In this unit you will learn about the legal and organisational requirements to protect the rights of individuals at the end of life, as well as the key factors that can affect individuals’ end-of-life care. You will also find out more about the purpose and systems for advance care planning and how to provide support both to individuals and the key people involved during end-of-life care.

This unit will also equip you with the knowledge that is required to understand how to address sensitive issues that may arise in relation to end-of-life care. The role of organisations, support services and the wider team in relation to supporting individuals and key people will also be explored in more detail.

Being able to support individuals through the process of dying, knowing the actions to take following the death of individuals, as well as being able to manage your feelings in relation to the dying or death of individuals, are integral aspects of supporting end-of-life care. This chapter will provide you with the opportunity to explore these in more detail.

By the end of this unit you will:

1. Understand the requirements of legislation and agreed ways of working to protect the rights of individuals at the end of life.
2. Understand factors affecting end-of-life care.
4. Be able to provide support to individuals and key people during end-of-life care.
5. Understand how to address sensitive issues in relation to end-of-life care.
6. Understand the role of organisations and support services available to individuals and key people in relation to end-of-life care.
7. Be able to access support for the individual or key people from the wider team.
8. Be able to support individuals through the process of dying.
9. Be able to take action following the death of individuals.
10. Be able to manage own feelings in relation to the dying or death of individuals.
LO1 Understand the requirements of legislation and agreed ways of working to protect the rights of individuals at the end of life

AC 1.1 Outline legal requirements and agreed ways of working designed to protect the rights of individuals in end-of-life care

End-of-life care refers to the care and support provided to an individual with a life-threatening illness and to all those others involved, such as the individual’s family, friends, carers and professionals. The General Medical Council defines individuals as at the end of their life when they are likely to die within the next 12 months.

The World Health Organization defines end-of-life care as follows:
- Provides relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten nor postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
- Will enhance quality of life, and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Legal requirements
There are a number of key pieces of legislation that can protect the rights of individuals in end-of-life care.

Equality, diversity and discrimination
- The Equality Act 2010 applies fairness and equality in making decisions and policies, including those that relate to end-of-life care.
- The Health and Safety at Work etc. Act 1974 sets out the responsibilities for maintaining the health, safety and welfare of everyone at work, including individuals, their families, carers, visitors and all those other professionals who work with them.
- The Safeguarding Vulnerable Groups Act 2006 was passed to help avoid harm, or the risk of harm, by preventing people who are deemed unsuitable to work with children and vulnerable adults from gaining access to them through their work.

Data protection, recording, reporting, confidentiality and sharing information
- The Data Protection Act 1998 was implemented in March 2000 and gives individuals a right to access information held about them by organisations such as adult social care providers. It consists of eight key principles that govern how information is recorded, reported, shared and maintained confidentially.
- The Freedom of Information Act 2000 gives everyone a right of access to all types of recorded information held by public authorities, including publicly funded organisations, local authorities and the NHS.
- The Human Rights Act 1998 sets out everyone’s fundamental rights and freedoms in the UK. In relation to handling information in end-of-life care this includes the rights to privacy and security as well as respect for private correspondence.

The making of wills and living wills; removal of medical equipment from people is covered on page 367.

- The Mental Capacity Act 2005 sets outs the rights of those who lack the mental capacity to make a will to have a will executed on their behalf and to apply to manage the property, money and possessions of an individual who has died.
- This Act also sets out how to make an Advanced Decision to Refuse Treatment legally binding, in
case an individual is unable to communicate the treatment they do not want to receive such as life support or CPR.

- **The Deprivation of Liberty Safeguards (DOLS)** is an amendment to this Act and provides additional rights in relation to an authority such as a hospital or care home that wishes to act on behalf of an individual that is unable to make a decision about their liberty or care.

**Visitors**

The Health and Safety at Work etc. Act 1974 sets out the responsibilities for maintaining the health, safety and welfare of everyone at work including individuals, their families, carers, visitors and all those other professionals who work with them.

**Safeguarding of vulnerable adults**

Safeguarding Vulnerable Groups Act 2006 was passed to help avoid harm, or the risk of harm, by preventing people who are deemed unsuitable to work with children and vulnerable adults from gaining access to them through their work.

**Agreed ways of working**

Organisations and work settings will also have agreed ways of working and policies and procedures in place to comply with these legislative requirements and protect the rights of individuals in end-of-life care.

- **Equality, diversity and discrimination** – working practices to follow for ensuring that the individual is respected and that their privacy and dignity are maintained throughout their end-of-life care including when they are deceased.

- **Data protection, recording, reporting, confidentiality and sharing information** – working practices to follow for ensuring that all verbal and written communications remain confidential and that information is only shared with those involved in the individual’s end-of-life care.

- **The making of wills and living wills** – working practices to follow for ensuring that the team are aware if an individual has made a living will and the actions to take if an individual requests that they would like to make or change their will, including what to do when an individual lacks capacity to make decisions about their care or treatment.

- **Dealing with personal property of deceased people** – working practices to follow for ensuring how the personal property of the deceased person will be kept secure, respected and to whom it may be released.

- **Removal of medical equipment from deceased people** – working practices to follow for the removal of medical equipment from deceased people, i.e. if a death is being referred to the coroner and there is any complaint about the care of the deceased then all medical equipment such as an intravenous cannula or a catheter must be left in situ so that potential evidence that may be examined at a later stage is not destroyed.

- **Visitors** – working practices to follow for maintaining the safety of all visitors including ensuring their privacy is maintained and their welfare safeguarded.

- **Safeguarding of vulnerable adults** – working practices to follow to protect the rights and safety of individuals during end-of-life care, including how to act on behalf of an individual when they lack the capacity to do so.

Agreed ways of working are also based on national guidance and frameworks:

- The government’s **National End of Life Strategy**, published in 2008, provides guidance around the provision of high-quality end-of-life care, including promoting individuals’ rights regarding where they would like to live and die.

- The **Six Steps Programme** (see Figure 20.1) is based on the six steps required to provide good end-of-life care as set out in the 2008 National End of Life Strategy.

- The **Supporting People to Live and Die Well (2010)** framework involves sharing best practice across services and organisations that provide end-of-life care.
Agreed ways of working are your work setting’s policies and procedures, as well as the specific guidelines that are in place for the individuals to whom you provide care and support. They may be less formally documented with smaller employers.

**Key term**

1.1 Protecting the rights of individuals in end-of-life care

Research the agreed ways of working for protecting the rights of individuals in end-of-life care in your local area.

**AC 1.2 Explain how legislation designed to protect the rights of individuals in end-of-life care applies to own job role**

The legislation that is designed to protect the rights of individuals at the end of life underpins the way organisations and work settings develop their own agreed ways of working. You and others who work in supporting end-of-life care must follow these agreed ways of working.

Table 20.1 considers how legislation designed to protect the rights of individuals in end-of-life care can apply to your job role and its associated responsibilities and working practices – can you think of any others?
Advance care planning is a process that enables individuals to share with others how they would like to plan for their future end-of-life care.

**Case study**

1.1, 1.2 Luciano

Luciano is a senior community carer. As part of his job role he supports a team of carers who provide end-of-life care to individuals living in their own homes. Luciano’s job role includes providing information and support to individuals and their families and to the team of carers. Luciano will be meeting with and inducting three new carers who have recently been recruited to the team.

1. What legal requirements designed to protect the rights of individuals in end-of-life care must Luciano share with the team?
2. What agreed ways of working designed to protect the rights of individuals in end-of-life care must Luciano share with the team?
3. How does the relevant legislation designed to protect the rights of individuals in end-of-life care apply to Luciano’s job role?

