



INFORMED ABOUT PALLIATIVE AND END OF LIFE CARE

Learning Resource



ABOUT THIS RESOURCE

Welcome to this learning resource for Palliative and End of Life Care.

This resource is based on the knowledge statements at the Informed Level of the Enriching & Improving Experience framework developed by NHS Education for Scotland and Scottish Social Services Council. You can access the framework using the link below.

<http://hub.careinspectorate.com/media/534745/enriching-and-improving-experience.pdf>





INFORMED ABOUT PALLIATIVE AND END OF LIFE CARE
ABOUT THIS RESOURCE

LIKE THE FRAMEWORK THIS RESOURCE HAS FIVE SECTIONS:





INFORMED ABOUT PALLIATIVE AND END OF LIFE CARE

ABOUT THIS RESOURCE

WHO IS THIS RESOURCE FOR?

This is an introductory resource for anyone who comes into contact with people and their families and carers who need palliative and end of life care.

You can use this resource wherever you work – in a care home, in a hospital, in a community setting, in a hospice or anywhere else where people need palliative and end of life care.

It doesn't matter if you work with children or adults or older people – this resource will still help you understand more about palliative and end of life care. This resource has a mixture of reading and learning activities; the learning activities will help you connect the content to your own area of work.

Palliative and end of life care is for people with many illnesses, conditions and frailty. It isn't only for people with cancer but it is also for people with any life limiting or life shortening illness and we explain some of these in the next section.

LEARNING OUTCOMES FOR INFORMED RESOURCE

On completing this resource you should be able to:

1. Describe the main principles of a palliative care approach and what is meant by palliative care, end of life care and last days and hours of life.
2. Recognise a range of attitudes to death, dying and bereavement, including your own, and how these may influence thoughts, feelings and behaviours.
3. Identify verbal and non-verbal communication skills that can support a person facing death, dying and/or loss.
4. Describe the potential impact of living and working with loss, grief and bereavement.
5. Give key examples of person centred and holistic approaches to palliative and end of life care.
6. Describe some of the essential actions required around the time of death.



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USING THIS RESOURCE

Your own learning

- You can work through this resource on your own, reading the different sections and completing the learning activities. There is a video clip to watch, and there are links to extra information so that you can find out more about things that interest you. You can decide whether to complete the whole resource at once or in stages with breaks in between. We suggest it is probably best to complete one section at a time so you finish the resource over a few days or weeks. This way you have time to reflect and to talk with your manager or colleagues if you need to.
- You can also use this resource to learn with others. If you have colleagues who want to complete the resource, you could get together and work through each section as a small group. This way you have a chance to talk through the information and hear what other people think. You can do the learning activities together too, and reflect on the palliative and end of life care you all provide. You don't all have to be working in the same team or area to learn together.





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USING THIS RESOURCE

Supporting others' learning

- You can use this resource to support others' learning. If you have staff members who would like help to work through the resource, you could be a facilitator. You don't need to be an expert on palliative and end of life care to do this because the information you need is in the resource. You can support learners by arranging a regular space and time for learning, providing access to a computer or laptop, helping with digital skills, encouraging discussion, and helping people share ideas and reflect on the work they do as they complete the learning activities.
- If your team meets regularly, you could use some time to focus on working through the different sections of the resource. Some teams get together to share CPD (Continuing Professional Development) updates so you could use the resource during one of those meetings, or you could use part of a team meeting. You could use the resource with individual staff members as part of supervision or induction.
- If you deliver training, you can use this resource to provide sessions. You can use the sections to prepare presentations, or you can ask participants to complete parts of the resource in advance. You can use the learning activities to guide small group discussions. The resource can also be used to prepare teaching sessions, or for self-study, in college or university programmes of education.



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LEARNING ACTIVITIES IN THIS RESOURCE

Each section contains a learning activity for you to complete.

Each learning activity asks you to reflect on something related to working with people receiving palliative and end of life care. Reflection is a way of thinking carefully about a situation or something that happened, and asking yourself questions like:

- What exactly happened?
- What was I thinking?
- What were my feelings?
- What might the other people involved have been thinking and feeling?
- What went well, and what did not go so well?
- What sense can I make of what happened?
- What else could I have done?
- If something like that happened again, what might I do differently?

Gibbs (1998)

Each learning activity in this resource has some guiding questions to help you reflect. If you record and save the answers to these questions you will have five reflective accounts when you finish.

These reflective accounts can be used as evidence to support your learning and development.

Remember not to use anyone's real name when you write reflective accounts. This is because you must protect the confidentiality of people who use services.



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COMPLETING THIS RESOURCE

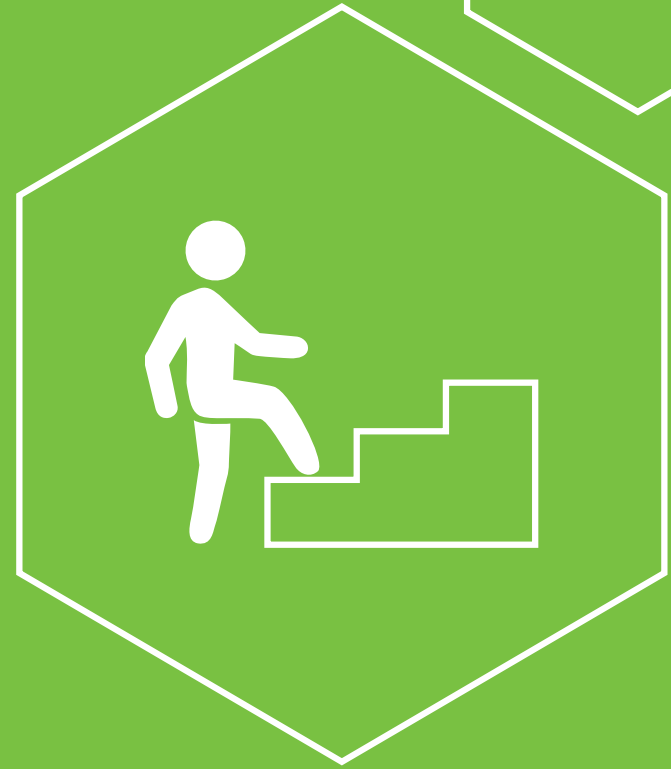
Sometimes it can be difficult to think about palliative and end of life care. We know that facing loss, death and dying is not easy, even when it is part of your job.

If this resource makes you feel emotions that you find hard to deal with, please take some time to speak to someone about it. You could speak to a colleague, line manager, mentor or supervisor.

You can take as much time as you need to complete this resource. You can start and stop and then come back to it when you feel able to.



1 | FUNDAMENTALS OF PALLIATIVE CARE – INFORMED LEVEL





WHAT DOES PALLIATIVE CARE, END OF LIFE CARE AND LAST DAYS AND HOURS OF LIFE MEAN?

Many words and phrases are used to describe palliative and end of life care. These can mean different things to different people. In this resource we offer you definitions for the terms palliative care, end of life care and last days and hours of life.

These will help you understand the care and support that may be needed and when that may be appropriate.

PALLIATIVE CARE

Here is a definition that is recognised and used in many countries:

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

– *World Health Organisation (2017)*

The World Health Organisation recognises palliative care as a human right for everyone although access to and quality of services are different across the world.

