

# Managing success in dementia care

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A support resource for implementing Tier 2 of the Dementia Training Standards Framework in health and social care settings



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# Contents

Introduction: Managing Success in Dementia Care .....	4
What do staff need to know and do? .....	6
Subject 2: Dementia identification, assessment and diagnosis.....	11
Subject 3: Dementia risk reduction and prevention .....	18
Subject 4: Person-centred dementia care .....	21
Subject 5: Communication, interaction and behaviour in dementia care .....	29
Subject 6: Health and well-being in dementia care .....	35
Subject 7: Pharmacological interventions in dementia care .....	51
Subject 8: Living well with dementia and promoting independence.....	54
Subject 9: Families and carers as partners in dementia care .....	66
Subject 10: Equality diversity and inclusion in dementia care .....	72
Subject 11: Law, ethics and safeguarding in dementia care.....	81
Subject 12: End of life dementia care.....	86
Subject 13: Research and evidence-based practice in dementia care .....	91

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# Introduction: Managing Success in Dementia Care

A support resource for implementing the *Dementia Training Standards Framework* in health and social care settings

*Managing Success in Dementia Care*, commissioned by Health Education England (HEE), has been developed to support leaders and managers working across health and social care to implement the learning outcomes of the Dementia Training Standards Framework<sup>1</sup>. The Framework is there to support staff to have the right knowledge and skills to deliver high quality, person-centred care for people living with dementia as well as their families/carers, across health and care services. It identifies what staff need to know and be able to do, set out as a range of subject areas and learning outcomes. It comprises three tiers (awareness, basic skills and leadership) which reflect the role and degree of contact different staff have with people living with dementia.

The Framework makes clear that it is up to managers/training leads to determine how the learning outcomes are met. This can be in a variety of different ways including formal training through to mentorship and activities within team meetings and supervision.

*Managing Success in Dementia Care* is not in and of itself a training resource. It is designed to support managers and others responsible for training within organisations to identify resources they can use to deliver education and training activities at tier 2 (core skills and knowledge for people who regularly work directly with people living with dementia). Each section provides an overview of the subject area, explanations of the learning outcomes and signposts to relevant freely available resources or information. These can be used to supplement existing training provision, or combined with additional resources to create new training programmes. It is not an exhaustive list of all freely available training materials, but is intended to signpost to a range of useful and accessible resources.

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<sup>1</sup> Skills for Health, Health Education England, Skills for Care, 2018. *Dementia Training Standards Framework*. Skills for Health, London: Available to download from <https://hee.nhs.uk/our-work/dementia>

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*Managing Success in Dementia Care* is designed to be used in conjunction with the HEE 'Dementia Training Resource List'<sup>2</sup>, the Framework Learning Outcomes Mapping Document<sup>3</sup> and the DeTDAT training audit tool and manual<sup>4</sup>, all of which can be freely downloaded from the links provided (see footnotes below).

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<sup>2</sup> Health Education England and Leeds Beckett University 2018 *Dementia Training Resource List*. Available to download from <https://www.hee.nhs.uk/our-work/dementia>

<sup>3</sup> Surr, C. (2018) *Dementia Training Standards Framework: Learning Outcomes Mapping Tool v3.0*. Leeds: Leeds Beckett University. Available to download from <http://www.leedsbeckett.ac.uk/school-of-health-and-community-studies/what-works/>

<sup>4</sup> Surr, C., Sass, C., Griffiths, A., Oyebode, J., Smith, S., Parveen, S., Drury, M., 2017. *Dementia Training Design and Delivery Audit Tool (DeTDAT) v4.0*. Leeds Beckett University, Leeds. All available to download from <http://www.leedsbeckett.ac.uk/school-of-health-and-community-studies/what-works/>

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# What do staff need to know and do?

The *Dementia Training Standards Framework* is designed to be used flexibly by managers and training leads. This section will help you to consider the different subject areas and learning outcomes that staff within your organisation need to cover within their training, recognising that dependent on the service type and staff role some subjects and outcomes will be more relevant or crucial for them to understand and cover in more or less depth than others. For example, staff working in memory assessment services will need to have a much more in-depth knowledge of dementia assessment and diagnosis processes than a member of staff working in home care services. However, it is important for staff working in all service settings and roles to have tier 1 knowledge and skills including understanding the signs and symptoms of dementia and to be able to signpost or refer onto diagnostic services. The Framework will help your service deliver services and support that uphold the 'We statements' contained within the National Dementia Declaration<sup>5</sup>.

## What is a subject area within the Framework?

The Framework contains 14 Subjects, 12 of which have learning outcomes at tier 2. The subject areas are broad topics associated with key components of the diagnostic, treatment, care and support processes for those living with dementia and for their family members/supporters. They are designed to break down the Framework into manageable components. However, it is important to recognise there is considerable overlap or interrelationship between the subjects. For example, while there is a subject of 'Families and carers as partners in care' the need to involve and support families appears within a range of the subject areas. Therefore, it will be necessary to have a good general overview of the whole Framework before making decisions about which subject areas staff in your organisation need to cover during training. It can also be useful to discuss individual learning needs with staff members during supervision and personal development planning meetings.

## What is a learning outcome?

Each of the Framework subject areas contains a number of learning outcomes. These are split into outcomes for tier two with additional outcomes for achieving tier 3.

**“A learning outcome is an active statement that outlines something that a learner should know or be able to do on completion of the training.”**

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<sup>5</sup> <https://www.dementiaaction.org.uk/nationaldementiadeclaration>

In training that does not include any formal assessment, there may be informal ways of understanding whether learners have met these outcomes for example through the points they raise and answers they give in activities and discussions, use of practical exercises or quizzes where skills are applied in situations similar to those practice. In formal accredited education or training, learning outcomes are assessed and so the assessments (essays, clinical assessments, practice projects, exams etc.) are designed to measure the extent to which learners have met the outcome. Learning outcomes, whether for accredited or less formal unaccredited training, should drive or guide the training content and delivery.

## Assessing training needs

Before you commence commissioning, development or review of training in your organisation it is important to assess what subjects and learning outcomes it is relevant for staff to be achieving and then, if and how current training provision meets these needs. It can be useful to do this by staff group as the knowledge and skills required by different staff groups may differ. For example, in social care direct staff knowledge and skills will be different from those for ancillary staff, even though both groups have regular contact with people with dementia and so require tier 2 training. Likewise, in healthcare settings nurses may have slightly different needs than physiotherapists or radiographers.

It may be helpful to develop a matrix like the example below to map training needs by staff group. You may wish to then create a subjects and learning outcomes profile per role so that the detail of which learning outcomes each staff role needs to cover are provided in a single document.

	Subject 2	Subject 3	Subject 4	Subject 5
<b>Care staff</b>	Some	All	All	All
<b>Senior carers</b>	Some	All	All	All
<b>Deputy/ Manager</b>	All	All	All	All
<b>Cleaning</b>	No	No	Some	All
<b>Catering</b>	No	Some	Some	All
<b>Admin</b>	No	No	Some	All

You can then use the *Framework Learning Outcomes Mapping Document*<sup>6</sup> to map current provision against the Framework subjects and learning outcomes to identify areas already covered by existing training and gaps in current provision.

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<sup>6</sup> Surr, C. (2018) Dementia Training Standards Framework: Learning Outcomes Mapping Tool v3.0. Leeds: Leeds Beckett University: Available to download from <http://www.leedsbeckett.ac.uk/school-of-health-and-community-studies/what-works/>

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When considering how to provide staff with training that meets the identified gaps, it is important to consider the quality of training provided and not just the content that is covered. The next sections will help you to identify key components of good quality training.

## What does good quality training look like?

Researchers from Leeds Beckett, Bradford and Leeds Universities completed the ‘What Works? in dementia training and education’ study in 2017, which aimed to look at the components that make up good quality dementia training, which is most likely to be effective. You can find all the outputs from the research on the study website <http://www.leedsbeckett.ac.uk/school-of-health-and-community-studies/what-works/>

The *DeTDAT audit tool*, which can be downloaded from there, along with its auditor’s manual provides an overview of the key components the study identified and way of assessing whether training you currently provide, are planning or commissioning meets these best practice criteria. Key features of training that was best received by learners, which had the greatest impact on learner knowledge, skills, attitudes, behaviours and made a difference to practice outcomes included:

- Face-to-face delivery by an experienced facilitator able to create a safe learning environment that supports questioning and discussion
- Engaging and interactive content that includes opportunities for discussion
- The use of in-person, video or written scenarios as a basis for discussion
- Being tailored to the service setting and role of learners
- Inclusion of theoretical/knowledge-based content alongside opportunities to apply learning in practical ways
- The ability to tailor training to the individual needs of groups of learners, including opportunities for them to bring along and discuss their own practice examples and problems
- Materials that were clear, succinct and jargon free and which considered the learners and their literacy levels
- Being at least 3.5-hours in total and preferably more than 8-hours in total, with individual sessions of at least 2-hours

### **E-learning and learning through self-study booklets**

We recognise the role that e-learning or use of study booklets plays in training provision for many providers. The *What Works? study* found that face-to-face learning could be combined with other methods such as e-learning and be beneficial. This worked best when learners were given only short learning tasks to complete on-line or using booklets and then came together to discuss what they had read. The main challenges associated with e-learning or self-study booklets were that staff



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consistently reported they did not enjoy learning by this method, completion rates were often poor and knowledge gains were not always seen. Therefore, provision of training solely via e-learning or self-study booklets is unlikely to be effective and provide staff with the knowledge and skills you want them to have. We therefore recommend you carefully consider the delivery methods that are most likely to be effective and useful for your staff.

Within the *DeTDAT tool* you will find a section of the tool dedicated to e-learning. This will help you to identify which models and approaches within e-learning are most likely to lead to positive outcomes. If you do decide to use an e-learning component, we advise you combine it with face-to-face small group sessions to provide staff with an opportunity to discuss and consolidate their learning.

## The Health Education England Dementia Training Resource List

This is a list of resources compiled by Health Education England and audited by staff from The Centre for Dementia Research, Leeds Beckett University using the *DeTDAT tool*. To be included in the resource list training materials or programmes needed to have met a minimum standard against the audit criteria and to cover a number of the Framework learning outcomes, in an appropriate depth for their tier and intended audience. Some of the materials in the list are freely available and can be used by staff within your organisation to deliver training. Another outcome from the *What Works? study* was the importance of training being delivered by an experienced facilitator who also has relevant professional experience of dementia care. Therefore, it is important organisations ensure that those responsible for delivering training have the right skills and experience to do so. There is no single programme that covers all of the tier 2 learning outcomes. Therefore, you will need to combine a number of the free resources with other materials highlighted in this guide in order to bring together a comprehensive tier 2 dementia training programme.

Other training programmes included on the resource list are available to purchase from a training provider. Most of these are programmes aimed at tier 3. You should note that their inclusion on the list is based on audit of their content areas and delivery methods and not on observation of the training delivery. Therefore, Skills for Health, Skills for Care, Health Education England and Leeds Beckett University cannot guarantee the quality of delivery of these programmes should you decide to purchase them.

## Additional resources identified in this guide

This guide highlights a range of resources under each learning outcome that you may find helpful in considering methods for upskilling the workforce within your organisation. None of the identified resources stand as a training programme or source in their own right. Most provide a starting point

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for further discussion, exercises or activities. They will therefore, need to be combined with other materials into a training session or programme.

The resources contained in this guide are not intended to be an exhaustive list of all available dementia training resources. It should be noted that while all resources were freely available via the external web-links provided at the time of going to press, on-line information can change and we are unable to guarantee continued availability of all included resources.

Please note that not all subject areas and learning outcomes currently have resources that we have identified, which are available to support them.

You will also find a range of other freely available resources that may help you to implement the learning outcomes within the Framework from the following web-sites. These are being updated on an ongoing basis so we would advise visiting the sites regularly:

Health Education England - <https://www.hee.nhs.uk/our-work/dementia>

Skills for Care - <http://www.skillsforcare.org.uk/Home.aspx>

Skills for Health - <http://www.skillsforhealth.org.uk/>

SCIE - <http://www.scie.org.uk/>

The Alzheimer's Society - <https://www.alzheimers.org.uk/>

Alzheimer's Research UK - <https://www.alzheimersresearchuk.org/>

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# Subject 2: Dementia identification, assessment and diagnosis

## Introduction

Understanding how to identify potential signs and symptoms of dementia in someone without a diagnosis and then what to do or advise a person and those who support them (family, friends etc.) is an important skill set to have for any member of health and social care staff who has contact with older people but also with working age adults. There are currently over 40,000 people under the age of 65 who are diagnosed with dementia and so staff working with those in their 40s, 50s and 60s also need to understand potential signs and symptoms, particularly as those affected and their families may not suspect dementia as a potential cause.

## Subject level resources and training programmes

Please refer to the HEE *Dementia Training Resource List* for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

### **a) know the most common types of dementia in the UK and their underlying causes**

Understanding the most common types of dementia and their causes can be important for staff to know since this can help in considering whether any symptoms that people or their families report, or which they notice in people they are caring for, may be due to dementia. This can be particularly helpful if they also have access to information about the individual's medical history or background. For example, a past history of smoking and a previous stroke would increase an individual's risk of developing vascular dementia. Often when individuals or families have been through a diagnostic process they may have questions about the type of dementia they have been diagnosed with or about reducing their risk of developing the condition. They may turn to health, social care and housing staff outside of Memory Assessment Services for answers and support.

This web-site content and short video clips from SCIE provide information about the most common types of dementia.

<https://www.scie.org.uk/dementia/about/>

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This website content about the most common types of dementia and their causes is from Alzheimer's Research UK.

<https://www.alzheimersresearchuk.org/about-dementia/types-of-dementia/>

This video clip from SCIE includes interviews with leading scientists and experts in dementia research who talk in an accessible way about the different types of dementia and their causes.

<https://www.scie.org.uk/dementia/symptoms/diagnosis/causes-of-dementia.asp>

## **b) understand the signs and symptoms of dementia that would indicate the need for further assessment**

Individuals with suspected dementia and their family members may or may not spot potential signs and symptoms of dementia before a diagnosis is made. They may report puzzling symptoms or that they feel things are just 'not right', but may not associate this with potential dementia; particularly if the individual affected is younger. They may therefore rely on staff working in other health and social care services that they come into contact with to spot these and to suggest seeking further assessment.

This web-site content contains information about the early signs of dementia and is from SCIE.

<https://www.scie.org.uk/dementia/symptoms/diagnosis/early-signs-of-dementia.asp>

This web-site content from SCIE outlines some of the other treatable illnesses that can have symptoms similar to dementia and which need to be ruled out as part of a diagnostic process.

<https://www.scie.org.uk/dementia/symptoms/diagnosis/what-else.asp>

## **c) know why early diagnosis of dementia is important and the likely outcomes if assessment and treatment is delayed**

Dementia still carries with it a significant stigma and this can be a barrier to people seeking a diagnosis. While it is everyone's right to decide if and when they choose to seek a diagnosis, if they have symptoms that may indicate dementia, health and social care staff with who are able to talk about potential benefits of early diagnosis can help people to make an informed decision. It is also important that potentially treatable conditions that have similar symptoms to dementia are ruled out. The following resources may be useful:

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Video telling Christine's story of the process of getting her diagnosis of young onset dementia provided by the Alzheimer's Society.

<https://www.youtube.com/watch?v=3BTfaECDyik>

A web-page about early diagnosis and why this is important from NHS Choices.

<https://www.nhs.uk/conditions/dementia/early-diagnosis-benefits/>

Web-site information and a short video clip about early diagnosis from SCIE.

<https://www.scie.org.uk/dementia/symptoms/diagnosis/early-diagnosis.asp>

Alzheimer's Disease International (2011) World Alzheimer Report 2011 The benefits of early diagnosis and intervention.

<https://www.alz.co.uk/research/WorldAlzheimerReport2011ExecutiveSummary.pdf>

This video resource from SCIE presents the story of a person living with dementia, their experience of the diagnostic process and outlines some of the benefits that can be gained from an early/timely diagnosis.

