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# Pre-registration nursing dementia care resource

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## Introduction

**This workbook alongside your lectures and seminars over 3 years follows and meets guidance from Health Education England (HEE Oct 2105) who require all nurses and other NHS staff to achieve tier 1 and 2 foundation level dementia training. It is designed to give you that level and so enable you to identify the early symptoms of dementia, know how to interact with those with dementia and other confusional states, understand the needs of clients and carers, and deliver safe, dignified, compassionate care.**

Caring for people with dementia and their families is central to nursing and this dementia care resource is designed to assist you to care for people with dementia skilfully, compassionately and knowledgeably, in a variety of settings. Worldwide there are growing numbers of people with dementia and these figures are predicted to rise considerably, due to an increase in the number of people living longer (Alzheimer's Disease International 2010). In the United Kingdom, over 800,000 people live with dementia and the number is expected to double in the next 30 years (Department of Health [DH] 2010). One in four people in acute hospital settings have dementia (Alzheimer's Society 2009); they may be in hospital for a range of clinical reasons, e.g. infections, falls or strokes. In addition, at least two-thirds of people in care homes have dementia (DH 2009) and many other people with dementia live at home, supported by community health and social care teams.

This resource complements your university-based teaching by supporting you in learning about dementia care during practice learning, using reflective activities. It can be regarded as a sort of workbook directing you to a range of online and other learning resources to support your learning. We are grateful to our colleagues from the University of Bedfordshire who initially designed this workbook to ensure that you meet Skills for Health and Skills for Care (2011) *Common core principles for supporting people 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)

- We recognise that website addresses can change over time. If you find that any website address does not work, try searching the keywords or locate an alternative source to access the information you need. Dementia care is a developing field and you will find additional resources which you can use to support you in your learning.
- Please also send in any useful sites you find or interesting books and films or any other material you come across so that we can update the workbook and add to it.

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## References

Alzheimer's Disease International (2010) *World Alzheimer Report 2010: the global economic impact of dementia*. London: Alzheimer's Disease International.

Alzheimer's Society 2009. *Counting the cost: caring for people with dementia on acute hospital wards*. London: Alzheimer's Society.

Department of Health (2009) *Living Well with Dementia – A National Dementia Strategy*. Gateway reference 11198. London: DH.

Health Education England 2015. *Dementia Core Skills Education and Training Framework*. HEE <http://www.skillsforhealth.org.uk/images/projects/dementia/Dementia%20Core%20Skills%20Education%20and%20Training%20Framework.pdf?s=cw1>

Department of Health (2010) *Quality outcomes for people with dementia: building on the work of national dementia strategy*. Leeds: DH.

Skills for Health and Skills for Care (2011) *Common core principles for supporting people with dementia: a guide to training the social care and health workforce*. Leeds: Skills for care.

## Useful resources

### Textbooks

Adams T and Manthorpe J 2003 *Dementia Care* London. Arnold

Barker S and Board M 2012 *Dementia care in nursing*. London sage

Brooker, D. (2007) *Person centred dementia care : making services better*. London : Jessica Kingsley

Cheston R and Bender M 1999 London. *Understanding dementia; The man with the worried eyes*. Jessica Kingsley

Downs, M.; Bowers, B. (Eds) (2008) *Excellence in dementia care: research into practice*. Maidenhead : Open University Press

Heath, H. (2010) *Improving quality of care for people with dementia in general hospitals*. London Royal College of Nursing

Kitwood T 1997. *Dementia reconsidered; The person comes first*. Buckingham. Open University Press.

May, H.; Edwards, P.; Brooker, D. (2009) *Enriched care planning for people with dementia: a good practice guide for delivering person-centred dementia care*. London: Jessica Kingsley

Moniz-Cook, E.; Manthorpe, J. (Eds) (2008) *Psychosocial interventions in early dementia : evidence-based practice*. London : Jessica Kingsley

Morris, G; Morris, J. (2010) *The dementia care workbook* Maidenhead : McGraw-Hill Open University Press

Steele, C. (2010) *Dementia care* New York/ London: McGraw-Hill Medical

Stokes, G. (2010) *And still the music plays: stories of people with dementia*. London : Hawker Publications Ltd

Stokes G and Goudie F 2002 *The essential dementia care handbook*. Milton Keynes; Speechmark

Walsh D 2006 *Dementia Care Training Manual for Staff working in Nursing and Residential Settings*. London; Jessica Kingsley Publishers

Walsh D 2012 *The Activity and Reminiscence Yearbook*. Milton Keynes. SpeechmarkMilton Keynes. Speechmark