DEFINITION OF PALLIATIVE CARE

Palliative care:

- Supports people to enable them to be as well as they can be throughout their illness until they die
- Supports family members throughout the illness and after the person has died
- Uses a team approach to meet the needs of the person and their family
- Takes a positive view of life and views death as a normal part of life
- Can help people have a better quality of life
- Can be started as soon as someone is known to have a life limiting or shortening condition and alongside medical treatments and investigations.

World Health Organisation (2017)

DEFINITION OF PALLIATIVE CARE FOR CHILDREN

There is also a definition for children's palliative care:

An active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement

– *Together for Short Lives (2017)*

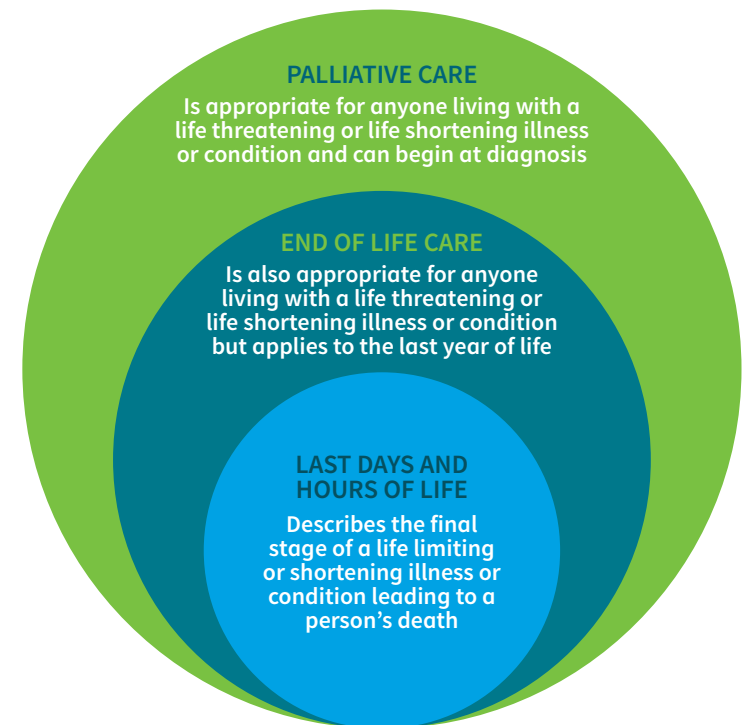
END OF LIFE CARE

End of Life Care is a term that is being used more and more across the UK. Just like palliative care it includes physical, emotional, social and spiritual care but it is used to describe the needs of people thought to be in the last year of life.

– *Scottish Government (2015)*

LAST DAYS AND HOURS OF LIFE

The last days and hours of life is the final stage of a life limiting or life shortening illness leading to a person's death.



DEFINITIONS

Have you noticed there is no mention of specific conditions?

Sometimes people think that palliative care is only for people with cancer. A palliative care approach can be appropriate for anyone living with a life-limiting or life-shortening illness or condition.

Examples include advanced lung or heart conditions, advanced neurological conditions such as dementia, motor neurone disease or multiple sclerosis and childhood life-shortening illness such as muscular dystrophy.

As people get older they are more likely to be living with more than one life-limiting or life-shortening illness or condition and can become frail.

Palliative and end of life care and support is provided in many settings including the person's home, care homes, prisons, hospices and hospitals.



PALLIATIVE AND END OF LIFE CARE AND SUPPORT – WHAT IS IT?

Palliative and end of life care and support is about caring for all aspects of a person's life. Care and support can help with physical, emotional, social and spiritual issues or concerns. This is really important because we know that being unwell can affect any and all aspects of a person's life. When one aspect of your life is concerning you or causing you distress then it is usual for other aspects of your life to be affected too.

An example could be someone experiencing pain. The pain may affect their ability to do the things that give them pleasure and purpose. This could then make them feel down and sad. By offering care and support for a physical symptom, it may also help with someone's emotional and/or social well being.

It works the other way too. Sometimes when people feel low or sad and we provide care and support to help them with this, they find that they can cope much better with any physical concerns or issues.

Everyone is different and each person's illness, condition and experience will be unique to them. What care and support will look like will depend on the individual's needs, circumstances and preferences. It may change over time if and when the individual's needs change. What is important or desirable for one person's care may not be appropriate or wanted by another.

FAMILY FOCUSED CARE AND SUPPORT

Defining family will be different for all of us and include many diverse members of our communities. We need to ask people who they consider to be their family and not make assumptions that this will be a relative. Many people consider friends and neighbours to be part of their family.

Providing care and support to the family is a really important part of palliative and end of life care. Coping with serious illness or conditions and coming to terms with what is happening to the person is not easy. Families have many different ways of living their lives and coping with difficulties. When families access the support that is right for them, it can help during the illness and after the person dies.

It is important to recognise and value the contribution the family make to the person's care and support. People might have different ideas about how much they would want their family to be involved in their care and support. It is important that we ask about this and include the family in these discussions.

Sometimes the person's biggest worry has nothing to do with their illness or condition. Other life events and issues happening in their lives or those of their families may be more distressing than their illness or condition.



WHO PROVIDES PALLIATIVE AND END OF LIFE CARE AND SUPPORT?

- There are a range of services and agencies providing palliative and end of life care, support and information. They include health and social services, voluntary, charitable and private organisations.
- Care and support can come from lots of different people and services. It might involve a nurse, doctor, social support worker or pharmacist but it may also be a volunteer worker, faith leader or welfare rights advisor.
- The availability of services may differ depending on where you work and live.
- Directing people to someone who could help them or give them further information is important. People may need help to know what services are available and how they can access these.

SERVICES, AGENCIES AND SOURCES OF SUPPORT

Ask the person what information or support they are looking for and then speak to your senior, mentor or manager about this. They can then direct the person to the right information or service.

Organisations such as NHS Inform, Macmillan Cancer Support, Marie Curie, Alzheimer's UK, Children's Hospices Across Scotland have websites with lots of useful information. Some of these organisations provide direct services as well as information.

Local libraries have information that can direct people to local sources of support.

PROTECT AND PROMOTE PEOPLE'S RIGHTS AND SAFETY

Sometimes people receiving palliative and end of life care or the family providing care and support feel or become more vulnerable or at risk of harm. Everyone has the right to be safe and well looked after.

If you have concerns about someone who may be at risk of harm please don't ignore it. Trust your instincts – if something feels wrong, say something. Speak to your manager, mentor or senior about your concerns.

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FUNDAMENTALS OF PALLIATIVE CARE

If someone tells you that they feel more vulnerable or are being harmed then it is really important that you listen to them and respond appropriately. It is important that you speak to your manager or a senior member of staff so the person can get the right support and help.



RESPECTING DIVERSITY

Scotland is described as a diverse and multi-cultural society. The people we provide palliative and end of life care and support to will have different faiths, cultures, circumstances, sexual orientation, physical and learning abilities and lifestyle choices. It's important to respect people's differences and take them into consideration when providing care or support as it may influence the service you provide.