**Table 20.1 How legislation can apply to your job role**

<table>
<thead>
<tr>
<th>Aspect of your job role</th>
<th>Relevant legislation</th>
<th>Relevance to your job role</th>
</tr>
</thead>
</table>
| Discussing end-of-life care with individuals and/or important others involved, such as their families | Data Protection Act 1998  
Equality Act 2010  
Human Rights Act 1998  
Mental Capacity Act 2005 | • Being open to and respecting individuals’ and others’ views and beliefs about end-of-life care.  
• Promoting an individuals’ dignity and privacy.  
• Promoting individual’s families dignity and privacy.  
• Providing holistic support to individuals and their families about advance planning. |
| Carrying out assessments, care plans and reviews | Data Protection Act 1998  
Equality Act 2010  
Health and Safety at Work etc. Act 1974  
Human Rights Act 1998  
Mental Capacity Act 2005 | • The process you follow for completing an advance care plan.  
• Supporting those involved in the advance care planning process.  
• Carrying out care planning.  
• Sharing information about an individual’s wishes, needs and preferences.  
• Recording information and maintaining records of end-of-life care. |
| Providing care and support to individuals’ families and others, such as their carers, after the individual’s death | Equality Act 2010  
Human Rights Act 1998 | • Knowing how to comply with your work setting’s agreed ways of working.  
• Knowing how to comply with local and national policies.  
• Providing information about the support and services available to individuals’ families and others.  
• Accessing support and services for yourself. |

**Key term**

Advance care planning is a process that enables individuals to share with others how they would like to plan for their future end-of-life care.

**Time to think**

1.2 How well do you know your job role?

Read through your job description.

• What does it say about protecting the rights of individuals in end-of-life care?
• How do you apply this to your working practices?
There are theories about the emotional and psychological processes that individuals and key people – such as family members, friends and others who are important to the well-being of the individual – may experience with the approach of death. These theories can be useful tools to help you and others who support end-of-life care to gain a better insight into the thoughts and feelings of individuals and others.

A well-known theory is the Kübler-Ross theory, which suggests that there is a series of stages that people go through with the approach of death. It is important to remember that each person’s experience with the approach of death will be unique and therefore not everyone may experience all of these stages or in the order as detailed in this theory.

Look at Figure 20.2, which provides more details about each of the stages involved in the Kübler-Ross theory.

Figure 20.2 Kübler-Ross theory 1965
Other theories that may be useful and that include different approaches are Corr’s theory model and Zlatin’s theory model, as shown in Figures 20.3 and 20.4.

### Corr’s theory model
- Emphasises respecting individuals’ different methods of coping
- Emphasises empowering individuals and key people involved
- Emphasises how to improve key people’s methods of coping

### Zlatin’s theory model
- Focuses on the individual’s experience
- Focuses on the individual’s relationship to ‘life themes’
- Focuses on how key people can make use of the individual’s ‘life themes’

#### Figure 20.3 Corr’s theory model 1992

#### Figure 20.4 Zlatin’s theory model 1995

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**Research and investigate**

**2.1 Theories of emotional and psychological processes**

Research different theories about the emotional and psychological processes that individuals and key people may experience with the approach of death.

---

**AC 2.2 Explain how the beliefs, religion and culture of individuals and key people influence end-of-life care**

Individuals and key people – such as family members, friends and others who are important to the well-being of the individual – all have unique needs and preferences that are based on their personal beliefs, religion and culture. These will influence end-of-life care.

Respecting and following individuals’ and key people’s personal beliefs, religions and cultures is crucial for ensuring that the care and treatment provided are dignified and in accordance with their wishes as doing so can provide much needed comfort and strength to all those involved.

Table 20.2 includes some more information about how personal beliefs, religion and culture can impact on end-of-life care.

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**Table 20.2 How personal beliefs, religion and culture can impact on end-of-life care**

<table>
<thead>
<tr>
<th>Personal beliefs</th>
<th>Religion</th>
<th>Culture</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rinzen is her husband’s main carer. She believes in the reincarnation of her husband, who is at the end of his life. This is a great source of comfort for her.</td>
<td>As a Buddhist, Rinzen has asked the team to ensure that the image of Buddha is always in the view of her husband.</td>
<td>Rinzen has agreed with her husband that as he approaches the end of his life, he will no longer take his medication so that he can restore his inner peace in preparation for his reincarnation (see AC 4.5 for more information).</td>
</tr>
<tr>
<td>Maria is in end-of-life care and believes that it is important to continue to have communion every day. Maria also likes to keep her Bible close to her at all times.</td>
<td>As a Roman Catholic, Maria has requested a visit from a priest to administer Holy Unction.</td>
<td>Maria’s family get great support from participating in regular prayers with the hospice chaplains.</td>
</tr>
<tr>
<td>Jawad, a senior home carer, believes that every person to whom he provides support will be judged in death by how they have lived their life.</td>
<td>As a Muslim, Jawad visits the care home’s prayer room during every shift he works.</td>
<td>Jawad finds that reciting prayers from the Qur’an is a comfort to him.</td>
</tr>
</tbody>
</table>

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Beliefs are a strong feeling that we hold as true.
Religion is a system of faith or worship.
Culture refers to the characteristics of a particular group or society.
Communion is a Christian ritual where bread and wine are made sacred and shared.
Holy Unction is a Christian ritual where the individual at the point of dying is anointed with holy oil.
The Qur’an is the holy book of Islam.
A multi-disciplinary team is a team made up of professionals from a range of different organisations and services, each of which has its own individual roles and responsibilities.

AC 2.3 Explain the reasons why key people may have a distinctive role in an individual’s end-of-life care

Good-quality end-of-life care involves the expertise of a range of key people, including individuals’ family members, friends and others who are important to their well-being, providing physical, emotional, social and spiritual support. Figure 20.5 identifies some of the key people who may be involved in an individual’s end-of-life care.

- Meeting an individual’s physical needs will involve a range of key people – for example, a hospital consultant or other specialist such as an oncologist or urologist – who provide information about the diagnosis as well as the treatments available. Carers can provide day and night physical care and support to individuals, and specialist nurses such as Marie Curie and Macmillan nurses can provide information and guidance regarding pain relief and control. An individual’s social worker is vital for establishing the support and services they require to meet their needs, and therapists such as occupational therapists can provide information and advice on adaptations that it

Figure 20.5 Key people involved in end-of-life care

2.2 How well do you understand the influences of end-of-life care?
Reflect on two individuals you support with end-of-life care.
- Discuss with a member of the multi-disciplinary team each individual’s beliefs, religion and culture.
- How much did you know about each individual?
- How can you find out more about them?
may be beneficial to make to an individual’s living environment.

- An individual’s emotional needs can be met through their carers, family and friends, or through someone independent like an advocate or a counsellor with whom they can share their feelings and fears in confidence (see Figure 20.6).

- Volunteers in support groups play a vital role in ensuring social needs are met in terms of providing opportunities for the individual to meet up with others and participate in activities outside of their immediate environment. Family and friends are also important for maintaining relationships and companionship with the individual.

- Spiritual support can be provided by a variety of religions, groups and people such as hospital and hospice chaplains.

The support required during end-of-life care will vary for different individuals and so it is important that you are aware of the different roles key people have within a multi-disciplinary team. This will allow you to be able to draw on their areas of expertise and provide individuals with high-quality end-of-life care that meets their individual needs.

**Key terms**

- Macmillan nurses are specialist end-of-life care nurses; many have specialist knowledge in a particular type of cancer.
- Sensory impairment is a loss of hearing or vision or both in an individual.

**Evidence activity**

2.3 Key people

- List the reasons why key people play such an important part in an individual’s end-of-life care.
- Why is it important to involve family and friends in an individual’s end-of-life care?

**AC 2.4 Explain why support for an individual’s health and well-being may not always relate to their terminal condition**

As you have learned, good-quality end-of-life care is holistic and takes account of an individual’s unique needs and preferences. For this reason the support provided may not always directly relate to their terminal condition, but is still important for an individual’s health and well-being.

- An individual may have concerns over their financial or housing situation and may seek support to ensure their financial affairs are in order or to find more secure and affordable housing.
- An individual may request support to remain involved in meaningful activities such as charity work or a new hobby, which will enable them to socialise with others and feel good about themselves.
- An individual may wish to address unresolved issues they have in relationships or friendships with others, and may request support to do so.
- An individual may wish to fulfil their wishes and ambitions and may request financial and/or practical support to do so.