## Websites

Alzheimer's Society: <http://www.alzheimers.org.uk/>

Dementia Carers: <http://www.dementiacarers.com>

Social Care Institute for Excellence, Dementia Gateway:  
<http://www.scie.org.uk/publications/dementia/index.asp>

UK Wandering Network Weblink: <http://wanderingnetwork.co.uk/Welcome.htm>

My Home Life <http://myhomelife.org.uk/resources/dementia/>

<http://www.alzheimersresearchuk.org/dementia-information>

<http://www.lost-chord.org.uk/>

<http://tommy-on-tour-2011.blogspot.co.uk/>

<http://www.e-lfh.org.uk/programmes/dementia/>. A useful introductory resource

IDEA (Improving Dementia Education and Awareness)  
Information on topics such as Singing for the Brain. It also has many free online courses.  
Visit [www.idea.nottingham.ac.uk](http://www.idea.nottingham.ac.uk)

### Teepa Snow

If you like to learn by watching, try the short video clips of Teepa Snow on Youtube. She is an American OT who specialises in dementia care and teaching carers to manage challenging and distressing behaviours.  
[www.youtube.com/user/teepasnow](http://www.youtube.com/user/teepasnow)

Stirling University has a website with a huge amount of information on research, publications, creativity in dementia, designing environments – lighting, signs, colours.  
[www.dementia.stir.ac.uk](http://www.dementia.stir.ac.uk)

The Kings Fund have some interesting documents on environments for people living with dementia. <http://www.kingsfund.org.uk/publications/developing-supportive-design-people-dementia>

Bradford University similarly have information on research and training.  
<http://www.bradford.ac.uk/health/career-areas/bradford-dementia-group>

College of Occupational Therapy has developed a 'Toolkit' of ideas for activities to use with people in care homes. Although not just for people with dementia, this has very useful information and ideas. Look on the 'Care home staff resources' section  
[www.cot.co.uk/living-well-care-homes](http://www.cot.co.uk/living-well-care-homes)

## Reports

Alzheimer's Disease International (2010) *World Alzheimer Report 2010: the global economic impact of dementia*. London: Alzheimer's Disease International.

Alzheimer's Society (2009). *Counting the cost: caring for people with dementia on acute hospital wards*. London: Alzheimer's Society.

Department of Health (2009) *Living Well with Dementia – A National Dementia Strategy*. Gateway reference 11198. London: DH.

Department of Health (2010) *Quality outcomes for people with dementia: building on the work of national dementia strategy*. Leeds: DH.

National Institute of Health and Clinical Excellence (2006) *Dementia: Supporting people with dementia and their carers in health and social care. Clinical Guideline 42*. Amended 2011. London: NICE.

Nuffield Council on Bioethics (2009) *Dementia: Ethical Issues*. London: Nuffield Council on Bioethics.

Royal College of Psychiatrists (2011). *Report of the National Audit of Dementia Care in General Hospitals*. Editors: Young J, Hood C, Woolley R, Gandesha A and Souza R. London: Healthcare Quality Improvement Partnership.

**Note also that the University has a *Dementia Interest Group* which you can access and join. Just email [dwalsh@lincoln.ac.uk](mailto:dwalsh@lincoln.ac.uk) and ask me to enrol you to the blackboard group where you will find details of our work and meetings. Those not registered with the university who wish to join us can send their email details and will be sent meeting details.**

## Student and mentor guidance

### Student nurses

- The activities are written for each year but you can complete them at any stage of your practice experience as opportunities arise. It may be that on your very first placement you have the opportunity to address some of the year 3 issues and learning opportunities.
- Remember that you will come across dementia in many of your placements so you do not have to be on a dementia unit to undertake these activities.
- Remember that any work you produce in relation to practice-based activities must be anonymised to ensure confidentiality of patients, families, staff and organisations.
- Your personal tutor will be asking to see this workbook on a regular basis and it will form part of your end of year OAR appraisal. Don't leave it until the third year. Begin it early and review it regularly. At the beginning of each placement ask your mentors which experiences it might be possible to explore. On successful completion of the work book at the end of your course you will be issued with a dementia awareness certificate.
- Each of the activities in this workbook have been mapped to the NMC standards of competence for registered nurses which are in your OAR. So the evidence you provide here can be used as OAR evidence too.

### Mentors

- Thank you for helping the student to achieve the outcomes and gain the experiences suggested here. Whilst they are set out year by year the student will need to grab opportunities as they arise and there is no reason why they cannot do any of the exercises at any stage of their training.
- There are certain exercises where we ask the student to work especially closely with their mentor and ask you to sign off that particular piece of work. We are not looking for essays or large pieces of writing here just your satisfaction that the student has undertaken the work and understood. The work does not have to be at any particular level academic, Bondy or otherwise it is simply the experience and understanding that is important here.