<https://www.scie.org.uk/dementia/symptoms/diagnosis/early-diagnosis-and-drug-treatment.asp>

This video resource aimed at families from South Asian communities provides some information on why an early diagnosis might be helpful and also identifies some of the concerns people may have around seeking a diagnosis.

<https://mediacentral.ucl.ac.uk/Player/6615>

#### **d) know the progressive nature of dementia and some of the major impairments and difficulties people may face as dementia progresses**

If staff are to adapt their approaches effectively as dementia progresses, they need to understand the impairments that it may cause and how these can impact on daily functioning.

An interactive, on-line tour of the brain, its functions and how dementia affects the brain.

<https://www.alzheimersresearchuk.org/about-dementia/helpful-information/the-brain-tour/>

This podcast from the Alzheimer's Society discusses the progression of different types of dementia.

<https://www.youtube.com/watch?v=CuXY33n-kes>

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## **e) understand the criteria and the process to be used to gain a diagnosis**

When people have symptoms that they suspect might be due to dementia, they may have lots of questions and concerns about what the diagnostic process involves and how clinicians will decide if they have dementia or not. They may turn to health and care staff for this advice.

Web-page content about the process used to gain a dementia diagnosis from NHS Choices.

<https://www.nhs.uk/conditions/dementia/diagnosis/>

Web-page content on the diagnostic process from SCIE.

<https://www.scie.org.uk/dementia/symptoms/diagnosis/getting-a-diagnosis.asp>

This information from SCIE outlines the difficulties that can occur when undergoing diagnosis for dementia when living with sensory loss.

<https://www.scie.org.uk/dementia/symptoms/diagnosis/sensory-loss.asp>

The NICE guideline on dementia assessment, management and support.

<https://www.nice.org.uk/guidance/ng97>

The National Collaborating Centre for Mental Health (NCCMH) Dementia Care Pathway.

<https://www.dementiaresearcher.nihr.ac.uk/the-dementia-care-pathway/>

## **f) be able to explain the need for an investigation of signs of dementia with sensitivity and in a way that is appropriate to the person**

The ability to explain why an investigation into symptoms an individual may be experiencing may be beneficial in a sensitive manner will rely on the staff member having a good understanding of the potential signs and symptoms of dementia, the potential benefits that having an early diagnosis can offer, an understanding of some of the concerns individuals and their families may have and good communication skills.

See Subject 5: Communication, interaction and behaviour in dementia care for resources on effective and sensitive communication approaches

## **g) be able to appropriately refer patients to access specialist services and support networks**

‘Referral’ may take a number of forms in this context depending on the service setting and role of the staff member and the services and support the individual with dementia or their family member may

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need. In some cases, this might be a formal referral to a Memory Assessment Service or Dementia Advisor, in others it may be providing advice about going to see their GP or about local services and support that are available. Available services and support can vary considerably across the country and so you and the staff in your organisation will need to know what is available in your local area. It may be helpful to collate within your organisation, information on a range of available local services and support so that staff are able to draw on this when advising people with dementia and their family members. Some national support services and networks include:

Dementia UK

<https://www.dementiauk.org/get-support/admiral-nursing/>

TIDE (Together in Dementia Everyday) Network for Carers

<http://tide.uk.net/>

Alzheimer's Society

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

Citizen's Advice (for help around benefits, rights and legal aspects of care)

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

AGE UK

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

## Support for managers in health and care in implementing learning outcomes

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 2, you also need to be confident that your team are implementing guidelines effectively.

A quick checklist of things to consider:

Framework outcome	Things to consider
a) know the most common types of dementia in the UK	Are staff aware of the main types of dementia? Are staff aware of the different underlying causes of Alzheimer's Disease compared to vascular dementia for example? Would they be able to explain this to a person with dementia or a family member?

and their underlying causes	Do they understand the relevance of knowing this for care and support of people with dementia?
b) understand the signs and symptoms of dementia that would indicate the need for further assessment	<p>Can staff explain the potential benefits of early diagnosis to someone who may be showing symptoms that might indicate dementia? Do they appreciate the concerns that someone who may have the condition or their family members might have about seeking a diagnosis and are they able to confidently discuss this with them? Can they also appreciate that seeking diagnosis is an individual decision and that some people may not be ready to do so at a particular time point?</p> <p>Is there information or resources available to staff to give to people about early diagnosis?</p> <p>Are there ways that your organisation can better support individuals who might be concerned about seeking a diagnosis?</p>
c) know why early diagnosis of dementia is important and the likely outcomes if assessment and treatment is delayed	<p>Do staff understand the progressive nature of dementia and are they able to assess the changing needs of individuals over time, in order to provide support that is appropriate?</p> <p>Are there things you could do better?</p>
d) know the progressive nature of dementia and some of the major impairments and difficulties people may face as dementia progresses	<p>Would staff be able to explain the diagnostic process to someone who suspects they may have dementia, so they can understand what that might mean and appreciate the tests and criteria that might be used to make the diagnosis?</p> <p>Are there sources of information available to staff to give to individuals in this position to prepare them to seek a diagnosis?</p> <p>Are there further things that the organisation or individual staff could do to support people you provide care or services for, through the diagnostic process? How might you understand better how well you are doing in this area?</p>
e) understand the criteria and the	Do staff feel confident to discuss diagnosis seeking with individual who may have dementia or with their family members?



<p>process to be used to gain a diagnosis</p>	<p>Do you know how to access the diagnosis rates for your area and what they are? Are diagnosis rates what you might expect in people accessing your service?</p>
<p>f) be able to explain the need for an investigation of signs of dementia with sensitivity and in a way that is appropriate to the person</p>	<p>Do staff know about the referral process and who they should signpost or refer people to if they suspect they may have dementia?</p> <p>How many people are your service referring on for diagnosis? Is this figure what you might expect?</p> <p>Are staff aware of local services and support that may be available to people pre and post-diagnosis and are they referring or signposting people to them?</p>

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# Subject 3: Dementia risk reduction and prevention

## Introduction

As there is no cure for dementia, addressing lifestyle factors that can help people to reduce their risk of dementia is an important consideration. These lifestyle factors can also be helpful to consider when someone is living with dementia as they may help to reduce the risk of decline or more rapid decline and can assist with broader components of living well with dementia such as supporting maintenance of mobility, activities of daily-living and reducing risk of ill-health and depression.

## Subject level resources and training programmes

Please refer to the HEE *Dementia Training Resource List* for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

### **a) know the lifestyle factors that may increase the risk of developing certain types of dementia and how lifestyle changes may delay the onset and severity of certain types of dementia**

There is good evidence that a range of lifestyle factors can increase an individual's risk of developing dementia. Action needs to be taken from mid-life to support people to change lifestyle behaviours that might put them at increased risk of dementia. For example staff who deliver the NHS Health Check, which is for adults aged 40-74, can provide individuals with advice on dementia risk reduction.

This information from Public Health England is aimed at health and care professionals who have a role in providing advice to people about reducing their dementia risk prevention.

<https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk>

Web-site content from SCIE about family and lifestyle risk factors for dementia.

<https://www.scie.org.uk/dementia/symptoms/diagnosis/risk-factors.asp>

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A factsheet from the Alzheimer's Society outlining ways to reduce your risk of developing dementia.  
[https://www.alzheimers.org.uk/info/20010/risk\\_factors\\_and\\_prevention/737/how\\_to\\_reduce\\_your\\_risk\\_of\\_dementia](https://www.alzheimers.org.uk/info/20010/risk_factors_and_prevention/737/how_to_reduce_your_risk_of_dementia)

This booklet from Alzheimer's Research UK informs individuals about what they can do to reduce their risk of dementia.

<https://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/RRD-0515-0517-Risk-Reduction-Low-Res.pdf>

### **b) understand motivational factors that may impact on the ability to make changes**

There are many motivational factors that may impact on people's ability to make lifestyle changes in the broader literature. These may be relevant to individual factors e.g. stopping smoking, or losing weight. We have not identified any dementia specific materials that provide coverage of this learning outcome. However, there are a variety of generic materials pertaining to smoking cessation or weight loss and motivation factors associated with these.

The NHS Live Well web-site is a good starting point of accessing materials and information.

<https://www.nhs.uk/livewell/Pages/Livewellhub.aspx>

### **c) be aware of the challenges to healthy living that may be experienced by different socioeconomic and/or ethnic groups**

See b above.

### **d) be able to signpost sources of health promotion information and support**

See a and b above.

### **e) know how to effectively communicate messages about healthy living according to the abilities and needs of individuals**

See Subject 5: Communication, interaction and inclusion.

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## Support for managers in health and care in implementing learning outcomes

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 3, you also need to be confident that your team are implementing guidelines effectively.

A quick checklist of things to consider:

Framework outcome	Things to consider
a) know the lifestyle factors that may increase the risk of developing certain types of dementia and how lifestyle changes may delay the onset and severity of certain types of dementia	<p>Are staff aware of the lifestyle factors that may increase the risk of developing dementia and lifestyle and healthy-living behaviours that may reduce the rate at which dementia progresses? Do they regularly discuss these with people who use your service in order to encourage a healthier lifestyle?</p> <p>Can they explain why these factors might increase the risk of developing dementia and advise individuals on leading a healthier lifestyle?</p>
b) understand motivational factors that may impact on the ability to make changes	<p>Can staff discuss with individuals the barriers they feel exist to leading a healthier lifestyle and support them to make changes or signpost on to other services who may be able to do so?</p> <p>Do the environment and practices within your organisation encourage a healthy lifestyle?</p> <p>Are there things your organisation could do encourage and support people to lead healthier lifestyles? This includes staff as well as service users and their family members.</p>

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# Subject 4: Person-centred dementia care

## Introduction

Our teams need to know and respect that everyone is first and foremost an individual. We all have unique personalities and life experiences. Teams need to know that understanding an individual and their needs, is critical to delivering personalised care. If people are focusing too much on the tasks of care and not thinking about the individual, this moves away from best practice. To support new team members, managers can ask new staff to think about what makes them unique and how this may shape the care and support they would wish to receive.

As well as understanding what ensures care is person-centred, staff should also be able to support a culture of person-centred care and be able to appropriately challenge and support colleagues when this is not the case. In addition, an awareness of different roles across health and social care is important and how they can best contribute to care and support.

If team members need more information, they should speak with the person living with dementia and/or their family/carer to ensure care is person-centred. In addition, where appropriate engaging family/carers in decisions about care and support can be a further way to support relationships.

## Subject level resources and training programmes

Please refer to the *HEE Dementia Training Resource List* for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

### **a) understand the principles of person-centred dementia care i.e.**

- **the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them**
- **the individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia**
- **the importance of the perspective of the person with dementia**
- **the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being**

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The above model is called the VIPS Framework, which was developed by Professor Dawn Brooker<sup>7</sup> as a way of summarizing the key principles of person-centred care. It is this model that underpins the NICE/SCIE Clinical Guideline (CG42) on dementia<sup>8</sup>.

This book by Dawn Brooker and Isabelle Latham (2015) *Person Centred Dementia Care: Making Services Better 2<sup>nd</sup> edition*. London: Jessica Kingsley, gives a detailed overview of the VIPS model and provides an audit tool for organisations to assess how person-centred their services are.

The Care Fits for VIPS free, on-line tool kit can help care homes, domiciliary care services and day centres improve their person-centred care through auditing their services against the VIPS areas.  
<https://www.worcester.ac.uk/discover/care-fit-for-vips-online-dementia-care-toolkit.html>

## **b) understand how person-centred care can provide insights into the experiences of the person with dementia and support care approaches and solutions to meet individual needs**

At the heart of person-centred care lies an understanding of that person as an individual and an empathic appreciation of their experience. Training is most powerful when people with dementia are given a direct voice about their experiences. This can be achieved through inviting people with dementia to talk about their experiences as part of training, or through using some of the freely available video resources that can be used as a point for discussion.

This moving video from SCIE includes the direct stories and experiences of three people living with dementia and the difference that supportive relationships can make.  
<https://www.scie.org.uk/dementia/living-with-dementia/video.asp>

This video from SCIE covers a range of topic areas including people with dementia talking about their experiences and what helps them on a day-to-day basis.  
<https://www.scie.org.uk/dementia/after-diagnosis/knowning-the-person/impact-of-diagnosis.asp>

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<sup>7</sup> Brooker, D., 2004. What is Person Centred Care for people with Dementia? *Reviews in Clinical Gerontology* 13 (3), 215-222.

<sup>8</sup> NICE/SCIE (2018) *Dementia: assessment, management and support for people living with dementia and their carers*  
<https://www.nice.org.uk/guidance/ng97>

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The 'Walk Through Dementia' resources developed by Alzheimer's Research UK present a visit to the supermarket, a walk down a street and trying to make a cup of tea through the eyes of a person with dementia. They highlight some of the challenges that dementia may cause for individuals when they are completing everyday tasks and activities. These can be accessed as a video clip via a computer or there are 3-D virtual reality versions and you can purchase cardboard headsets to gain the full 3-D experience.

<http://www.awalkthroughdementia.org/>

### **c) understand the role of family and carers in person-centred care and support of people with dementia**

See Subject 9: Families and carers as partners in care.

### **d) understand how a person-centred approach can be implemented, including the use of advance planning and life story work**

Leaders and managers should be aware that there are a number of different ways for person-centred care to be implemented and should support staff with this. In essence, these are all about better understanding of people with dementia and their specific needs and personality and ensuring care and support is delivered in line with these.

Some of the best techniques to support people with dementia include life story, reminiscence work and advance planning. Reflective practice is also a very useful tool, both for individuals in supervision and during team meetings. Life story work is very important, everything that makes an individual unique forms our life story. Simply put, the better we understand someone else's life story, the more effectively we can understand their care and support needs. Reminiscence is supporting people with dementia to reminisce to earlier things/times in their life that they can still recall. Frequent examples are of people who have perhaps carried out a particular job or role before developing dementia and wanting to continue with this. Examples are known of long distance lorry drivers still wanting to drive, cleaning staff wanting to help clean and caretakers wanting to fix broken things in health and social care environments. Providers have found innovative ways to support all of these. Other examples include meeting specific cultural needs.

The more that is understood about an individual, the better care planning that can take place and be shared with everyone who will be supporting the person with dementia. This is particularly important

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for planning for the later stages when communication about care and support needs will become much more difficult.

This video resource from SCIE discusses the importance of getting to know a person with dementia, their likes and dislikes and to understand their life history.

<https://www.scie.org.uk/dementia/after-diagnosis/knowning-the-person/importance-of-memories.asp>

The charity Dementia UK has developed resources to support life story work with people living with dementia.

<https://www.dementiauk.org/for-healthcare-professionals/free-resources/life-story-work/>

The Life Story Network has a range of resources, including an on-line tool to support conduct of life story work

<http://www.lifestorynetwork.org.uk/>

The Liverpool House of Memories has developed a free reminiscence app, which contains pictures of objects from across the decades that are brought to life with sound, music and descriptions. It can be used to support reminiscence with people with dementia.

<https://houseofmemories.co.uk/things-to-do/my-house-of-memories-app/>

The *Sporting Memories Network* has a range of sports-based archive materials, as well as a free to download app to help facilitate sports-based reminiscence.

<http://www.sportingmemoriesnetwork.com>

## **e) understand that a person's needs may change as the disease progresses**

Dementia affects different people in different ways; however, as a progressive condition all will experience increasing cognitive impairment over time and as a result will see an impact on their ability to manage independently. Broadly, an individual's dementia is described as being mild, moderate or severe.

An individual or their family members usually first notices a decline in their cognitive ability when they have mild dementia – advance planning at this stage, is very important and teams should make people aware of this. Staff should be supporting people to live as independently as possible, including positive risk taking.



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When someone's dementia is moderate everyday tasks and living become much more difficult. It is likely that people with moderate dementia will need some level of additional care and support through family or through the workforce. The person is likely to need more practical assistance, therefore person-centred care at this stage is very important.

When living with severe dementia people will need a significant amount of care and support with most activities. Again person-centred care at this stage can have positive and beneficial effects on individuals wellbeing, this includes understanding and supporting complex or distressed behaviours.

