

Unit 21: Understanding the Impact of Dementia on End of Life Care

Level:	3
Unit type:	Optional (Group B1)
Credit value:	2
Guided learning hours:	20

Unit introduction

A diagnosis of dementia can be a challenging experience for individuals and their relatives so care workers must have a good understanding of the needs associated with dementia and how individuals can be supported.

In this unit, you will consider the impact of dementia on end-of-life care provision, including how to support individuals with dementia affected by pain and distress at end of life. You will examine what is meant by person-centred care for individuals with dementia and will consider what is currently viewed as best practice in the sector. You will explore the support needed to ensure that an individual who has dementia and requires end-of-life care maintains independence and dignity while responding to their changing needs. You will also understand the nature of the support needed by the carers of individuals with dementia.

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 end of life care provision for individuals with dementia	1.1 Outline ways in which dementia can be a terminal illness
		1.2 Compare the differences in end of life experiences of an individual with dementia to that of an individual without dementia
		1.3 Explain why end of life care for an individual with dementia must be person-centred

Learning outcomes		Assessment criteria
		1.4 Explain why individuals with dementia need to be supported to make advance care plans as early as possible
2	Understand how to support individuals with dementia affected by pain and distress at end of life	2.1 Explain why pain in individuals with dementia is often not recognised and undertreated 2.2 Describe how to assess whether an individual with dementia is in pain or distress 2.3 Describe ways to support individuals with dementia to manage their pain and distress at the end of life using: • medication • non-medication techniques
3	Understand how to support carers of individuals with dementia at end of life	3.1 Explain why carers may experience guilt and stress at the end of life of an individual with dementia 3.2 Describe ways of supporting carers to understand how the end of life process may differ for individuals with dementia 3.3 Describe how others caring for individuals with dementia may experience loss and grief 3.4 Describe ways of supporting carers when difficult decisions need to be made for individuals with dementia at the end of life 3.5 Describe how to enable carers and others to support an individual with dementia in the final stages of life

Unit content

What needs to be learned

Learning outcome 1: Understand end of life care provision for individuals with dementia

Individual

- Someone requiring care or support; it will usually mean the person or people supported by the learner.

Ways in which dementia can be a terminal illness

- Individual becomes more frail.
- More frequent falls.
- More susceptible to infections.
- Becomes less mobile.
- Eats less frequently with potential impact on nutritional intake.
- Less communicative so not so able to report pain, illness or anxiety.
- Weaker immune system.
- Unusual or unpredictable behaviour potentially leading to accidents, incidents or falls.

The difference in end of life experiences of an individual with dementia to that of an individual without dementia

- Communication and interaction with carers.
- Confusion or anxiety regarding condition and symptoms.
- Limited or lack of capacity in relation to decision making.
- Decision making made by others in their best interests.
- Limitations of individuals with dementia in information processing.
- Behavioural differences.
- Anxiety or confusion regarding the possible changes to the environment.

Person-centred end of life care

- Holistic approach to care needs.
- Ongoing care planning and review.
- Dignity, privacy and respect, independence.
- Rights and empowerment.
- Rights under the Mental Capacity Act 2005.
- Recognition of cultural and religious differences and requirements.
- Entitlement to advocacy.

What needs to be learned

- To ensure physical, psychological, social and spiritual needs are met.

Importance of making advance care plans as early as possible

- Understanding of dementia as a progressive illness.
- Greater understanding and awareness of the decisions to be made in the early stages of dementia.
- Increased capacity in relation to decision making in the early stages.
- Increased involvement in decision making in the early stages.

Learning outcome 2: Understand how to support individuals with dementia affected by pain and distress at end of life

Why pain in individuals with dementia is often not recognised and undertreated

- Limited communication can affect interaction with carers.
- Individual less able to express pain, distress or discomfort.
- Signs and symptoms of pain may be confused with symptoms of dementia.
- Increased risk of pain, distress or discomfort due to the normalisation of pain by carers.

Assessment of individuals with dementia that are in pain or distress

- Monitoring and observation of facial expressions and body language.
- Changes to behaviour.
- Verbalisation through speech, moans, grunting, asking for help.
- Emotional indicators.
- The use of pain assessment tools.