### Mentor signatures

Mentor name	Signature	Placement

## Dementia in the Arts

### *A few films to help you gain an insight.*

People with dementia are increasingly represented in the arts, especially films and novels. This is probably a reflection of the growing number of older people in the global population and the concurrent increase in the number of older people with dementia, especially in the developed world. The challenges presented to the individual and their family by dementia are complex and numerous. As such they lend themselves well to interpretation by the arts.

Using the arts to explore a non-arts subject has long been recognised as beneficial for learning. The arts also have the bonus of being pleasurable for most people! One of the benefits of the arts in this context is their ability to engage us personally. When this happens we are also normally engaged emotionally, so it is possible to evoke empathetic responses to what we see or read. This enables us to gain some insight into the lived experiences of others, e.g. that of people with dementia and their families. From there it is possible to consider how one might more effectively meet the specific needs of individuals with dementia and their families.

### *Films about dementia*

- **Away From Her (2007)** Julie Christie portrays a woman with Alzheimer's who voluntarily enters a long-term care facility to avoid being a burden on Grant, her husband of 50 years. After a 30-day separation (recommended by the facility), Grant visits Fiona and finds that her memory of him has deteriorated and that she's developed a close friendship with another man in the facility. Grant must draw upon the pure love and respect he has for Fiona to choose what will ensure his wife's happiness in the face of the disease.
- **A Song For Martin (2001)** Sven Wollter and Viveka Seldahl -- married in real life -- play married couple Martin and Barbara in this Swedish movie with English subtitles. Martin is a conductor and composer; Barbara, a violinist. They meet and marry in middle-age, but soon after, they find out that Martin has Alzheimer's disease. This moving story is considered one of the most realistic depictions of care-giving on film.
- **Aurora Borealis (2006)** Donald Sutherland plays a grandfather with dementia who requires more care than his wife (played by Louise Fletcher) can handle. They enlist the help of a home health aide (Juliette Lewis) and their grandson (Joshua Jackson), who forge a friendship as Sutherland's character -- who insists he can see the Northern Lights from his window -- becomes increasingly impaired.
- **Iris: A Memoir of Iris Murdoch (2001)** Based on the book *Elegy for Iris* by John Bayley, this movie tells the true story of English novelist Iris Murdoch's descent into Alzheimer's disease and the unconditional love of Bayley, her partner of 40 years. Jim Broadbent played Bayley in his later years. Judi Dench and Kate Winslet played Murdoch in her older and younger years respectively.
- **Age Old Friends (1989)** Hume Cronyn plays John Cooper, who chose to live in a retirement home instead of live with his daughter (played by real-life daughter Tandy Cronyn) as a symbol of maintaining his independence. He befriends Michael (Vincent Gardenia), who starts showing signs of dementia. When John's daughter extends her offer to live with her again, he must decide between leaving the rigid structure of the retirement home and staying to help his friend cope with his disease.



- **I Never Sang For My Father (1970)** This intense story about family conflict stars Gene Hackman as a New York professor planning on starting anew by marrying his girlfriend and moving to California. When his mother dies and his father develops dementia, he must choose between living the life he's dreamed about or abandoning his plans to care for his father.
- **The Iron Lady (2011)** Meryl Streep's portrayal of Margaret Thatcher has drawn much praise and an Oscar. However, the film has also been criticised for its portrayal of Margaret Thatcher as having dementia as questions have been raised about consent for this portrayal of a living person. The film was released on DVD on 30 April 2012.
- **Losing Myself (2007)** Three Minute Wonders commissioned by Channel 4 and produced by Clarity Productions. There are four films in this series, here are two of them.

Losing Myself: <http://www.dementiaworks.co.uk/losingmyself>

Or try <http://vimeo.com/42001233>

- **Still Alice (2015)** Alice Howland (Oscar & BAFTA nominee Julianne Moore), happily married with three grown children (Kristen Stewart, Kate Bosworth and Hunter Parrish), is a renowned linguistics professor. When she receives a devastating diagnosis of early-onset Alzheimer's disease, Alice and her family find their bonds thoroughly tested. Her struggle to stay connected to who she once was is frightening, heartbreaking and inspiring.
- **Dementiaville (2015)** <http://www.channel4.com/programmes/dementiaville>

A set of 4 programmes produced by Channel 4 exploring the Butterfly Approach to working with those living with dementia in a care home

## Year 1

### Learning outcomes

The following activities will help you to:

1. Understand the nature of dementia and how it affects each individual and their family.
2. Gain insight into the impact of the hospital environment on people with dementia.
3. Begin to acquire specific skills in communicating with and caring for people with dementia.
4. Understand and respect people with dementia.

