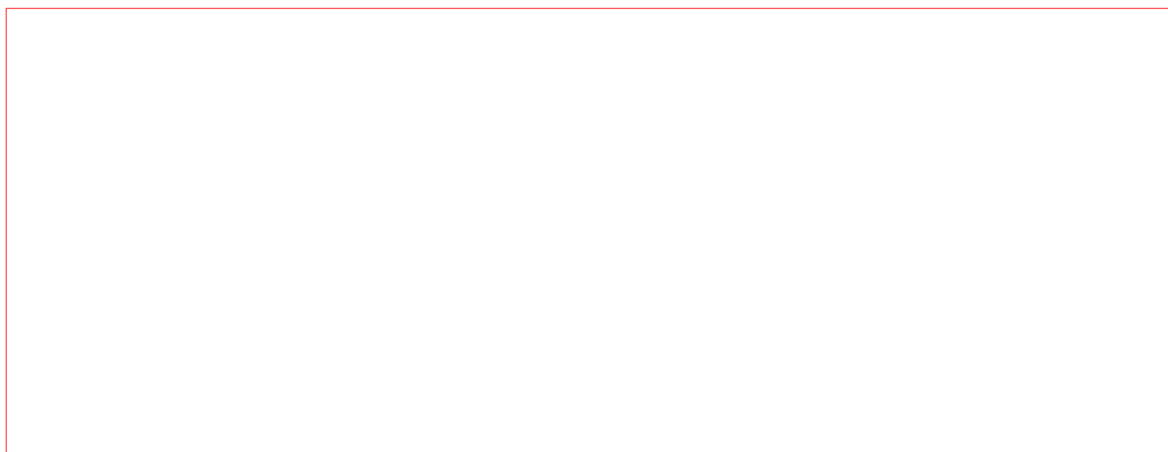
Someone in the later stages of dementia may show the following signs of decline in functioning:

- Become increasingly frail
- Experience frequent falls or infections
- Become less mobile
- Sleep more
- Eat and talk less

The most important aspect of providing good person centred care is by knowing as much as possible about the person you are caring for. This can be helped by completing the life story process. This ideally should be done at earlier stages, for example, when a person becomes known to your service.

Life story allows information to be captured on a person knowing their likes, dislikes and preferred choices. This may be done with the person or alongside families or those that have known the person well.

If you knew that there may come a time when you weren't able to communicate your needs, what would you want people to know about you? How would you want to be made to feel comfortable?



Capacity

Whenever you are making decisions about the care being provided, you must assess capacity and follow the guidance included within the advance care planning section.

Communication

Dementia affects the brain tissue responsible for sending, receiving and interpreting communication messages; therefore as the disease progresses the ability to communicate becomes increasingly difficult. A person in the later stages of dementia may have limited or no speech, and will be less able to understand what people are saying to them. Relying only on verbal communication can make it difficult to understand what the person is trying to communicate; although it is important to know that a person may continue to have feelings about what is going on, being with them and hearing familiar voices may provide a positive feeling.

You need to be aware of non-verbal signs to look out for in a person such as their use of body language and facial expressions they may use to communicate a particular need. This should be documented in a person's care plan.

Tips

- Talk to the person, continue to do this even if you think they are not able to understand what is being said. They may respond to the tone of your voice and feel a level of connection with you.
- Talk about things of interest to the person or reminisce about things from their life (this is where life story helps)
- Keep sentences short and simple
- Give one bit of information at a time
- Ask only one question at a time
- Maintain good eye contact
- Use of gestures - giving a smile and positive facial expression, show a relaxed and calm body language.
- Use of appropriate touch - holding a person's hand or giving a gentle hug, this can offer reassurance and comfort

Effective pain management

For a person with advanced dementia they often cannot tell you if they are experiencing any pain or discomfort; a good way to establish this is by recognising changes to their behaviours and the non-verbal cues they may give. This can help be achieved through the use of pain assessment tools.

Pain assessment tools usually involves recording information about the person and using a scale, chart or checklist to help identify and rate pain.

