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The Dementia Academic Action Group (DAAG) was commissioned by Health Education England Thames Valley and is a collaboration between University of Bedfordshire, Oxford Brookes University, University of Northampton and University of West London. For further information about the DAAG Tier 1 Dementia Awareness training, please contact Health Education England Thames Valley.

Web add: https://www.hee.nhs.uk/hee-your-area/thames-valley

Email: enquiries@thamesvalley.hee.nhs.uk

Tel: 01865 785500

The content of this package has been developed with a view to raising awareness of what dementia is and how it affects people with dementia along with their family, relatives, carers, friends and significant others. It has been delivered as face to face training to over 1,500 clinical and non-clinical staff working in a variety of health and social care settings.



Tier 1 Dementia Awareness Training Unit 3

Understanding the person with dementia

"It is important for people to remember that the person with dementia was once somebody who did a job, raised children, ran businesses."

A Healthcare Assistant, Acute General Hospital

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Welcome to Unit 3

The quote from a Healthcare Assistant working in an Acute General Hospital helps to set the scene for what this unit will consider.



Welcome to Unit 3

- Unit 2 focused on what it means to live with dementia and it gave you the opportunity to develop an insight into the lived experience of people with dementia and their carers.
- Unit 3 will build on what you learned in Unit 2 by raising your awareness about what it means to be person-centred.



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Welcome to the Unit

Setting of ground rules including disclosure of sensitive information and confidentiality.

Link to Unit 2

Participant health and wellbeing ~ make yourself available to debrief and to sign post after the session has ended.

Get participants to sign the attendance register

Inform the participants about the length of the session, including a short comfort break if it is going to be longer than 30 minutes.

Give out Tier 1 Training Evaluation Form for each participant to complete page 1.

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Objectives of the Unit

By the end of this unit, you will be able to:

- · Explain what it means to be person-centred
- Describe the experiences of some people who are living with dementia
- Explain person-centred approaches that can be used with people with dementia
- Discuss the importance of culture in person-centred dementia care

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Objectives of the Unit:

It is important to state these at the start of the unit.



Activity (3 minutes)

Pause & think: What does it mean to be a person?

Ask participants to look at the picture on the slide and to think about the question.

"What does it mean to be a person?" (3 minutes).

Ask participants to respond verbally to the questions that you pose.

Main message is:

"I am not a condition, I am a person"

We need to help people to live well with dementia

We need to move from the medical model to a social/disability model

Teaching point:

The facilitator needs to emphasise that about 25-30 years ago, a diagnosis of dementia was generally seen as a death sentence, similar to how HIV, AIDS & Cancer were seen. In 2015, the view of dementia is very different. There is more emphasis on keeping people with dementia well in order for them to live well with their dementia.

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Personhood

- To improve the care & experience of an individual with dementia, care should be geared to promoting personhood.
- Dementia affects a person's cognitive functioning (memory, orientation, problem solving, comprehension & planning), but personhood is more than just those abilities.
- People with dementia are still Fred, Mary or Rachel, each with unique identities, needs & preferences.

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Present Slide 6 - Personhood

Emphasise that after diagnosis, people with dementia go on a journey.

As their condition progresses they may need to access services, and find solutions to emerging issues, but each person's journey will be unique

You will come across many different people who may share a diagnosis of dementia, but that is it.

Note:

- Link back to the SCIE TV Video called "Living with Dementia" that was featured in Unit 2
- Remember the experiences that Barry, Judith, Bob and Olive shared with us
- \bullet They all had a strong sense of identity $^{\sim}$ "I am still me...despite the dementia".

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Video Presentation

The importance of knowing the person with dementia

Barbara's Story Part 1

This video shows us what happens when we do not understand the needs of the person with dementia.

Barbara's Story - Her experience of attending a hospital appointment

13 minutes

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Video presentation (13 minutes) Participants to watch the video:

"Barbara's Story Part 1" 2 minute feedback (15 minutes in total)

Facilitator explains: "This is a video that lasts for 13 minutes and it is from Guys & St Thomas' Hospital NHS Trust. It presents the experience of Barbara, a lady with dementia who was attending a hospital appointment. It shows us what happens when you do not understand the needs of the person with dementia."

After 13 minutes, involve audience in a discussion about what they just viewed.

"Any lessons learned?"