### What is dementia?

#### Activity 1.1

What do you already know about dementia and how it affects people? Write down a list of points below.

Mapped to competencies 1.7, 3.2

Watch this clip of Dr Graham Stokes explaining dementia.

<http://www.youtube.com/watch?v=2-ILROXBZ8M>

## Activity 1.2

Use the following resources to further investigate the nature of dementia and how it affects people:

- BBC News Dementia: A family's story at <http://news.bbc.co.uk/1/hi/health/8491946.stm>
- Social Care Institute for Excellence at <http://www.scie.org.uk/publications/dementia/index.asp>  
*Note that dementia can occur in adults at younger ages, not only in older people.*
- Alzheimer's Society at <http://www.alzheimers.org.uk/>
- RCN Dementia Care at <http://www.rcn.org.uk/development/practice/dementia>  
*In particular, listen to the podcast on the RCN Dementia website that provides a concise nursing-orientated background to dementia care.*

[http://www.rcn.org.uk/development/practice/dementia/understanding\\_dementia](http://www.rcn.org.uk/development/practice/dementia/understanding_dementia)

Bullet point what you have learnt from these resources?

Mapped to competencies 1.5, 1.7, 1.9, 3.1

## **Walking the walk. 'Experiencing the hospital through my eyes.'**

### **Activity 1.3**

Watch the video about Rose at the YouTube connection below. Consider her home environment and the people around her, and how they help her to feel safe and comfortable.

Remaining independent. Living alone with dementia at 92:

<http://www.youtube.com/watch?v=BGLBytHHg6Y&feature=relmfu>

If Rose had to go into hospital as an emergency admission, how might she feel if she did not know where she was and why, who the people around her were and what they were going to do to her and she wasn't able to express how she feels in a way that others can understand.

Mapped to competencies 1.2, 1.3, 2.4, 3.4, 3.7

### **Activity 1.4**

Compare Rose's home environment with a typical hospital environment. What aspects of the hospital environment might be distressing and difficult for her?

Mapped to competencies 1.2, 1.3, 1.5, 1.7, 2.4, 3.4, 3.7, 4.2

## Communication and person centred care skills.

### Activity 1.5

With your mentor identify a person with dementia or confusion and initiate a conversation with them. Reflect below on what difficulties you encountered and what interpersonal and communication skills you used to overcome these.

*Mentors signature and date;*

Mapped to competencies 1.2, 1.4, 2.1, 2.2, 2.3, 2.5, 4.4

### Activity 1.6

You can care for a person with dementia more effectively if you understand them as an individual with their own likes/dislikes, personality and history. The Alzheimer's Society has developed a leaflet entitled 'This is me', "a simple and practical tool that someone going into hospital can give to staff to help them understand the condition"

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1290](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1290)

Look at the leaflet and consider what things you would include if you were filling this in for yourself: how might this help staff care for you as an individual if you were unable to communicate your own needs? What would you want staff to know about you if you could not communicate this to them?

Mapped to competencies 1.4, 2.1, 2.6, 3.1, 3.4

**Additional Activity:** If you see 'This is me' being used with a patient while you are on placement, reflect on what you thought you knew about this person and compare this with what additional information you find in their 'This is me' document.

See also **All About Me** a similar tool devised and used by ULHT to help nurses identify and understand individual needs and so enable patient centred care planning.

### Activity 1.7

With your mentor in practice identify an individual who has dementia or another person who might have difficulties in expressing their needs or are confused (e.g. person with a learning disability, person who has had a stroke). Look again at the 'This is me' leaflet and make notes in response to the questions in the box below then discuss these with your mentor.

What don't you know about the individual in your care which you might need to know?

How you could find out more information about the person?

How would this information assist you to care for the person with sensitivity and compassion?

*Mentor signature and date;*

Mapped to competencies 1.1, 1.3, 1.4, 2.3, 2.6, 2.7, 2.8, 3.1, 3.3, 3.4, 4.2

**Life story work**..... Here is a link to making a life story book with a person with dementia and their carer which will be a great reminiscence tool for them and a great way for you to get to know the real person.

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

### Activity 1.8

Still focussing on the person you identified in activity two, consider each of the following areas of care:

- Communication
- Eating and drinking
- Washing and bathing
- Maintaining continence
- Moving and walking about
- Dealing with challenging and unpredictable behaviour
- Recognising pain and why it has occurred
- Orientation

In relation to these areas of care;

~ Are there any difficulties that the person and / or you are currently experiencing?

~ What strategies have you employed thus far to overcome these difficulties? How successful have they been?

~ Is there anything else you would like to do to be able to improve the care for this person?