The following things may help when assessing whether the person is in pain:

- Knowledge of the person – there may be certain things that they typically do when they are in pain, such as cry out or become very withdrawn.
- Observation – signs that someone is in pain include their behaviour (such as being agitated, irritable, tearful, or unable to sleep), facial expressions (such as grimacing), body language (if they are tense or rocking, or pulling at a particular part of their body) and vocalisations (for example, shouting out, screaming and moaning).
- Bodily changes – a high temperature, sweating or looking very pale can also indicate pain.

(Alzheimer's Society 2017)

Nutritional support/swallowing difficulties

As dementia progresses, people often develop problems with eating and drinking. The person's appetite decreases and in the later stages of dementia they often have difficulties with swallowing safely.

People with swallowing problems are at risk of choking and of food or saliva going down the windpipe.

Advice should be sought from a speech and language specialist, they will be able to help support care planning to help manage problems for a person with swallowing difficulties.

If there is no reversible cause and treatment for the swallowing difficulties then it may be considered that it is due to the progression of the person's dementia. Dieticians may also provide additional support due to people being at risk of malnutrition. Soft/ pureed food is often easier for a person to eat and liquids that are thickened may cause fewer problems with choking. It is better if the person is able to sit upright when eating and drinking and is at most alert.

A person's medication may also be converted to liquid or injectable form so that it may still be taken.

Someone in the later stages of dementia should be offered food and fluids for as long as they show an interest and can take them safely. It may mean them just taking a few mouthfuls or sips. This is usually referred to as **comfort feeding**, with the aim that eating and drinking is providing pleasure to the person. Knowing about a person's food and drink preferences will help here in offering what you know they will enjoy. This is the time to ensure good mouth care is given.

Tips

- The person might enjoy things that stimulate their senses, such as familiar music or aromas and gentle hand massages. The use of 'Namaste' is becoming a well-used approach to caring for a person in advanced stages of dementia, with further details included in the online resources
- Don't always assume that agitation is due to the dementia, there may be many reasons why the person with dementia is agitated. Look for an underlying cause. Are they uncomfortable, is the environment too noisy or do they need some stimulation?
- If the person with dementia remains agitated despite excluding other causes, and there has been a general deterioration in function, then this may be part of the dying process. Whenever possible, it's best to ensure the person is in a calm, familiar environment.

Chronic heart failure

Chronic heart failure is an incurable life limiting condition in which the heart is unable to pump enough blood to meet the body's needs, usually as a result of weakness of the heart muscle or problems with the heart valves.

Heart failure can affect the left or right side of the heart or both. Diagnosis requires a scan of the heart, usually an echocardiogram.

People with heart failure should have a low salt diet and consistent fluid intake. They should be encouraged to mobilise frequently within their own limits and should take regular short rests. It is important that they are helped to maintain their activity levels.

Symptoms

Fluid retention

Fluid can collect in the lowest part of the body. This is generally seen in the feet and ankles extending further up the legs. There may also be swelling of the abdomen (ascites).

With left sided heart failure, fluid retention may also affect the lungs causing severe breathlessness; there may also be a cough, sometimes with white frothy saliva.

Breathlessness

This may be on exertion and may limit a person's mobility and the ability to perform self-care. Breathlessness on exertion which resolves with a short rest is not a cause for concern so long as it is normal for that person.

People with heart failure may also become breathless if they lie too flat or lie too flat for too long. They may require to be propped up with pillows to sleep or may need an electric profiling bed. If they are not sufficiently upright or if they slip down the bed they may wake due to breathlessness which can be very severe, this is sometimes mistaken for panic or anxiety but is a physical symptom of heart failure. A fan may help with symptoms of acute breathlessness.

Fatigue

This may or may not be associated with breathlessness and like breathlessness can limit exercise tolerance, mobility and self-care. Many people with advanced heart failure simply do not have the energy to carry out activities they seem physically able to perform.

Treatment

People with heart failure will generally be on a wide range of drugs many of which control symptoms as well as improving prognosis. In most cases people should continue on their treatment for as long as they are able. Diuretics such as Furosemide helps with symptoms and ACE inhibitors and beta-blockers can help with symptoms and survival. However, advanced heart failure is associated with an increased incidence of side effects which may outweigh the benefits of treatment.