Other areas of support that an individual may require and that are not related to their terminal condition could relate to their mental health needs, a learning difficulty or a sensory impairment.
LO3 Understand advance care planning in relation to end-of-life care

AC 3.1 Describe the benefits to an individual of having as much control as possible over their end-of-life care

Person-centred approaches and ways of working involve supporting individuals to have as much control as possible over their end-of-life care. Figure 20.7 identifies some choices and decisions that an individual may wish to make with respect to their end-of-life care.

Knowing that they are in control of their own end-of-life care can be a source of great comfort to individuals, their families and any others close to them. Having their wishes respected will not only enable them to feel at peace but will also mean that they are able to die with dignity; this is sometimes referred to as ‘a good death’.

Evidence activity

2.1, 2.2, 2.3, 2.4 Legal requirements and agreed ways of working

- Reflect on two individuals whom you support with end-of-life care. For each individual, provide brief details of the key points of theories about the emotional and psychological processes that they and the key people involved may experience with the approach of death (AC 2.1). Also include details with examples of how the beliefs, religion and culture of both the individuals and the key people involved influence their end-of-life care (AC 2.2).

- Reflect on both individuals and identify all the key people involved in their end-of-life care and the reasons why each has a distinctive role to play (AC 2.3). Then provide details with examples of why support for an individual’s health and well-being may not always relate to their terminal condition (AC 2.4).

Case study

2.1, 2.2, 2.3, 2.4 Tracy

Tracy is a senior carer providing support to individuals who have been discharged from hospital and have chosen to spend their last weeks at home. As part of her senior role Tracy provides one-to-one supervision and assists with carrying out team members’ initial ten-day induction and training.

1 What key points of theories about the emotional and psychological processes that individuals and key people may experience with the approach of death could Tracy include in team members’ induction and training?

2 What examples could Tracy provide of how the beliefs, religion and culture of individuals and key people may influence end-of-life care?

3 What information could Tracy provide in relation to the distinctive roles that key people – such as individuals’ family, friends and others who are important to the well-being of the individual – play in an individual’s end-of-life care?

4 What examples could Tracy provide of why support for an individual’s health and well-being may not always relate to their terminal condition?

Key terms

Self-worth means an individual’s sense of their worth or value as a person.

Self-determination is how an individual controls their own life.
The UK government’s ‘End of life care strategy’ for England defines ‘a good death’ as:

- being treated as an individual, with dignity and respect
- being without pain and other symptoms
- being in familiar surroundings
- being in the company of close family and/or friends.

Maintaining as much control as possible over end-of-life care will also provide individuals with a sense of purpose and increase their self-worth and self-determination.

**AC 3.2 Explain the purpose of advance care planning in relation to end-of-life care**

Advance care planning facilitates individuals’ rights to have as much control as possible over their end-of-life care. It provides them with an opportunity to discuss in advance their choices, decisions and wishes with respect to their end-of-life care in case they are unable to express their preferences at a later stage. The discussions that are held are documented in full in an advance care plan.

The aims of the advance care planning process in relation to end-of-life care include:

- communicating an individual’s wishes and preferences about their end-of-life care and treatment
- placing the individual at the centre of their end-of-life care
- making an individual’s personal beliefs and values known to key people
- empowering an individual to make their own choices and decisions
- exploring an individual’s hopes, fears and concerns
- furthering an individual’s understanding of their illness and prognosis (see page 376 for definition)
- raising an individual’s awareness of the services and support available
- documenting all discussions held with an individual.

The concept of advance planning has led to the development of a number of frameworks and tools. These are designed for use by care providers providing end-of-life care so as to enable ‘a good death’. Table 20.3 provides details of some of these.
Gold Standards Framework (GSF)

- GSF involves three key steps:
  - **Step 1**: Identifying individuals in need of care.
  - **Step 2**: Assessing and recording individuals’ needs.
  - **Step 3**: Planning and providing individuals’ care.
- GSF involves seven key tasks known as the ‘7 Cs’:
  1. Communication
  2. Co-ordination of Care
  3. Control of symptoms and ongoing assessment
  4. Continuing support
  5. Continued learning
  6. Carer and family support
  7. Care in the final days

Preferred Priorities for Care (PPC)

- PPC involves three key steps:
  - **Step 1**: Thinking about end-of-life care.
  - **Step 2**: Discussing end-of-life care.
  - **Step 3**: Recording what care an individual would like.
- PPC involves making important decisions, such as:
  - what an individual would like and not like as part of their care
  - where an individual would like to receive their end-of-life care
  - by whom an individual would like to be represented when they are unable to make their own decisions.

Improving End of Life Care (EoLC) – a toolkit for care homes

- The toolkit was designed for care home providers but is relevant also for all social care providers to help them to assess and plan for good-quality end-of-life care.
- The toolkit consists of three steps:
  - **Step 1**: How to provide end-of-life care as an organisation.
  - **Step 2**: How to assess and quality-ensure end-of-life care provision.
  - **Step 3**: Practical ways to care for individuals and their families.

**Research and investigate**

3.2 Systems for advance care planning

Research systems for advance care planning in your local area and in your work setting.

**AC 3.3 Describe your role in supporting and recording decisions about advance care planning**

Your role in supporting and recording decisions about advance care planning will vary according to your responsibilities and your work setting’s agreed ways of working. There are a number of principles that should be followed for supporting and recording all decisions about advance care planning; the top ten principles are detailed below.

**Top ten principles for supporting decisions about advance care planning**

- Support individuals to make their own decisions about their end-of-life care and treatment.
- Support key people to understand the individual’s decisions about advance care planning.
- Support individuals to review and update their advance care plan regularly.
- Ensure you communicate the individual’s advance care plan to other members of the multi-disciplinary team only with the individual’s permission; the same goes for aspects of discussions with the individual and/or revisions made. If the individual lacks capacity, share aspects of the plan only when it is in their best interests to do so.
- Support individuals through the process of making advance statements; these will inform best interests decisions made at a later stage.
- Support individuals through the process of making advance decisions to refuse treatment.
- Support individuals through the process of appointing lasting powers of attorney.

**Key term**

- **Prognosis** is the likely progress and life span associated with a medical condition.
AC 3.4 Outline ethical and legal issues that may arise in relation to advance care planning

As you will have learned advance care planning involves discussing and listening to sensitive and personal information about an individual’s wishes and preferences for end-of-life care. It is not surprising therefore that a number of ethical and legal issues can arise during the advance care planning process.

- **Ethical issues** – an individual may express a wish to make an advanced decision to refuse treatments, such as resuscitation or artificial feeding, and may decide that they do not wish to seek the advice of a healthcare professional. An individual may share with you whom they wish to inform of and involve in their end-of-life care; this might not be their family or those people who are emotionally attached to the individual, it might be you or another carer. Conflicts may arise among those involved in the individual’s multi-disciplinary team in relation to what type of care should be provided; conflicts over how an individual’s end-of-life care or treatment should be provided may also arise among the individual’s family.

- **Legal issues** – withdrawing and withholding life-sustaining treatments for an individual is one example of a legal issue that can arise in relation to advance care planning. The appointment of lasting powers of attorney to make decisions on an individual’s behalf and determining whether an individual has capacity are examples of other legal issues that can arise as well as where and who you want to be with when you receive care and treatment.
Level 3 Health and Social Care Diploma

**Case study**

3.1, 3.2, 3.3, 3.4   Dechen

Dechen is a senior carer and an end-of-life care lead. As part of her role Dechen provides guidance to carers delivering end-of-life care, raises awareness of end-of-life issues and provides end-of-life care training to carers and to other professionals working in different multi-disciplinary teams.

1. How can Dechen communicate the benefits to an individual of having as much control as possible over their end-of-life care?
2. What information and examples can Dechen provide in terms of the purpose of advance care planning in relation to end-of-life care?
3. What tools can Dechen use to detail the different roles in supporting and recording decisions about advance care planning?
4. About what examples of ethical and legal issues that can arise during advance care planning could Dechen provide more information?

