

# **Unit 57: Support End of Life Care in Adult Care**

**Unit reference number: Y/616/7428**

**Level: 4**

**Unit type: Optional**

**Credit value: 7**

**Guided learning hours: 48**

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## **Unit summary**

Providing support and care at the end of life is essential to the manager's role in adult care. It is a period of care that requires efficient and sensitive planning and resourcing. It also requires there to be effective partnerships with users of services and their families and friends, and with other agencies. End of life care has been developed and is supported by a national care strategy. Leading this care requires knowledge, skills and awareness of the demands of this work on self and staff teams.

This unit gives you the knowledge and skills you need to be able to support end of life care. You will review the agreed ways of working in your own organisation in line with national guidance. As a leader, you will review your own role in ensuring effective practice and planning, as well as supporting users of services, families and staff teams.

## Learning outcomes and assessment criteria

To pass this unit, the learner needs to demonstrate that they can meet all the learning outcomes for the unit. The assessment criteria outline the requirements the learner is expected to meet to achieve the unit.

Learning outcomes	Assessment criteria
<p>1 Understand the impact of regulatory and national guidance on developing agreed ways of working in end of life care in adult care</p>	<p>1.1 Explain the legal requirements and agreed ways of working designed to protect the rights of users of services in end of life care</p> <p>1.2 Review current national policies and regulatory guidance in maintaining high standards of end of life care</p> <p>1.3 Evaluate opportunities for service improvement and policy review in end of life care in own setting, based on governance frameworks</p>
<p>2 Understand the factors that can affect planning of end of life care in adult care</p>	<p>2.1 Explain how to adapt end of life care to the beliefs, religion and culture of users of services</p> <p>2.2 Assess social factors that may affect the way a user of services and their family respond to planning and support in end of life care</p> <p>2.3 Review the role of family and social networks in end of life care</p> <p>2.4 Analyse theoretical approaches to death, dying and grieving in considering the psychological support needs of the user of services and their family and friends</p>
<p>3 Understand the importance of promoting person-centred planning in end of life care</p>	<p>3.1 Explain the approaches used in own setting to promote person-centred planning in end of life care</p> <p>3.2 Review own role in supporting and recording decisions about advance care planning</p> <p>3.3 Assess ethical and legal issues that may arise in relation to advance care planning</p>

Learning outcomes	Assessment criteria
<p>4 Be able to lead on the development and implementation of agreed ways of working in end of life care</p>	<p>4.1 Lead development of policies and procedures in response to national guidance on end of life care</p> <p>4.2 Facilitate training and staff development opportunities in end of life care in line with organisational policy</p> <p>4.3 Provide support in accordance with organisational policy for a user of services and their family and friends that respects their beliefs, religion and culture</p> <p>4.4 Provide information in line with organisational policy to a user of services and/or family and friends about the illness of the user of services and the support available</p> <p>4.5 Support staff team to provide individualised end of life care according to any advance directives or wishes and preferences of the user of services in line with organisational policy</p> <p>4.6 Contribute to partnership working with family and friends to support the wellbeing of the user of services in accordance with organisational policy</p>

Learning outcomes	Assessment criteria
<p>5 Be able to address sensitive issues in relation to end of life care in adult care</p>	<p>5.1 Support the user of services and family and friends to explore their thoughts and feelings about death and dying</p> <p>5.2 Promote a sensitive and caring ethos for staff team to review their own feelings and responses to death and dying</p> <p>5.3 Discuss how to respond to conflicts and legal or ethical issues that may arise in relation to death, dying or end of life care</p>
<p>6 Understand the role of organisations and support services available to users of services and their family and friends in end of life care in adult care</p>	<p>6.1 Discuss the role of support organisations and specialist services that may contribute to end of life care</p> <p>6.2 Assess the role and value of an advocate in relation to end of life care</p> <p>6.3 Analyse sources of support to address spiritual needs of users of services and their families in end of life care</p> <p>6.4 Reflect on own role in working as a part of a team to develop effective end of life care and support to users of services and their families, and how these experiences could inform future practice</p>

### What needs to be learned

#### **Learning outcome 1: Understand the impact of regulatory and national guidance on developing agreed ways of working in end of life care in adult care**

##### **Legislation and rights of individual**

- Equality Act 2010.
- Mental Capacity Act 2005 – best interests principle.
- Consent and capacity.
- Equalities and human rights – Human Rights Act 1998.
- Lasting power of attorney (LPA).

##### **Regulatory guidance and national policy**

- NICE quality standard for end of life care for adults (2011).
- National End of Life Care Strategy, Department of Health (2008).
- The National Council for Palliative Care guidance on planning future care (2014).
- The National Gold Standards Framework (GSF) guidance on end of life care (2017).