Here are just some examples:

- Food and drink preferences
- The importance of worship or prayer
- Medication requirements, including refusal to use medication
- Discussing private issues with health and social care staff or non-family members
- Person's ability/accessibility requirements
- What care is needed when they have died, such as care of the body and associated rituals

Your beliefs and how you live your life may be very different from the people you are supporting. Treating everyone with dignity and respect is essential so that we do not discriminate or exclude people from receiving person centred palliative and end of life care.

ATTITUDES TO DEATH, DYING AND BEREAVEMENT IN SOCIETY

Sometimes we find it hard to think about death, dying and bereavement. If you are working with people with palliative and end of life care needs, then it is very important to let them talk about their thoughts and feelings, if they want to.

Some people find it easier to talk to staff than their family and friends. This might be because the people in their lives are not comfortable talking about these issues. Sometimes the person wants to protect their family and friends from the emotions of living with loss and dying.

Death and dying has always been a part of people's lives yet we know that people can be uncomfortable talking or thinking about death and dying.

The way people die, where they die and who looks after them has changed in the past 100 years. The way we grieve and understand bereavement has also changed.

In the past people experienced death much more frequently than we do today. It was as common for babies and young people to die as it was for older people. Dying in your own home was the norm and it was often quick with little or no medical input.

Today advances in treatments and medicines have meant that people live much longer but with more long term conditions and frailty requiring longer term care and support. More people die in hospitals than their own homes so families may not know what to expect or will have not seen a person die before.

KNOW ABOUT ATTITUDES TO DEATH, DYING AND BEREAVEMENT IN SOCIETY

When people talk to you about their thoughts on death and dying and what might be important to them it is important to listen and respond to them sensitively and respectfully. Sometimes people working in health and social care have not thought about their own death or they find it uncomfortable talking about or thinking about death and dying.

We know that when people have thought about their own attitudes to death and dying and what might be important to them they are more comfortable with having these conversations.



LEARNING ACTIVITY

This Learning Activity asks you to think about and reflect on what matters to people when they are dying.

A study asked a group of older people to think about what would be important to them if they knew they were dying.

The study recorded their thoughts and wishes and made a list which is replicated here.

Take some time to think about the responses. Write down or record your thoughts about these responses.

Think about your workplace, are there opportunities for people to discuss what matters to them? Write down or record your thoughts.

These are some of the things that the older people said would be important to them if they knew they were dying.

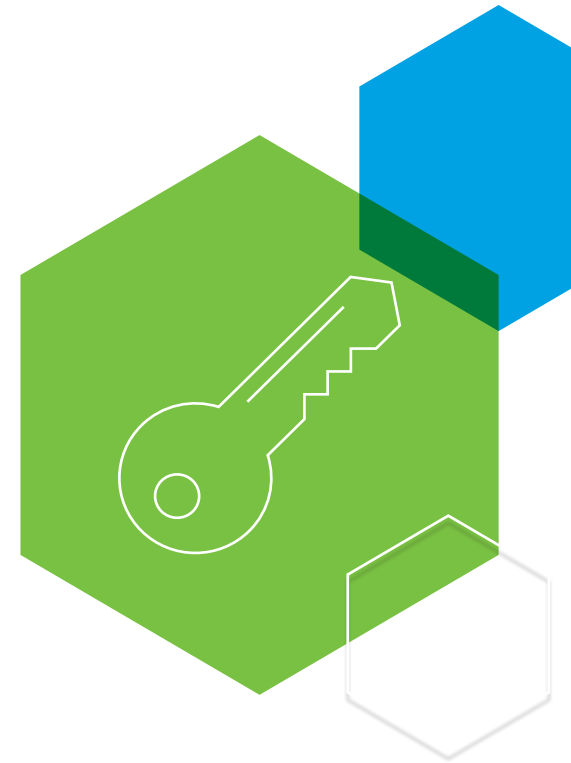
- Knowing when death is coming and what can be expected
- Retaining control of what happens
- Dying with dignity and privacy
- Having pain and other symptoms managed
- Choosing and controlling where death occurs
- Having access to information and expertise of whatever kind is necessary
- Having access to spiritual or emotional support
- Having access to hospice care in any location
- Controlling who is present and who shares the end
- Having a legal document in place to ensure wishes are respected
- Having time to say goodbye and control over other aspects of timing
- Dying when ready and not having life prolonged pointlessly

Age Concern (2010)

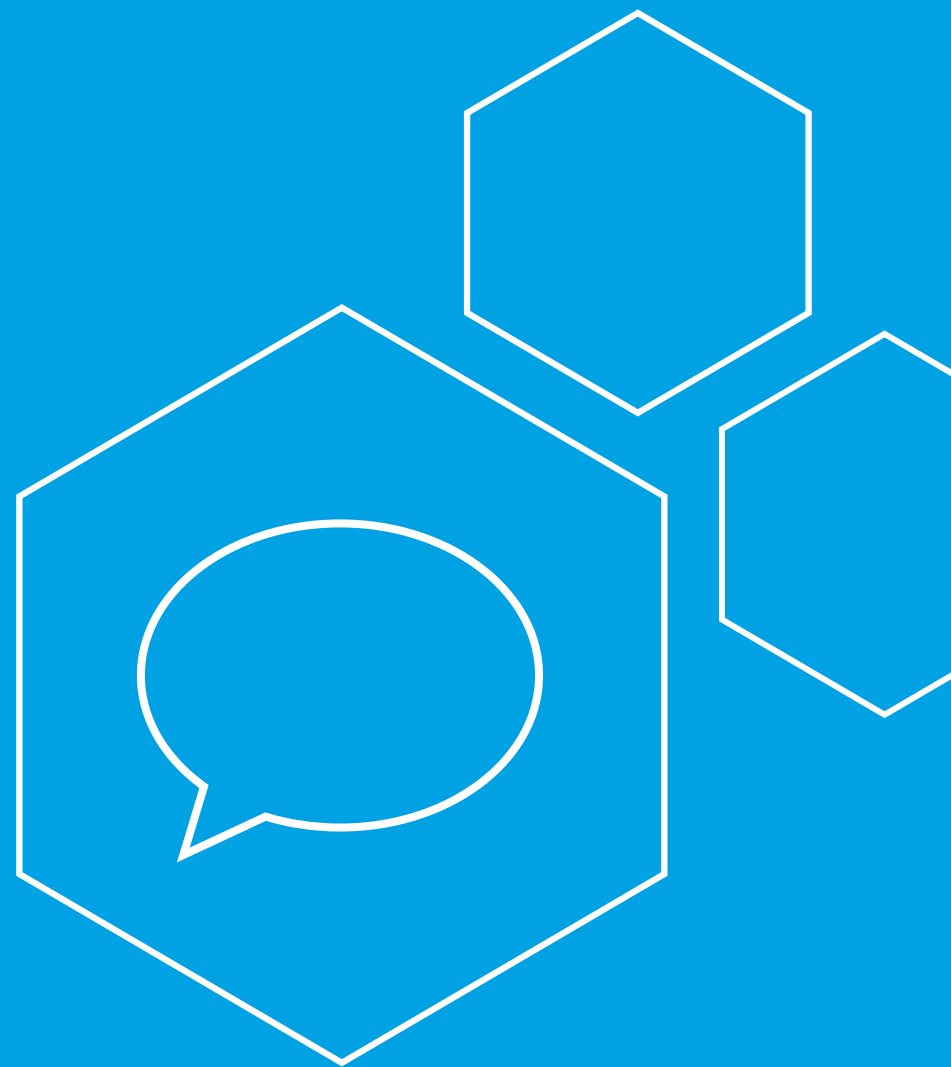
KEY LEARNING POINTS

The key learning points are:

- Palliative and end of life care takes a whole person approach
- Many people, services and agencies can be involved in the care and support of someone with palliative and end of life care needs
- Everyone in health and social care has a duty to protect and promote people's rights and safety
- Treating everyone with dignity and respect, including our co-workers is essential in health and social care
- Attitudes to death, dying and bereavement can have an impact on care and support.