Monitoring

All people with heart failure should be monitored for increased weight, fluid retention and breathlessness.

End of life care

- Heart failure is associated with a high incidence of sudden death and many people will die unexpectedly when they appear stable. In most others deterioration is generally rapid once it begins and death often seems sudden.
- As with all non-cancer conditions, good advance care planning is the key to the best possible management of advanced heart failure. The more is known and documented about the person's wishes in advance, the easier it is to ensure they are met.

Multiple Sclerosis (MS)

Multiple sclerosis (MS) is a condition which can affect the brain and/or spinal cord, causing a wide range of potential symptoms, including problems with vision, arm or leg movement, sensation or balance.

It's a lifelong condition that can sometimes cause serious disability, although it can occasionally be mild. In many cases, it's possible to treat symptoms. Average life expectancy is slightly reduced for people with MS.

It is estimated that there are more than 100,000 people diagnosed with MS in the UK. It's most commonly diagnosed in people in their 20s and 30s, although it can develop at any age. MS is about two to three times more common in women than men.

Outlook

MS can cause a wide range of symptoms and can affect any part of the body. Each person with the condition is affected differently. The average life expectancy for people with MS is around 5 to 10 years lower than average.

The symptoms are unpredictable. Some people's symptoms develop and worsen steadily over time, while for others they come and go.

Periods when symptoms get worse are known as "relapses". Periods when symptoms improve or disappear are known as "remissions".

Some of the most common symptoms include:

- fatigue
- vision problems
- numbness and tingling
- muscle spasms, stiffness and weakness
- mobility problems
- pain
- problems with thinking, learning and planning
- depression and anxiety
- sexual problems
- bladder problems
- bowel problems
- speech and swallowing difficulties

Most people with MS only have a few of these symptoms.

Treatment

There's currently no cure for multiple sclerosis (MS), but it's possible to treat the symptoms with medications and other treatments.

Treatment for MS depends on the specific symptoms and difficulties the person has.

It may include:

- treating relapses of MS symptoms (with steroid medication)
- treating specific MS symptoms
- treatment to reduce the number of relapses (disease-modifying therapies)

End stage MS (adapted from the MS Trust)

As MS becomes more advanced, it leads to a chance of developing other complications which can lead to death.

If a person reaches this stage, where their disabilities result in severe difficulties which may not respond to treatment and lead to life-threatening complications, they are considered to have end stage MS. Some of the symptoms that can make someone vulnerable are:

- Severe bladder and/or bowel problems - which lead to recurrent infections or regular hospitalisation
- Increased susceptibility to respiratory infections - which can lead to repeated bouts of pneumonia
- Swallowing problems - which can cause choking or aspiration pneumonia (where food or fluid enters the lungs)
- Feeding difficulties - which may require a feeding tube or result in severe weight loss
- Difficulties breathing due to weakening of the respiratory muscles
- Losing the ability to speak
- Pressure sores due to immobility - which are at risk of becoming infected
- Developing blood clots due to lack of mobility
- Increased levels of pain
- Mental confusion or disorientation

End of life care

All of the above can lead to a person needing an increasing number of trips to hospital. If someone with MS experiences an infection it can put them at risk of developing sepsis, where the body begins to attack its own organs and tissues in response to the infection, which is a potentially life-threatening condition. Some other signs which might indicate end stage MS include physical decline, weight loss and multiple health conditions (comorbidities). A person with end stage MS will often require 24 hour care.

Many of these symptoms are similar to those seen in someone with advanced MS. However, whilst treatment for advanced MS aims to help a person improve medically, in end stage MS the focus shifts to helping a person live to the end of their life with respect, dignity and as comfortable as possible.

Spirituality



Spirituality

Spiritual care reassures to people that they have value and are loved simply for who they are regardless of their colour or creed, health, wealth, education or sexuality, and it can be given by any carer whatever their rank or profession.

All good caring is spiritual.

The spiritual is that which gives a person's life purpose, meaning and value. It may include a religious dimension but does not have to.

