

## Unit 39: Supporting Individuals at the End of Life

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<b>Level:</b>	3
<b>Unit type:</b>	Optional (Group B2)
<b>Credit value:</b>	6
<b>Guided learning hours:</b>	48

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### Unit introduction

Providing care at the end of an individual's life requires sensitivity, awareness and respect for the individual's choices and decisions. End of life care can occur in any setting, including the individual's own home. As a care worker, your responsibilities are to support the individual's care, wishes and preferences leading up to their death and their care after death.

Your role will extend to supporting family, carers or other people who are important to the individual. Individuals who are approaching the end of life are entitled to high-quality care, wherever they are being cared for.

In this unit, you will develop knowledge of the requirements of legislative frameworks and agreed ways of working in the setting. It is important that you have an understanding of advanced care planning and the factors that affect end of life care. This unit will give you the opportunity to demonstrate and reflect on your skills in supporting individuals at the end of their lives.

### Learning outcomes and assessment criteria

To pass this unit, learners need to demonstrate that they can meet all the learning outcomes for the unit. The assessment criteria determine the standard required to achieve the unit.

Learning outcomes	Assessment criteria
1 Understand current legislation and agreed ways of working to protect the rights	1.1 Explain the legal requirements and agreed ways of working designed to protect the rights of individuals in end of life care

Learning outcomes	Assessment criteria
of individuals at the end of life	1.2 Assess how legislation designed to protect the rights of individuals in end of life care applies to own job role
2 Understand factors affecting end of life care	2.1 Explain key theories about the emotional and psychological processes that individuals and key people may experience with the approach of death 2.2 Explain how the beliefs, religion and culture of individuals and key people influence end of life care 2.3 Explain how an individual's wellbeing can be enhanced in end of life care by: <ul style="list-style-type: none"> <li>• environmental factors</li> <li>• non-medical intervention</li> <li>• use of equipment and aids</li> <li>• alternative therapies</li> </ul> 2.4 Discuss why support for an individual's health and wellbeing may not always relate to their terminal condition
3 Understand advance care planning in relation to end of life care	3.1 Explain the benefits to an individual of having as much control as possible over their end of life care 3.2 Explain the purpose of advance care planning in relation to end of life care 3.3 Evaluate own role in supporting and recording decisions about advance care planning 3.4 Explain ethical and legal issues that may arise in relation to advance care planning
4 Be able to provide support to individuals and key people during end of life care	4.1 Support the individual and key people to explore their thoughts and feelings about death and dying, in line with agreed ways of working 4.2 Provide support to the individual and key people in a way that respects their beliefs, religion and culture, in line with agreed ways of working 4.3 Demonstrate ways to help the individual feel respected and valued throughout the end of life period, in line with agreed ways of working

Learning outcomes	Assessment criteria
	<p>4.4 Provide information to the individual and/or key people about the individual's illness and the support available, in line with agreed ways of working</p> <p>4.5 Contribute to partnership working with key people to support the individual's wellbeing in line with agreed ways of working</p>
<p>5 Understand how to address sensitive issues in relation to end of life care</p>	<p>5.1 Explain the importance of recording significant conversations during end of life care</p> <p>5.2 Explain factors that influence who should give significant news to an individual or key people</p> <p>5.3 Explain conflicts and legal or ethical issues that may arise in relation to death, dying or end of life care</p> <p>5.4 Discuss ways to address such conflicts</p>
<p>6 Understand how symptoms might be identified in end of life care</p>	<p>6.1 Identify symptoms that may be related to an individual's condition, pre-existing conditions and treatment itself</p> <p>6.2 Explain how symptoms can cause an individual and others distress and discomfort</p> <p>6.3 Explain signs of approaching death</p> <p>6.4 Discuss different techniques for relieving symptoms</p>
<p>7 Understand the role of organisations and support services available to individuals and key people in relation to end of life care</p>	<p>7.1 Explain the role of support organisations and specialist services that may contribute to end of life care</p> <p>7.2 Explain the role and value of an advocate in relation to end of life care</p> <p>7.3 Explain how to establish when an advocate may be beneficial</p>
<p>8 Be able to take action following the death of individuals</p>	<p>8.1 Explain the importance of recognising and supporting the individual's wishes for their after-death care</p>