2 | COMMUNICATION AND CONVERSATIONS
IN PALLIATIVE AND END OF LIFE CARE –
INFORMED LEVEL





EFFECTIVE PERSON-CENTRED COMMUNICATION SKILLS IN PALLIATIVE AND END OF LIFE CARE

Why do person centred communications skills matter in palliative and end of life care?

Whether you are the person living with a life threatening illness or condition, a family member, friend or worker you may experience a range of feelings and emotions. These can include feeling sad, worried, disbelief, frightened, angry, overwhelmed or shocked. Some people may feel some or all of these emotions.

Sometimes we worry about what to say to people who are feeling like this. We can find it uncomfortable to be with people who are upset, sad or angry. We may think we should say or do something that will make them feel better. What is really important is how we respond and listen to people.

PERSON CENTRED COMMUNICATION SKILLS IN PALLIATIVE AND END OF LIFE CARE

Showing people you are really listening to what they are saying and responding to them in a caring and compassionate way is part of person centred communication skills.

Take a moment to think about a conversation you have had recently when you felt the other person wasn't listening to your concerns. It might have been a face to face conversation, a telephone call or an email exchange. What did the person do or say to make you feel that you weren't being listened to? How did you feel afterwards?

People know when they are not being listened to, they can pick up on cues that people are distracted, rushed or not interested.

When this happens we miss an opportunity to let the person say how they feel which may lessen their worry or distress. We also miss an opportunity for them to get the right care and support.

EFFECTIVE PERSON-CENTRED COMMUNICATION SKILLS

Here are some skills that can help you to connect with and listen to someone:

Non-verbal actions - such as nodding, eye contact, stopping what you are doing and sitting down, sitting at a comfortable distance apart; not too close or too far from the person, using touch if this is appropriate.

Creating a sense of privacy - it is always better to offer to take the person to a private room but sometimes there isn't a room or space that is private.

Using some of these techniques can help:

Pull up a chair and sit with your back to anyone else in the area, draw the curtains around the person's bed if you are in a hospital setting, take the person to a quieter, less populated area, say in a waiting room.

Posture - leaning forward and using eye contact can help people feel listened to.

Facial expressions - a smile can show you are interested but your facial expressions need to be consistent with what is being said.

Don't rush to speak during moments of silence - this can help the person to gather their thoughts or show emotion and it's important to give people time to do this.

Describing feelings - "you seem upset, angry, not yourself."

Showing empathy - a genuine expression of trying to understand what the other person is experiencing

Connecting - responding with warmth, genuineness and humanity

- If you think someone is upset or wants to talk don't ignore them, ask them if they want to talk and listen to them. If you can't listen to them then find someone who can. If someone doesn't want to talk, respect that
- You don't have to provide answers, offer advice or say something that you think will make them feel better
- Even if it feels difficult, remember the person may already be thinking about difficult things and your support is likely to help
- It can be normal for people to cry or get upset; don't feel you have to make them stop
- Do know when you are out of your depth and it's ok to say so but find someone else who can provide the support.

Here is an example of what you could say: "I can hear that you are worried about X and Y. I am not sure how to help but if it's ok with you I am going to ask a colleague to come and speak with you. Would that be ok?"

COMMUNICATION SUPPORTS

Sometimes people have speech, language and communication needs because they have difficulties with:

- Expressing themselves through speaking, writing, or non-verbal communication
- Understanding spoken or written words, body language or facial expressions
- Looking and listening, paying attention and understanding
- Remembering information they receive
- Expressing their feelings and emotions in appropriate ways.

People in every community can have speech, language and communication needs – children, young people, adults and older adults. An example may be someone with a visual, hearing or learning impairment. There are things you can do to remove or lessen the barriers they face in communicating.

Here are some examples:

1. Find out what their communication preferences are, and match the way you communicate to the way the person understands. People might prefer:

- Written information in advance
 - Texts or emails
 - Audio versions of information
 - Access to pictures, photographs or symbols
 - Extra time to make sense of information
 - An interpreter using British Sign Language
 - For people whose first language is not English don't rely on a carer or member of the family to interpret or translate. Use a language interpreter.
2. Reduce background noise so you can both concentrate.
 3. Face the person you are talking to and make eye contact, but remember everyone is different – some people find too much eye contact uncomfortable.
 4. It sounds obvious but give people plenty of time to reply. You might need to wait longer than usual – don't be tempted to finish sentences for people. It's better to offer and agree a different way of communicating, as in (1) above, if someone is really struggling.
 5. Be honest about how much you've understood, so that the other person has a chance to correct you if you've made a mistake.

MORE INFORMATION ON COMMUNICATION SUPPORT NEEDS

There are tools such as picture books, Talking Mats, Communications Passports and electronic devices that people use to help communicate with others. If you would like further information on communication support needs please access the resources below:

- **Alternative and Augmentative Communication Scotland**
www.aacscotland.org.uk/Home
- **Making Communication Even Better**
<http://www.nes.scot.nhs.uk/education-and-training/by-discipline/allied-health-professions/resources,-publications-and-useful-links/making-communication-even-better.aspx>



LEARNING ACTIVITY – PRACTISING COMMUNICATION SKILLS

Choose and then review some of the suggested ways of improving communication you have read in this section. Find an opportunity to use them in your workplace. For example, you might have contact with someone who becomes upset, or you might help someone to communicate. You might listen to a colleague who needs your support.

Afterwards, write a short reflective account about what happened. Include:

- ◆ A description of the situation
- ◆ How you felt, and how you think the other person might have felt
- ◆ Any communication skills you used well
- ◆ Any communication skills you would like to improve

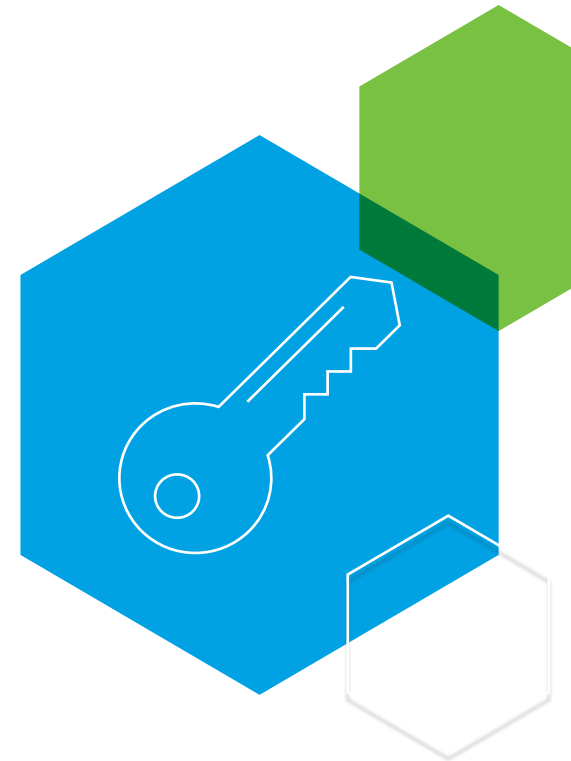
You might want to discuss this learning activity and your reflective account with your mentor, manager or senior.