##### **Benchmarks for best practice**

- 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).

##### **Service improvement**

- Clear care pathways.
- Understanding needs of users of services.
- Working as part of wider team.
- Supporting needs of users of services and family and friends.
- Developing approaches that promote dignity and respect empowerment, choice and control.

#### **Learning outcome 2: Understand the factors that can affect planning of end of life care in adult care**

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

- Preparing for death and last wishes.
- Spirituality, rejoicing in past life, wanting to make amends, wanting to share feelings.
- Religious factors, different religious customs and last rites.
- Customs relating to death.
- Funeral preparations, family roles and preparation of the body.
- Burial, cremation and natural burial.
- Wakes, celebrations of life.
- Belief structures regarding afterlife, e.g. heaven, reincarnation.

## What needs to be learned

### Social factors

- Influence of life circumstances, e.g. age, gender, sexuality, disability.
- Family/friends support networks; how they react to death and dying.
- Feelings, e.g. fear, guilt, anxiety about death process and what happens next.
- Taboos and superstitions.
- Preparing for death, e.g. wanting to support those left behind, wanting to make contact with lost friends/family.
- Making plans, e.g. wills, advance directives, paying funeral costs.
- Effective communication between professionals; discussion regarding death.
- Organ donation.

### Role of family and social networks

- Support to user of services, e.g. comfort, care, shared memories, reassurance, company, allay fear and anxiety.
- Provide information about last wishes.
- Can contact wider family and ensure all preparations are in place.

### Theoretical approaches

- Stages of grieving – Kübler-Ross (1969) five stages.
- Bowlby's theory of grief (1961).
- The Dual Process Model of Coping with Bereavement – Stroebe and Schut (1999).
- The Theory of Continuing Bonds – Klass, Silverman and Nickman (1996).
- Emotional and psychological impact of bereavement.
- Complicated grieving, e.g. unable to move on.
- Support, e.g. counselling, cognitive behaviour therapy.

### Learning outcome 3: Understand the importance of promoting person-centred planning in end of life care

#### Person-centred planning

- Individualised.
- Responsive to needs.
- Innovative.
- Gives choice and control.
- Promotes dignity and respect.
- Supports independence.
- Promotes quality of life, tailored to the religious, cultural and ethnic needs of users of services.

## What needs to be learned

### Advance care planning

- Identifying wishes and preferences.
- Refusing specific treatments; putting a do not resuscitate (DNR) order in place.
- Requesting an advocate.
- Making a lasting power of attorney.
- Support from medical team.
- Recording information.
- Open dialogue.

### Ethical and legal issues

- Conflict over advance directives.
- Interpreting information.
- Changes to care planning.
- Family disagreement.
- Ability to give consent.
- Mental capacity.

## Learning outcome 4: Be able to lead on the development and implementation of agreed ways of working in end of life care

### Policies and procedures

- End of life care.
- Data protection.
- Health and safety.
- Infection control.
- Advance directives.

### Staff development

- Team meetings and feedback, agreement on care.
- Training, e.g. staff training, dedicated courses, accredited certification courses.
- Developing organisational approaches.
- Standardisation of care pathways.
- Response to changing legislation.
- Evidence-based practice.

### Supporting users of services and key people

- Effective methods of communication, e.g. reading cues to talk, sharing life experiences, showing respect.
- Confidentiality.
- Enabling privacy.
- Listening skills.
- Record keeping.

## What needs to be learned

- Encouraging opportunities for user of services to talk with family and friends.
- Effective communication across agencies, integrated planning.
- Building relationships based on trust.
- Recognising boundaries of role.

### Supporting staff

- Emotional impact, e.g. grief and grieving, stress, anxiety, worry about what will happen due to lack of experience, fear of own responses.
- Self-awareness.
- Links to personal experiences.
- Coping with grief of others.
- Seeking support.
- Sources of support, e.g. support groups, internet, manager.
- Adhering to policies and procedures.

### Partnership working

- Working collaboratively.
- Effective planning.

## Learning outcome 5: Be able to address sensitive issues in relation to end of life care in adult care

### Thoughts and feelings

- Communication and listening.
- Empathy.
- Sharing feelings.
- Professional approach.
- Understanding and allaying fears.

### Caring ethos

- Promoting feelings of security and safety.
- Allowing for expressions of grief.
- Recognising different responses.
- Promoting opportunities to discuss feelings.

### Dealing with conflict

- Showing understanding.
- Promoting calm.
- Recognising states of anxiety.
- Supporting the needs of the user of services.

### Own feelings and support needs

- Recognising own feelings.
- Identifying with past experiences.
- Seeking support through mentors.
- Reflecting on experiences.