*Mentor signature and date;*

Mapped to competencies 1.1, 1.3, 1.4, 1.6, 1.8, 2.2, 2.7, 2.8, 3.3, 3.4, 3.5, 3.6, 3.7, 3.8, 3.10, 4.1, 4.2, 4.7

The Alzheimer's Society has produced some 'top tips' "designed to help nurses and other hospital staff in their delivery of good person-centred dementia care". Go to the link below and use these 'top tips' to explore ways of improving your skills when caring for people with dementia. 'Top tips for nurses' from Alzheimer's Society:

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1211](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1211)

### Activity 1.9

What have you learned from these resources?

Mapped to competencies 1.3, 1.5, 1.7, 3.1, 3.4, 3.8

## Understanding and respecting people with dementia

*Never forget the most powerful force on earth is love. Nelson Rockefeller*

*A man does not consist of memory alone. He has feeling, will, sensibilities, moral being --- matters of which neuropsychology cannot speak. And it is here, beyond the realm of an impersonal psychology, that you may find ways to touch him, and change him.*

A.R. Luria ....from a personal letter to Oliver Sacks quoted in his 1985 book *The Man Who Mistook His Wife For a Hat*. London: Picador

### Activity 1.10

Thinking about a person with dementia who you have met or cared for, consider what would help the person to feel understood and respected. To assist you may wish to have a look at the link below and then write down some key points:

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=84](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=84)

Mapped to competencies 1.1, 1.2, 1.3, 1.4, 1.9, 3.1, 4.4, 4.7



**Activity 1.11**

An important aspect of promoting dignity in care is involvement in decision-making. This can be challenging in the care of someone with dementia, particularly where communication is difficult. See <http://www.scie.org.uk/publications/dementia/decisions/index.asp>

Identify how nurses and others can involve those with dementia in decisions.

Mapped to competencies 1.4, 2.1, 2.2, 2.3, 2.4, 3.1, 4.4, 4.7

## Year Two

### Learning outcomes

The following activities will help you to:

1. Promote independence and engage in activity for people with dementia.
2. Differentiate between dementia, delirium/acute confusional states and depression.
3. Work in partnership with the family and informal carer[s] of people with dementia.
4. Understand and apply legislation, policies and national guidelines related to the care of people with dementia.

### Promoting independence and encouraging activity for people with dementia

#### Activity 2.1

With your mentor choose a patient with dementia for whom you are currently caring. Focus on what they **can** do, rather than what they cannot do. Conduct a nursing assessment of the individual's needs in relation to promoting independence and the activities they may be able to engage in. Involve the family in this assessment as they are likely to know the person's past history and their current abilities. Write up the assessment in the box below using suitable headings.

*Mentors signature and date;*

Mapped to competencies 1.1, 1.2, 1.3, 1.4, 1.5, 1.9 and all domain 2 and 3

### **Activity 2.2**

Look at this video about encouraging activities in a nursing care home.

<http://vimeo.com/19662113>

How could you adapt this approach to the acute hospital setting?

Mapped to competencies 1.4, 1.5, 2.6, 4.1, 4.3

### **Activity 2.3**

How could an understanding of the person's life history assist you to plan activities to promote independence and minimise boredom and frustration?

Mapped to competencies 1.1, 1.4, 1.5, 2.4, 3.1, 3.4, 3.8, 4.1, 4.2

*I have seen deeply demented patients weep or shiver as they listen to music they have never heard before, and I think they can experience the entire range of feelings the rest of us can, and that dementia, at least at these times, is no bar to emotional depth. Once one has seen such responses, one knows that there is still a self to be called upon, even if music, and only music, can do the calling. Oliver Sacks (2007) *Musicophilia: Tales of Music and the Brain*. New York: Knopf (p.346)*

## **Dementia, delirium and depression – responding to distress caused by these underlying conditions**

Sometimes the behaviour associated with depression, delirium or dementia can appear similar in older people.

### **Activity 2.4**

Read and watch some of the following;

‘Experiences of dementia, delirium and depression’ which explores these experiences for residents at a care home. <http://vimeo.com/3736766>

Arnold, E. (2005) Sorting out the 3 D's: Delirium, dementia, depression *Holistic Nursing Practice* 19[3]: 99-104

Pountney, D. (2007) Dementia, delirium or depression? *Nursing Older People* 19[5]: 12-14

Canadian summary resource developed by Toronto Region Best Practice  
<http://rgp.toronto.on.ca/torontobestpractice/ThreeDcomparison.pdf>

What are the differences and similarities between dementia, delirium and depression? List them here.

Discuss with your mentor why it is important for a nurse to understand these differences so that they can more effectively care for the person?

*Mentors signature and date;*

Mapped to competencies 1.3, 1.7, 1.9, 3.1, 3.2

## Working in partnership with family and informal carers

### Activity 2.5

Have a look at the following to give you an understanding of the role and needs of carers of those living with dementia.