Remember not to use anyone's real name when you write reflective accounts. This is because you must protect the confidentiality of people who use services.



KEY LEARNING POINTS

- In palliative and end of life care people can experience a range of feelings and emotions and providing support is not easy.
- Sometimes we worry that we will say the wrong thing, cause people to become upset, not know what to say, or not know how to finish the conversation.
- But it is better to respond sensitively to people than ignore their concerns or distress.
- Good conversations are helpful for everyone involved in palliative and end of life care and this includes the people giving care and support.
- This resource will have helped you to identify what helps and what to avoid during your conversations with people who are receiving palliative and end of life care and support.



3 | LOSS, GRIEF AND BEREAVEMENT – INFORMED LEVEL





INTRODUCTION

Loss and death will affect all of us at some point in our life.

When you work in health and social care it is very likely that you will come across people, families, carers or work colleagues who are experiencing loss, grief or bereavement.

Our past experiences may affect the way we cope with loss and death in our work or in our personal lives.

Living and working with loss and death can be difficult.

Knowing about loss, grief and bereavement and how you can care for yourself is an important part of palliative and end of life care and support.

UNDERSTANDING THE TERMS LOSS, GRIEF AND BEREAVEMENT

- **Loss:** is being deprived of someone or something of value
- **Grief:** is the emotional response to loss and death
- **Bereavement:** is when you have lost someone through death and the time when grief is experienced and mourning happens.

Wilson (2014)

LOSS

Loss and change are part of life and everyone will experience these in their life time.

In palliative and end of life care people can experience many forms of loss and it is not always about death and dying.

How someone feels about and copes with the loss will vary and this may influence the support they require.

Different forms of loss can include:

- Loss of a relationship you have had with someone through death, divorce, friendships, moving away

- Loss of self-image caused by hair loss, a limb or body part being removed, losing or gaining lots of weight
- Loss of not being able to do things that give you pleasure and enjoyment
- Losing your security, your job, your home
- Loss of how you see your role in life such as being a parent, a partner, a valued member of your workplace.



RANGE OF LOSS IN PALLIATIVE AND END OF LIFE CARE

Loss can affect people in different ways. It can affect people physically, emotionally, socially and spiritually. Here are some examples:

- **Physically** - such as losing your ability to get around, loss of hearing or sight, loss of a part of your body
- **Emotionally** - such as your memory, your way of being, your dignity, of how you cope with things, your self-esteem
- **Socially** - such as your financial stability, relationships with friends, family or colleagues, your independence
- **Spiritually** - such as not being able to do things that give your life meaning and strength, not being able to take part in practices and rituals that are important to you, losing trust in people or doubting your values.

RANGE OF FEELINGS, THOUGHTS AND BEHAVIOURS

People can experience lots of different feelings, thoughts and behaviours when they have experienced a loss or bereavement. They might not realise this and it may be important to offer reassurance. Examples include:

FEELINGS

Sometimes people feel angry in response to their grief. This might be anger that is directed at the illness, the person who is ill or has died, the people looking after them or their family member, they might feel anger directed at their faith for letting this happen to them. Sometimes people feel guilt or regret at the life they have led or the things they have done. They might feel anxious, helpless or lonely. Sometimes people also feel a sense of relief that the person has died or is no longer suffering. Sometimes people just feel numb.

PHYSICAL SENSATIONS

Grief can cause physical sensations too. For example people have described a hollowness in their stomach, a lump in the throat, a tightness in the chest. Sometimes children respond to the loss of a parent or family member by describing symptoms that the person experienced with their illness or condition, for example complaining of a sore head, feeling sick.

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LOSS, GRIEF AND BEREAVEMENT – INFORMED LEVEL

THOUGHTS

People describe all sorts of thoughts ranging from disbelief and confusion about what has happened and is happening to them, thinking they have seen the person who has died or they may feel guilty or responsible even when they are not.

BEHAVIOURS

People describe not being able to sleep or wanting to sleep all the time, they may be forgetful or find it hard to concentrate, they may lose interest in their usual activities or hobbies. They may not want to be with anyone or might not want to be alone, they may dream about the person who has died and this maybe comforting or distressing to them. Sometimes people describe a searching or calling out for the person who has died. They may wish to cherish or remove physical reminders of the person who has died.

SOCIAL DIFFICULTIES

People describe changes in relationships or friendships caused by the illness or condition or changes in relationships and friendships after the person dies. Some people find having to cope with everyday tasks difficult. They may have not had to cook before, sort out finances, or fix something in their home.

SPIRITUALITY

Sometimes people find their grief causes them to question things in their life that were previously important to them. They may have held strong beliefs and values in certain things that they now find themselves doubting. They may struggle to make sense of what has happened and why it happened. People may find that their faith/beliefs can help them cope with their grief.

GRIEF AS A NORMAL RESPONSE TO LOSS

There is no right or wrong way to express or cope with grief. Some people may want to talk to others and express their feelings or they might find support groups help them. Sometimes people may wish to be alone.

They may use social media as a way of seeking support or expressing their grief. Some may talk to family or want to talk to someone who isn't part of their family and that might be you.

HOW WE RESPOND TO LOSS, GRIEF AND BEREAVEMENT

People remember how they were treated, spoken to and how staff behaved, especially during emotionally difficult times. They can recall acts of kindness and compassion with amazing detail and they find comfort in these long after the event.

Sometimes when we are busy or distracted we can forget how the smallest detail can influence people's experience of their care and support. People will remember when their experience could have been better. This experience stays with them for a long time and can have an impact on how they view and access future care and support.

WORKING WITH LOSS, GRIEF AND BEREAVEMENT

Working in health and social care can mean that you will have more contact with people who are experiencing loss, grief and bereavement and sometimes this is hard. If you then experience a loss or bereavement in your personal life that can make it more difficult for you at work.

Sometimes situations at work can trigger an emotional response related to your own loss. Sometimes this can happen unexpectedly. It might be that the person reminds you of someone who has died. It might be that you recognise

and relate to something about the family or situation. It is important to be aware of this and get the support that is right for you.

Even if we haven't experienced a personal loss or bereavement it is important to look after ourselves.

CARE OF SELF

Care of self is about taking care of yourself and getting the support that is right for you in your workplace. Taking care of your own wellbeing helps you provide better care and support to others.

Here are some examples:

- Looking after your own physical, emotional, social and spiritual health
- Recognising when you might be getting stressed at work and taking steps to get support
- Having a good balance between your personal life and your working life

Everyone has different ways of keeping well and getting support.

We can often be so busy taking care of others in our work and personal life that we don't take time to care for ourselves.