This factsheet from the Alzheimer's Society provides an overview of how dementia progresses.  
[https://www.alzheimers.org.uk/info/20073/how\\_dementia\\_progresses](https://www.alzheimers.org.uk/info/20073/how_dementia_progresses)

As dementia progresses and people become more reliant on others for their care in many cases that may mean they will need to consider long-term care as a potential option. They may wish to discuss this with health and social care staff to gain advice and support. This video from SCIE covers the dilemma's that families face when considering the changing care needs of a loved one with dementia and promotes the idea that moving into a high quality care home can be a positive choice.  
<https://www.scie.org.uk/dementia/supporting-people-with-dementia/living-care-home-positive-outcome.asp>

## **f) know how to adapt the physical environment to meet the changing needs of people with dementia**

Increasingly, research is providing evidence that even small changes to a physical environment can help people with dementia and improve wellbeing. There are a vast array of environmental adaptations and products available that can be helpful in supporting people to live independently. However, it is important to choose carefully from these in order to select things that meet an individual's needs. Some adaptations and products can be very costly, whereas others can be achieved relatively cheaply and easily.

The University of Stirling have a range of on-line information available about dementia friendly design including virtual hospital and care home environments.  
<http://dementia.stir.ac.uk/design/virtual-environments>

SCIE have developed further guidance in this area.  
<http://www.scie.org.uk/dementia/supporting-people-with-dementia/dementia-friendly-environments/>

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SCIE have also produced a video resource outlining some of the simple environmental changes that can be made in people's own homes to support people with dementia to have independence and well-being.

<https://www.scie.org.uk/dementia/supporting-people-with-dementia/dementia-friendly-environments/video-environment-at-home.asp>

This SCIE video resource covers some of the simple environmental changes that can be made in care home settings to support people with dementia to have independence and well-being.

<https://www.scie.org.uk/dementia/supporting-people-with-dementia/dementia-friendly-environments/video-environment-care-home.asp>

**g) understand the significance of a person's background, culture and experiences when providing their care**

See Subject 10: Equality, diversity and inclusion.

**h) understand the importance of clear documentation to communicate the care needs of the person with dementia**

Teams should be aware of documenting care plans to support person-centred care so everyone understands a person's wishes and preferences. In addition, teams should be aware of the potential need to communicate between services, whilst being mindful of data protection and confidentiality processes and legislation.

NHS England has produced a resource to support care planning documentation for people living with dementia.

<https://www.england.nhs.uk/wp-content/uploads/2017/02/dementia-good-care-planning.pdf>

**i) understand the need for a balance between healthy living, a nutritionally balanced diet and providing the opportunity for those living with dementia to enjoy the food and drink of their choice (preference or cultural etc.) but also recognising that their nutritional needs may be different from general population healthy eating/prevention messages**

See Subject 6: Health and well-being in dementia care.

## Support for managers in health and care in implementing learning outcomes

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 4, you also need to be confident that your team are implementing guidelines effectively.

A quick checklist of things to consider:

Framework outcome	Things to consider
a) understand the principles of person-centred dementia care	<p>How confident are you that all your team members understand the principles of person-centred care and apply them?</p> <p>Are you questioning your team and observing interactions in a health and care environment?</p> <p>How person-centred are your team discussions?</p> <p>How much time do you spend discussing individuals and how you best meet their needs?</p>
b) understand how person-centred care can provide insights into the experiences of the person with dementia and support care approaches and solutions to meet individual needs	<p>How are your teams finding out about the person with dementia?</p> <p>How do you ensure information is shared about providing care and support in a person-centred way?</p>
c) understand the role of family and carers in person-centred care and support of people with dementia	<p>Are your teams working with families/carers/friends to get a better understanding of the individual?</p> <p>How could your service improve how it works with families and carers?</p>
d) understand how a person-centred approach can be implemented, including the use of	<p>Do your teams carry out life story work with people with dementia/their families/carers?</p> <p>How is this recorded and shared?</p> <p>How does this impact on care and support planning?</p>

advance planning and life story work	Do you support your team members to reflect during supervision as to how they may improve care and support and make it more person-centred?
e) understand that a person's needs may change as the disease progresses	Do all team members providing direct care and support understand the types of dementia and how it may affect people?
f) know how to adapt the physical environment to meet the changing needs of people with dementia	Does your service consider if your physical environment is as supportive to people with dementia as possible?  Do you have a specific staff member who takes responsibility for this?
g) understand the significance of a person's background, culture and experiences when providing their care	How well do you feel your service supports people with different backgrounds and cultures?  Has your team received diversity training?
h) understand the importance of clear documentation to communicate the care needs of the person with dementia i) understand the need for a balance between healthy living, a nutritionally balanced diet and providing the opportunity for those living with dementia to enjoy the food and drink of their choice (preference or cultural etc.) but also recognising that their nutritional needs may be different from general population healthy eating/prevention messages	Do you have care plans in place (where appropriate)? How person-centred are these? How could they be improved? How often are they reviewed by the team?  How do care plans balance care needs with choice and inclusion?

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# Subject 5: Communication, interaction and behaviour in dementia care

## Introduction

Health and Social Care is constantly evolving and as we work more closely with people living with dementia we find that not only do our generic skills come to the fore, but up-to-date best practice techniques also emerge. We learn more about how people want to be supported from the feedback we receive from individuals with dementia and their carers, based on their personal experiences. Good care and support, therefore, depends on effective communication and is vital in any health and social care setting.

Clearly there are key skills, knowledge and attitudes required when communicating and interacting with people living with dementia. The following learning outcomes are essential for all health and social care staff in settings where they are likely to have regular contact with people living with dementia.

## Subject level resources and training programmes

Please refer to the HEE *Dementia Training Resource List* for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

### **a) understand the importance of effective communication in dementia care**

Effective communication has many benefits within the caring relationship. It can support well-being, reduce the occurrence of behaviours such as agitation and can help to include people with dementia and their family members fully in their care and support. If communication breaks down or is ineffective this can lead to a range of problems.

This factsheet from the Alzheimer's Society, which is also available as an audio file, explains some of the benefits of effective communication.

[https://www.alzheimers.org.uk/info/20064/symptoms/90/communicating\\_and\\_language](https://www.alzheimers.org.uk/info/20064/symptoms/90/communicating_and_language)

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## **b) understand the impact of memory and language difficulties on communication**

Over time as dementia progresses a person's ability to communicate, understand and remember can become more impaired. Difficulties with language and communication can occur in all forms of dementia but the extent and specific types of difficulties people experience will vary depending on the type of dementia someone has and their degree of cognitive impairment. Communication abilities may also vary from day to day and at different times of the day. Common problems people experience can be not being able to find the right words or remember names of people and difficulties understanding what other are saying or following a conversation. People living with dementia who have reduced or lost their ability to verbally communicate may use alternative ways of communicating their needs through changes in behaviour.

This factsheet from the Alzheimer's Society explains the impact dementia can have on language and communication.

[https://www.alzheimers.org.uk/info/20064/symptoms/90/communicating\\_and\\_language/2](https://www.alzheimers.org.uk/info/20064/symptoms/90/communicating_and_language/2)

This video from the Royal College of Speech and Language Therapists present the impact of dementia-related communication difficulties on Ken and Faye.

<https://www.youtube.com/watch?v=kX53p-pLm-Q&feature=youtu.be>

This leaflet/poster from the Royal College of Speech and Language Therapists outlines some of the main types of communication difficulties that people with dementia may experience.

[https://www.rcslt.org/governments/docs/dementia\\_and\\_communications\\_poster](https://www.rcslt.org/governments/docs/dementia_and_communications_poster)

This video from Cardiff University discusses the different communication challenges people with dementia may face and provides hints and tips on things we can do to support effective communication.

<https://www.youtube.com/watch?v=u6ccchefGn2M>

## **c) be able to demonstrate active listening skills**

Active listening skills are important, they require us to fully concentrate, understand, respond and then remember what has been said. Some staff may be unfamiliar with active listening and should be supported to practice it as a skill.

This video summarises some key active listening skills.

[https://www.youtube.com/watch?v=z\\_rNd7h6z8](https://www.youtube.com/watch?v=z_rNd7h6z8)

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## **d) be able to gain a person's attention before asking a question or beginning a task with them**

As health and social care professionals, gaining people's attention is not new but when working with people with dementia the approach may be different. For example, the person may not be aware of a staff member's presence due to perceptual difficulties caused by their dementia, sensory impairments, or because of environmental distractions. Staff should understand a range of approaches they can use to gain a person's attention in a person-centred way in order to reinforce a caring attitude.

This information about having a conversation with someone with dementia from SCIE outlines some of the key environmental considerations that can help to gain and maintain someone's attention before talking to them.

<https://www.scie.org.uk/dementia/after-diagnosis/communication/conversation.asp>

## **e) understand the importance of speaking clearly, calmly and with patience**

People living with dementia retain their feelings and emotions despite the fact that they may struggle to understand what is being said to them. Our role as health and social care professionals is to maintain an individual's self-esteem in everything we say and do. It is also important to acknowledge that providing care for people with dementia can be difficult for staff and that at times they may feel stressed, angry, impatient, scared or at a loss as to how to help. Being mindful of the importance of being clear, calm, respectful and patient with people with dementia is an essential skill within person-centred communication.

This factsheet from the Alzheimer's Society outlines a number of tips for effective communication with individuals with dementia.

[https://www.alzheimers.org.uk/info/20064/symptoms/90/communicating\\_and\\_language/3](https://www.alzheimers.org.uk/info/20064/symptoms/90/communicating_and_language/3)

## **f) know how to adapt the environment to minimise sensory difficulties experienced by an individual with dementia**

Having dementia can bring with it a range of sensory difficulties including problems with spatial awareness (visuo-perception) where the brain is unable to process visual information at the speed or in the same way it may have previously. Hypersensitivity to noise and noisy environments is another sensory issue often experienced by people living with dementia as are changes around touch, taste, smell and hallucinations.

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This TED talk discusses the ways in which we are able to communicate in busy environments. This highlights the difficulties that people with dementia may face if they are no longer able to filter out the busy environment. It also asserts the importance of listening in communication.

[https://www.ted.com/talks/julian\\_treasure\\_5\\_ways\\_to\\_listen\\_better](https://www.ted.com/talks/julian_treasure_5_ways_to_listen_better)

Problems with sensory impairments can also impact on people, compounding the difficulties with communication and day-to-day functioning that are caused by dementia. This video from SCIE made in partnership with the Thomas Pocklington Trust, shares the stories of three people living with dementia. One who also experiences sight loss, one with hearing loss and one with both sight and hearing loss. It provides tips for carers on what can help.

<https://www.scie.org.uk/dementia/living-with-dementia/sensory-loss/video.asp>

See also d above and g below.

**g) know the importance of ensuring that individuals have any required support (e.g. dentures, spectacles, hearing aids) to enable successful communication and the role that a clean, pain-free mouth plays in speech**

See also f above.

See also Subject 6: Health and well-being in dementia care, learning outcome a.

**h) know how life story information may enable or support more effective communication**

Knowing about the person and their life history offers a range of benefits that can help to support good quality dementia care.

This video from Jean Tottie that was made as part of the Portrait of a Life Toolkit, explains the benefits that life story work can have for supporting positive communication with people living with dementia.

<https://www.youtube.com/watch?v=iBjLtW0lus&feature=youtu.be>

**i) understand the importance of effective communication with family and carers and the expertise that they may be able to offer to support effective communication with the person with dementia**

See Subject 9: Families and carers as partners in care.



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## **j) be able to adapt communication techniques according to the different abilities and preferences of people with dementia**

The progressive and variable nature of dementia makes the importance of adapting communication and behaviour strategies imperative. Staff need to understand that we must change our communication approach as the person living with dementia cannot change theirs. Knowing the person we are supporting, involves gathering as much information as possible and the involvement of family/carers. Physical limitations may be more obvious but building upon the person's abilities and preferences will make communication easier.

See a-e above.

## **k) be aware of the importance of non-verbal communication e.g. body language, visual images and the appropriate use of touch**

Verbal communication is the main way of communicating between people so speaking clearly is important, however, communication is not just about talking. Communicating through body language and physical contact can also be effective. Facial expressions and gestures can also convey meaning. Where verbal communication becomes more difficult, engaging with the person with dementia can be via the use of pictures, which will appeal directly to them.

This video from Newcastle University outlines approaches to non-verbal communication with people with dementia.

<https://www.futurelearn.com/courses/dementia-care/0/steps/18883>

## **l) understand that the behaviour of a person with dementia is a form of communication and how behaviours seen in people with dementia may be a means for communicating unmet needs**

The behaviours of a person with dementia are likely to change over time. Please avoid thinking of these behaviours as challenging as they are in fact changes arising from the condition and are alerting us to something important. The behaviour may have numerous causes including fear brought about by confusion, pain, feeling threatened, boredom, feeling lonely, unmet emotional or physical needs and feeling out of control.

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This video 'The Waiting Room' by Jane Harris, from the resources list available from the Life Story Network presents in her own words and those of her father Gerry, about how feelings underpin behaviour and can be a form of communicating unmet needs.

<https://vimeo.com/80791217>

### **m) understand how a person's feelings and perception may affect their behaviour**

People with dementia describe the impact of the condition in terms of losses and describe how adjusting to this is challenging. For people with dementia trying to understand and respond to expressed feelings and emotional needs is important, particularly given people living with dementia may forget details of a situation that provoked a strong emotion but may retain the feelings associated with the event for some time afterwards.

This resource from SCIE uses real experiences gathered from people with dementia to create a resource about what it might be like to experience dementia and how feelings and perceptions might affect their behaviour.

<https://www.scie.org.uk/dementia/about/dementia-from-the-inside.asp>

See also Subject 8: Living well with dementia and promoting independence outcome 1.

### **n) understand how the behaviour of others might affect a person with dementia**

Changes in the brain of a person with dementia can affect their behaviour, mood and personality. Review what triggered the behaviour. Staff should consider if their reaction to the behaviour made the situation worse. People living with dementia may respond to the behaviour of others particularly if they are displaying frustration or anger and this will only exacerbate the situation, leaders and managers should encourage staff to keep calm, avoid confronting the person and not to take the behaviour personally.

The 'Walk Through Dementia' resources developed by Alzheimer's Research UK present a visit to the supermarket, a walk down a street and trying to make a cup of tea through the eyes of a person with dementia. They highlight some of the challenges that dementia may cause for individuals when they are completing everyday tasks and activities. These can be accessed as a video clip via a computer or there are 3-D virtual reality versions and you can purchase cardboard headsets to gain the full 3-D experience.

<http://www.awalkthroughdementia.org/>

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## **o) understand common causes of distressed behaviour by people with dementia**

See l, m and n above

## **p) be able to recognise distressed behaviour and provide a range of responses to comfort or reassure the person with dementia**

Distressed behaviour is a form of communication and may be alerting us to an unmet need or an expression of an emotional state. Our response to the distressed person will begin with showing respect. There are then a range of verbal and non-verbal approaches that staff may draw on to interpret, understand and respond to distressed behaviour. Having knowledge of and being willing to try different approaches is essential for providing comfort and reassurance, as well as recognising that what works for one individual may not work for another, and also what works one day with an individual might not work the next.

This information sheet from the Alzheimer's Society covers a range of distressed behaviours and looks at their potential causes and approaches to responding.

[https://www.alzheimers.org.uk/info/20064/symptoms/87/behaviour\\_changes](https://www.alzheimers.org.uk/info/20064/symptoms/87/behaviour_changes)

This factsheet from Sussex Partnership NHS Trust contains hints and tips on assessing and responding to distressed behaviours.

[https://www.sussexpartnership.nhs.uk/sites/default/files/documents/dementia\\_information\\_for\\_carers\\_of\\_people\\_living\\_with\\_dementia\\_who\\_are\\_distressed\\_or\\_behaving\\_unusually\\_-\\_ver\\_2\\_-\\_oct\\_15.pdf](https://www.sussexpartnership.nhs.uk/sites/default/files/documents/dementia_information_for_carers_of_people_living_with_dementia_who_are_distressed_or_behaving_unusually_-_ver_2_-_oct_15.pdf)

These videos from Healthtalk include carers describing strategies they have found helpful in supporting distressed behaviours.