<http://www.carersuk.org/professionals/resources/quick-statistics>

<http://www.scie.org.uk/publications/misc/dementia/dementia-grg.pdf> (page 21)

<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200343>

Mapped to competencies 1.4, 1.5, 2.8

### Activity 2.6

Person-centred care looks at the individual as a whole. The diagnosis of dementia influences many aspects of family relationships.

Looking at <http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200355> think about how relationships may change as a result of dementia:

Watch the YouTube video about Enid and George at the link below:

<http://www.youtube.com/watch?feature=endscreen&NR=1&v=b7ZcbHrJP6o>

What challenges do you think George faces as an informal carer?  
How might the diagnosis of dementia affect their relationship?

Mapped to competencies 1.4, 1.5, 2.4, 2.6, 3.5, 3.7, 3.9

### Activity 2.7

Focus on a person with dementia who you are currently caring for in hospital, or have cared for recently. Consider their family: How have you and other staff worked in partnership with the family, in relation to the person's care? Think of some examples of how the team have involved the family. Discuss this with your mentor.

*Mentors signature and date;*

Mapped to competencies 1.4, 1.5, 1.6, 2.4, 2.6, 3.5, 3.7, 3.9, 4.4

### Activity 2.8

With your mentor identify a carer who is willing to talk and interview them about the role of caring and its impact upon their lives. Ask about what support services they get and would like. Summarise the points made below.

*Mentors signature and date;*

Mapped to competencies 1.1, 1.2, 1.3, 1.4, 1.5, 1.6, 1.8 all domain 2 and 3.3, 3.5, 3.7, 3.9

### Activity 2.9

Access

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=119](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=119) and think about the support needs of informal carers of people with dementia and resources and organisations that could support them.

Looking at your local community, identify at least three support organisations or other resources available to carers of people with dementia

Mapped to competencies 1.4, 1.5, 1.6, 4.1, 4.5, 4.7

### Activity 2.10

How does the healthcare team ensure that informal carers are aware of the support available to them?

Mapped to competencies 2.2, 2.6, 3.5, 4.1

## Understanding legislation, policies and national guidelines

The Registered Nurse needs to be aware of the political, social and economic issues that affect the availability, organisation and quality of local services for people with dementia, and their informal carers. Look at some of the link below to further your understanding here.

<http://www.alzheimers.org.uk/ndstrategies>

Look at the recommendations in this report <http://www.hqip.org.uk/assets/NCAPOP-Library/Dementia-National-Audit-Report-2011-Final.pdf> and think about what needs to be done to improve this situation.

Read <http://www.alzheimers.org.uk/countingthecost>

This does not make for very comfortable reading and reflects badly upon our care.

### Activity 2.11

Discuss with your mentor what we can do as nurses to improve the situation for those living with dementia when they enter into a general hospital?

*Mentors signature and date;*

Mapped to competencies 1.4, 1.5, 1.6, 2.6, 2.8, 3.4, 4.4, 4.5, 4.7



## Year Three

### Learning outcomes:

The following activities will help you to:

1. Promote integrated care and engage with multi-agency working for people with dementia.
2. Respond appropriately to common ethical dilemmas when caring for people with dementia and advocate on their behalf.
3. Provide high quality end of life care for people with dementia.
4. Evaluate care of people with dementia and lead on local service improvement initiatives.

### Integrated care and multi-agency working

#### Activity 3.1

Read <http://www.scie.org.uk/publications/misc/dementia/index.asp>

Consider a person with dementia who you have cared for:

Which professional groups/agencies were involved with this person's care? What did each profession contribute to the overall care package?

How did the different professionals/agencies communicate within the team and with the person with dementia and their family? What methods of recording information were used and how were these accessed by all concerned?

Can you identify any additional professional group/agency, not involved with this person's care, who might have made a useful contribution? Why do you think they were not involved?

Mapped to competencies 1.1, 1.4, 1.5, 1.6, 1.8, 2.7, 2.8, 3.3, 3.6, 4.2, 4.6, 4.7

### Activity 3.2

Watch these audio clips that give families' perspectives on multi-agency working:  
[http://www.healthtalkonline.org/carers/Carers\\_of\\_people\\_with\\_dementia/Topic/2118/](http://www.healthtalkonline.org/carers/Carers_of_people_with_dementia/Topic/2118/)

Were there any common themes that carers identified?

What worked well for the person with dementia and their family, and why?

What did not work so well and why?