Sometimes we develop habits that are not good for our work/life balance. Examples include: always working late, not taking regular breaks, not taking annual leave, worrying about work when not at work, not seeking support when struggling with something at work, not taking opportunities for protected time to learn or for supervision or support.

It can be really helpful to take some time to think about what maintains or enhances your own well-being.

Taking time to think about your own wellbeing at work is especially important when you work with people who are facing death, dying and bereavement.

There are many different situations that workers can find challenging, for example:

- Having a conversation where you felt out of your depth
- Feeling extremely sad about the illness or death of someone you cared for
- Trying to stay calm when someone you cared for, or their family, became angry or upset
- Finding it difficult to focus on work when something in your personal life is upsetting you

- Caring for someone you found difficult to care for
- Feeling overwhelmed by the needs of people you care for

Your wellbeing at work will be affected by the kind of work you do, the kinds of support you have at work, all kinds of things in your personal life, and how much of a comfortable balance you have between your work and personal life. It is also important that your organisation recognises how difficult this work can be. Some organisations provide support. You could ask your manager/mentor/supervisor what is available for you to access.



INFORMED ABOUT PALLIATIVE AND END OF LIFE CARE LOSS, GRIEF AND BEREAVEMENT – INFORMED LEVEL

REFLECTION POINT

Take some time to think about how well you take care of yourself. Some examples of things to consider are:

- Having regular time to speak with a senior colleague about your work and your learning
- Having time to share experiences and concerns with other workers
- Being able to learn new things that interest you
- Getting enough rest, exercise and healthy food
- Spending time with family and friends
- Doing things you enjoy just because you enjoy them.

IF YOU WANT TO KNOW MORE

You may wish to find out more about grief and bereavement for yourself, for your family or to help you support others. Further information and support about grief and bereavement can be found at:

NHS Inform – this link takes you to information on coping with grief and practical advice following a death.

<https://www.nhsinform.scot/care-support-and-rights/death-and-bereavement>

The Good Life, Good Death, Good Grief website provides resources and information to support changing knowledge, attitudes and behaviours towards death, dying and bereavement.

<https://www.goodlifedeathgrief.org.uk/>

Childhood Bereavement UK supports families and educates professionals when a baby or child of any age dies or is dying, or when a child is facing bereavement.

<https://childbereavementuk.org/>

LEARNING ACTIVITY

Write down your answers to the following questions to create a reflective account.

- What kinds of support do you get at work?
- What does your team do to support one another?
- What are the things outside of work that help you feel healthy and well?
- What kinds of support work well for you?
- Are there particular work situations you find especially difficult, or times when you need more support?

Decide on one thing you could do to improve your wellbeing at work.



KEY LEARNING POINTS

- ◆ Loss, grief and bereavement affects us all at some point in our life.
- ◆ Grief is a normal response to loss, however everyone will have a different experience and reaction to it.
- ◆ Dealing with loss, grief and bereavement is challenging and can be stressful.
- ◆ Personal experiences and circumstances can have an impact on how we cope with loss, grief and bereavement in our workplace.
- ◆ Taking time to reflect on our experiences can support our learning and well-being.



4 | CARE PLANNING AND DELIVERY – INFORMED LEVEL





INTRODUCTION

It is important that we are aware of how care and support should be planned and delivered so that we can respond and contribute appropriately.

Palliative and end of life care and support should be centred on the person, take a whole person (holistic) approach and include family, carers and those that are important to the person.

INFORMED ABOUT PALLIATIVE AND END OF LIFE CARE CARE PLANNING AND DELIVERY – INFORMED LEVEL

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PLANNING CARE AND SUPPORT

People should be at the heart of the assessment and planning of their care, as they are the experts in their own lives. They know how they feel. They know about who and what offers them support in their life. They will know what is important to them. They may have thoughts about how and where they would like to receive care and support.

Being involved and having choice and control about decisions, care and support is central to maintaining a person's dignity at a time in their life when they may be facing uncertainty and feeling vulnerable.

When a person has an advanced illness or condition it may be easy to focus on their physical care needs, for example help with personal care or the symptoms of the illness. However it is important also to consider their:

- emotional and psychological wellbeing
- spiritual wellbeing
- social wellbeing.

A PERSONAL OUTCOMES APPROACH

When a person has palliative and end of life care needs we need to understand what is important to them in their life and what their hopes and aspirations are. Even when someone's health is getting worse taking a personal outcomes approach can focus on helping the person to identify what needs to happen to make the best of the life that they have. A team approach to supporting personal outcomes is needed.

For example it may be important for a person to be at home and be able to spend time with their family, rather than spending time in hospital. For someone else they may not want to be alone and wish to be with people.

An outcomes focussed approach means that care and support reflect both assessed needs and the person's outcomes. Outcomes are about the effect of care and support and can include things like:

- Increased confidence
- Reduced symptoms
- Improved wellbeing
- Increased mobility
- Being involved in my community.

Cook & Miller (2012)

A PERSONAL OUTCOMES APPROACH IS ACHIEVED THROUGH:

Engaging with individuals and carers using services about:

- **what** is important to them in life
- **why** these things are important (outcomes)
- **how** to go about achieving these things
- **who** will be involved.

This may include thinking about:

- what has helped them in the past
- what strengths and abilities they have
- the networks and community supports around them
- what help or support do they think would help them achieve their goal or outcome.

A personal outcomes approached is achieved through:

Recording this information about what matters to people and their personal outcomes.

Planning care and support using this information.

Reviewing the extent to which their personal outcomes are being achieved, including what helps and what gets in the way of these outcomes.

If we help people be at the centre of creating their own care and support plan they are more likely to get the most out of it and live and die they way they wish to.

Personal Outcomes Collaboration

People say that being listened to, treated with respect and being included in decision-making really matter when facing difficulties in their lives.

Good communication and conversations are the key to care and support planning. Sometimes people need support and encouragement to take part in discussions and to make decisions about their health and social care. People may choose to talk you about things that are important to them.

You may not be directly involved in assessment or planning care but you can listen, and encourage them to participate in decision-making to help ensure that care and support is right for them.

RECOGNISING AND SUPPORTING CARERS

In palliative and end of life care the person with the illness is central but of equal importance is the care and support of their family and carers.

Individuals are not islands, we all have relationships with other people. When someone is becoming more unwell and needing more care and support this is likely to impact on those close to them too. We also need to consider care and support for those in a carer role.

In your role do you come into contact with people who are providing unpaid support to a family member or friend? Perhaps they do not see themselves, or are not recognised as a carer.

Many carers are well supported but others are not. Caring responsibilities can affect carers' physical and mental health. Nearly half of carers have long term conditions themselves. Many carers are looking after people with complex needs, and carers are getting older.

CARERS IN PALLIATIVE CARE

Caring for a person with palliative and end of life care needs can be demanding physically and emotionally so it is important that we recognise these carers.

Taking on a caring role is often a gradual process. People are more likely to see themselves as a wife, a son or daughter or a friend rather than as a carer. Carers often put the needs of the cared for person before their own. This can impact on their own health and wellbeing.

Carers can experience high levels of stress and anxiety. A carer may experience feelings of loss and grief. It can be very difficult when the person they care for is becoming more unwell and they are aware that they may die soon.