Spirituality can be described as a search for the meaning of self in relation to the world. Spirituality can refer to the essence of human beings as unique individuals:

"What makes me, me and you, you", so it is the power, energy and hopefulness in a person. It is life at its best, growth and creativity, freedom and love. It is what is deepest in us, what gives us direction, motivation. It is what enables us to survive bad times...to overcome difficulties...to become ourselves...'

(Bradford Social Services 1999)

Spirituality in end of life care

What is life for?

What am I going to do about it?

These questions may become more important when people are faced with the ending of their life...

Consider some of the issues a person may face when they have a life limiting condition:

- Becoming ill
- Pain
- Having treatment
- Communicating feelings in a therapeutic setting
- Coping with stress in illness

The person faces many losses and threats:

- Threat to self-image
- Threat to / loss of bodily integrity
- Interruption of work
- Loss of independence
- Loss of dignity
- Loss of identity
- Threats to cognitive functioning
- Whole future under threat (including family life)
- Strain on relationships with loved ones
- Loss of ability to express oneself
- Loss of faith



Spiritual care aims to “reflate the balloon”, to help people’s sense of wellbeing be as best as it possibly can be under the circumstances, regardless of if they have a faith. Those with no beliefs will still have a spiritual need, and may be coming to terms with the life that has been, which may not always be the life they hoped for.

What lifts your spirits? What makes you cheerful?

Basic spiritual care needs:

- Being listened to
- Being valued
- Being respected
- Being given emotional support
- Being understood
- Being given access to religious support
- Being allowed to simply ‘be’ without judgment

Triggers for spiritual distress:

- When bad news is broken
- When a situation becomes imminently terminal
- When treatment is being withdrawn
- After a trauma (e.g. a fall, vomit, incontinence)
- When bereavement is being experienced
- When a person is isolated and receiving no visitors
- When a person is a long way from home
- When undergoing a personal crisis (as well as in health)
- On a significant anniversary

Signs of spiritual distress:

Everyone is different, some people may show very clear signs whilst others may think it but not show it.

Some common signs of spiritual distress:

- Tearfulness or weeping
- Withdrawal or lack of interest
- Restlessness or being unable to settle
- Complaining or being angry
- Suddenly becoming more religious, or abandoning previously held belief
- Fear (of being alone or falling asleep and so on)

Helping to deal with the person's emotions:

The person may also experience a variety of emotions during the final days of their life. This often varies from person to person, dependent upon their age, family situation and the experiences they have had in life. Some people may want to settle 'unfinished business', such as:

- resolving any problems in family relationships
- visiting certain places
- buying gifts for their loved ones
- sorting out their belongings and giving special items to members of their family
- ensuring a will is in place
- seeing a religious leader

It is important to help the person with any of these requests but if a person approaches you with a situation you feel you can't handle, you should raise this with a senior member of staff or line manager. Part of our spiritual care is caring for ourselves. If the person you support is unable to discuss these things with you, it's a good idea to hold a 'best interests' meeting with staff members or their family.

This way you can discuss a favourite place they might want to visit for one last time, or arrange for the relevant religious leader to visit.

It also helps to prepare people close to the dying person. They may be aware that something is happening but a little confused by it all. Explaining the circumstances often helps any concerns they may have. This could involve providing them with easy-to-read literature or the use of pictures for reference.

Bereavement



Bereavement

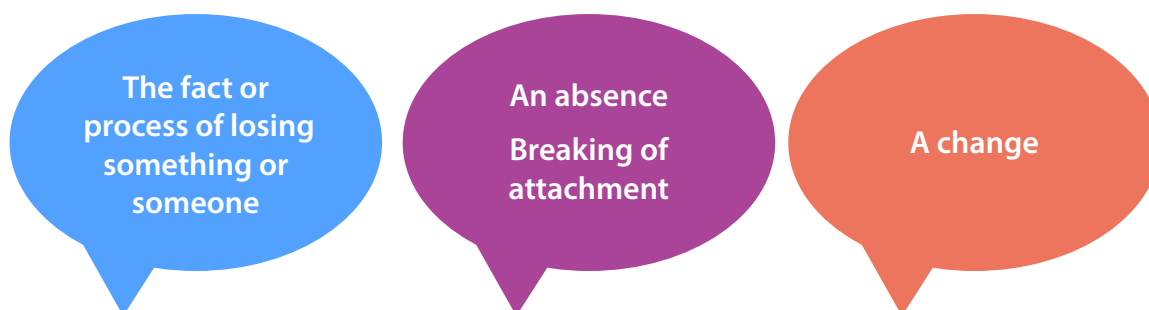
We recognise that many staff will form long-term relationships with the person they care for and their family, which forms a fulfilling part of their role. When a person dies, it is no surprise that members of staff may feel a sense of loss whilst also being in the position of supporting relatives with their grief and bereavement. It is important to consider your own feelings and emotional reactions as well as recognising if your colleagues may need an opportunity to share theirs.