Learning outcomes	Assessment criteria
	<p>8.2 Carry out actions immediately following a death that respect the individual's wishes and follow agreed ways of working</p> <p>8.3 Demonstrate that support given to key people immediately following an individual's death comply with agreed ways of working</p> <p>8.4 Discuss national guidelines, local policies and procedures relating to care after death</p>
<p>9 Be able to manage own feelings in relation to an individual's dying or death</p>	<p>9.1 Explain ways to manage own feelings in relation to an individual's death</p> <p>9.2 Use support systems to manage own feelings in relation to an individual's death</p>

## Unit content

### What needs to be learned

#### **Learning outcome 1: Understand current legislation and agreed ways of working to protect the rights of individuals at the end of life**

##### **Individual**

- An individual is the person requiring end-of-life care.

##### **Legal requirements**

- Equality Act 2010.
- Human Rights Act 1998.
- Mental Capacity Act 2005.
- National Institute for Health and Care Excellence (NICE), gives information on end of life care for adults.
- Health and Safety at Work etc. Act 1974.
- Safeguarding Vulnerable Groups Act 2006.
- Deprivation of Liberty Safeguards (DoLS).

##### **Agreed ways of working**

- Agreed ways of working relating to:
  - Confidentiality, data protection, recording, reporting, confidentiality and sharing information
  - equality and diversity
  - infection control
  - personal care
  - end of life care- rights to a 'good death', respecting the individual's viewpoint and decisions, promoting choice and dignity, empowering the individual, individualised care
  - advance care planning e.g. refusal of treatment; capacity to give consent; support from advocates
  - care and support to the individual's families and others, e.g. visitors
  - dealing with personal property of deceased people
  - removal of medical equipment from deceased people.

#### **Learning outcome 2: Understand factors affecting end of life care**

## What needs to be learned

### **Key theories**

- Kübler-Ross model (1969):
  - stages of grief.
- Corrs' theory model (1992).
- Zlatin's theory model (1995).

### **Beliefs, religion and culture**

- Family may need additional support.
- Different customs at end of life.
- Care staff need to show understanding and tolerance.
- Develop effective working relationships with religious leaders across the community.

### **Enhancing the individual's wellbeing**

- Promote dignity and respect.
- Time and patience.
- Effective communication skills.
- Respect the wishes of the individual.
- Involve the individual in all decisions made.
- Advise the individual if there are any changes to the care plan.
- Seek consent.

### **Environmental factors**

- Control over where they receive end of life care.
- Support from palliative care team.
- Care in home.
- Care in hospice.

### **Non-medical intervention**

- Counselling.
- Spiritual support.
- Empathy.
- Engage in alternative therapies such as music, yoga.

### **Use of equipment and aids**

- Equipment to relieve difficulties and promote independence.
- Use of hoists for moving; change of position; bathing; toileting.
- Pressure-relieving mattresses.

### **Alternative therapies**

- Aromatherapy.
- Massage.
- Reflexology.
- Reiki.

## What needs to be learned

- Meditation.

### **Support for an individual's health and wellbeing for conditions other than their terminal condition**

- Meeting emotional needs; supporting emotional health and wellbeing.
- Maintaining symptom control for underlying conditions.
- Maintaining support for chronic existing conditions; asthma; diabetes; epilepsy.
- Regular review of treatment plans and care needs.

## **Learning outcome 3: Understand advance care planning in relation to end of life care**

### **Benefits to an individual having as much control as possible over end of life care**

- Supports feelings of involvement and ability to influence decisions about care.
- Allays fears of death.
- Empowers the individual to question care processes.
- Encourages individuals to discuss wishes and preferences.

### **Advance care planning**

- Voluntary process of discussion about future care.
- Recognise important values or personal goals for care.
- Promote understanding about the individual's illness and prognosis.
- Acknowledge the individual's preferences and wishes.
- Individual must be in agreement to share decisions.
- Mental Capacity Act 2005 and power of attorney.
- Professional responsibilities and acting in 'best interests'.
- Advance decision to refuse treatment.

### **Supporting and recording decisions**

- Clear communication and record-keeping strategies.
- Record the individual's wishes and preferences as they want them.
- Share information with the care team.
- Ensure information regarding refusal of further medical intervention is communicated effectively to professionals in other settings; in cases of transfer of care to acute settings.