We need to ensure that carers are recognised and offered support in their caring role. It is also important to recognise that when someone dies and someone who has been caring is bereaved they may require ongoing support to adjust to their loss. Local carers' centres provide a wide range of support for carers.

Carduff et al (2014)

CARER SUPPORT PLANS

Carers are recognised and valued more than ever before. However, we need to better support carers so that they can continue to care, if they want to, in good health and have a life alongside caring.

In relation to young carers (children and young people under 18 years old, or still at school), we need to provide better support but we also need to make sure young carers have a childhood like other children, and are not undertaking any caring that is inappropriate.

The Carers' Act (Scotland) 2016 introduces, among other things:

- Carers' right to an adult carer support plan
- Young carers' right to a young carer statement

Both are to set out the agreed personal outcomes that matter to the carer/young carer, and any identified support that will be provided.

For more information about working in partnership with carers you can go to the Equal Partners in Care website.

Equal Partners in Care

The Carer (Scotland) Act (2016)

REVIEW OF CARE AND FORWARD PLANNING

In palliative care and towards the end of life it is important to recognise that things can change. Some changes happen slowly over time, for example as someone becomes more frail and gradually needs more help. Other changes happen more quickly or unexpectedly. Sometimes there are changes in family or social circumstances.

A plan of care and support will need regular review. When things change the plan should be reviewed and a response coordinated.

It is helpful to think ahead about future changes in health and wellbeing. Thinking ahead is not just about the end of life but can be helpful when someone's needs are changing and becoming more complex.



ANTICIPATORY CARE PLANNING

You may have heard about an approach called “Anticipatory Care Planning”. In Scotland Anticipatory Care Planning is about thinking and planning ahead for future changes in health and wellbeing.

Having an Anticipatory Care Plan (ACP) can help people make clear their wishes in anticipation of future changes in their health. This may include a time when they are not able to make decisions or communicate their wishes to others. Having an ACP can help people feel more in control, prevent a crisis, reduce stress and help decision making.

An ACP is usually developed over time and through conversations and shared decision making between the person, those that are important to them and their care team. These conversations can raise many emotions and need sensitivity and skill, especially as people near the end of their life.

It is suggested that having an ACP can be helpful when people’s needs become more complex but it can be started at any time in a person’s care. Creating an ACP is voluntary and it can be updated and changed at any time. Sometimes people change their mind as their health deteriorates or their circumstances change. An ACP is not legally binding in any way.

It is helpful for people to talk to those that are important to them and people that they trust to help shape the right plan for them.

Even if you are not directly involved with developing anticipatory care plans people may chose to talk to you about their wishes and preferences for the future. You might be the person they see everyday when you are providing care, cleaning their room or delivering their meals. People sometimes choose to speak to a familiar person who is not directly involved in their care and support planning. It is important to listen, pass on information when appropriate and to be able to direct them to further sources of support for ACP.

[Anticipatory Care Planning Toolkit](#)

INFORMED ABOUT PALLIATIVE AND END OF LIFE CARE CARE PLANNING AND DELIVERY – INFORMED LEVEL

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WHAT MIGHT BE IMPORTANT?

In palliative and end of life care the types of things that people may wish to think and talk about for their ACP may include:

- Where they would like to be cared for if they become more unwell and at the end of their life
- Their preferences about their care and treatment
- Who they would like to speak for them or make sure their wishes are known
- Their responsibilities for others, for example as a parent or carer
- Organising their affairs, for example making a will.

An ACP can help by making wishes known so that those providing care and support are not left wondering what the person would have wanted or did not want.

An Anticipatory Care Plan should:

- reflect a summary of the “thinking ahead” discussions between the person, those close to them and care team supporting them
- provide a record of the person’s personal outcomes, preferences, views and concerns

- provide a plan of what should happen if the person’s care and support needs change
- be reviewed and updated if person’s condition or needs change and different things take priority.



LEARNING ACTIVITY

Please now access and watch the ACP Matters 2017 video from Healthcare Improvement Scotland. This video has a range of people talking about what ACP means to them.

<https://www.youtube.com/watch?v=UkiQTUpbwBU>

[Accessible video transcript](#)

The video lasts under 5 minutes.

Perhaps you were aware of anticipatory care planning before you read this resource and watched the video. Or perhaps this is something completely new to you.

- Can you think of someone who might benefit from thinking about an ACP?
- What would you say to them if they asked you about it?
- Write down what you could say to them.

You may wish to find out more about ACP for yourself, for your family or to help you support others. Further information and support about Anticipatory Care Planning can be found at www.Myacp.scot



KEY LEARNING POINTS

- Palliative and end of life care and support planning takes a whole person approach
- What matters to the person and their personal outcomes should be central to the plan of care and support
- Having choice and control supports dignity and quality of life
- Carers are equal partners in care and have a right to their own care and support plan
- Anticipatory care planning is a ‘thinking ahead’ approach that can help people receive the right care and support at the right time in the right place.



5 | CARE IN THE LAST DAYS OF LIFE—
INFORMED LEVEL





INTRODUCTION

Death and dying is an inevitable part of life. People will die in all types of care settings; at home, in care homes, in hospices, in hospitals and in prisons.

The help and support we provide can make a big difference to people at what may be a very difficult time.

The care and support people receive when someone is dying will be remembered long after the person has died.

This experience can have an impact on how families, carers and workers deal with future loss, death and dying.

CARE IN THE LAST DAYS AND HOURS OF LIFE

There are essential areas of care that need to be addressed so teams can provide good care in the last days and hours of life for dying person, their family and carers. These include:

Communication - by providing the correct information to inform care and choices at the time it is needed, and be sensitive to what is happening to the person, their family and carers.

Decisions - around care and the person's condition, should be the result of a discussion with all the teams involved. The decisions taken should also recognise and support that the person is dying and is in the last days of their life.

Individual persons needs - should be assessed, planned and managed with respect and dignity. Their physical, psychological, social and spiritual needs require to be reviewed daily. This will help to identify what matters to the person and try to achieve this, as far as is possible.

Well-being - of the family and carers at this time should be recognised and support should be available and offered to meet their individual needs.

Scottish Government 2014

PREDICTING THE LAST DAYS AND HOURS OF LIFE IS NOT EASY

There can be uncertainty involved in identifying when someone is dying, even when death is expected. Each person is an individual and their experience of dying will be unique to them.

Illness or someone's condition can be unpredictable and change can occur suddenly and unexpectedly. Some people may have a sudden change in their illness/condition or equally could have a longer period in the dying phase.

Knowing when someone is in the last days and hours of life is not always easy. It is important to get the views of all those involved so that everyone is in agreement that the person is in the last days and hours of life and a death is expected.



LEGISLATION, POLICY AND GUIDANCE

When a person dies, it is important that care given after death promotes dignity and respects the person's wishes, preferences, culture and religious practices.

When someone dies there are a number of things that should happen. For example:

- A death needs to be confirmed by a registered health care professional before a body can be removed from the place of death
- Family members should be offered the opportunity to participate in personal care and faith, spiritual or cultural rituals and practices. Support should be provided if they wish to do this
- The body of the person who has died needs to be prepared for transfer to the mortuary or funeral directors
- The belongings of the person who has died should be safely and respectfully returned to the family.