<http://www.healthtalk.org/peoples-experiences/nerves-brain/carers-people-dementia/strategies-some-suggestions-carers>

## **Support for managers in health and care in implementing learning outcomes**

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 5, you also need to be confident that your team are implementing guidelines effectively.

A quick checklist of things to consider:

Framework outcome	Things to consider
a) understand the importance of effective communication in dementia care	Have staff in your organization had communication skills training and do they understand the role good communication plays in care and support, especially for those living with dementia?
b) understand the impact of memory and language difficulties on communication	<p>Are staff able to link their knowledge about dementia and its symptoms to understanding the impacts this can have on communication?</p> <p>Do they employ communication approaches that are appropriate and tailored to each individual and their abilities and needs?</p>
c) be able to demonstrate active listening skills	Do staff understand and practice the skills of active listening? Are they encouraged to take the time to do this within their day to day practice?
d) be able to gain a person's attention before asking a question or beginning a task with them	Do staff consistently ensure they have an individual's attention before commencing a conversation or care activity?
e) understand the importance of speaking clearly, calmly and with patience	<p>Do staff always communicate clearly, calmly and with patience?</p> <p>Are they provided with opportunities to reflect on their communication skills and to receive feedback on them?</p>
f) know how to adapt the environment to minimise sensory difficulties experienced by an individual with dementia	<p>Has an environmental assessment been completed to identify potential areas or issues that may lead to communication difficulties e.g. TV volume, noise levels at mealtimes?</p> <p>Have strategies been developed with the staff team for them to adapt the environment when required to support effective communication?</p>
g) know the importance of ensuring that individuals have any required support (e.g. dentures, spectacles, hearing aids) to enable	<p>Is value placed on those living with dementia having sensory aids such as glasses and hearing aids with them at all times?</p> <p>Are staff aware of who requires what sensory aids?</p> <p>Are service users supported or encouraged to have regular optician and hearing checks?</p>

successful communication and the role that a clean, pain-free mouth plays in speech	
h) know how life story information may enable or support more effective communication	<p>Is life story work practiced in your organization? What methods are used?</p> <p>Is this viewed as a means for supporting effective communication?</p> <p>How much do staff know about the individuals with dementia they provide care and support to?</p>
i) understand the importance of effective communication with family and carers and the expertise that they may be able to offer to support effective communication with the person with dementia	See Subject 9
j) be able to adapt communication techniques according to the different abilities and preferences of people with dementia	See b above
k) be aware of the importance of non-verbal communication e.g. body language, visual images and the appropriate use of touch	<p>Do staff use the range of non-verbal communication approaches?</p> <p>Are they encouraged to consider and reflect on their non-verbal communication on a regular basis?</p>
l) understand that the behaviour of a	Do staff perceive behaviours such as agitation, walking around, being withdrawn as a means of communicating unmet need or as

<p>person with dementia is a form of communication and how behaviours seen in people with dementia may be a means for communicating unmet needs</p> <p>m) understand how a person's feelings and perception may affect their behaviour</p> <p>n) understand how the behaviour of others might affect a person with dementia</p> <p>o) understand common causes of distressed behaviour by people with dementia</p> <p>p) be able to recognise distressed behaviour and provide a range of responses to comfort or reassure the person with dementia</p>	<p>'challenging behaviour'? Are they aware of their own potential role in triggering that behaviour?</p> <p>Does the organization promote an environment of understanding and exploring behaviours as a form of communication rather than a strategy of management?</p> <p>Does a person with dementia displaying a distressed behaviour raise cause for concern and lead staff to work together to try and understand its potential cause and methods for alleviation? Are methods of trying different approaches encouraged and supported?</p> <p>Is there good record keeping so all staff are aware of strategies that can be helpful in supporting someone who is experiencing distressed behaviours?</p>
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# Subject 6: Health and well-being in dementia care

## Introduction

It is estimated that at least a quarter of general hospital beds in England are occupied by people living with dementia<sup>9</sup>. The majority of these people will not be in hospital because of health problems related to their dementia, but due to other comorbidities. It is therefore crucial that staff working across all areas of general hospitals have a good understanding of dementia and the needs of people with the condition, since these will be pertinent to providing holistic care for someone attending hospital for treatment for another health condition.

When someone develops dementia, it is important not to forget their broader physical and mental health and well-being. As dementia progresses it may become more difficult for people with the condition to communicate their health and well-being needs. This means that health and care staff need to be more vigilant in assessing someone who may be unwell and in conducting ongoing monitoring of individuals with chronic conditions as well as any emergent acute problems. For social care staff this may mean calling a GP or other health professional to undertake a full assessment if you are concerned about the health of a person with dementia you support.

## Subject level resources and training programmes

Please refer to the HEE 'Dementia Training Resource List' for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

**a) understand the importance for individuals with dementia to maintain good physical, mental and oral health through food, drink, exercise and a healthy life-style that includes social engagement**

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<sup>9</sup> Alzheimer's Society, 2009. Counting the cost. Caring for people with dementia on hospital wards. Alzheimer's Society, London.

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This video from the Alzheimer's Society presents Linda's story about the importance of remaining socially engaged and active when living with the condition.

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

This resource from Bournemouth University provides detailed coverage of the importance of good nutrition and hydration for people living with dementia.

<https://research.bournemouth.ac.uk/project/understanding-nutrition-and-dementia/>

This factsheet from the Alzheimer's Society covers the importance of staying healthy when living with dementia.

[https://www.alzheimers.org.uk/info/20029/daily\\_living/22/staying\\_healthy](https://www.alzheimers.org.uk/info/20029/daily_living/22/staying_healthy)

SCIE have web-site content on the importance of staying healthy and things for staff to consider in supporting someone with dementia to maintain good physical and mental health.

<https://www.scie.org.uk/dementia/after-diagnosis/support/staying-healthy.asp>

This video from the Government of South Australia takes you through the steps to consider when preparing to and then supporting someone with dementia to brush their teeth.

[https://www.youtube.com/watch?v=0mcpUK\\_URzA](https://www.youtube.com/watch?v=0mcpUK_URzA)

This series of short video clips from the Registered Nurses Association of Ontario cover good oral healthcare for a person with dementia.

Please note: Some practices in these videos may not reflect what we consider best practice e.g. some carers are standing over a person while delivering care. They should therefore be used as a discussion point with staff identifying what is good and what is less good practice. Videos 4-6 in this series are not recommended for use for this reason.

Video 1 of 6 <https://www.youtube.com/watch?v=MP576ht84Fg> – why supporting oral health may be difficult or avoided by care staff.

Video 2 of 6 [https://www.youtube.com/watch?v=WS\\_GUvq906Y](https://www.youtube.com/watch?v=WS_GUvq906Y) – the importance of good oral care.

Video 3 of 6 <https://www.youtube.com/watch?v=a4J1mTP0Z20> – supporting good oral care for those with mild to moderate dementia.

This web-page from the Alzheimer's Society describes some of the dental problems that people with dementia may face and methods for treatment and prevention.

<https://www.alzheimers.org.uk/get-support/daily-living/dental-care>



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This Alzheimer's Society factsheet discusses dental care and oral health for people with dementia.  
[https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dental\\_care\\_and\\_oral\\_health.pdf](https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dental_care_and_oral_health.pdf)

This web-site information from Dementia UK discusses mouth care for people with dementia.  
<https://www.dementiauk.org/understanding-dementia/advice-and-information-2/mouth-care-dementia/>

There is an e-learning for health package entitled 'Improving Mouth Care'.  
<https://www.e-lfh.org.uk/programmes/improving-mouth-care/>

The Faculty of General Dental Practice (UK) (FGDP) have produced a 'Dementia-Friendly Dentistry' guide.  
<https://www.fgdp.org.uk/guidance-standards/dementia-friendly-dentistry>

The Royal College of Surgeons has produced a guide called 'Improving older people's oral health'.  
<https://www.rcseng.ac.uk/-/media/files/rcs/fds/media-gov/fds-improving-older-peoples-oral-health-2017.pdf>

## **b) be aware of anticipating an individual's health needs e.g. to prevent fatigue, falls, dehydration and hunger**

Regular assessment of health needs can help to prevent individuals from becoming at increased risk of fatigue, falls, dehydration and hunger. People with dementia can become at greater risk if they are not adequately supported to eat and drink and if intake is not monitored.

This guide produced by the Bournemouth University provides a comprehensive overview of a range of issues associated with supporting nutrition and hydration in people with dementia.  
<https://research.bournemouth.ac.uk/project/understanding-nutrition-and-dementia/>

They have also produced a leaflet on eating and drinking well.  
<https://research.bournemouth.ac.uk/wp-content/uploads/2017/07/Eating-and-Drinking-Well-Supporting-People-Living-with-Dementia-A4-v3-3.pdf>

SCIE has a range of web-based content around eating and drinking well and maintaining good nutrition and hydration.  
<https://www.scie.org.uk/dementia/living-with-dementia/eating-well/>

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### **c) know the action to take in response to identification of fatigue and falls**

See b above.

This checklist from Alzheimer Society Manitoba provides a range of things staff should consider to help reduce the risk of falls in a person with dementia.

<https://www.alzheimer.mb.ca/wp-content/uploads/2013/09/2014-Dementia-Fall-Risk-Checklist-template.pdf>

This web-site from NHS Inform in Scotland provides a range of information and links to resources on potential causes, risks and methods for reducing the risk of falls in people with dementia.

<https://www.nhsinform.scot/healthy-living/preventing-falls/falls-and-dementia>

There is also an accompanying video aimed at older people more generally, which provides advice on ways to reduce risks of falling.

<https://www.nhsinform.scot/campaigns/falls>

This short video clips highlights some of the factors that may increase the risk of a person with dementia falling.

<https://www.futurelearn.com/courses/falls/0/steps/13195>

There is a NICE guideline on assessing risk and prevention of falls in older people.

<https://www.nice.org.uk/guidance/cg161>

### **d) know how to take action in response to dehydration and hunger (including unplanned weight-loss), how to improve the provision of good nutrition and hydration through monitoring food and drink intake using appropriate tools and understand the factors that influence mealtimes to provide a positive mealtime experience**

See a and b above.

### **e) know where to find evidence-based information and resources and when to refer for more specialist advice from a registered dietitian/registered nutritionist on**

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## **nutrition or other health care professional e.g. speech and language therapist for textured modified foods**

This web-site from the British Dietetics Association (BDA) explains what a dietician does.

<https://www.bda.uk.com/improvinghealth/yourhealth/dietitians>

This web-site content from the BDA, the Association of UK Dieticians explains the difference between a dietician, nutritionist and other roles in this field.

[https://www.bda.uk.com/improvinghealth/yourhealth/dietitian\\_nutritionist](https://www.bda.uk.com/improvinghealth/yourhealth/dietitian_nutritionist)

This factsheet from the Royal College of Speech and Language Therapists explain more about the role and support that Speech and Language Therapists can play in the care of people with dementia.

[http://www.rcslt.org/speech\\_and\\_language\\_therapy/docs/factsheets/dementia](http://www.rcslt.org/speech_and_language_therapy/docs/factsheets/dementia)

## **f) know how to recognise and manage pain in people with dementia**

Due to communication difficulties that may be caused by dementia, people with the condition may be less able to communicate pain or to identify its source. Pain may be expressed very differently by different individuals including as withdrawal, calling out or becoming agitated and sometimes aggressive reactions, particularly if being assisted to move or undertake personal care which may exacerbate the pain. Assessing pain at end of life should also be undertaken so that individuals can be provided with comfort. There are a number of pain assessment tools that can help support staff to identify if someone with dementia may be experiencing pain.

This guide to pain assessment in dementia from the British Geriatrics Society provides a pain assessment process to follow and copies of a range of scales that might be used.

[http://www.bgs.org.uk/Publications/clinical\\_guides/pain\\_concise.pdf](http://www.bgs.org.uk/Publications/clinical_guides/pain_concise.pdf)

This resource from SCIE looks at identifying and managing pain in those with advanced dementia.

<https://www.scie.org.uk/dementia/advanced-dementia-and-end-of-life-care/end-of-life-care/pain.asp>

Dementia Australia have produced this factsheet on pain and dementia.

[https://www.dementia.org.au/files/helpsheets/Helpsheet-DementiaQandA16-PainAndDementia\\_english.pdf](https://www.dementia.org.au/files/helpsheets/Helpsheet-DementiaQandA16-PainAndDementia_english.pdf)

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This information sheet in pain in dementia from Alzheimer Scotland Action in Dementia also has an audio version.

[https://www.alzscot.org/information\\_and\\_resources/information\\_sheet/1784\\_pain\\_in\\_dementia](https://www.alzscot.org/information_and_resources/information_sheet/1784_pain_in_dementia)

### **g) be able to support an individual in maintaining personal appearance, cleanliness and good oral hygiene**

Maintenance of personal appearance and hygiene are very individual issues. It is therefore important to consider this in the context of a person-centred approach. Some people may have had very high personal hygiene and appearance standards throughout their lives, others may have been less concerned. It is important to note that these preferences may change and sometimes personal care can be a very distressing experience for people. This may require careful and sometimes difficult decisions to be made about balancing personal hygiene against well-being and distress that delivering personal care may cause.

This podcast from the Alzheimer's Society discusses identifying when someone may need support with personal care and how to support people effectively. Whilst aimed at family caregivers the hints and tips can be useful for staff working in all types of settings and also who may be advising carers on strategies to support personal care delivery.

<https://www.youtube.com/watch?v=DLE315b3s9M>

This factsheet from the Alzheimer's Society covers washing and bathing.

[https://www.alzheimers.org.uk/info/20029/daily\\_living/6/washing\\_and\\_bathing](https://www.alzheimers.org.uk/info/20029/daily_living/6/washing_and_bathing)

SCIE have produced this information about what to do if someone refuses help with personal care.

<https://www.scie.org.uk/dementia/living-with-dementia/difficult-situations/refusing-help.asp>

See also a above.

### **h) be aware of the impact of delirium, depression and social stressors**

Depression and delirium can have similar symptoms to dementia and so may go undetected in someone with dementia, or dementia may sometimes be misdiagnosed as one of these conditions. Both depression and delirium are treatable conditions and therefore staff working across health and care services need to be able to identify the signs and symptoms of both conditions in those with dementia and to understand what action to take if they suspect the person may have either condition.

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The Knowing Me! Resource from the Life Story Network contains written information about depression and delirium including definitions, signs, symptoms and treatment.

<http://www.lifestorynetwork.org.uk/knowning-me/>

This video from the Australian Commission in Safety and Quality in Health Care discusses delirium, its causes, risk factors and management approaches.

<https://www.youtube.com/watch?v=7LCltOk0iBg>

This factsheet from the Alzheimer's Society outlines what delirium is and treatment and support approaches.

[https://www.alzheimers.org.uk/info/20029/daily\\_living/370/delirium](https://www.alzheimers.org.uk/info/20029/daily_living/370/delirium)

### **i) understand triggers and responses to stressed or distressed behaviours**

See Subject 5: Communication, interaction and behaviour in dementia care outcomes l, m and n.

### **j) understand the role of family and carers in supporting the health and well-being of people with dementia**

See Subject 9: Families and carers as partners in care.

### **k) be aware of the benefits and limitations of medication to manage behavioural and psychological issues including associated risks**

See Subject 7: Pharmacological interventions in dementia care.

### **l) be able to support individuals in undertaking psycho-social interventions including validation, counselling, reminiscence and life story work**

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Non-pharmacological or psycho-social interventions have a range of benefits for individuals with dementia. There are many different psychosocial interventions beyond validation, counselling, reminiscence and life story work that staff may wish to use within their practice.

This guide from the British Psychological Society lists a broad range of psychosocial interventions that might be used with people with mild to moderate dementia.