### **Ethical and legal issues**

- Decisions about advance planning.
- Refusing treatment and resuscitation.
- May not share decisions with family and others.
- Legal issues – withdrawing and withholding life-sustaining treatments.
- Lasting power of attorney.

## What needs to be learned

- Assessing capacity.

### **Learning outcome 4: Be able to provide support to individuals and key people during end of life care**

#### **Support individual and key people**

- Open and honest discussions.
- Empower individuals.
- Listen to their choices.
- Support families.
- Support team.

#### **Respecting culture, religion and beliefs**

- Belief structures; customs at death; what happens after death.
- Accepting and respecting beliefs; not questioning or trivialising.
- Support for specific activities; prayer; rituals; dress; meetings; mourning.

#### **Respect and values**

- Promote dignity and respect.
- Give time.
- Listen.
- Respect the wishes of the individual.
- Involve the individual in all decisions made.
- Advise the individual if there are any changes to the care plan.
- Seek consent.

#### **Providing information**

- Providing alternative sources of advice.
- Advice regarding support networks.
- Signposting to support groups.

#### **Partnership working**

- Work with family and friends.
- Advocates.
- Professionals.
- Review care plan.
- Person-centred planning.
- Working flexibly.
- Providing clear and honest information.
- Training and support.
- Valuing contributions.

### **Learning outcome 5: Understand how to address sensitive issues in relation to end of life care**

#### **Recording significant conversations**

## What needs to be learned

- Sharing information.
- Accessed by key people.
- Promote high-quality care.
- Encourage communication.
- Ensure the individual's preferences and wishes are understood and acknowledged.
- Consistency in care.
- Update care plan.
- Working in the individual's best interests.

### **Conflicts and legal/ethical issues**

- Differing beliefs and cultures of the multidisciplinary team.
- Lack of awareness of the individual's needs.
- Recognising and respecting the individual's wishes.
- Putting aside personal experiences.

### **Ways to address conflicts**

- Clear communication channels.
- Recognising others' feelings.
- Offering support.
- Negotiation and open-minded approaches.
- Seek advice from other professionals.
- Opportunities to reflect on feelings.

## **Learning outcome 6: Understand how symptoms might be identified in end of life care**

### **Symptoms**

- Pre-existing conditions:
  - dementia; confusion; lack of ability
  - cardiovascular disease; breathlessness; pain
  - diabetes; coma
  - arthritis; stiffness; lack of mobility; pain and discomfort
  - sensory loss; lack of communication; fear; distress.
- Related to condition, e.g. pressure sores, incontinence, lack of mobility, restlessness, pain, discomfort, confusion.
- Related to treatment:
  - drowsiness
  - loss of consciousness
  - changes in breathing.

### **Distress and discomfort**

- Confusion.

## What needs to be learned

- Calling out.
- Not eating and drinking.
- Rattle of phlegm in back of throat.
- Incontinence.

### **Signs of approaching death**

- Change in consciousness levels.
- Fewer periods of awareness.
- Increased pain.
- Higher levels of pain control.
- Cyanosis around mouth; fingertips.
- Hands and feet cold.
- Changes in breathing patterns: Cheyne–Stokes respiration.

### **Relieving symptoms**

- Holistic approaches.
- Care planning.
- Effective pain control.
- Change of position.
- Oral and skin care.
- Reassurance.
- Calm environment.
- Contact with family and friends.
- Not left alone.
- Soft lighting.
- Relaxing environment.
- Avoid excess noise.
- Sensitive care.

## **Learning outcome 7: Understand the role of organisations and support services available to individuals and key people in relation to end of life care**

### **Support organisations**

- Palliative care.
- Hospice service.
- Home support.
- Domiciliary care.
- Care homes.
- Respite services.
- Day services.
- Funeral directors.

### **Role and value of an advocate**

- Independent.

## What needs to be learned

- Supports the individual.
- Voices the individual's wishes and preferences.
- Individual may want to discuss anxieties with an independent person.

### **Support for spiritual needs**

- Recognise ending of life.
- Rituals of death.
- Puts a person at peace.
- Comfort for individual and family.