**Evidence activity**

3.1, 3.2, 3.3, 3.4   Do you understand advance care planning?

Reflect on an individual you know has completed an advance care plan in relation to their end-of-life care.

- Provide details of the benefits to this individual of having as much control as possible over their end-of-life care. Explain with examples the purpose of this individual’s advance care plan in relation to end-of-life care.
- Provide details of your role in supporting and recording decisions about advance care planning, and briefly detail the ethical and legal issues that may arise in relation to advance care planning.

**Time to think**

3.4   What are your ethics?

Reflect on an ethical issue that arose during the advance care planning process with an individual.

- How did you feel about it? Why?
- What did you do?

**LO4** Be able to provide support to individuals and key people during end-of-life care

**AC 4.1** Support the individual and key people to explore their thoughts and feelings about death and dying

Being able to support individuals and key people to explore their thoughts and feelings about death and dying can be very difficult for some carers. They may feel that they will not know what to say, or may find the thought of doing this too upsetting or uncomfortable, or may be afraid of becoming upset in front of the individual and their family, friends or others.

Providing supportive end-of-life care involves having the skills and confidence to support not only the individual but also their families, friends and other carers in the team to explore their thoughts and feelings about death and dying. Before doing so it is important that you have had the relevant training from your work setting, which will have enabled you also to explore your own thoughts and feelings about death and dying. There must also be relevant support systems in place that you can access.

There is a range of different ways to support individuals and key people to explore their thoughts and feelings about death and dying. Having open and honest discussions with the individual is one way of doing this. For example, you could empower the individual by asking them how they would like you to support them – some individuals may have specific questions that they want to ask you, other individuals may say nothing but may want to explore their thoughts and feelings by doing an activity with you, such as painting or writing. It is important for you to be honest with the individual when you feel uncomfortable or upset about any aspect of your discussion with them; it is better for you to tell the individual how you are feeling, as if you don’t they will still be able to sense that something is wrong through your body language and tone of voice and thus they may mistakenly think that you
are not interested in what they are saying or that you are angry or upset with them.

Support for families
Supporting individuals’ families to explore their thoughts and feelings about death and dying will involve not only providing sufficient time and opportunity for them to do so but also being flexible over when they can do so. Each family member may prefer to speak with you on their own, or the family may decide that they would like to speak with you and have the discussions together. You may come across some family members who find it difficult to think about the topic of death; providing these family members instead with supportive information about death and dying, or referring them to a counsellor or specialist nurse, may be more appropriate.

Support for your team
The team that is caring for the individual will also need to be provided with the opportunity to explore their thoughts and feelings about death and dying. One-to-one discussions and forums for the team to listen to each other and explore their thoughts and feelings are important, particularly during the provision of an individual’s care and after they have died. You may decide also to arrange for a professional or specialist to facilitate the discussions with the team, or you may decide to undertake a course and support the team to do this yourself.

AC 4.2 Provide support for the individual and key people that respects their beliefs, religion and culture

As you learned in AC 2.2, individuals and key people such as family members, friends and others all have unique needs and preferences based on their personal beliefs, religion and culture. Supportive end-of-life care involves therefore being respectful of individuals’ and key people’s unique beliefs, religion and culture and any associated practices and rituals.

Figure 20.8 identifies some of the ways in which you can do this; what other ways do you use?

Research and investigate

AC 4.3 Demonstrate ways to help the individual feel respected and valued throughout the end-of-life period

An individual’s end-of-life period could be a year or a few months, weeks or days. Throughout this period – however long or short it may be – it can be very comforting for an individual to know that their wishes and preferences, as discussed with them and documented in their advance directives, are being followed by you; it is also a way of showing your utmost respect.

Key term

An advance directive is documented information agreed with an individual, which lets others know an individual’s wishes and preferences for their end-of-life care.
Ask questions
Other ways of assisting an individual to feel respected and valued can involve you asking them questions. For example, you might ask whether they require anything else, such as additional support from a professional to speak to them or to their family. Or you might ask whether they want to do anything else, such as request a visit from someone or have a particular type of spiritual or religious practice carried out, or have a change made to their environment.

Listen attentively
Attentively listening to an individual and observing what they are expressing is a way of acknowledging their feelings and thoughts; the individual will feel listened to, respected and valued. Understanding more about what an individual is experiencing will enable you to access any additional support or services that they may require. This may, for example, be in relation to supporting an individual to manage their physical well-being; the individual may require advice from their GP or a specialist nurse such as a Macmillan nurse on how to alleviate any physical pain they may be experiencing or how to change their nutrition as their appetite decreases.

Adapt to individuals’ needs
Helping an individual to feel valued and respected will also involve you and others being able to adapt to the individual’s changing needs. For example, respecting an individual’s decision if they decide during the end-of-life period that they no longer want a treatment, and ensuring this is documented clearly. Or for example when an individual is no longer able to communicate with you verbally it will be important for you to develop other methods of communication so that they can continue to be informed and understood, as well as to understand what others are communicating.

AC 4.4 Provide information to the individual and/or key people about the individual’s illness and the support available

Providing high-quality end-of-life care involves promoting not only an individual’s physical well-being but also their emotional, social and spiritual well-being. Providing information to the individual and/or key people about the individual’s illness and the support available to meet their physical, emotional, social or spiritual needs is crucial to supporting them effectively and professionally through end-of-life care. Information may be provided through discussions with you or other professionals, or through group and individual forums such as support groups and counselling sessions, or may consist of literature such as leaflets and books that can be provided in a variety of formats: digitally recorded, in writing including in large print, using pictures, in different languages. Figure 20.9 identifies sources of information that may be useful for communicating to an individual and/or key people about the individual’s illness and the support available.

![Figure 20.9 Sources of information](image-url)
Give examples of how an individual’s well-being can be enhanced by environmental factors, non-medical interventions, use of equipment and aids, and alternative therapies

Supportive end-of-life care involves being aware of how an individual’s environment and other factors can play an important role in their physical, emotional, social and spiritual well-being.

- **Environmental factors** – as mentioned in AC 3.2, ensuring an individual has control over where they receive their end-of-life care is important to them being valued and respected. For some this may be at home surrounded by their family, or for others in a hospice where they feel they can relieve their family of the burden of their care. The people who are present in an individual’s environment can also make the individual feel like they belong and feel confident that their wishes and preferences will be respected, for instance a carer who spends time with an individual attentively listening to their fears and wishes. An individual’s well-being will also be enhanced if they feel comfortable in their environment, e.g. by it being neither too hot nor too cold, by it being private, by it having background noise in it such as a radio, or by it being quiet and peaceful.

- **Non-medical interventions** – interventions such as counselling can enhance an individual’s physical, emotional and spiritual well-being because listening with empathy can enable the individual to express their innermost thoughts and feelings. Supporting the individual to engage in activities such as music or the arts can enable them to meet with others and provide them with a sense of fulfilment and enjoyment.

- **Use of equipment and aids** – using equipment and aids that can promote an individual’s independence or maintain their comfort is important for an individual to have a ‘good death’ and can therefore enhance their physical and emotional well-being. For example, a pressure-relieving mattress for an individual who is unable to move independently, or a hoist for an individual who wishes to change position, e.g. from their bed to a chair, or hand rails for an individual who wishes to have a bath in the mornings.

- **Alternative therapies** – alternative therapies, for example aromatherapy, reflexology and relaxation techniques, are useful for relieving and controlling an individual’s symptoms and improving their sense of ‘inner peace’.