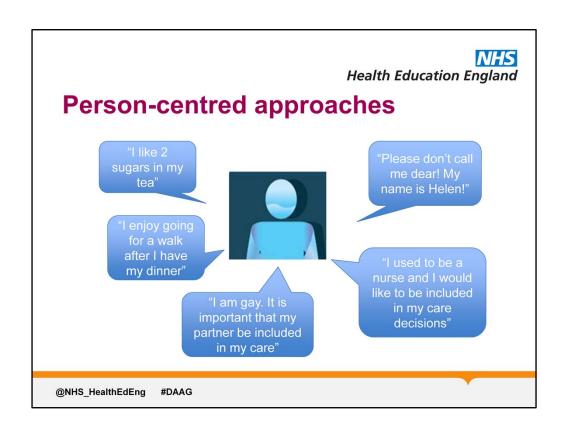
Note to facilitator: People may express negative emotions about Barbara's experience. For example feelings of hopelessness about the NHS staff, nobody was there to help her, only one person cared. Explain that is why we need to be person centred.

Please make sure that you end the discussion by saying: "We will now explore some person-centred approaches that we can use."

Alternative videos:

If you are delivering training in Primary Care, you may want to use the video called "The Appointment" which features Barbara attending an appointment at the dentist. It is 14 minutes and 20 seconds long. This can be accessed via: https://www.youtube.com/watch?v=EnPUq00UA8c

If you are delivering training in the Emergency Services such as in the Accident & Emergency Department, Police or Fire Services, you may want to use the video entitled, "Fred's Story Part 2". This features the story of an older man who absconds from an acute general hospital and is found walking around or "wandering" in the streets in his pyjamas. This video is 11 minutes & 1 second long. It can be accessed via: https://www.youtube.com/watch?v=YNDBB-6s1S0

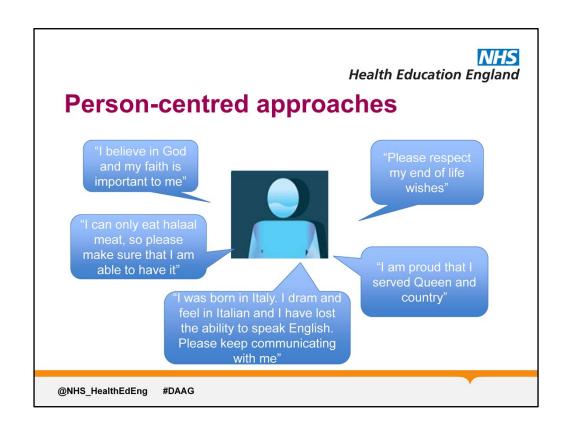


Group interaction

Have you ever heard anyone say these things?

People will have their own; Likes and dislikes Habits Skills Wishes Cultural or religious beliefs

Therefore our interaction needs to respect this, and to be individual and specific to their needs.



Group interaction

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Dementia & Culture

Person centred approaches"

What do we mean when we use the word culture

(6 minutes)

If time permits, ask the audience:

"Have you heard anyone say these things?"

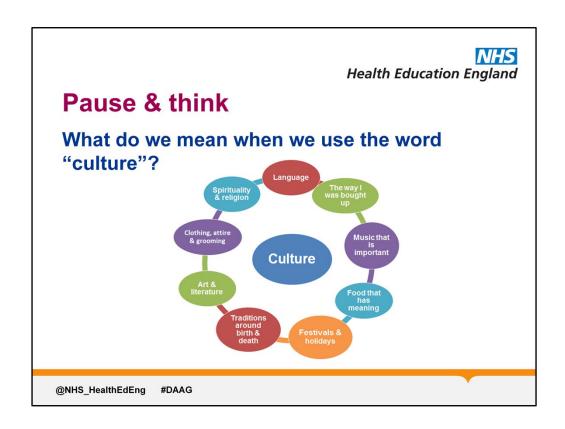
If time permits, invite participants to share their thoughts.

Notes:

Person centredness is a concept that is widely accepted in health and social care, which emphasises that each patient should be seen as a unique individual.

We live in an increasingly multicultural society

Culturally sensitive care looks to address the specific cultural needs of individuals. E.g. related to food (Hala/Kosher) festivals (Christmas/Ramadan/Purim/Divali) or religious practices (prayers/end of life rituals and burials).



Person centred approaches"

What do we mean when we use the word culture

(6 minutes)

If time permits, ask the audience:

If time permits, invite participants to share their thoughts

Notes on languaguage:

When we mention terminology and stigma – the equivalent word for dementia in some Asian languages is 'Madness', in japan it is 'Idiocy/Metal Retardation' and in Poland it is 'Deeply Mentally Disturbed'. In each case the stigma of dementia is made worse by the stigma of the associated phrases and their interpretations.