## What needs to be learned

### **Learning outcome 6: Understand the role of organisations and support services available to users of services and their family and friends in end of life care in adult care**

#### **Support organisations and specialist services**

- Palliative care team.
- Hospice care.
- Social care.
- Voluntary agencies.
- Macmillan nurses.
- Hospice staff.
- Consultants/GP.
- Pharmacists.
- Palliative care social workers.
- Psychologists.
- Grief counsellors.
- Funeral directors.

#### **Role of advocate**

- Non-biased approach.
- Speaking for user of services.
- Promoting personal preferences and choices for user of services.

#### **Meeting spiritual needs**

- Liaising with clergy/ministers.
- Awareness of main spiritual/religious teachings.
- Supporting visits and enabling privacy.
- Respect for beliefs of others.

#### **Teamwork**

- Shared communication.
- Integrated support and planning.
- Support for families.
- Practical support, e.g. finances, benefits, funeral planning.
- Best interests meetings, advance planning directives.

## Information for tutors

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### Suggested resources

#### Books

Chapman C – *The Mental Capacity Act in Practice: Guidance for End of Life Care* (National Council for Palliative Care, 2008) ISBN 9781898915621

Katz J, Peace S – *End of Life in Care Homes: A Palliative Care Approach* (Oxford University Press, 2003) ISBN 9780198510710

Kübler-Ross E – *On Death and Dying* (Routledge, 1973) ISBN 9780415040150

#### Websites

<a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a>	Alzheimer's Society
<a href="http://www.cqc.org.uk">www.cqc.org.uk</a>	Care Quality Commission
<a href="http://www.goldstandardsframework.org.uk">www.goldstandardsframework.org.uk</a>	The National Gold Standards Framework (GSF) – training for providing end of life care
<a href="http://www.ncpc.org.uk">www.ncpc.org.uk</a>	The National Council for Palliative Care
<a href="http://www.nice.org.uk">www.nice.org.uk</a>	National Institute for Health and Care Excellence
<a href="http://www.scie.org.uk">www.scie.org.uk</a>	Social Care Institute of Excellence
<a href="http://www.skillsforcare.org.uk">www.skillsforcare.org.uk</a>	Skills for Care

#### Other

*Advance Care Planning: A Guide for Health and Social Care Staff* (NHS End of Life Care Programme and University of Nottingham, 2007) PDF available online: [www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf](http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf)

*Advance Decisions to Refuse Treatment: A Guide for Health and Social Care Professionals* (NHS End of Life Care/National Council for Palliative Care, 2008) PDF available online: [www.londonhp.nhs.uk/wp-content/uploads/2011/03/EOLC-advance-decisions-to-refuse-treatment.pdf](http://www.londonhp.nhs.uk/wp-content/uploads/2011/03/EOLC-advance-decisions-to-refuse-treatment.pdf)

*Building on Firm Foundations – Improving end of life care in care homes: examples of innovative practice* (NHS End of Life Care Programme/National Council for Palliative Care, 2007) PDF available online: [www.ncpc.org.uk/sites/default/files/BuildingOnFirmFoundations.pdf](http://www.ncpc.org.uk/sites/default/files/BuildingOnFirmFoundations.pdf)

*Talking about end of life care: right conversations, right people, right time* (NHS, 2011) PDF available online: [socialwelfare.bl.uk/subject-areas/services-activity/health-services/nhsnationalendoflifecareprogramme/140380TalkingAboutEndOfLifeCare20110124.pdf](http://socialwelfare.bl.uk/subject-areas/services-activity/health-services/nhsnationalendoflifecareprogramme/140380TalkingAboutEndOfLifeCare20110124.pdf)

## **Assessment**

This guidance should be read in conjunction with the associated qualification specification for this unit.

This unit is internally assessed. To pass this unit, the evidence that the learner presents for assessment must demonstrate that they have met the required standard specified in the learning outcomes and assessment criteria, and the requirements of the assessment strategy.

To ensure that the assessment tasks and activities enable learners to produce valid, sufficient, authentic and appropriate evidence that meets the assessment criteria, centres should follow the guidance given in *Section 8 Assessment* of the associated qualification specification and meet the requirements from the assessment strategy given below.

Wherever possible, centres should adopt an holistic approach to assessing the units in the qualification. This gives the assessment process greater rigour and minimises repetition, time and the burden of assessment on all parties involved in the process.

### **Unit assessment requirements**

This unit must be assessed in accordance with the assessment strategy (principles) in *Annexe A* of the associated qualification specification.

Assessment decisions for learning outcomes 4 and 5 (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. Simulation cannot be used as an assessment method for learning outcomes 4 and 5. Learning outcomes 4 and 5 must be assessed in a real work environment in ways that do not intrude on the care of a user of services at the end of life.

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