Contribute to partnership working with key people to support the individual’s well-being

Supportive, good-quality end-of-life care that enhances an individual’s well-being involves actively working in partnership with their family, friends and others, such as carers, advocates and professionals from a range of services, by:

- **finding out their individual needs**, e.g. by listening to the support or services they require to effectively support an individual’s well-being

- **having open discussions**, e.g. by being approachable so as to ensure issues of concern or aspects of an individual’s end-of-life care can be discussed honestly

- **working flexibly**, e.g. by being responsive to key people’s needs for information or support so that they can provide the best possible support to the individual

- **providing clear information**, e.g. by having one person key people can approach with questions or for advice on how to support an individual’s well-being, and providing

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**Key terms**

- **Empathy** is the ability to understand how an individual feels and thinks.
- **Aromatherapy** is an alternative therapy that involves the use of plant extracts and essential oils to manage physical and emotional well-being.
- **Reflexology** is an alternative therapy that involves the application of pressure to different reflex points on the body to manage physical and emotional well-being.
- **Inner peace** means mental, emotional and spiritual well-being.
clear information about everyone’s roles and responsibilities.

- **Providing training and support**, e.g. by providing a range of different types of training and support based on key people’s individual requirements, and that can be easily accessed.

- **Valuing contributions**, e.g. by actively recognising the valuable roles key people play in supporting an individual’s well-being in terms of their experience and knowledge of the individual.

**Working in partnership** involves different people working towards the same objectives. For this to be effective there must be good communication, effective co-operation and clear co-ordination between all the different partners.

**Case study**

**4.1, 4.2, 4.3, 4.4, 4.5, 4.6  Joshua**

Joshua has a learning disability and lives in supported living. He has recently been diagnosed with terminal cancer. This has come as a shock to him, his team of carers and his family and friends, as up until now he has never experienced any problems with his physical or mental health and has always maintained a healthy lifestyle.

1. How can Joshua and the key people involved be supported to explore their thoughts and feelings about death and dying?
2. How can the support provided respect the beliefs, religions and cultures of Joshua and the key people involved?
3. What methods can be used to enable Joshua to feel respected and valued throughout the end-of-life period?
4. What information about Joshua’s illness and the support available can be provided to Joshua and/or the key people involved?
5. How can Joshua’s well-being be enhanced by his environment, by non-medical interventions, use of equipment and aids, and alternative therapies?
6. What methods of partnership working with key people could support Joshua’s well-being?

**Evidence activities**

**4.1, 4.2, 4.3, 4.4, 4.5  Supporting individuals during end-of-life care**

Reflect on two individuals you have supported during end-of-life care. For each individual detail:

- how you supported them to explore their thoughts and feelings about death and dying
- how the support you provided respected their beliefs, religion and culture, and helped the individual to feel respected and valued.

Include in your accounts the information you provided to each individual about their illness and the support available, and provide examples of how each individual’s well-being was enhanced by environmental factors, non-medical interventions, use of equipment and aids, and alternative therapies.

**4.1, 4.2, 4.4, 4.6  Supporting key people during end-of-life care**

Reflect on two key people you have supported during end-of-life care. For each key person detail how you supported them to explore their thoughts and feelings about death and dying, and how the support you provided respected their beliefs, religion and culture (AC 4.1).

- Include in your accounts the information you provided to each key person about the individual’s illness and the support available (AC 4.2), and your contributions to partnership working with each key person to support the individual’s well-being (AC 4.6).

- You will also need to be observed by your assessor or an expert witness supporting individuals and key people during end-of-life care to explore their thoughts and feelings about death and dying (AC 4.1), respecting their beliefs, religion and culture, and providing information about the individual’s illness and the support available (AC 4.2). You must also demonstrate ways to help individuals feel respected and valued throughout the end-of-life period (AC 4.3) and your contribution to partnership working with key people to support the individual’s well-being (AC 4.6).
**Key term**

**Working in partnership** is an approach to working with others that enables working together to support an individual’s well-being.

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**Time to think**

4.6 Can you work in partnership?

Interview three key people you have supported in individuals’ end-of-life care.

- Ask each of them whether they feel you worked in partnership with them.
- Reflect on the areas they felt worked well.
- Reflect on the areas that require improvements.

**LO5** Understand how to address sensitive issues in relation to end-of-life care

**AC 5.1** Explain the importance of recording significant conversations during end-of-life care

The UK government’s ‘End of life care strategy’ (2008) states that:

‘all people approaching the end of life, and their carers, should be entitled to know that systems are in place to ensure that information about their needs and preferences can be accessed by all relevant health and social care staff, with their permission.’

Recording significant conversations during end-of-life care – which could involve, for example, a request for additional support or a preference for who should be present in the individual’s last hours – is important for the following reasons:

- It ensures that the information recorded can be accessed by key people involved in the individual’s end-of-life care so that they can provide high-quality care that meets the individual’s wishes and preferences.
- It encourages communication (with the individual’s permission) between different members of the multi-disciplinary team to ensure consistent working approaches.
- It avoids key people providing care that does not respect the individual’s personal beliefs or preferences.
- It is a way of ensuring that the individual’s plan of care remains up to date throughout their end-of-life care.
- It is a way of maintaining the individual’s ‘best interests’ if they lose capacity to make their own decisions at a later stage.

**AC 5.2** Explain factors that influence who should give significant news to an individual or key people

Giving significant news to an individual or key people in relation to end-of-life care is a sensitive issue that requires skill and empathy. There are a number of factors that influence who should give significant news:

- **The individual’s preferences** – some individuals or key people may prefer to receive significant news from someone they know well or have a close relationship with; others may prefer to receive it from a trained professional.
- **The individual’s capacity** – some individuals may lack capacity and therefore an independent person such as an advocate or a family member may act as their representative in deciding who should give significant news, and how.
- **The type of significant news** – depending on what the significant news is, the knowledge and expertise of the person giving it will be important, as the individual and key people will require as much information as possible and may at this point raise questions and concerns with the person providing the news.
- **Relationships with individuals or key people** – giving significant news may provoke a range of different reactions from individuals and/or key people, such as denial, anger, fear
and/or shock, and therefore it is important that the person giving the news feels able to manage these emotions in a supportive way. In some cases it may be more appropriate to ensure different people are involved in giving significant news to individuals and key people, for example a key worker who knows the individual well could provide the news to the individual, while a manager could provide the news to the individual’s family and members of the team.

**AC 5.3 Describe conflicts and legal or ethical issues that may arise in relation to death, dying or end-of-life care**

Building relationships with different individuals and key people, and working as part of a multi-disciplinary team where each person has their own personal beliefs, religion and culture, can mean that from time to time conflicts, legal and ethical issues can arise. These may arise in relation to death, dying or end-of-life care between professionals, individuals and their families and friends. Look at Figure 20.10, which includes some examples of these; have you come across any others? You may also find it useful to revisit AC 3.4, which detailed legal and ethical issues that may arise in advance care planning.

**Conflicts**
- withholding or withdrawing treatments
- an individual’s best interests

**Legal issues**
- wills
- powers of attorney

**Ethical issues**
- the discussions to have in relation to death, dying or end-of-life care
- how much care an individual requires as they approach the end of their life

**Figure 20.10 Conflicts, legal and ethical issues**

**AC 5.4 Analyse ways to address such conflicts**

Conflicts may arise in relation to death, dying or end-of-life care between professionals, individuals and their families and friends. How you and others address these conflicts will depend on the nature and extent of the conflicts and your work setting’s agreed ways of working, as well as your role and responsibilities. Below is a list of five top tips for addressing such conflicts:

1. Use different communication methods to explain more about the care provided, the treatments available and agreed ways of working, e.g. verbally and in writing.
2. Use negotiation strategies to enable different perspectives and opinions to be considered.
3. Provide more information on, for example, treatments and the well-being of the individual, as this will improve key people’s
understanding of what treatments are available and of the current physical and emotional well-being of the individual.

4 Seek advice from others, such as specialists and other professionals.

5 Provide opportunities to meet with others to talk about and reflect on such conflicts.

**Case study**

5.1, 5.2, 5.3, 5.4 **Lynn**

Lynn is a senior home carer and leads a team of ten carers who provide live-in care and support to individuals who require end-of-life care and to their families. As part of her role Lynn works closely with the local hospice and the hospital palliative care team to provide regular training and mentoring.