Mapped to competencies 1.4, 1.6, 4.2, 4.7

### Activity 3.3

Read the Alzheimer's Society fact sheet on discharge  
[http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1816](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1816)

Write a list of key points for your future practice;

Mapped to competencies 1.5, 1.8, 4.4

## Ethical issues and advocacy

### Activity 3.4

Reflect on people with dementia who you have cared for in different settings. Write notes on each of the following:

What ethical dilemmas have you encountered? List these down below.

Mapped to competencies 1.1, 1.2, 1.5, 3.9, 4.4, 4.5, 4.6

**Activity 3.5** Which dilemma have you found most difficult to respond to? Why was it difficult? Discuss it with your mentor.

*Mentors signature and date;*

Mapped to competencies 1.1, 1.2, 1.5, 3.9, 4.4, 4.5, 4.6

### Activity 3.6

Read the relevant sections in this report related to your answers above

<http://www.nuffieldbioethics.org/sites/default/files/Nuffield%20Dementia%20report%20Oct%2009.pdf> For further reading, we recommend that you read Chapters 2 and 3 of this report which include many illuminative case studies as well as explorations of the issues.

Go to <http://www.scie.org.uk/publications/dementia/living-with-dementia/difficult-situations/index.asp>

Do any of the sections on this website relate to the situation you identified in Activity 1, Question 2 (the dilemma you found most difficult to respond to)? If so read through this section now. How does this material relate to the situation you encountered? Is there anything you would do differently having read this?

Mapped to competencies 1.1, 1.5, 1.8, 1.9, 2.4, 2.8, 3.2, 3.3, 3.4, 3.6, 3.7, 3.9, 3.10

Ensure that you access the following sections, and reflect on the material provided in relation to people you have cared for, and write a paragraph on each of these.

*'A different reality'*: this material tackles issues like truth and lies: for example, how to respond if the person asks for a relative who is long since dead.

*'Refusing help'*: how to approach situations where a person with dementia might appear to be acting against their best interests, such as refusing to eat.

*'Walking'*: this section considers issues such as reasons for walking and considering risks. For further information see also UK Wandering Network Weblink: <http://wanderingnetwork.co.uk/Welcome.htm>. The Frequently Asked Questions is particularly useful.

*'Anti-psychotic medication and dementia'*: there are particular concerns about how anti-psychotic medication has been used. This section introduces these issues. These will be explored more in Activity 3.7.

### Activity 3.7

You may be aware that there are concerns that anti-psychotic medication has been used too readily and often inappropriately with people with dementia.

<http://www.bbc.co.uk/news/health-13698487>

The Dementia Action Alliance is campaigning on this issue, in partnership with the NHS Institute for Innovation and Improvement. Access the site below and watch the video which presents the call for action:

[http://www.institute.nhs.uk/qipp/calls\\_to\\_action/Dementia\\_and\\_antipsychotic\\_drugs.html](http://www.institute.nhs.uk/qipp/calls_to_action/Dementia_and_antipsychotic_drugs.html)

More information can be had at this Alzheimer's Society page .....

[http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=548](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=548)

Have you seen anti-psychotic medication used with people with dementia? If so do you know why it was being used and what impact did it have on the person?

How might the use of anti psychotic medication be avoided? Discuss with your mentor.

*Mentors signature and date;*

Mapped to competencies 1.1, 1.3, 1.7, 1.9, 3.7, 3.9, 4.1

## Mental Capacity

Read through the information from Alzheimer's Society about the Mental Capacity Act (MCA):

[http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=354](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=354)

Now focus on one person you have cared for who has dementia.

### Activity 3.8

Consider the person's capacity to make decisions for themselves in relation to the Mental Capacity Act. Could the person:

- understand information given to them?
- retain that information long enough to be able to make a decision?
- weigh up the information available to make a decision?
- communicate their decision by any possible means?

Summarise your responses below.

Mapped to competencies 1.7, 1.9, 2.2, 2.4, 2.7, 2.8, 4.4

### Activity 3.9

Look at the five principles of the MCA (cited on the Alzheimer's Society website).

See <https://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act>

Consider each of these principles in relation to the person with dementia you have focused on in this activity. Then write brief notes on each principle.

Mapped to competencies 1.7, 1.9, 2.2, 2.4, 2.7, 2.8, 4.4

### Raising Concerns

**Activity 3.10** There have been repeated reports about poor care of people with dementia in hospital settings. Here is a link to one such example, which is a report from the Ombudsman.

<http://www.ombudsman.org.uk/care-and-compassion/case-studies/mrs-as-story3>

If you observed a person with dementia who was receiving such poor care: how would you go about raising your concerns? Write a plan of action here.....

Now check the NMC guidelines in relation to this so that you are clear about what to do.....