In Japan there have been cases of the families of an older person with dementia who was killed by a train being sent a huge bill by the railway company for the economic losses caused by their death. The families are expected to stop them from wandering.

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Review of Unit 3

At the end of this unit, you should be able to:

- Explain what it means to be person-centred.
- Describe the experiences of some people who are living with dementia.
- Explain person-centred approaches that can be used with people with dementia.
- State the importance of culture in person-centred dementia care.

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Conclude Unit 3

Complete evaluations

Complete presentation & review objectives for Unit 3

Verbal feedback to the group about how it felt for facilitator.

Sign post to electronic resources, dementia apps and any relevant dementia support services.

Sign certificates. Give out Certificates for Unit 3

Sign post to Unit 4



Useful Dementia Apps

Free in the Apple App Store:

- · Sea Hero Quest Glitchers Ltd (2016)
- Dementia Guide for Carers and Care Providers Text Matter Ltd (2016)
- MindMate Empowering People with Dementia MindMate (2016)
- Understanding Dementia for Care & Support Workers v.2 by Scottish Social Services Council (2016)
- Dementia: Understanding Stress & Distress v.2 by Scottish Social Services Council (2016)
- Dementia: Personal Outcomes v.2 –by Scottish Social Services Council (2016)
- Dementia Support by Swedish Care International (2013)
- Pathways Through Dementia by Patriona Briggs (2013)



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Useful Dementia Apps

Free in the Android Play Store:

- Confusion: Delirium & Dementia: A Bedside Guide by Confusion App (2014)
- · Vascular Dementia Information by Pachara Kongsookdee (2014)
- Dementia Support by Swedish Care International (2013)
- · Pathways Through Dementia by Patriona Briggs (2013)
- Fronto-temporal Dementia by Emanuel Bolachi (2014)
- Lewy Body Dementia by T. Boonmarkmee (2014)

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Some sources of help

- Alzheimer Society: http://www.alzheimers.org.uk/
- Berkshire Health Care (2014) Your Dementia handbook: http://www.berkshirehealthcare.nhs.uk/page sa.asp?fldKey=344
- · Carers of people with dementia: http://www.healthtalk.org/peoples-experiences/nervesbrain/carers-people-dementia/topics
- Dementia Action Alliance: www.dementiaaction.org.uk
- Dementia Friends: http://alzheimers.dementiafriends.org.uk/
- Dementia UK: http://www.dementiauk.org/
- · Dementia Services Development Centre: http://dementia.stir.ac.uk/

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Notes:

Show this slide and encourage participants to access the freely available resources.

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Some sources of help

- Dementia Web Oxfordshire DAA: http://www.dementiaweboxfordshire.org.uk/
- Improving Dementia Education and Awareness (IDEA): http://idea.nottingham.ac.uk/
- Young Dementia UK: http://www.youngdementiauk.org/
- Social Care Institute for Excellence (SCIE): http://www.scie.org.uk/socialcaretv/topic.asp?t=dementia
- Skills for Care (2014) Better domiciliary care for people with dementia Best practice case studies from domiciliary care employers developing their workforces to support people with dementia. Leeds: Skills for Care: http://www.skillsforcare.org.uk/Document-library/Skills/Dementia/Better-domicilary-care-for-people-with-dementia.pdf

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Notes:

Show this slide and encourage participants to access the freely available resources.

Evaluation - Now what?

• After completing this Dementia Awareness Training Unit, one thing I will do from now on is........

• One thing I will stop doing from now on is........

Evaluation of Unit:

- Encourage participants to complete their Tier 1 Dementia Awareness Training Unit Evaluation Form
- Collect the evaluation forms and prepare to send them to your Local Education & Training Lead
- Thank all the participants for attending the training.



Acknowledgements

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Jacqueline Fairbairn Platt, Associate Dean Quality Improvement

Zoe Scullard, Health Dean

Project Team

University of Northampton

Institute of Health and Wellbeing

Professor Jacqueline Parkes (Chair)

Alison Ward (Phase 1 Lead)

Dr Matthew Callender Professor Judith Sixsmith

Dr Jane Youell

Project Team continued:

University of Bedfordshire

Melsina Makaza (Phase 2 Lead)

Professor Mike Fisher

Samson Ojo

Oxford Brooks University

Peter Zaagman (Phase 2 Lead)

Casey Law

Catherine Wheatley

Kim Fredman-Stein

University of West London

Professor Heather Loveday (Phase 3 Lead)

Debi Joyce

Samantha Chan

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