1 What explanation could Lynn provide to her team about the importance of recording significant conversations during end-of-life care?

2 What explanation could Lynn provide to her team about the factors that influence who should give significant news to an individual or key people?

3 What examples could Lynn provide to the team regarding conflicts and legal or ethical issues that may arise in relation to death, dying or end-of-life care?

4 What different strategies could Lynn and her team use to address such conflicts?

**Evidence activity**

5.1, 5.2, 5.3, 5.4 **Addressing sensitive issues**

Reflect on two occasions where you had to address sensitive issues in relation to end-of-life care.

- Provide details with examples of the importance of recording significant conversations during end-of-life care, and the factors that influence who should give significant news to an individual or key people.

- Detail examples of conflicts and legal or ethical issues that may arise in relation to death, dying or end-of-life care, and examine in detail the different ways to address such conflicts. Did you use different methods for different conflicts? Why?

**LO6 Understand the role of organisations and support services available to individuals and key people in relation to end-of-life care**

**AC 6.1 Describe the role of support organisations and specialist services that may contribute to end-of-life care**

Being able to seek advice, support and information from support organisations and specialist services is integral to providing high-quality end-of-life care that meets an individual’s needs, wishes and preferences. Such support organisations and specialist services include nursing and care homes, specialist palliative care services, domiciliary, respite and day services, as well as funeral directors.

Table 20.4 provides some more information about the role of each of these support organisations and specialist services in relation to end-of-life care.
### AC 6.2 Analyse the role and value of an advocate in relation to end-of-life care

The role of an **advocate** is to represent or speak up for an individual. The end-of-life care advocate can be involved in:

- **A** Assisting the individual to have control over their life.
- **D** Decisions about end-of-life care in line with an individual’s wishes and preferences.
- **V** Valuing an individual’s beliefs, religion and culture.
- **O** Open conversations with the individual and others.
- **C** Choices about end-of-life care.
- **A** Assisting the individual to access services and facilities available.
- **T** Trust building.
- **E** Ensuring the individual is listened to.

### Key term

**Advocates** represent individuals or speak on their behalf to ensure their rights are supported.

Having an end-of-life care advocate can be a very effective way of ensuring that the individual remains at the centre of the end-of-life care being provided and that their views, wishes, preferences and rights continue to be listened to, respected and upheld.

### AC 6.3 Explain how to establish when an advocate may be beneficial

An end-of-life care advocate is independent. Their sole role is to support an individual to make their own choices and decisions about their end-of-life care and to communicate these to others.

An end-of-life care advocate may be requested by an individual as they may prefer to discuss their concerns and/or anxieties with an independent person than with someone who knows them well, who may get upset by discussing this with them.

### Table 20.4 The role of support organisations and specialist services

<table>
<thead>
<tr>
<th>Support organisation or specialist service</th>
<th>Role in relation to contributing to end-of-life care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing homes</td>
<td>Provide individuals with a home. Provide nursing care to individuals and support to their families and friends.</td>
</tr>
<tr>
<td>Care homes</td>
<td>Provide individuals with a home. Provide care to individuals and support to their families and friends.</td>
</tr>
<tr>
<td>Specialist palliative care services, e.g. those based in hospitals, hospices</td>
<td>Provide individuals and key people with information, advice and support on end-of-life care, such as pain control and emotional support.</td>
</tr>
<tr>
<td>Domiciliary services</td>
<td>Provide individuals and key people with additional support at home with tasks such as personal care, household tasks and shopping that may be difficult to do when providing end-of-life care to an individual.</td>
</tr>
<tr>
<td>Respite services, e.g. Marie Curie nursing service</td>
<td>Provide nurses that enable individuals’ families and friends to have respite from caring during the day or at night time.</td>
</tr>
<tr>
<td>Day services</td>
<td>Provide individuals and/or their families and friends with opportunities to meet with others, engage in meaningful activities and share their feelings and thoughts in relation to end-of-life care.</td>
</tr>
<tr>
<td>Funeral directors</td>
<td>Look after and wash the individual’s body after death in accordance with the individual’s and their family’s beliefs, religion and culture. Can also provide support with arranging a funeral and a burial or cremation.</td>
</tr>
</tbody>
</table>
When an individual wishes to make plans for their end-of-life care an advocate can be beneficial in preparing advance directives with an individual. Discussions with an advocate can also be a source of comfort to the individual and provide them with reassurance that their wishes and preferences are not only being listened to but will also be acted on.

An individual may also seek help from an advocate when meeting with others, such as their family, carers and other professionals, to discuss plans for end-of-life care.

**AC 6.4 Explain why support for spiritual needs may be especially important at the end of life**

As individuals near the end of their lives they may develop a desire for self-worth or meaning and this may involve talking through their feelings and beliefs with someone else or taking part in prayers or other rituals to meet their spiritual needs.

Support for spiritual needs is particularly important at the end of life for the following reasons:

- It can be how the individual achieves their ‘inner peace’, i.e. by resolving issues or conflicts they have with key people.
- It can be comforting for the individual to take part in prayers, or to speak with someone about their spirituality.
- It can be comforting for the individual’s family, friends and others involved in their life to know that their relative is at peace at the end of life.

**AC 6.5 Describe a range of sources of support to address spiritual needs**

Meeting an individual’s spiritual needs is crucial to providing good-quality end-of-life care. This involves being able to empathise with an individual. It is important that you are aware of your own limitations in this and when to refer to others for support.

A range of sources of support is available within your own work setting, including your manager and other members of staff who may be more experienced than you. The individual’s family and friends can also be involved as they will know the individual well and may be able to talk through with the individual their innermost thoughts and feelings, for example.

**Time to think**

**6.4 Do you understand spirituality?**

Reflect on an occasion when you supported an individual and their key people through end-of-life care.

- What agreed ways of working did you follow?
- How did these address spiritual needs?
- Why was this important?

- It can be a way of reflecting on an individual’s achievements in life.
- It can be a way of providing the individual with companionship.

**Case study**

**6.1, 6.2, 6.3, 6.4, 6.5 Shoi-ming**

Shoi-ming is meeting with his manager today to talk through how he has found his first week in his new role as an end-of-life enabler. Shoi-ming’s role involves supporting a team of carers to provide high-quality end-of-life care that involves meeting individuals’ physical, mental, emotional, social and spiritual needs. Shoi-ming has drawn up a list of questions to ask his manager in relation to the role of organisations and support services available to the individuals and key people who use the service.

1 What details could Shoi-ming’s manager provide him with about the role of support organisations and specialist services that may contribute to end-of-life care?
2 What details could Shoi-ming’s manager provide him with about the role and value of an advocate in relation to end-of-life care, and how to establish when an advocate may be beneficial?
3 What explanation could Shoi-ming’s manager provide him with about why support with spiritual needs may be especially important at the end of life?
4 What details could Shoi-ming’s manager provide him with about the range of sources of support to address spiritual needs?
Other sources of support can include professionals who work in specialist services such as counsellors, psychologists and chaplains, all of whom can provide specialist support in addressing an individual’s spiritual needs. Volunteers from support groups can also play a vital role in visiting individuals to address their spiritual needs. It is important to remember that some individuals may also find solace in reading about spirituality.

**Research and investigate**

**LO6** Find out about your team’s understanding of spirituality.

**Evidence activity**

**6.1, 6.2, 6.3, 6.4, 6.5** Support organisations and specialist services
- Provide details of the roles of three support organisations and three specialist services that are available in relation to end-of-life care for the individuals and key people with whom you work.
- Examine in detail the role and value of an advocate for the individuals and key people with whom you work in relation to end-of-life care; include details and examples of how to establish when an advocate may be beneficial.
- Detail the range of support services available to the individuals and key people with whom you work in relation to addressing spiritual needs; include details and examples of why support with spiritual needs may be especially important at the end of life.