[https://www1.bps.org.uk/system/files/user-files/DCP%20Faculty%20for%20the%20Psychology%20of%20Older%20People%20\(FPoP\)/public/a\\_guide\\_to\\_psychosocial\\_interventions\\_in\\_dementia.pdf](https://www1.bps.org.uk/system/files/user-files/DCP%20Faculty%20for%20the%20Psychology%20of%20Older%20People%20(FPoP)/public/a_guide_to_psychosocial_interventions_in_dementia.pdf)

This Alzheimer's Society Factsheet covers counselling and other psychological therapies and their use with people with dementia.

[https://www.alzheimers.org.uk/download/downloads/id/3419/talking\\_therapies\\_including\\_counselling\\_psychotherapy\\_and\\_cbt.pdf](https://www.alzheimers.org.uk/download/downloads/id/3419/talking_therapies_including_counselling_psychotherapy_and_cbt.pdf)

This video from Naomi Feil, who developed validation therapy explains the method and its principles.

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

This video shows Naomi Feil practising validation therapy with Gladys who is living with advanced dementia.

<https://www.youtube.com/watch?v=CrZXz10FcVM>

For reminiscence and life story work see Subject 4: Person-centred dementia care outcome d.

### **m) be aware of the role of therapeutic work including complementary therapies and sensory stimulation**

Complementary therapies such as aromatherapy and massage and sensory therapies can have a range of benefits for well-being and quality of life. These could be delivered by external experts or staff can learn to use some of the techniques as part of their approach to care.

This video from Alzheimer Scotland Action on Dementia outlines the benefits of sensory stimulation particularly for people with moderate to severe dementia.

[https://www.alzscot.org/information\\_and\\_resources/therapeutic\\_interventions/sensory\\_intervention](https://www.alzscot.org/information_and_resources/therapeutic_interventions/sensory_intervention)

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Dementia UK have some web-based content on different complementary therapies that may be helpful for people with dementia.

<https://www.dementiauk.org/understanding-dementia/advice-and-information-2/complementary-therapies/>

The Alzheimer's Society has web-based information on the research evidence for different alternative therapies for dementia.

[https://www.alzheimers.org.uk/info/20074/alternative\\_therapies](https://www.alzheimers.org.uk/info/20074/alternative_therapies)

This guide on how to make a sensory room for people with dementia has been produced by the University of Southampton and Kingston University London.

<http://cdn.kingston.ac.uk/documents/faculties/kingston-school-of-art/research-and-innovation/centre-for-research-through-design/projects/How-to-make-a-Sensory-Room-for-people-with-dementia.pdf>

## **n) know how to support people with dementia to access local services and referral pathways including voluntary and community services which would promote their physical, mental and oral health**

What is available locally to people with dementia and their carers varies from location to location. Therefore, you will need to work with staff in your service to identify what is available locally for the client group you serve. The local Council, NHS Trusts and charities may have on-line or written information available or you may need to undertake your own research to identify relevant local services.

## **Support for managers in health and care in implementing learning outcomes**

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 6, you also need to be confident that your team are implementing guidelines effectively.

A quick checklist of things to consider:

<b>Framework outcome</b>	<b>Things to consider</b>
a) understand the importance for	Does your organisation, and do the staff encourage individuals with dementia to lead a healthy lifestyle?

<p>individuals with dementia to maintain good physical, mental and oral health through food, drink, exercise and a healthy life-style that includes social engagement</p> <p>b) be aware of anticipating an individual's health needs e.g. to prevent fatigue, falls, dehydration and hunger</p> <p>c) know the action to take in response to identification of fatigue and falls</p> <p>d) know how to take action in response to dehydration and hunger (including unplanned weight-loss), how to improve the provision of good nutrition and hydration through monitoring food and drink intake using appropriate tools and understand the factors that influence mealtimes to provide a positive mealtime experience</p> <p>e) know where to find evidence-based information and resources and when to refer for more specialist advice from a registered dietitian/registered</p>	<p>Is good hydration, nutrition and oral health considered a key component of good care?</p> <p>How are hydration, nutrition and oral health monitored? What action is taken if staff have concerns?</p> <p>Is there opportunity for those living with dementia to engage in a range of regular social activities? How could such opportunities be encouraged? Do all those with dementia accessing the service engage?</p> <p>Is there opportunity for those living with dementia to access appropriate services such as a dentist, dietician, nutritionist or speech and language therapist when required?</p>
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nutritionist on nutrition or other health care professional e.g. speech and language therapist for textured modified foods	
f) know how to recognise and manage pain in people with dementia	<p>Are staff trained on pain assessment and management?</p> <p>Do you have pain assessment tools that staff can use to assess and monitor pain?</p> <p>Is this recorded in care plans (where appropriate)?</p>
g) be able to support an individual in maintaining personal appearance, cleanliness and good oral hygiene	<p>Are staff aware of an individual's preferences when it comes to washing, dressing and personal hygiene? Are people with dementia offered choice about washing, dressing and personal hygiene? If people are unable to express their choices, do care plans provide detailed information on individual preferences?</p> <p>What priority do staff give the tasks of washing and dressing versus well-being and choice?</p> <p>Are there processes for staff to follow if individuals refuse personal care or do not wish to get dressed? Are staff supported to implement these and to be able to explain them to relatives and friends?</p>
h) be aware of the impact of delirium, depression and social stressors	<p>Are staff aware of the signs and symptoms of delirium and depression and what to do if they suspect someone has either condition?</p>
i) understand triggers and responses to stressed or distressed behaviours	<p>See Subject 5</p>
j) understand the role of family and carers in supporting the health and well-being of people with dementia	<p>See Subject 9</p>
k) be aware of the benefits and limitations of medication to	<p>See Subject 7</p>

<p>manage behavioural and psychological issues including associated risks</p>	
<p>l) be able to support individuals in undertaking psychosocial interventions including validation, counselling, reminiscence and life story work m) be aware of the role of therapeutic work including complementary therapies and sensory stimulation</p>	<p>Are staff aware of the range of psychosocial and therapeutic interventions that can be used to support well-being and quality of life in people with dementia? Have they received training to implement them where applicable? Are these approaches used regularly within your service?</p> <p>Does your organization have information about external provision of more specialist services such as counselling that people with dementia may wish to access?</p>
<p>n) know how to support people with dementia to access local services and referral pathways including voluntary and community services which would promote their physical, mental and oral health</p>	<p>Do you have information available on local services and support that staff can pass on to individuals and their families, or use to make referrals or provide advice?</p>

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# Subject 7: Pharmacological interventions in dementia care

## Introduction

While there is no cure for dementia some medications are available that can slow the progression of some types of dementia for a period of time. Drug treatments have frequently been used as a means of ‘treating’ what are often called symptoms of dementia such as agitation, aggression and calling out. As is highlighted in Subject 5, behaviours of this type are often a way of communicating unmet needs that should be addressed through care-based interventions. Prescribing of anti-psychotic medications for such behaviours causes increased risk of stroke, falls and death<sup>10</sup>. However, some people with dementia do experience periods of acute neuropsychiatric symptoms that may need short term, carefully monitored drug treatment to alleviate symptoms and distress.

We have located very few freely available training resources on pharmacological interventions. Therefore, we have identified some written information in the form of factsheets that provide some helpful basic information on the main drugs and their uses and risks. However, if you feel staff in your organisation require a more in-depth understanding of these learning outcomes we recommend you explore options for more formal training provision from experts in this area.

## Subject level resources and training programmes

Please refer to the HEE *Dementia Training Resource List* for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

### **a) know the most common medications used to treat the symptoms of dementia**

This factsheet from the Alzheimer’s Society provides an overview of the main drug treatments for dementia.

[https://www.alzheimers.org.uk/download/downloads/id/1760/factsheet\\_drug\\_treatments\\_for\\_alzheimers\\_disease.pdf](https://www.alzheimers.org.uk/download/downloads/id/1760/factsheet_drug_treatments_for_alzheimers_disease.pdf)

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<sup>10</sup> All-Party Parliamentary Group on Dementia (2008) *Always a last resort. Inquiry into the prescription of antipsychotic drugs to people with dementia living in care homes*. The Stationary Office, London.

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**b) know the main risks and benefits of using anti-psychotics, anti-depressants, anxiolytics, anticonvulsants and cognitive enhancers and be aware of the impact drugs may have on daily living, including common side effects such as taste disturbances and a dry mouth**

This Alzheimer's Society factsheet discusses drugs that may be prescribed to treat neuropsychiatric symptoms of dementia, including their risks and benefits.

[https://www.alzheimers.org.uk/download/downloads/id/2628/factsheet\\_drugs\\_used\\_to\\_relieve\\_behavioural\\_and\\_psychological\\_symptoms\\_in\\_dementia.pdf](https://www.alzheimers.org.uk/download/downloads/id/2628/factsheet_drugs_used_to_relieve_behavioural_and_psychological_symptoms_in_dementia.pdf)

**c) be aware of issues around polypharmacy for people with dementia**

Polypharmacy is the use of multiple medications by an individual. It can be problematic as some medications can interact with others and this can cause problems for health, particularly if new medicines are prescribed without appropriately reviewing those an individual is currently taking. Polypharmacy can be associated with increased cognitive and functional decline<sup>11</sup>. Your local pharmacist can conduct a medicines review and will be able to highlight any potential problems and make recommendations to the GP about changing prescriptions.

This video from the Royal Pharmacological Society highlights some of the issues around polypharmacy and the important role of medicines review.

<https://www.rpharms.com/making-a-difference/projects-and-campaigns/pharmacists-improving-care-in-care-homes>

**d) understand the importance of recording and reporting side effects and/or adverse reactions to medication**

Recording accurately in care records and appropriately reporting any potential side effects or adverse reactions to medicines is important at an individual and wider level. If an individual has a reaction it is important this is recorded and reported so the person can potentially be prescribed a different medication and that this is accurately recorded in their care records so they are not prescribed it

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<sup>11</sup> Clague, F. and Guthrie, B. (2017) Comorbidity and Polypharmacy in Dementia - Time for Action?

<https://www.rcpsych.ac.uk/workinpsychiatry/faculties/oldagepsychiatry/newsletters/enewsletterjanuary2017/comorbidityandpolypharmacy.aspx>

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again. National reporting of reactions and side effects can help to make drugs safer, provide better patient information and support decision-making around which medicines to prescribe. They should always be reported to the GP or person prescribing the medication as soon as possible.

This video from the MHRA outlines the yellow card scheme, which is one mechanism for reporting side effects and adverse reactions to drugs.

<https://yellowcard.mhra.gov.uk/the-yellow-card-scheme/>

**e) be able to administer and review medication safely and appropriately in consultation with people affected by dementia.**

See c above.

## Support for managers in health and care in implementing learning outcomes

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 7, you also need to be confident that your team is implementing guidelines effectively.

A quick checklist of things to consider:

Framework outcome	Things to consider
All outcomes	<p>Do staff have awareness about the different medications that might be used in treatment of people with dementia, at a level relevant to their role?</p> <p>Does your organization have a good and proactive relationship with GPs and local pharmacists to support regular medication review and prescribing within good practice guidelines?</p> <p>Are staff encouraged to seek appropriate professional advice if they have concerns about the medications someone with dementia is taking, or their side effects?</p>

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# Subject 8: Living well with dementia and promoting independence

## Introduction

The phrase 'living well' can mean different things to different people. It can mean simple things or it can refer to an array of things that need to be in place in order for us to acknowledge that we are in fact living well. For example, making good choices about our health and well-being and doing what makes us happy, or feeling confident and in control. For someone with dementia living well can be the interplay of things that are familiar or important and things that are essential to day-to-day living. Each person will have differing needs and wants and our role as health and social care professionals is to recognise the contribution that we may make to this in our regular contact with people with dementia and their families/carers.

Finding individual solutions for a person living with dementia can help them maintain their independence for as long as possible. As we know, promoting independence is key to improving a person's confidence thus enabling a heightened sense of purpose. Relationships are also central to wellbeing and this includes our professional interaction with people living with dementia. There are key skills, knowledge and attitudes required when working with people living well with dementia and the following learning outcomes are fundamental to all health and social care staff in settings where they are likely to have regular contact with people living with dementia.

## Subject level resources and training programmes

Please refer to the HEE *Dementia Training Resource List* for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

### **a) understand the importance of physical activity (including access to outside space) in maintaining a person's independence and abilities**

Being physically active and reducing sedentary behaviour (sitting time) is important for physical and mental well-being and for day-to-day functioning. Physical activities which also provide social interaction with others offers the opportunity to improve a person's confidence. When people develop dementia they may lose confidence in being socially and physically active. Fear of falls, getting lost or embarrassment about doing or saying the wrong thing can restrict what people do.

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Therefore, it is important health and care staff understand the benefits of physical activity and can advise and support people with dementia about staying active.

This Alzheimer's Society factsheet covers the benefits of physical activity and exercise for people with dementia.

<https://www.alzheimers.org.uk/get-support/daily-living/exercise>

This Alzheimer Australia factsheet discusses the benefits of physical activity and tips for staying active.

[https://www.dementia.org.au/files/helpsheets/Helpsheet-DementiaQandA08-PhysicalExercise\\_english.pdf](https://www.dementia.org.au/files/helpsheets/Helpsheet-DementiaQandA08-PhysicalExercise_english.pdf)

This video from Age UK Oldham explores the benefits of conducting exercise and socialisation activities in care homes from the perspective of residents, staff and activity facilitators.

<https://www.youtube.com/watch?v=5SiSnoY6MFg>

This video from RACV presents the benefits of physical activity for older people and dispels some of the myths about being too old to exercise.

<https://www.youtube.com/watch?v=xBnk9GnQAv0>

## **b) be able to support individuals to meet their daily living needs**

There are many daily living needs people may have. Important physical care needs include washing and being supported to maintain personal hygiene to standards they are happy with, dressing, eating and drinking including a healthy diet and maintaining hydration, toilet needs including promoting independence and supporting continence, and dental and eye care. Daily care of teeth is an important routine to encourage as is visiting a dentist. Dental and optician appointments can be easily overlooked or forgotten by the person living with dementia or once they enter long-term care. Visits to the optician or dentist may prove more difficult as the dementia progresses, but regular eye and dental checks up are important for the individual's health and well-being.

This video from the Alzheimer's Society presents Rose's story about the importance of appropriate support in helping her to remain independent.

<https://www.youtube.com/watch?v=BGLBytHHg6Y>

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### **c) be able to support individuals to continue their interests, social life and community involvement and know why this is important**

After a diagnosis people living with dementia and their carers often think that everything that went before needs to change or stop. Supporting staff to enable individuals living with dementia continuing with their interests is important to living well with dementia. As we have discussed earlier, physical and mental activities are stimulating and can provide a sense of identity and well-being. Support to continue with interests can take on many guises. For example, it may involve providing transportation, accompanying the person or modifying the person's participation.

#### **Example: Bob's story**

Bob was a keen cyclist but after his diagnosis was anxious about getting lost. Bob and his wife discussed using an electronic tracker (assistive technology) but it appeared that Bob's confidence was shattered. By chance, a family friend mentioned a local cycling club which used an outdoor athletic track as part of its weekly training. The club did not have any members with dementia at that time but when approached to see if they could assist Bob to continue his love of cycling the response was incredible. Bob now regularly attends the club (which his wife drives him to), and confidently cycles alongside other members.

Health and social care professionals can provide information, advice or signpost people living with dementia to organisations or local activities and these do not necessarily need to be 'dementia specific'.

A video from the Alzheimer's Society presenting Chris's story about the importance of keeping active when living with dementia.

<https://www.youtube.com/watch?v=qn-dInwYRQ0>

SCIE web-based content on keeping people with dementia active and occupied.

<https://www.scie.org.uk/dementia/living-with-dementia/keeping-active/>

Alzheimer's Society factsheet offering advice on how to keep active and involved.

<https://www.alzheimers.org.uk/get-support/staying-independent/keeping-active-involved>

NHS Choices web-based content on activity for people with dementia.

<https://www.nhs.uk/conditions/dementia/activities/>

Alzheimer Scotland guide for carers of people with dementia on activities.