There will be local and regional policies and guidance within your place of work or organisation. It is important that you know about any specific responsibilities that you have in your workplace at and around the time of a person's death.

Information and support for the family and carers should be provided with care and compassion.

We need to recognise that family members may want to spend time with the person after they have died. Being sensitive to this and providing the family with privacy is important.

CARE IN THE LAST DAYS AND HOURS OF LIFE - WHAT ELSE CAN I DO?

We can all make a difference to the experiences people have during the last days and hours of life, and to the experiences of their families and carers.

A kind gesture, a listening ear, sitting with someone quietly, if wanted, can go a long way to helping people during what may be a very difficult time.

Often small gestures and acts of kindness will be remembered with appreciation and gratitude for a long time afterwards.

LEARNING ACTIVITY

Please access the NHS Education for Scotland Multi-faith resource.

Read the introduction on page 4. Then choose two or three faiths that you don't know about. Read about the practices, wishes and preferences that relate to care and support when someone is dying (in the Multi-faith resource this is referred to as death customs).

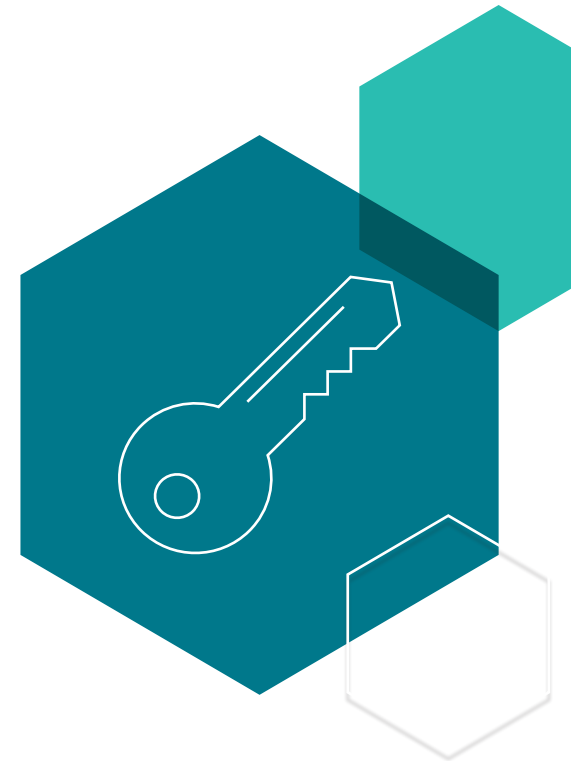
Think about and write down or record how your workplace supports people's faith practices, cultures and beliefs in the last days and hours of life.

What else could be done in your workplace to support people's faith practices, cultures and beliefs in the last days and hours of life?



KEY LEARNING POINTS

- ◆ Dying is part of life and is surrounded with uncertainty as to how and when someone will die. This can cause distress not only to the person dying but to their families, friends and carers and equally those providing care and support from health and social care.
- ◆ Little things make a big difference. It is important to consider the choices and preferences of the person, family, and carers so that people can be involved as much as possible in any decisions made about their care and support.
- ◆ Legislation, policy and guidance directs the actions that need to be taken when a person is approaching death and when a death occurs.





CONCLUSION

Now that you have completed the Informed Level Resource for Palliative and End of Life Care you should be able to:

- Describe the main principles of a palliative care approach and what is meant by palliative care, end of life care and last days of life
- Recognise a range of attitudes to death, dying and bereavement and how these may influence people's thoughts, feelings and behaviours
- Identify verbal and non-verbal communication skills that can support a person facing death, dying and/or loss
- Describe the potential impact of living and working with loss, grief and bereavement
- Give key examples of person centred and holistic approaches to palliative and end of life care
- Describe some of the essential actions required around the time of death.

If you would like to further develop your knowledge and skills, you can use the Enriching and Improving Experience framework to help you.

<http://hub.careinspectorate.com/media/534745/enriching-and-improving-experience.pdf>

Use the skills statements at informed level, for each of the 5 domains, to identify things you might be able to focus on at work. Talk to your mentor, manager or senior about how you might develop your practice.

If you are interested in becoming more skilled in palliative and end of life care you could use the next level of the framework. Talk to your mentor, manager or senior about whether any aspect of the Skilled level of the framework would help support you.



INFORMED ABOUT PALLIATIVE AND END OF LIFE CARE

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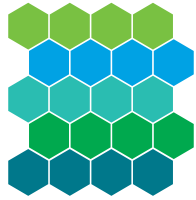
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INFORMED ABOUT PALLIATIVE AND END OF LIFE CARE KNOWLEDGE STATEMENTS FOR INFORMED RESOURCE

KNOWLEDGE STATEMENTS

The statements were developed following extensive consultation with individuals, groups and organisations from the public, independent and third sectors.

These statements outline the essential knowledge required by all workers in palliative and end of life care.

The statements are divided into 5 domains, which reflect the core knowledge considered integral to the delivery of high quality palliative and end of life care.

The knowledge statements are listed in the following pages.





INFORMED ABOUT PALLIATIVE AND END OF LIFE CARE KNOWLEDGE STATEMENTS FOR INFORMED RESOURCE



FUNDAMENTALS OF PALLIATIVE CARE

- Know the meaning and principles of palliative and end of life care, that it is appropriate for all life-limiting conditions across the life-course, and is applicable in all care settings.
- Know the meaning of person-centred and family-focused care and support in the context of palliative and end of life care.
- Know the range of services, agencies and sources of support and information that may be involved in providing palliative and end of life care.
- Know that professional, legal and ethical frameworks exist to protect and promote people's rights and safety.
- Know the importance of respecting diversity, culture and beliefs in the context of palliative and end of life care.
- Know about attitudes to death, dying and bereavement in society.



INFORMED ABOUT PALLIATIVE AND END OF LIFE CARE KNOWLEDGE STATEMENTS FOR INFORMED RESOURCE



COMMUNICATION & CONVERSATIONS

- ◆ Know about effective person-centred communication skills and barriers to communication.
- ◆ Know about verbal and non-verbal behaviours that can support someone who is distressed.



LOSS, GRIEF AND BEREAVEMENT

- ◆ Know that grief is a normal response to loss, and understand the range of thoughts, feelings and behaviours that may be experienced by those living with loss and grief.
- ◆ Know that people may experience a range of losses in a palliative and end of life care context.
- ◆ Know about the process of reflection.
- ◆ Know about the importance of care of self.



INFORMED ABOUT PALLIATIVE AND END OF LIFE CARE KNOWLEDGE STATEMENTS FOR INFORMED RESOURCE



CARE PLANNING & DELIVERY

- Know the importance of ensuring that the person, family and carers have choice and control in care assessment and planning.
- Know about personal outcomes in the context of palliative and end of life care.
- Know that carers have a right to their own care and support plan.
- Know about the concept of anticipatory care-planning.



CARE IN THE LAST DAYS OF LIFE

- Know that dying is part of life, and that uncertainty surrounds how and when someone may die.
- Know the importance of considering the choices and preferences of the person, family and carers in the last days of life.
- Know that action when a person dies is directed by legislation, policy and guidance.