**LO7** Be able to access support for the individual or key people from the wider team

**AC 7.1** Identify when support would best be offered by other members of the team

As you learned in AC 2.3, support for individuals and key people can be accessed from other members of the multi-disciplinary team, including your line manager, individuals’ family and friends, religious representatives, social workers, psychologists and other professionals such as specialist doctors and nurses, occupational therapists, physiotherapists and complementary therapists.

When support would best be offered by other members of the team will depend on a number of factors:
- The individual’s or key person’s needs, e.g. a deterioration in an individual’s physical or emotional condition may result in a referral to a specialist.
- The individual’s or key person’s preferences, e.g. whether they would like support early on or not.
- The individual’s or key person’s personal coping strategies, e.g. this may affect when support is required.

**Research and investigate**

**7.1** Members of your wider team
Find out who the members of your wider team are and what support they offer.

**AC 7.2** Liaise with other members of the team to provide identified support for the individual or key people

Your role in end-of-life care will involve working closely with other members of the multi-disciplinary team to provide the support required for the individual or key person. Effective liaison with other members of the team in relation to end-of-life care involves:
- understanding all team members’ roles and responsibilities
- sharing agreed ways of working for making decisions and communicating decisions made to individuals and key people
- supporting each other
- listening to each other
- valuing each other
- respecting each other
- developing shared principles and goals
- being open and honest
- being able to work constructively through conflicts or other issues that arise.
Case study

7.1, 7.2 Aishita

Aishita is supporting her team of residential carers to provide support to an individual who has had a stroke and who has recently developed difficulties with breathing, as well as kidney disease. Aishita has noted that this individual is visited regularly by her son and husband, and that – although the individual is very accepting of her condition – her husband and one of her carers who knows her well are finding it difficult and upsetting.

1. When would support best be offered by other members of the team to the individual, her husband and the carer?
2. How could Aishita liaise with other members of the team to provide identified support for the individual, her husband and the carer?

Evidence activity

7.1, 7.2 Accessing support from the wider team

- Reflect on an occasion when you accessed support from the wider team for an individual or key people in relation to end-of-life care.
- Discuss with your manager when and why you accessed support, and the type of support that was offered by other members of the team. Discuss how you liaised with other members of the team to provide the identified support.
- You will also need to be observed by your assessor or an expert witness supporting individuals and key people through end-of-life care, identifying when support would best be offered by other members of the team and liaising with other members of the team to provide identified support for the individual or key people.

Time to think

7.2 Can you liaise effectively?

Reflect on an occasion when you liaised with other members of the team to provide identified end-of-life care support to an individual or key people.

- On a scale of 0 to 10, rate yourself on how effective you were.
- What were your strengths?
- What were your areas for development?
- How can you develop these?

LO8 Be able to support individuals through the process of dying

AC 8.1 Carry out own role in an individual’s care

Your role in an individual’s care when they are going through the process of dying will involve providing holistic support in relation to an individual’s physical, mental, emotional and spiritual needs. The process of dying will be experienced differently by each individual, and may happen slowly or quickly. When supporting individuals through the process of dying it is important that you follow the agreed ways of working of your work setting and are able to meet individuals’ unique and varying needs. Below are some examples of the different ways you may provide support to individuals through the process of dying.

- **Physical care and support** – an individual may become incontinent and you will need to support them to manage their incontinence and ensure that they remain dry and comfortable. As an individual becomes weaker they may no longer be able to eat and drink independently; you may be required to assist them.

- **Mental care and support** – an individual’s mental well-being may decline as they approach death. Answering an individual’s questions and talking through their fears, anxieties and concerns can play a crucial role in restoring their mental health.

- **Emotional care and support** – as an individual approaches death they may become more drowsy. You may be required to sit with an individual and talk to them, as although the individual may not be able to engage with you they may get comfort from hearing you talk to them.

- **Spiritual care and support** – an individual may show anxious or restless behaviour, which may be due to the treatments they are receiving. Reading with an individual during these times or simply placing your hand on theirs can restore their sense of ‘inner peace’. Similarly, ensuring you support individuals with any religious or spiritual practices may also be of great comfort.
Your role will also involve reporting and recording the support you have provided and any concerns that have arisen, as well as any referrals you have made to other members of the multidisciplinary team.

**AC 8.2 Contribute to addressing any distress experienced by the individual promptly and in agreed ways**

Fear of the unknown, pain and the reactions of key people can underlie individuals’ distress as they approach the end of their lives. Read through Table 20.5, which provides details of how you can address different types of distress that individuals may experience. Your job role and your work setting’s agreed ways of working will determine the actions you must follow so it is important that you are familiar with these and understand how to comply with them.

### Key term

**Spiritual practice** means actions or activities that support an individual’s sense of self.

<table>
<thead>
<tr>
<th>Area of distress</th>
<th>Actions to take</th>
</tr>
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</table>
| **An individual develops a fear of the unknown and becomes increasingly anxious** | • Reassure the individual immediately.  
• Listen to the individual’s fears and anxieties.  
• Ask the individual how you can help.  
• Ask the individual if they want to talk to someone else or have someone else present, such as a chaplain or another member of the team.  
• Record your observations and agreed actions promptly.  
• Report your observations and agreed actions promptly. |
| **An individual is in pain** | • Seek advice immediately from the doctor, nurse or palliative care team, providing them with as much information as possible.  
• Reassure the individual and tell them what actions you have taken.  
• Ask the individual if there is anything else they would like.  
• Support the individual to communicate with key people.  
• Monitor the individual’s condition.  
• Record your observations and agreed actions promptly.  
• Report your observations and agreed actions promptly. |
| **An individual is distressed by the reactions of key people** | • Reassure the individual immediately.  
• Ask the individual how you can help.  
• Be sensitive when speaking with key people; they may be upset, angry or in denial about the imminent death of the individual.  
• Ask key people whether they would like to talk to someone else about how they are feeling.  
• Record your observations and agreed actions promptly.  
• Report your observations and agreed actions promptly. |

**Table 20.5 Different types of distress**

### Key terms

**Distress** can refer to anxiety, pain or sorrow that is experienced.

A **palliative care team** is a team of end-of-life care specialists, who assess and treat individuals and provide information, advice and support to meet both individuals’ and key people’s holistic needs.

### Research and investigate

**8.2 Strategies for managing an individual’s distress**

Research strategies for managing an individual’s distress during the dying process.
AC 8.3 Adapt support to reflect the individual’s changing needs or responses

The support you provide to individuals through the process of dying must also be flexible so as to reflect the individual’s changing physical, mental, emotional or spiritual needs or responses during their last days or hours. You can adapt your support in different ways; Figure 20.11 provides some examples of how you can do this.

Figure 20.11 Ways of adapting support

AC 8.4 Assess when an individual and key people need to be alone

Although communication and support are important in supporting individuals through the dying process, it is also important to remember that there may be times when an individual and key people need to have some time alone. Respecting their privacy during these times is crucial. There is no definitive way to tell when an individual and key people need to be alone, as all people are different, but the five key questions provided below may be useful to consider, as these can be indicators that there is a need for time alone.

1. Do the individual and key people stop communicating when you enter the room?
2. Are the individual and key people sharing private feelings and/or memories?
3. Do key people leave the room when you enter?
4. Have the individual or key people received significant news?
5. Do you sense you are in the way?

Case study

Vanessa

Vanessa is being shadowed by a new member of staff who has never supported individuals through the process of dying. As a carer, Vanessa will be mentoring her and supporting her.

1. How could Vanessa explain to the new member of staff what her role in an individual’s care will involve?
2. What agreed ways of working will Vanessa need to explain in relation to addressing any distress experienced by an individual?
3. What ways of adapting the support provided to meet individuals’ changing needs or responses will Vanessa need to explain?
4. What tools could Vanessa use to explain to the new member of staff how to assess when an individual and key people need to be alone?

Evidence activity

Supporting an individual through the dying process

Reflect on an occasion when you supported an individual through the dying process.