<https://www.alzscot.org/assets/0000/0266/activities.pdf>



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SCIE web-based information about supporting people with advanced dementia to be active.  
<https://www.scie.org.uk/dementia/living-with-dementia/keeping-active/activity-in-later-stages.asp>

The Alzheimer's Society web-site allows people to search for their local activity group.  
<https://www.alzheimers.org.uk/get-support/your-support-services/activity-groups>

## **d) know about community initiatives such as the development of dementia friendly environments**

As increasing numbers of people are touched by dementia, awareness continues to grow within communities driven, by the commitment of dementia focused organisations and national and local initiatives.

Dementia Friends is a well-known national initiative supported by the Alzheimer's Society. You may be one of the million plus people who have become a Dementia Friend who learn what it is like to live with dementia and then actively identify small and different ways to affect change.

It should be noted that Dementia Friends sessions are information sessions that are designed to raised awareness in the general public about dementia. While some dementia training courses have been permitted to include the Dementia Friends pledges at the end and to also award Dementia friend status, the standard Dementia Friends sessions are not a training course and do not equate to tier 1 (Dementia Awareness training).

You can visit the Dementia Friends web-site here.  
<https://www.dementiafriends.org.uk/>

Dementia Friendly Communities is a national programme which facilitates the creation of dementia-friendly communities across the UK. The focus is on different aspects of the community assuming part of the responsibility for ensuring that people living with dementia feel valued and able to contribute to their community.

You can read more about Dementia Friendly Communities here.  
[https://www.alzheimers.org.uk/info/20079/dementia\\_friendly\\_communities](https://www.alzheimers.org.uk/info/20079/dementia_friendly_communities)

This video discusses the small changes that dementia friendly communities can make that may make a big difference.  
<https://www.youtube.com/watch?v=Fz8ACEu7Lho>

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When a person living with dementia is trying to make sense of the world around them, their immediate surroundings can make all the difference to their quality of life. Dementia friendly environments are initiatives designed to improve the care environment for people with dementia. For example, the Department of Health funded a pilot programme whose aim was to create custom designed facilities for people with dementia in both health and social care settings. The evaluation of the pilot highlighted that by creating the right environment there may be benefits not only for people living with dementia, but also for their families, friends and staff.

There are many resources on dementia friendly environments and adapting the environment to be more supportive to people living with dementia see learning outcome k below and also Subject 4: Person-centred Care learning outcome f.

### **e) understand the needs of individuals for day to day closeness with others e.g. sharing thoughts and feelings**

A person living with dementia can often feel anxious about their diagnosis and the impact this has on those around them. They may experience a variety of emotions including loss, anger, grief and fear. For some people, it is possible to discuss their confusion and fears with family members but others may not wish to worry those closest to them. As managers and leaders, you must ensure staff from health and social care professions understand their person-centred approach to supporting individuals' needs allowing time to talk and listen to people living with dementia. Having the opportunity to be listened to and be reassured can relieve some of the anxiety around the symptoms of dementia and the day-to-day struggle sometimes experienced. Those people who feel socially isolated or who are without family are likely to value contact with a professional who understands their daily confusion with aspects of the world around them.

This *Dementia Diaries* entry from Agnes highlights the importance of friendships for people with dementia

<https://dementiadiaries.org/entry/7052/agnes-says-since-my-diagnosis-i-have-few-visitors-i-want-to-chase-away-the-silence-and-the-isolation-i-am-feeling>

This help sheet from the Cornwall and District Alzheimer's Society in Canada gives some hints and tips on maintaining relationships with someone with dementia.

<http://www.alzheimer.ca/sites/default/files/files/chapters-on/cornwall/info/fact%20sheets%20en/maintaining%20relationships%20ascd%20may%2025%202013.pdf>

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This *Dementia Diaries* post by Dory records her concerns about some of the loss of relationships people may experience if they move into long-term care

<https://dementiadiaries.org/entry/6371/dory-talks-about-a-series-of-losses-for-her-friends-going-in-to-care>

## **f) understand how to recognise and respond to cultural, spiritual and sexual needs of people with dementia**

For cultural needs see Subject 10: Equality, diversity and inclusion.

**Spiritual** - Meeting spiritual needs may not purely be a matter of providing opportunities for religious observance, although this might be significant for those who have a specific faith.

In 2012 the Royal College of Nursing published a pocket guide entitled 'Spirituality in Nursing Care' to assist nurses to understand some of the issues that can arise when caring for others. For further details, visit the RCN website.

<https://www.rcn.org.uk/professional-development/publications>

**Sexual needs** - The Alzheimer's Society has produced a factsheet on sexual and intimate relationships which addresses a number of topics including sex, intimacy and dementia; adapting to changes and ways of coping with frustration. Care professionals may find this factsheet helpful to have to hand or to highlight for couples coping with dementia, especially if people wish to raise questions directly with them.

<https://www.alzheimers.org.uk/get-support/daily-living/forming-new-relationships>

## **g) understand the role of family and carers in enabling people with dementia to live well**

See Subject 9: Families and carers as partners in care.

## **h) understand how activities can be adapted to suit an individual's changing needs**

see Subject 4: Person-centred Care learning outcome e.

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## **i) be able to incorporate assistive technology to support self-care and meaningful activity**

Sometimes technology is a component in living well. Technology can be used in a variety of ways to help people with dementia in their daily living, and is referred to as 'assistive technology'. Some technology is simple and easy to install, whilst solutions that are more complex may require specialist installation. There can be an overwhelming amount of assistive technologies available, so people with dementia and their family members may need support and guidance to decide what might work best for them.

This factsheet from the Alzheimer's Society outlines the types of assistive technologies that are available.

<https://www.alzheimers.org.uk/get-support/staying-independent/what-assistive-technology-available>

The *at dementi'* web-site developed by the Trent Dementia Services development Centre contains a search facility for assistive technology products.

[https://www.atdementia.org.uk/productSearch.asp?page\\_id=16](https://www.atdementia.org.uk/productSearch.asp?page_id=16)

This web-site content from the Dementia Services Development Centre at the University of Stirling discusses technology and its potential benefits and outlines some of the available technologies.

<http://dementia.stir.ac.uk/blogs/dementia-centred/2016-02-08/can-technology-improve-care-people-dementia>

This web content from SCIE looks at assistive technology.

<https://www.scie.org.uk/dementia/supporting-people-with-dementia/dementia-friendly-environments/assistive-technology.asp>

## **j) be able to develop strategies to reduce the struggle with unfamiliar environments**

Unfamiliar environments can be a challenge for all of us but people living with dementia may find being somewhere different very confusing. Using the knowledge and experience that you have from working with people with dementia, consider what might appear confusing about your work setting and design a simple strategy to adapt the environment. Design strategies can enhance people's experience.

See outcome k below.

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**k) be aware of ways to adapt the physical environment to promote independence, privacy, orientation and safety (e.g. to reduce risk of falls)**

Evidence suggests environments that have been adapted to support individuals with cognitive impairments can reduce the possibility of falls, lessen agitation and distressed behaviour. There is a large range of available information on design of home and formal care environments for people living with dementia.

The Dementia Action Alliance has produced a Dementia Friendly Physical Design Checklist.

[https://www.dementiaaction.org.uk/assets/0000/4336/dementia\\_friendly\\_environments\\_checklist.pdf](https://www.dementiaaction.org.uk/assets/0000/4336/dementia_friendly_environments_checklist.pdf)

This booklet from the Alzheimer's Society provides hints and tips on how people can make their own homes safer and more familiar.

[https://www.alzheimers.org.uk/info/20001/get\\_support/783/making\\_your\\_home\\_dementia\\_friendly](https://www.alzheimers.org.uk/info/20001/get_support/783/making_your_home_dementia_friendly)

The Kings Fund undertook a range of work on dementia friendly environments for people with dementia.

<https://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-in-dementia-care>

This has subsequently been taken forward by the University of Worcester.

<https://www.worcester.ac.uk/discover/ads-enhancing-the-healing-programme.html>

The University of Sterling has undertaken extensive work around the physical environment and dementia. Their web-site includes a range of resources including two virtual tours of a dementia friendly care home and hospital environment.

<http://dementia.stir.ac.uk/design/virtual-environments>

The Department of Health has produced guidance on design principles for dementia friendly design and the adaption of existing care environments.

<https://www.gov.uk/government/publications/dementia-friendly-health-and-social-care-environments-hbn-08-02>

NHS Choices provides some short, simple information about the home environment and dementia.

<https://www.nhs.uk/conditions/dementia/home-environment/>

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The 'Walk Through Dementia' resources developed by Alzheimer's Research UK present a visit to the supermarket, a walk down a street and trying to make a cup of tea through the eyes of a person with dementia. They highlight some of the challenges that dementia may cause for individuals when they are completing everyday tasks and activities. These can be accessed as a video clip via a computer or there are 3-D virtual reality versions and you can purchase cardboard headsets to gain the full 3-D experience.

<http://www.awalkthroughdementia.org/>

### **l) know about perceptual distortions that may occur in dementia and how the impact of such distortion can be minimised by changes to the environment**

An individual's perceptions can change as the dementia progresses and it is important that health and care staff understand this. Things which we take for granted become an issue for the person with dementia. People living with dementia can experience difficulty with colour discrimination, depth perception and sensitivity to contrast (Cronin-Golumb, 1995). Visuo-perceptual problems experienced by people will be different depending on the type of dementia they have.

The 'Walk Through Dementia' resources developed by Alzheimer's Research UK present a visit to the supermarket, a walk down a street and trying to make a cup of tea through the eyes of a person with dementia. They highlight some of the challenges that dementia may cause for individuals when they are completing everyday tasks and activities. These can be accessed as a video clip via a computer or there are 3-D virtual reality versions and you can purchase cardboard headsets to gain the full 3-D experience.

<http://www.awalkthroughdementia.org/>

### **m) understand the importance of food-related activities to stimulate appetite and support engagement and independence in food preparation, eating and drinking**

See Subject 6: Health and well-being in dementia care outcome b.

## **Support for managers in health and care in implementing learning outcomes**

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 8, you also need to be confident that your team are implementing guidelines effectively.

A quick checklist of things to consider:

Framework outcome	Things to consider
a) understand the importance of physical activity (including access to outside space) in maintaining a person's independence and abilities	<p>Are people who access your service encouraged to be physically active? What provision do you make to support an active lifestyle?</p> <p>Is there access to outside space and are those who use your service encouraged to spent time outside?</p>
b) be able to support individuals to meet their daily living needs	<p>Are staff aware of individual needs, how these may change over time and what they can do to support people to remain independent?</p> <p>Are care plans written with abilities and maintaining independence in mind?</p>
c) be able to support individuals to continue their interests, social life and community involvement and know why this is important	<p>Are staff aware of the interests and hobbies of people living with dementia they support? Do they encourage continued involvement in these activities?</p> <p>Does your organization offer a supportive environment for engagement and community involvement?</p>
d) know about community initiatives such as the development of dementia friendly environments	<p>Are staff across the organization aware of dementia friendly initiatives and their role in including people with dementia fully in society?</p> <p>What does your organization and its staff contribute to this?</p> <p>Have you undertaken an environmental assessment of your service or setting? Could improvements be made to make the space more accessible and supportive to people with dementia?</p>
e) understand the needs of individuals for day to day closeness with others e.g. sharing thoughts and feelings	<p>Are supportive relationships between people with dementia, family, friends and staff encouraged within your organization?</p> <p>Is the way the service operates one that promotes continuity of relationships?</p>

	Are staff encouraged to offer opportunities for people with dementia to talk about their feelings and thoughts on a daily basis as an integral part of good quality care?
f) understand how to recognise and respond to cultural, spiritual and sexual needs of people with dementia	See Subject 10
g) understand the role of family and carers in enabling people with dementia to live well	See Subject 9
h) understand how activities can be adapted to suit an individual's changing needs	See Subject 4
i) be able to incorporate assistive technology to support self-care and meaningful activity	<p>Are staff aware of the role that assistive technology may play in supporting people living with dementia?</p> <p>Do staff have access to information and advice about available technologies that they can use to support their own practice and advise people with dementia and their family members?</p> <p>Does your organization use assistive technologies (where applicable)?</p>
<p>j) be able to develop strategies to reduce the struggle with unfamiliar environments</p> <p>k) be aware of ways to adapt the physical environment to promote independence, privacy, orientation and safety (e.g. to reduce risk of falls)</p> <p>l) know about perceptual</p>	Have you undertaken an environmental assessment? Have adaptations been made to ensure the environment is supportive, non-restrictive and supports safety, privacy and orientation?



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distortions that may occur in dementia and how the impact of such distortion can be minimised by changes to the environment	
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# Subject 9: Families and carers as partners in dementia care

## Introduction

Many examples of developing person-centred care have come from implementing information provided by family/carers. Sometimes communication with people living with dementia can be very difficult, particularly when they enter the later stages of the disease. In the absence of being able to communicate with the individual, the family/carers/people that know the person well are going to provide the best insights into the individual and their care and support needs and preferences.

Also, for health and social care staff providing care and support in the individuals own home, awareness of relationships and being able to work in co-production with families and carers who will also need advice and support is very important.

## Subject level resources and training programmes

Please refer to the HEE *Dementia Training Resource List* for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

### **a) understand the significance of family, carers and social networks in planning and providing care**

As managers and trainers, you need to support staff to understand that family members/carers are 'experts' in the partnership of quality care and support. Their knowledge of the person living with dementia is key to providing person-centred care and will go beyond any information gathered through routine assessment processes. If family/carers have helped complete life story/information such as 'This is me' (Alzheimer's Society) or similar, this will be valuable as a source for care planning. If not, perhaps you can encourage them to put together life story materials. If applicable, offering flexibility in terms of visiting (wherever possible) to family/carers can reduce the stress levels of the person with dementia and assist in situations where communication may be problematic due to unfamiliarity of the environment.

*This is me* tool.

<https://www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me>

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This web-based information from SCIE presents ideas on how to keep family members involved in the care of a person with dementia.

<https://www.scie.org.uk/dementia/living-with-dementia/keeping-active/involving-family-friends.asp>

## **b) understand the importance of developing partnerships with family members and carers**

The best way to achieve involvement of family members in the care and support of someone with dementia is to work in partnership with them.

This web-based content from SCIE covers working in partnership with family members.

<https://www.scie.org.uk/dementia/carers-of-people-with-dementia/working-in-partnership/>

The RCN's Triangle of Care is a therapeutic model for working in partnership with a person with dementia and their carer.

<https://www.rcn.org.uk/clinical-topics/dementia/triangle-of-care>

## **c) understand the impact that caring for a person with dementia in the family may have on relationships**

When someone develops dementia this can have a huge impact on family relationships. Taking on the role of carer and cared for can alter dynamics within marriages and between children and parents. Caring for someone with dementia can be tiring and stressful and this can put a strain on wider relationships with other family members and friends. Disagreements between family members about caring decisions and approaches can lead to disputes and in some cases the breakdown of family relationships. However, caring for someone with dementia can also be rewarding and fulfilling. Staff working across health and care services need to be able to support families throughout this often complex and challenging journey.

This video from the Alzheimer's Society presents Bruce's perspective on caring for his wife Jan who lived with advanced dementia. It provides insight into a carer's knowledge and perspective and the impact on their relationship.

<https://www.youtube.com/watch?v=chgshB6LCyc>

These videos from *Healthtalk* present carer's views of providing care for people with dementia.

<http://www.healthtalk.org/peoples-experiences/nerves-brain/carers-people-dementia/topics>

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These more general videos from *Healthtalk* discuss the impact that becoming a carer can have on relationships. Whilst the videos are not dementia specific, many of the issues described around changing relationships when someone takes on a caring role are relevant.

<http://www.healthtalk.org/peoples-experiences/dying-bereavement/caring-someone-terminal-illness/changing-roles-and-relationships>

This report from Alzheimer's Research UK (2015) *Dementia in the Family: The impact on carers* includes data from interviews with people with dementia to outline some of the major impacts on families. There are also a number of short videos of family members who took part in the research, sharing their stories.

<https://www.alzheimersresearchuk.org/about-us/our-influence/reports/carers-report/>

**d) understand the importance of recognising and assessing a carer's own needs, including respite**

See c above, h below and Subject 10 learning outcome f.