<http://www.nmc-uk.org/Documents/NMC-Publications/NMC-Raising-and-escalating-concerns.pdf>

Mapped to competencies 1.1, 1.8, 2.7, 3.6, 3.9, 4.1, 4.6, 4.7

### Activity 3.11

Read the following document on Deprivation Of Liberty and Safeguarding (DOLS) <http://www.scie.org.uk/publications/atalgance/atalgance43.asp>. Now consider the following scenario.

The care home has stopped a service-user's husband from going to the pub on his own because they say he drinks too much and can be distressing and dangerous to other residents when he has been drinking. Is this a deprivation of his liberty?

Write down your thoughts in the box below. Compare your thoughts to those provided within the example at the following link, and discuss your reflections upon this with your mentor [https://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1327](https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1327).

*Mentors signature and date;*

### End of life care

Dementia is often not perceived as a terminal condition, yet it is as it is not a condition from which a person can recover. It is a condition that deteriorates with time, though the speed and nature of that deterioration will vary with the type of dementia, the individual and the quality of support they receive.

It is possible that this misconception arises from the view that people die from conditions that are more obviously physical, such as cancer. This lack of appreciation of the terminal nature of dementia can mean that it is not recognised when a person with dementia has entered the final stage of their life. Consequently they may not receive the care they need and deserve to ensure a 'good' death.

As a general introduction to this theme, watch the SCIE video on end of life care for people with dementia <http://www.scie.org.uk/socialcare/v/video-player.asp?quid=6cddd9aa-041e-446e-b637-d47ab7b37643>

The failure to recognise that a person with dementia has reached the final stage of their life can be distressing for the individual and their family. This is because it may result in an emergency admission to hospital and the use of aggressive interventions, all done with good intentions but with limited or no benefit to all concerned, and possibly worsening an already distressing situation. To assist you in undertaking this activity, explore the SCIE End of Life Care for people with dementia online resource at the following address



<http://www.scie.org.uk/publications/dementia/understanding-dementia/end-of-life/index.asp>

## Pain

Pain is a common experience at the end of life and this is no different for people with dementia. However, the management of pain for people with dementia presents particular challenges for the family and the healthcare team. Explore this resource.....

<http://www.scie.org.uk/publications/dementia/understanding-dementia/end-of-life/pain.as>

and try to answer the following questions:

**Activity 3.11** What are the common causes of pain in dementia?

Mapped to competencies 1.7, 1.9, 3.2, 3.7

**Activity 3.12** How may the phenomenon of diagnostic over-shadowing affect the management of pain in people with dementia? Discuss with your mentor.

*Mentors signature and date;*

Mapped to competencies 1.1, 1.7, 3.1, 3.9, 4.4

To back up this learning read the two articles by Smith (2007) on assessing pain in people with dementia

<http://www.nursingtimes.net/nursing-practice-clinical-research/assessing-pain-in-people-with-dementia-1-the-challenges/197743.article>

<http://www.nursingtimes.net/nursing-practice-clinical-research/assessing-pain-in-people-with-dementia-2-the-nurses-role/197737.article>

*We forget that life can only be defined in the present tense; it is, and it is now ... and that nowness becomes so vivid to me that I am almost serene. Below my window the blossom is out in full. And it is the whitest, frothiest, blossomest blossom that could ever be. And I can see it; and things are both more trivial than they ever were and more important than they ever were, and the difference between the trivial and the important does not seem to matter. But the nowness of everything is absolutely wondrous.*

DENNIS POTTER, playwright 1994 (shortly before his death)

## **Making a difference; Evaluation of care and service improvement**

The ethos behind service improvement is that improvement is 'everybody's business' and that everyone should be able to improve their part of the service.

### **Activity 3.13**

Review your Dementia Care workbook activities and in particular, the experiences you have documented about caring for people with dementia. From these, list aspects of care for people with dementia which you think could be improved.

Mapped to competencies 1.9, 3.9, 4.1, 4.2, 4.3

### **Activity 3.14**

Select one of the aspects of care you have identified. How might it be improved? Plan how you might carry out this change and evaluate it.

Mapped to competencies 1.9, 3.9, 4.1, 4.2, 4.3

There are many excellent examples of innovations to improve care.

**Activity 3.15** Reflect on your practice learning experiences over the course. There are many innovative practices aimed at improving care for people with dementia in hospital settings? From your learning in this workbook write a summary of the main points you want to adopt in your own practice.

## Competencies chart

Use this chart to record the competencies you have met and this will help you to cross reference it to your Ongoing Achievement Record. It might also allow you to see the gaps in your dementia knowledge around these competencies.

### Domain 1

### Domain 2

1	2	3	4	5	6	7	8	9	1	2	3	4	5	6	7	8

### Domain 4

### Domain 3

1	2	3	4	5	6	7	8	9	10	1	2	3	4	5	6	7