Death, loss and bereavement are unavoidable human realities; given death is a part of living and a reality we must all face.

Experiencing feelings of loss following either a death of a person or multiple deaths of people over a longer period, might make you question your role.

This section of the workbook considers some of the practical techniques you can use to support others who may be going through the process of loss, grief and bereavement.

What is loss?



What is grief?



What is bereavement?



What might impact on your experience?

- A lack of confidence in being able to talk about death and dying openly
- Not enough support within your setting and pressures on time and capacity
- Your own personal experiences of bereavement
- How long you knew the person and how close you were with them
- The type and quality of the person's death

Think again about what causes you anxiety about providing care at the end of life and consider the prompts below.

- Fear
- Feeling you are being scrutinised
- A lack of skills
- Feeling out of depth
- Making things worse

Whilst bereavement following a death is well-known, grieving before someone dies, known as pre-bereavement or anticipatory grief is less recognised. This may be something you come across within your setting and with your interactions with families. As a worker you may feel out of your depth in dealing with family issues, wanting to help and not knowing how and being unsure about mentioning death and dying. Those experiencing pre-bereavement may have increased anxiety and feelings of being overwhelmed as well as experiencing fear and panic.

People's worlds have changed, and as they anticipate loss and death, they will mourn.

Tips

It is important to respond

It is important to acknowledge

It is OK to feel out of your depth

It is ok to feel scared

Listening is a natural phenomenon

Post bereavement:

Bereavement has two major parts-looking at the loss and continuing to live.

People will feel a lot of emotions and think differently once the loss itself has happened. You may be able to support them, but also signpost them to specialist help if they need it.

You will also need to consider the right environment, especially if people are distressed. Think about how you can offer a caring, comfortable and warm space, perhaps providing a hot drink in a quiet environment.

How do people present - both pre and post bereavement?

Varied
emotional state:
Up, down, anxious,
angry

Stress
Impact on functioning
Spiritual crisis

Cognitive -
distressing thoughts
Physical symptoms
Mental health
affected

How can you help?

As described within the communication section, listening is a key skill. You can show empathy by trying to enter their world as if you can feel it. It is possible to learn and develop your skills of empathy and with practice, being genuine, real, and warm will help you to be present in that moment and respond to what you are hearing.

Tips

Reflect what they are saying

Minimise distractions

Reflect the feeling words they use

Keep questions to a minimum

Paraphrase what you are hearing back to them in your own words

Summarise

Be present- make time

Pay attention to body language

Don't judge

Go at the person's pace

Only you know how you be 'YOU'

Stay beside them

Accept you are not responsible 'for' them

Be careful about giving advice

Signpost and refer on if necessary

How confident do you feel in understanding symptoms and how these can be managed?	1	2	3	4	5	6	7	8	9	10
	Evidence									

How able are you to understand non-malignant conditions in the end of life?	1	2	3	4	5	6	7	8	9	10
	Evidence									

How well do you understand the importance of spirituality and how you can offer holistic, spiritual care at the end of life?	1	2	3	4	5	6	7	8	9	10
	Evidence									

How confident do you feel in supporting someone through grief, loss and bereavement?	1	2	3	4	5	6	7	8	9	10
	Evidence									

Date Workbook completed:

Candidate Name and Signature:

Assessor Name and Signature:

This must be evidenced and discussed with your workplace mentor/supervisor

Resources and references

A full, up to date list of resources and references for both Kirklees and Calderdale staff can be found online, at:

www.kirkwoodhospice.co.uk/workbook

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