**e) be aware of the complexity and diversity in family arrangements**

See Subject 10 learning outcome c.

**f) be aware that the needs of carers and the person with dementia may not always be the same**

Sometimes balancing the needs of carers against the needs of a person with dementia can be difficult. For example, a person with dementia may have expressed a strong prior wish not to go into residential care, but a carer may find they are no longer able to cope caring for the person at home. Conversely, a carer may not wish to place a person with dementia in a care home, but may not be able to meet all of their needs at home.

**g) understand potential socio-cultural differences in the perception of the care giving role**

See also Subject 10 learning outcome c.

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## **h) be aware of the impact on younger carers and their concerns**

Many younger people have caring responsibilities for someone with dementia. This may be for a grandparent or for a parent who may have young onset dementia. It is important that staff consider the impact of caring responsibilities on the whole family and understand the needs and concerns that younger carers or members of a household with caring responsibilities, may have.

This article from the Alzheimer's Society presents the story of a teenager who cared for two of her grandparents who were living with dementia, in her own words.

[https://www.alzheimers.org.uk/info/20082/living\\_with\\_dementia\\_magazine/236/a\\_teenager\\_speaks\\_out\\_about\\_the\\_strain\\_of\\_being\\_a\\_young\\_carer](https://www.alzheimers.org.uk/info/20082/living_with_dementia_magazine/236/a_teenager_speaks_out_about_the_strain_of_being_a_young_carer)

## **i) be able to communicate compassionately, effectively and in a timely manner with care partners**

Effective communication with carers is just as important as with people living with dementia. The skills staff can employ are similar to those they would use when communicating with a person with dementia.

This article in Community Care presents some tips for communicating with service users and carers.

<http://www.communitycare.co.uk/2008/10/15/proven-practice-communicating-with-service-users-and-their-carers/>

## **j) be able to support family carers to access and use information and local support networks including housing sectors, providers and services**

What is available locally to people with dementia and their carers varies from location to location. Therefore, you will need to work with staff in your service to identify what is available locally for the client group you serve. The local Council, NHS Trusts and charities may have on-line or written information available or you may need to undertake your own research to identify relevant local services.

This video from the Alzheimer's Society outlines the support and services available for carers.

<https://www.youtube.com/watch?v=NTAohFT5Zis>

The Alzheimer's Society provides a range of web-based information about support for carers.

<https://www.alzheimers.org.uk/get-support/help-dementia-care/other-resources>

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## **k) be able to support family carers in considering options and making decisions**

Carers will have to make a range of difficult decisions as they support a person with dementia, particularly as dementia progresses and the person is no longer able to make those decisions for themselves. This can be stressful for the carer and people can experience a range of feelings such as worry or guilt about whether they are doing the right thing. Support from health and care professionals through this process can be vital.

This factsheet from the Alzheimer’s Society covers a range of difficult decisions a carer may have to make.

<https://www.alzheimers.org.uk/get-support/daily-living/making-decisions-and-managing-difficult-situations>

This guidance from NICE provides advice on involvement and choice in decision-making.

<https://www.nice.org.uk/about/nice-communities/social-care/tailored-resources/dementia/statement-2>

## **l) be able to gather information about a person’s history and preferences from family carers**

See Subject 4: Person-centred dementia care learning outcome d.

## **Support for managers in health and care in implementing learning outcomes**

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 9, you also need to be confident that your team are implementing guidelines effectively.

A quick checklist of things to consider:

<b>Framework outcome</b>	<b>Things to consider</b>
All outcomes	<p>Are relatives and friends involved in care and daily life of the person with dementia? Is this actively encouraged by staff and the organization’s policies, procedures and approaches?</p> <p>Are staff encouraged to involve family members in care planning and care delivery?</p>

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	<p>Have staff been provided with training on how to support family members and understand what they might be experiencing?</p> <p>Are staff able to signpost carers to services where they can receive support and advice?</p> <p>Are staff aware of the differences that may exist within families around caregiving, roles and responsibilities and are they encouraged to be non-judgmental in their support for families?</p> <p>Do staff consider the needs of younger carers and the impact that caregiving can have on the wider family and their relationships?</p> <p>Do staff have the confidence and skills to effectively support families through decision-making with the person with dementia?</p>
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# Subject 10: Equality diversity and inclusion in dementia care

## Introduction

Like any disease and condition, dementia does not discriminate and will affect people from all cultures and backgrounds. Issues of diversity may have an impact on how people experience dementia, including the acceptance of the condition within their family or community. A person's background and culture are important to them as an individual so are also an important consideration for the delivery of person-centred care.

Dementia is generally regarded as a condition affecting people over the age of 65. However, there are a significant number of people with younger onset dementia and they are likely to have specific needs and concerns. Indeed, for care to be person-centred, there are likely to be very specific needs and expectations based on a person's age and background.

In addition, many of the characteristics covered by the Equality Act and related to the wider determinants of health can have a significant bearing on experiences of dementia.

## Subject level resources and training programmes

Please refer to the *HEE Dementia Training Resource List* for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

### **a) be aware of cultural diversity and equality issues, and how they may impact on people with dementia**

A person's culture and background are a significant part of one's identity therefore will have a bearing on the care and support they would prefer to receive. Teams need to be aware of this and adjust care and support accordingly. For example, it is likely that people with dementia who have English as a second language will revert to their primary language as the condition progresses – this may present communication challenges. There are a number of things for staff to consider, and individual needs are likely to be different.



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The Skills for Care *Dementia and Diversity* resource highlights some key considerations for teams to consider.

<http://www.skillsforcare.org.uk/Documents/Topics/Dementia/Dementia-and-diversity-a-guide-for-leaders-and-managers.pdf>

The *Finding Patience* and *Finding Patience: The Later Years* video resources developed by Health Education England highlight important considerations for people living with dementia from Black, Asian and Minority Ethnic (BAME) communities.

Finding Patience.

<https://www.youtube.com/watch?v=Q7zJL8nPqFg>

Finding Patience: The Later Years.

<https://www.youtube.com/watch?v=VgVKw-Wfxy4>

This video from the Alzheimer's Society outlines the experiences of Samirah and Abdullah on living with dementia.

<https://www.youtube.com/watch?v=yh07Dj-G86U>

## **b) be able to adapt assessment and care planning taking account of equality issues (e.g. cultural diversity, disabilities, gender and sexual orientation)**

The assessment of needs and the planning of care and support for people living with dementia must take into account issues of diversity. In addition, staff, should also be aware that needs will change and that assessments and care planning processes should be regularly reviewed.

NHS England has produced a resource to support care planning for people living with dementia – including those from different cultures and backgrounds.

<https://www.england.nhs.uk/wp-content/uploads/2017/02/dementia-good-care-planning.pdf>

## **c) understand diversity in family arrangements and the local community**

The 2013 All Party Parliamentary Group on Dementia report on dementia in BAME communities said that health and social care providers needed to be sensitive to cultural stereotypes that mean some communities/families are assumed to 'look after their own', resulting in services that do not reach out to individuals and families in particular from BAME communities.

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Staff across health and social care should be very mindful of this. There are however some excellent examples of organisations that have developed specific services that support BAME communities. Support and advice can be provided by family members and friends as well as charity and community groups.

This is also important for staff to consider with respect to LGBT people living with dementia. It may be the case that close families may not be aware of someone's sexuality. In addition, some providers may be supporting people who had kept their sexuality private. It is important that same sex partners are included and made to feel welcome within care planning and services.

There is a growing range of helpful resources on LGBT issues in dementia.

The Alzheimer's Society has produced a factsheet on LGBT and dementia aimed at people with dementia and their partners who are LGBT.

[https://www.alzheimers.org.uk/info/20029/daily\\_living/1190/lgbt\\_living\\_with\\_dementia](https://www.alzheimers.org.uk/info/20029/daily_living/1190/lgbt_living_with_dementia)

This Alzheimer's Society factsheet is aimed at staff or other individuals caring for someone with dementia who is LGBT.

[https://www.alzheimers.org.uk/info/20046/help\\_with\\_dementia\\_care/38/supporting\\_gay\\_lesbian\\_and\\_bisexual\\_people\\_with\\_dementia](https://www.alzheimers.org.uk/info/20046/help_with_dementia_care/38/supporting_gay_lesbian_and_bisexual_people_with_dementia)

SCIE have produced web-site content and short video about caring for someone who has dementia and is LGBT.

<https://www.scie.org.uk/dementia/living-with-dementia/lgbt/>

The National Care Forum has produced a good practice paper on dementia care and LGBT communities.

<http://www.nationalcareforum.org.uk/documentLibraryDownload.asp?documentID=1228>

#### **d) be aware of the stigma, myths and stereotypes associated with dementia**

Teams do need to be aware that everyone may have a different perspective on dementia. The 'stigma' associated with dementia has moved positively over recent years with increased media coverage and public education particularly through initiatives such as Dementia Friends. However, we must be aware of stigma that still exists and evidence suggests that communities have an influence over this.

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There are examples of excellent programmes of support being provided to BAME communities. This can be when families are the main carers of people living with dementia and are less able or less comfortable with accessing the support of health and social care teams. However, in 2013 the All Party Parliamentary Group on Dementia found examples of poor care provided to people living with dementia from diverse backgrounds so staff teams should be aware of this and be prepared to adapt their practice.

Like any disease there are also myths and misunderstandings associated with dementia, and it is very important that staff teams are aware of signs and symptoms of dementia at each stage and offer support and advice to people who may be less knowledgeable about the effect that dementia can have on an individual and their family.

The Skills for Care and Skills for Health resource the *Common Core Principles for Supporting People with Dementia* can support staff teams with understanding some of the myths associated with supporting someone living with dementia.

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215562/dh\\_127587.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215562/dh_127587.pdf)

### **e) be aware of the prevalence and impact of younger onset dementia**

The Alzheimer's Society estimates there are approximately 42,000 younger people with dementia in the UK. This equates to 5% of all people with dementia.

People developing dementia when they are young present different considerations for teams across health and social care. Often one of the myths around dementia is that it is a disease affecting only people over the age of 65. For everyone, a diagnosis of dementia is going to be a very worrying and a life-changing event. For younger people diagnosed with dementia who may be still working or indeed have dependents, there are also likely to be other worries. In addition, expectations around all care and support are likely to be different and very specific to the individual therefore adopting the principles of person-centred care will be particularly important.

The charity Young Dementia UK has developed and gathered information and resources that can be used by people who are working with people with dementia.

<https://www.youngdementiauk.org/resources>

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This video from SCIE talks about the experience and impact of early onset dementia, particularly highlighting the often rapid deterioration someone may experience and the skilled support that is needed, particularly for carers.

<https://www.scie.org.uk/dementia/carers-of-people-with-dementia/supporting-carers/early-onset-living-at-home-with-nursing-support.asp>

This video from SCIE presents the stories of two people who were diagnosed with dementia while in their 50s and the support that they find helpful.

<https://www.scie.org.uk/dementia/symptoms/young-onset/living-with-young-onset-dementia-video.asp>

These videos from the Alzheimer's Society outline the experience of younger onset dementia from the perspective of people living with the condition and those who care for them.

<https://www.youtube.com/watch?v=95pTL9emhco>

<https://www.youtube.com/watch?v=MRtcaG2Gm0c>

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

## **f) be aware of legislation to support carers, including young carers**

The 2014 *Care Act* sets out carers rights in law in a number of different areas. It is important for teams to be able to support carers in the following areas. In particular, it is important for everyone to be aware of the role and responsibilities of Local Authorities in supporting carers.

This web-based information from Carers UK provides information about the *Care Act* and Carers' rights under the Act.

<https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/care-act-faq>

This video from Rochdale Borough Council explains the principles of the *Care Act* and carers' entitlements under this.

[https://www.youtube.com/watch?v=5g6c3geCD\\_k](https://www.youtube.com/watch?v=5g6c3geCD_k)

This video from NHS Choices explains carer's rights regarding entitlement to a carers' assessment.

<https://www.nhs.uk/conditions/social-care-and-support/carers-assessment/>

The *Care Act 2014* does not deal with assessment of people under the age of 18 who care for others. However, they can be supported under the law relating to children. The *Children and Families Act* gives young carers (and parent carers) similar rights to assessment as other carers have under the *Care Act* so it is important for teams to be aware of this.

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NHS Health Scotland has produced a guide for younger people who are carers of someone with dementia.

<http://www.healthscotland.com/uploads/documents/3884-Understanding%20Dementia-A%20guide%20for%20young%20carers-August%202017-English.pdf>

### **g) understand the additional concerns of younger carers**

See h above and Subject 9: Families and carers as partners in dementia care.

### **h) be aware of the impact of dementia on people with learning disabilities**

People with learning disabilities are unfortunately more likely to develop dementia. Providing care and support to people with a learning disability, who may also have dementia is likely to be an important consideration particularly for services supporting adults with learning disabilities.

If a person with a learning disability has additional communication needs, this needs to be considered very carefully by the team as communication will almost certainly become more challenging and complex as the dementia progresses. Care planning and life story work will be very important at this stage, particularly in social care settings.

The British Association of Learning Disabilities and The Alzheimer's Society have developed some factsheets about people who have a learning disability who are also living with dementia. They are available here:

<http://www.bild.org.uk/resources/ageingwell/dementiafactsheets/>

### **i) be aware of socio-cultural differences in the perception of the care giving role e.g. based on gender**

Some cultures and backgrounds may have certain perceptions of the care giving role and teams will need to be sensitive to this. They should also be careful not to assume how families will respond to dementia or perceive the caregiving role based on their characteristics such as ethnicity or gender. Key to managing this is working closely with main carers to try to understand their perspective and to working sensitively with them to support their needs.

See also Subject 9: Families and carers as partners in dementia care.

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**j) be able to actively challenge any discriminatory practice that may compromise a person’s right to dignity, respect and safety**

We are all entitled to our own views, however we all have a legal and moral responsibility to ensure we support everyone in the same way regardless of culture and background. People working in health and social care also have the right to have their culture and background respected by colleagues and people with dementia.

As the disease progresses, people living with dementia may lose inhibitions and may say or do things that may cause offense to people around them.

Staff will need to manage challenging scenarios relating to diversity issues with diplomacy, professionalism and fairness to all. There have been examples of people living with dementia who do not want care and support provided by a particular staff member for reasons personal to them. Whilst this may be difficult and potentially upsetting for staff, if alternative arrangements can be made this may be the best way of managing this.

## Support for managers in health and care in implementing learning outcomes

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 10, you also need to be confident that your team are implementing guidelines effectively.

A quick checklist of things to consider:

<b>Framework learning outcome</b>	<b>Things to consider</b>
a) be aware of cultural diversity and equality issues, and how they may impact on people with dementia	Does your team have a brief understanding of some of the key things to consider around equality and diversity for people with dementia?  How well do you feel your service is currently considering and managing equality and diversity issues for people living with dementia?

<p>b) be able to adapt assessment and care planning taking account of equality issues (e.g. cultural diversity, disabilities, gender and sexual orientation)</p>	<p>Do your staff actively demonstrate that they consider equality and diversity when care and support planning?</p> <p>Do you discuss this during supervisions and team meetings?</p> <p>How could you improve your care planning?</p>
<p>c) understand diversity in family arrangements and the local community</p>	<p>How well do your staff work with families and carers to better understand the person living with dementia and their culture and background?</p>
<p>d) be aware of the stigma, myths and stereotypes associated with dementia</p>	<p>Has your team faced issues around myths/stigma associated with dementia and had to manage challenging discussions because of this? How well was it managed? What would you/your team do differently?</p>
<p>e) be aware of the prevalence and impact of younger onset dementia</p>	<p>Does your team understand the key things to consider when supporting someone who has young onset dementia?</p> <p>What changes are you likely to have to make and how would you support your team implementing this?</p>
<p>f) be aware of legislation to support carers, including young carers</p>	<p>Does your team promote Local Authority carers assessments to family/ carers?</p>
<p>g) understand the additional concerns of younger carers</p>	<p>How would you support your team to support someone with young onset dementia who has children under the age of 18?</p>
<p>h) be aware of the impact of dementia on people with learning disabilities</p>	<p>See above</p>
<p>i) be aware of socio-cultural differences in the perception of the care giving role e.g. based on gender</p>	<p>What might be some of the key differences in perceptions around the caring role be?</p> <p>What might your team need to consider to be able to manage this?</p>

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j) be able to actively challenge any discriminatory practice that may compromise a person's right to dignity, respect and safety	Does your staff know what to do if they witness discriminatory behaviour from someone living with dementia / a family/carer / staff member?
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### **Additional resources**

Alzheimer's Disease International's *World Alzheimer Report* published in 2012 addressed the issue of overcoming stigma.