### **Sources of support to address spiritual needs**

- Counsellors.
- Psychologists.
- Religious leaders.
- Support group volunteers.

## **Learning outcome 8: Be able to take action following the death of individuals**

### **Individual's wishes for their after-death care**

- Ensure compliance with wishes.
- Respect and dignity.
- Reassurance for family and others.
- Follow rituals and practices.
- Support to carers – able to end period of care.
- Provide comfort.

### **Actions following death**

- Attending to the body of the deceased.
- Cleaning and preparation.
- May be left at rest.
- Acknowledge and respect religious and cultural acts.
- Report death through agreed channels, e.g. GP.
- Informing key people.
- Support family.
- Follow agreed ways of working.
- Complete documentation and record all actions.

### **Support to key people**

- Signpost to support groups.
- Talk through feelings.
- Reassurance.
- Explanation of processes.
- Information and advice.

## What needs to be learned

### **National guidelines, local policies and procedures**

- Common Core Principles and competences for social care and health workers working with adults at the end of life (Skills for Care and Skills for Health, 2014).
- NICE quality standards for end of life care (2017).
- The end of life care strategy: New ambitions (National Council for Palliative Care, 2013).
- Gold Framework Standards (2017).
- Policies in setting.

### **Learning outcome 9: Be able to manage own feelings in relation to an individual's dying or death**

#### **Own feelings**

- Grief.
- Loss.
- Grieving process.

#### **Support systems**

- Counselling.
- Bereavement support.
- Support from mentor and team.

## Essential information for tutors and assessors

### Essential resources

There are no special resources needed for this unit.

### Assessment

This unit is internally assessed. To pass the unit, the evidence that learners present for assessment must demonstrate that they have met the required standard specified in the learning outcomes and assessment criteria.

Assessment decisions for learning outcomes 4, 8 and 9 (competence) must be made based on evidence generated during the learner's normal work activity. Any knowledge evidence integral to these learning outcomes may be generated outside of the work environment, but the final assessment decision must be within the real work environment in ways that do not intrude on the care of an individual at the end of life. Simulation cannot be used as an assessment method for learning outcomes 4, 8 and 9.

Assessment of learning outcomes 1, 2, 3, 5, 6 and 7 (knowledge) may take place in or outside of a real work environment.

The unit is assessed by a portfolio of evidence. Further information on the requirements for portfolios is included in *Section 4 Assessment requirements*.

Wherever possible, centres should adopt a holistic and integrated approach to assessing the skills units in the qualification. This gives the assessment process greater rigour, minimises repetition and saves time. The focus should be on assessment activities generated through naturally occurring evidence in the workplace rather than on specific tasks. Taken as a whole, the evidence must show that learners meet all learning outcomes and assessment criteria over a period of time. It should be clear in the assessment records where each learning outcome and assessment criterion has been covered and achieved.

## Suggested resources

This section lists resource materials that can be used to support the delivery of the qualification.

### Textbooks

Kübler-Ross E – *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss* (Simon and Schuster, 2014) ISBN 9781471139888

Machin L – *Working with Loss and Grief*, 2nd edition (Sage Publications Ltd, 2013) ISBN 9781446248881

Nicol J and Nyatanga B – *Palliative and End of Life Care in Nursing* (Learning Matters, 2017) ISBN 9781473957282

### Websites

[www.dyingmatters.org](http://www.dyingmatters.org)

Dying Matters – a website aimed at raising awareness to promote public awareness of dying, death and bereavement.

[www.macmillan.org.uk](http://www.macmillan.org.uk)

Website for Macmillan Cancer Support.

[www.nhs.uk](http://www.nhs.uk)

National Health Service website – end of life care.

[www.nice.org.uk](http://www.nice.org.uk)

National Institute for Health and Care Excellence (NICE) – gives guidance on palliative cancer care for pain.

[www.rcnendoflife.org.uk](http://www.rcnendoflife.org.uk)

Royal College of Nursing website.

[www.skillsforcare.org.uk](http://www.skillsforcare.org.uk)

Skills for Care – includes a reference document on end of life care.

[www.scie-socialcareonline.org.uk](http://www.scie-socialcareonline.org.uk)

Social Care Institute for Excellence website – includes information on end of life care.