- Provide details of your role in the individual’s care, including how you addressed any distress experienced by the individual, how you adapted your support to reflect the individual’s changing needs or responses, and how you assessed when the individual and key people needed time to be alone.
- You will also need to be observed by your assessor or an expert witness supporting individuals and key people during end-of-life care to demonstrate how you carried out your role, contributed to alleviating any distress experienced by the individual promptly and in agreed ways, adapted support to reflect the individual’s changing needs or responses, and assessed when an individual and key people needed to be alone.
8.4 Time alone?
Reflect on an occasion when you provided end-of-life care for an individual and key people.
- How did you know when time alone was required?
- Do you think your assessment was correct? Why?

LO9 Be able to take action following the death of individuals

AC 9.1 Explain why it is important to know about an individual’s wishes for their after-death care

You will need to know also about your role in after-death care, once an individual has died. Knowing an individual’s wishes for their after-death care is very important for a number of reasons:
- To ensure compliance with an individual’s advance directives.
- To show respect for an individual.
- To show respect for an individual’s family and friends.
- To find out more about how to follow practices and rituals in line with an individual’s wishes.
- To be able to be involved in saying ‘goodbye’ to the individual.
- To provide comfort from the knowledge that the individual’s wishes were met.

AC 9.2 Carry out actions immediately following a death that respect the individual’s wishes and follow agreed ways of working

Following an individual’s death there are a number of actions that must be taken. It is important that these respect an individual’s wishes and follow your work setting’s agreed ways of working:
- Attending to the body of the deceased – your role will vary depending on the preferences and personal beliefs of individuals and their families in relation to after-death care. For example, some individuals may have agreed with their family in advance for their body to remain at home before the funeral; others may have agreed for it to be taken to a chapel of rest. Some individuals may want their families involved in washing and dressing their body after their death; others may not and may prefer you and your team to do it.
- Reporting the death through agreed channels – an individual’s death must be reported promptly to the GP or the out-of-hours doctor service promptly, i.e. within a few hours. Who does this will depend on your job role and responsibilities in line with the agreed ways of working of your work setting. Once a medical death certificate has been issued by the individual’s GP (this may take longer if the GP requests that a post mortem be carried out), this must be taken to the local registrar who will register the death; again, who does this will depend on your job role and responsibilities in line with your work setting’s agreed ways of working.
- Informing key people – once a death has occurred all relevant key people can be informed. Who is informed first and how will depend on the individual’s wishes as set out in their advance directives and also on advance discussions held with family members. Similarly, when informing members of the team it will be important to respect an individual’s and their family’s wishes and privacy; careful consideration

Key term

After-death care means the practices, rituals and reporting processes to follow after an individual’s death.

Research and investigate

9.1 After-death care practices
Research after-death care practices across different religions and cultures.
should be given to when team members are informed and how they can maintain confidentiality.

All actions taken must be documented fully in line with your work setting’s agreed ways of working.

**Key term**

A **post mortem** is the examination of a body to establish the cause of death.

**AC 9.3 Describe ways to support key people immediately following an individual’s death**

In the immediate moments following an individuals’ death support will need to be made available to key people, such as the individual’s family, friends and others who are important to their well-being. Figure 20.11 identifies some of the ways support can be provided.

![Diagram of Ways of supporting key people]

**Case study**

**9.1, 9.2, 9.3 Ben**

Ben is a senior support worker and is discussing with his manager in supervision the advance care plan in place for an individual who lives in supported living and is approaching death.

1. Why is it important for Ben and his manager to know about the individual’s wishes for after-death care?
2. How can Ben and his manager ensure that the individual’s wishes are respected after their death and that they follow agreed ways of working?
3. How can Ben and his manager support members of the team and the individual’s family and friends following the individual’s death?

**Evidence activity**

**9.1, 9.2, 9.3 After-death care**

Reflect on an occasion when you were involved in an individual’s after-death care.

- Provide details and examples of:
  - the importance of knowing about an individual’s wishes for their after-death care
  - the actions taken immediately following an individual’s death, including how these respected an individual’s wishes and agreed ways of working
  - the support provided to key people immediately following the individual’s death.

- You will also need to be observed by your assessor or an expert witness carrying out actions immediately following an individual’s death that respect the individual’s wishes and follow agreed ways of working.

**Time to think**

**9.3 Providing support**

Reflect on an occasion when you provided support to key people immediately following an individual’s death.

- How effective was your support?
- Why?
**LO10** Be able to manage own feelings in relation to the dying or death of individuals

**AC 10.1** Identify ways to manage own feelings in relation to an individual’s dying or death

Managing your feelings in relation to an individual’s dying or death forms part of the **grieving process**. How you grieve will be unique to you as it will depend on your relationship with the individual and how you found the experience of supporting them, as well as your personal beliefs, religion and culture. It is difficult to prescribe, therefore, how to manage your feelings in relation to an individual’s dying or death. Feelings may vary from being upset, to being in shock, angry or relieved. Below are examples of different ways of managing your feelings in relation to an individual’s dying or death; have you used any of these strategies or are there any others that you find useful for you?

**Key term**

The **grieving process** is the stages and emotions an individual experiences when another individual dies.

- Talking openly and honestly with others about how you feel can help you to acknowledge and manage your feelings.
- Resting and having sufficient sleep will help you to think more clearly.
- Eating healthy and nutritious meals will help to maintain your physical health and strength.
- Asking for support and help from others can provide reassurance and comfort. This could be from family or friends, or professionals such as bereavement counsellors.
- Saying ‘goodbye’ to the individual can help with acknowledging your feelings and sharing how you feel with others.
- Favourite pieces of music, looking at photos – can help you with making sense of what has happened.

**Research and investigate**

**10.1 The grieving process**

Research different models of the grieving process.

**AC 10.2** Utilise support systems to deal with own feelings in relation to an individual’s dying or death

There are many different support systems available to help you deal with your feelings in relation to an individual’s dying or death. These may include formal and informal sources of support available from your work setting and externally. Figure 20.13 below identifies some of these.

![Support systems diagram]

It is not always easy to ask for help from others, for fear of being a burden or feeling inadequate or not wishing to face talking through your emotions and the causes of these. Avoiding doing so will only prolong the grieving process, however; it cannot be avoided. It is vital therefore that you are able to make use of the support systems that are available and that you feel comfortable using, to deal with your feelings so that you can maintain your physical, mental, emotional and spiritual health and well-being, and enable others to do the same.
Laila is a senior residential carer and has supported three individuals through the dying process this week. Laila has also provided support to their families and friends and to different members of the team who were involved.

1. How can Laila manage her feelings in relation to supporting these individuals through the dying process?
2. What support systems can Laila make use of to deal with her feelings in relation to supporting individuals through the dying process?

Reflect on an occasion when you supported an individual through the dying process.

- Identify how you managed your feelings in doing so, and provide details of the support systems you used to deal with your feelings in relation to the individual's dying or death.
- You will also need to be observed by your assessor or an expert witness utilising support systems to deal with your feelings in relation to an individual's dying or death.

Reflect on what support is available in your work setting for dealing with your feelings in relation to an individual's dying or death.

- Identify an occasion you used the support available.
- How did it help you?

- Data Protection Act 1998
- Equality Act 2010
- Freedom of Information Act 2000
- Health and Safety at Work etc. Act 1974
- Human Rights Act 1998
- Mental Capacity Act 2005
- Mental Health Act 1983 (amended 2007)
- Safeguarding Vulnerable Groups Act 2006

Websites
Centre for Spirituality, Health and Disability
www.abdn.ac.uk/cshad/
Dying Matters
http://dyingmatters.org
Mental Health Foundation
http://mentalhealth.org.uk
National Council for Palliative Care
http://ncpc.org.uk
National End of Life Care Intelligence Network
http://endoflifecare-intelligence.org.uk
National Institute for Health & Clinical Excellence
www.nice.org.uk
Social Care Institute for Excellence
www.scie.org.uk
Skills for Care
www.skillsforcare.org.uk
Skills for Health
http://skillsforhealth.org.uk

Publications

Reports
Macmillan Cancer Support and Marie Curie Cancer Care (2011) ‘End of life: the facts, a booklet for people in the final stages of life and their carers’