<https://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf>

A report on the experiences of LGBT people who are living with dementia from DEEP.

<http://dementivoices.org.uk/wp-content/uploads/2015/03/Over-the-Rainbow-LGBTDementia-Report.pdf>



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# Subject 11: Law, ethics and safeguarding in dementia care

## Introduction

Staff working across health and social care should already have undertaken training on a range of legal and ethical issues and processes such as safeguarding, identification of potential abuse or neglect and what to do if they are concerned about an individual in their care. People with dementia may be at greater risk of potential abuse and neglect and may be less able to identify or report it. Having dementia does not automatically mean an individual is unable to make decisions for themselves. Therefore, it is important staff can work to support independence in decision-making for as long as possible and that they understand key legislation and processes for assessing capacity and supporting decision-making.

## Subject level resources and training programmes

Please refer to the HEE *Dementia Training Resource List* for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

### **a) understand how duty of care contributes to safe practice and facilitates decision-making**

All staff should have a sound awareness of their duty of care and its role in safe practice through wider training accessed as part of induction and/or any professional preparation or other training they may have undertaken.

Unison have produced a Duty of Care Handbook which contains useful information.

<https://www.unison.org.uk/content/uploads/2013/06/On-line-Catalogue197863.pdf>

Skills for Care have a Skills checklist associated with duty of care.

[https://www.scie.org.uk/workforce/careskillsbase/files/skillschecks/35\\_dutyofcare.pdf](https://www.scie.org.uk/workforce/careskillsbase/files/skillschecks/35_dutyofcare.pdf)

### **b) be aware of dilemmas that may arise between the duty of care and an individual's rights and carers wishes**

See a above.

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**c) be able to communicate effectively about proposed treatment or care to enable people with dementia to make informed choices as far as practicable**

See d below and also Subject 5: Communication, interaction and behaviour in dementia care.

**d) understand the protocols regarding consent to treatment or care for people who may lack mental capacity**

The *Mental Capacity Act* sets out clearly the process that must be followed in assessing if someone has capacity to give informed consent to treatment or care. Staff must apply this process for every treatment and care decision, as these are time and decision specific.

This video from Hounslow and Richmond Community Healthcare NHS Trust provides a good overview of the Principles of the *Mental Capacity Act*, a step-by-step guide to the process for assessing and recording capacity and tips on how to ensure individuals are given the best possible opportunity to have capacity to make their own decisions. The first example in the video is decision-making with a person with dementia.

<http://www.hrch.nhs.uk/mca-training-film>

It also has an accompanying information booklet.

[https://www.safeguarding-bathnes.org.uk/sites/default/files/hrch\\_usingthe\\_mental\\_capacity\\_act\\_in\\_the\\_community\\_booklet.pdf](https://www.safeguarding-bathnes.org.uk/sites/default/files/hrch_usingthe_mental_capacity_act_in_the_community_booklet.pdf)

NHS Choices provides web-based information on consent to treatment and capacity.

<https://www.nhs.uk/conditions/consent-to-treatment/capacity/>

**e) understand how ‘best interests’ decisions may need to be made for those lacking capacity**

If someone lacks capacity to make an informed decision, then a ‘best interests’ decision must be made about their care or treatment. This must be undertaken in line with the principles of the *Mental Capacity Act* and must involve consultation with the individual and their family members as well as health and care professionals.

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SCIE has a range of web-based content about best interests decision-making.

<https://www.scie.org.uk/mca/practice/best-interests>

<https://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/best-interest.asp>

The Alzheimer's Society has produced a factsheet on 'Best Interests Decisions'.

<https://www.alzheimers.org.uk/get-support/legal-financial/making-decisions-for-someone-lacking-mental-capacity>

## **f) know how advance directives can be used to provide information about the wishes of an individual**

Advance decisions, statements and legal provisions such as Lasting Power of Attorney can help make decision-making easier as this can clearly set out an individual's wishes and provides clarity about where responsibilities for decision-making lie. Any legal provision that sets out care wishes must be made while a person still has capacity so it is important staff are able to discuss this with people with dementia and their family members and are able to encourage and support them to undertake the required provision while the person is able to do so.

This podcast from the Alzheimer's Society provides information and advice about Lasting Power of Attorney.

<https://www.youtube.com/watch?v=OuCeJxCot2A>

This factsheet from the Alzheimer's Society looks at advance decisions or living wills.

<https://www.alzheimers.org.uk/get-support/legal-financial/advance-decision-living-wills>

Age UK also provides a range of advice information about advance decisions and advance statements.

<https://www.ageuk.org.uk/information-advice/money-legal/legal-issues/advance-decisions/>

<https://www.ageuk.org.uk/templates/adviceguidesection.aspx?id=16661>

## **g) be able to recognise a range of factors which may indicate neglect, abusive or exploitative practice**

Staff should already have safeguarding training as part of their induction and ongoing professional development within a health or care provider organisation.

SCIE provides web-based content on issues around safeguarding for people with dementia.

<https://www.scie.org.uk/dementia/after-diagnosis/support/safeguarding.asp>

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## **h) know what to do if neglect, abusive or exploitative practice is suspected, including how to raise concerns within local safeguarding or whistle blowing procedures**

Staff should already be aware of this as part of their wider training on safeguarding. They should know what the local reporting procedure is, and also about the organisations safeguarding and whistleblowing policies.

## **i) be aware of key legislation relevant to mental capacity, deprivation of liberty, equality and human rights**

There is a broad range of legislation relating to the protection and care of people with dementia. This may be updated and staff need to be supported to remain up to date.

This booklet by DEEP sets out the rights of people with dementia under the Human Rights Act. <http://dementiawithoutwalls.org.uk/wp-content/uploads/2016/10/Our-dementia-Our-rights-booklet.pdf>

This video provides an overview of the Deprivation of Liberty principles. <https://vimeo.com/154203484>

SCIE have produced a video about Deprivation of Liberty safeguards using real case studies. <https://www.scie.org.uk/mca/dols/supreme-court-judgment/explaining-the-2014-changes>

This video from the NHS, which is aimed at people who may have their liberty deprived, outlines their rights under the Mental Capacity Act. <https://www.youtube.com/watch?v=WzVdTx4kpo0>

See also a-h above.

## **Support for managers in health and care in implementing learning outcomes**

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 11, you also need to be confident that your team is implementing guidelines effectively.

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A quick checklist of things to consider:

<b>Framework outcome</b>	<b>Things to consider</b>
All outcomes	Are staff appropriately trained on all relevant legislation related to the safe and appropriate care of people with dementia and supported to implement it in their daily practice? Are the rights of people with dementia respected by staff and within your organisation?  Do organisational documents and procedures support implementation of legislation and support for individual rights?

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# Subject 12: End of life dementia care

## Introduction

Defining when end of life begins in dementia care is not straightforward. However, end of life care planning related to needs, preferences and wishes should be undertaken as early as possible so that people are able to discuss and record their wishes about their own end of life. This can be documented in an advance care plan. Death is a subject that many people find difficult or upsetting to talk about including people with dementia, their family members and care staff. Staff may also be worried about upsetting people if they try to discuss end of life care and death. It is important staff facilitate conversations about end of life care with people with dementia and their family members and that they have the appropriate knowledge and skills to do this well.

## Subject level resources and training programmes

Please refer to the HEE *Dementia Training Resource List* for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

### **a) understand the use of end of life care pathways and individualised care plans taking into account psycho-social needs**

Care planning for end of life care is important, in order that an individual's wishes are known and that staff can aim to support these through the end of life journey.

In this *Dementia Diaries* entry, Anne talks about the importance of advanced care planning for end of life.

<https://dementiadiaries.org/entry/4810/advanced-care-planning-is-very-important-the-burden-of-my-future-is-not-put-on-my-family>

This web-based content from NHS Choices provides an overview of end of life care issues and links to an end of life care plan.

<https://www.nhs.uk/conditions/dementia/palliative-care/>

Hospice UK provide a range of information about hospice-enabled end of life care for people with dementia.

<https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/hospice-enabled-dementia-care>

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The End of Life Care for All (e-ELCA) e-learning programme includes a module on end of life care planning.

<http://www.endoflifecareforall.com/>

**b) understand how advanced decisions/directives and best interest decisions will affect caring activities**

See Subject 11: Law, ethics and safeguarding in dementia learning outcomes c, d, e and f.

**c) know how to recognise and manage pain and address the broader physical needs (e.g. hydration, reduced appetite) in people with advanced dementia**

See Subject 6: Health and well-being in dementia care.

**d) be able to identify symptoms associated with end of life and how these symptoms can be managed with care and compassion**

Signs that someone is at end of life are not always identified and this can mean people do not receive appropriate care and support, or may receive aggressive treatments that may not be in their best interests. Therefore, understanding end of life signs and symptoms by staff and being able to use this information alongside knowledge of a person's wishes can help to support better end of life care.

This factsheet from the Alzheimer's Society looks at a range of components of end of life care including physical needs and provision of compassionate and supportive care.

<https://www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care>

This web-based content from Marie Curie looks at end of life care for people with dementia and identifies some of the key considerations for health and care staff.

<https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/condition-specific-short-guides/dementia>

SCIE has also produced a range of content about the signs of end of life care and the importance of care planning.

<https://www.scie.org.uk/dementia/advanced-dementia-and-end-of-life-care/end-of-life-care/introduction.asp>

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This includes a video about supporting dignity at end of life.

<https://www.scie.org.uk/socialcaretv/video-player.asp?v=dementiaendoflifecare>

The End of Life Care for All (e-ELCA) e-learning programme includes a module on symptom management.

<http://www.endoflifecareforall.com/>

### **e) be aware of concerns and needs affecting younger people at the end of life**

We have been unable to locate any resources specifically focussed on the concerns of younger people with dementia about end of life.

### **f) be aware of the needs of bereaved families and friends including the potential for conflicting emotions**

Supporting family members through grief forms part of good quality dementia care. Families may go through a range of emotions during the end of life care journey and once a person has died.

This Alzheimer's Society factsheet covers grief, loss and bereavement.

<https://www.alzheimers.org.uk/get-support/help-dementia-care/grief-loss-and-bereavement>

This web-based information from Dementia UK address grief and bereavement for carers.

<https://www.dementiauk.org/grief-bereavement-and-loss-in-dementia/>

This *Dementia Diaries* entry is about supporting carers around making decisions about end of life when they do not know a person's wishes.

<https://dementiadiaries.org/entry/7502/everybody-in-my-support-network-is-aware-of-my-wishes-including-type-of-funeral-what-kind-of-medical-intervention-if-any-even-how-i-want-my-life-celebrated-i-think-its-worth-noting-if-you-i>

This video from Cruse Bereavement Care Sheffield outlines some of the feelings people may go through when someone dies.

<https://www.youtube.com/watch?v=p2dNM5Za5U4>



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These video clips and web-based information from *Healthtalk* outline some of the practical things families need to do after a death.

<http://www.healthtalk.org/peoples-experiences/dying-bereavement/caring-someone-terminal-illness/practical-things-after-death>

### **g) be able to support family and friends to celebrate the life of the deceased person**

There are many things that families can do to celebrate the life of the person who has died, this can include having a service or gathering to celebrate their life and share stories, creating positive mementoes such as memory books through to memorial stones or ways of remembering the person such as planting a tree.

### **h) be aware of cultural and religious differences associated with death, care of the dying and the deceased person.**

The cultural and religious needs of individual will differ. Understanding these should form an important part of the care planning process.

## **Support for managers in health and care in implementing learning outcomes**

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 12, you also need to be confident that your team are implementing guidelines effectively.

A quick checklist of things to consider:

<b>Framework outcome</b>	<b>Things to consider</b>
All outcomes	<p>Are staff trained on and comfortable with providing end of life care and support?</p> <p>Do they feel confident in discussing end of life care needs and developing plans?</p> <p>Are staff equipped and supported to identify signs of end of life and to assess care needs and provide the right support?</p>

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	<p>Are there appropriate links with local organisations who can support provision of end of life care?</p> <p>Do all people with dementia your organisation provides end of life care or support to, have the death they and you would hope? Are there things you could do to improve the end of life experience for people?</p> <p>Are staff adequately supported when someone they care for dies and encouraged to express their feelings?</p>
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**Additional resources**

Health Education England have produced a range of resources around end of life care. This includes an *End of life core skills education and training framework*.

<https://www.hee.nhs.uk/our-work/end-life-care>

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# Subject 13: Research and evidence-based practice in dementia care

## Introduction

Research and service evaluation plays an important role in delivering good dementia care. It is only through conducting research and service evaluation that we can create an evidence-base that guides practice. Likewise, issues and challenges arising in practice should serve as drivers for the research agenda. Therefore, good interaction and engagement between researchers and health and care provider organisations is essential.

## Subject level resources and training programmes

Please refer to the HEE 'Dementia Training Resource List' for training programmes that cover more than one of the learning outcomes in this subject area.

## Learning outcome level information and resources

### **a) understand the difference between service evaluation and research**

Whether a project is research, service evaluation or audit will depend on what types of approvals it requires.

This leaflet from the HRA defines the difference between research, service evaluation and audit.

<https://researchsupport.admin.ox.ac.uk/sites/default/files/researchsupport/documents/media/defining-research.pdf>

This flow chart from Avon Primary Care Research Collaborative helps staff to identify if their project is research, service evaluation or audit.

[http://www.apcrc.nhs.uk/governance/is\\_it\\_research.htm](http://www.apcrc.nhs.uk/governance/is_it_research.htm)

This decision tool from the MRC and HRA helps staff identify if their study is research.

<http://www.hra-decisiontools.org.uk/research/>

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## **b) be able to participate in service evaluation and research in the workplace**

Taking part in research can offer a range of benefits to organisations or individuals. Making a decision to participate in research within the workplace should be one staff can make freely with no fear of the impact their decision may have on their role. Staff will often only have the opportunity to take part in research if the organisation they are working in is research active.

All NHS Trusts are research active, therefore staff need to speak to their local Research and Development Office if they are interested in undertaking research, service evaluation or audit.

The NIHR through its ENRICH work provides a wide range of information for care homes about engaging in research.

<https://enrich.nihr.ac.uk/>

## **c) understand how people affected by dementia may be involved in service evaluation and research.**

As with staff members, being offered the opportunity to take part in research can be beneficial to people with dementia. One way of registering interest in taking part in research is through signing up to the NIHRs Join Dementia Research programme.

Join Dementia Research web-site.

<https://www.joindementiaresearch.nihr.ac.uk/>

A slide set and session guide for talking about 'Join Dementia Research' from the Health Innovation Network and UCL Partners is available.

<https://healthinnovationnetwork.com/wp-content/uploads/2017/11/Join-Dementia-Research-Curriculum-Document-Suggested-PowerPoint-UCLP-Amendments-Version-312.pdf>

<https://healthinnovationnetwork.com/updated-lesson-plan-for-resource-pack/>

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## Support for managers in health and care in implementing learning outcomes

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 13, you also need to be confident that your teams are implementing guidelines effectively.

A quick checklist of things to consider:

Framework outcome	Things to consider
All outcomes	Are staff aware of research and service evaluation? Are they given the opportunity to take part if they wish?  Do they discuss research with people with dementia and encourage them to sign up to 'Join Dementia Research' if they are interested?

### Additional information

SCIE provide a free online bibliographic database of social care research and information called *Social Care Online*.

<https://www.scie-socialcareonline.org.uk/>