Supporting pain and distress at end of life

- Medication:
 - prescribed medication to treat specific symptoms and pain levels
 - ongoing monitoring and review of medication and impact on pain and distress.
- Non-medication techniques:
 - acupuncture
 - the use of heat/ice packs
 - repositioning in bed/chair
 - relaxation therapy
 - massage
 - relaxation exercises.

What needs to be learned

Learning outcome 3: Understand how to support carers of individuals with dementia at end of life

Why carers may experience guilt and stress at end of life of an individual with dementia

- Carer is the unpaid carer, often a relative or friend.
- Difficult for carers coming to terms with the loss of the individual.
- Guilt due to the possibly limited communication abilities of the individual with dementia.
- Anxiety focused on the level of care provided.
- Guilt in relation to meeting of all the individual's needs as this may not be possible due to capacity issues.

Ways end of life processes may differ for individuals with dementia

- Clear information.
- Involvement in the care planning and provision process.
- Availability of information, advice and guidance.
- Inclusion and involvement in decision making, as appropriate.

Caring for those with dementia

- Others, e.g. partner, family, friends, neighbours, care worker, colleague, manager, other professionals.
- Grief through loss of role and responsibility.
- Questioning of service delivery and the meeting of individual's needs.
- Challenges to practitioner role.
- Anxiety through the diagnosis of dementia to end of life for the individual.
- Stress through poor or limited communication with the individual.
- Negative emotions towards the individual.
- Anxiety through the meeting, or not meeting, of expectations.

Supporting carers

- Help to make difficult decisions.
- Knowledge and use of recognised frameworks and legislation.
- Advice, guidance and support available from external agencies.
- Support from practitioners, e.g. GP, nurses.
- Signposting to support groups and networks.
- Effective communication and interpersonal skills.
- Identification of roles and responsibilities.

What needs to be learned

- Consent from the individual.
- Ongoing assessment and review of care needs.
- Demonstration of tasks to be or being carried out.
- Inclusion in care activities.
- Currency of information.
- Availability of information and access in relation to confidentiality.

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.

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

Assessment of all learning outcomes (knowledge) may take place in or outside of a real work environment.

Centres are responsible for deciding on the assessment activities that will enable learners to produce valid, sufficient, authentic and appropriate evidence to meet the assessment criteria.

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

Baker C – Developing Excellent Care for People Living with Dementia in Care Homes (Bradford Dementia Group Good Practice Guides) (Jessica Kingsley Publishers, 2014) ISBN 9781849054676

Brooker D – Person-Centred Dementia Care: Making Services Better (Bradford Dementia Group) (Jessica Kingsley Publishers, 2006) ISBN 9781843103370

Genova L – Still Alice (Simon & Schuster, 2015) ISBN 9781471140822

Keady J et al – Partnerships in Community Mental Health Nursing & Dementia Care: Practice Perspectives (Open University Press, 2007) ISBN 9780335215812

Magnusson S – Where Memories Go: Why dementia changes everything (Two Roads, 2015) ISBN 978144475181

Oddy R – Promoting mobility for people with dementia: A problem solving approach (Alzheimer's Society, 2014) ASIN B00OP8PSCS

Pace V, Treloar A and Scott S – Dementia: From Advanced Disease to Bereavement (Oxford University Press, 2011) ISBN 9780199237807

Pool J – Alzheimer's Society guide to the dementia care environment (Alzheimer's Society, 2015) ASIN B00U2T530Q

Suchet J – My Bonnie: How dementia stole the love of my life (Harper, 2011) ISBN 9780007328413

Whalley LJ – *Understanding Brain Aging and Dementia: A Life Course Approach* (Columbia University Press, 2015) ISBN 9780231163835

Websites

www.alzheimers.org.uk

End-of-life care factsheet.

www.nhs.uk

Gives information on the Mental Capacity Act.

www.nice.org.uk

NICE Clinical Guidelines 42 (Nov 2006, reviewed April 2012) – Dementia: Supporting People with Dementia and their Carers in Health and Social Care

www.nice.org.uk

Social care tailored resources on dementia.

www.nice.org.uk

NICE (April 2013) Supporting people to live well with dementia, Quality Standard 30, statement 9 Independent advocacy

www.scie.org.uk/socialcaretv

Mental Capacity Act: the role of the IMCA (Independent Mental Capacity Advocate), SCIE Social Care TV video (2011), Best Interest Meetings Guidance.