

First Published in 2016 Health Education England (HEE)

This work is owned by Health Education England (HEE).

This training package is subject to HEE copyright and any reproduction of all or part of this package is expressly prohibited, unless HEE has granted its consent.

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 4

How does dementia affect the person & those around them?

"As a GP, this training session really reminded me of the emotional impact of dementia on the patient and those around them! We need to see the person behind the condition."

Feedback from a General Practitioner.

@NHS HealthEdEng

#DAA

Welcome to Unit 4

The quote from a General Practitioner, who attended the DAAG training, helps to set the scene for what this unit will consider.



Welcome to Unit 4

- Unit 3 introduced you to the concept of personhood & it gave you the opportunity to learn about some person-centred approaches that can be used when caring for people with dementia.
- Unit 4 will build on what you learned in Unit 3 by raising your awareness about how dementia affects the person & those around them.



@NHS HealthEdEng

DAAG

Welcome to Unit 4

Facilitator to engage in the setting of ground rules including disclosure of sensitive information and confidentiality.

Link to Unit 3

Think about the participants' 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.

Objectives of the Unit

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

- Explain the impact of dementia on people
- Describe how some people may feel after being diagnosed with dementia
- Discuss reasons why people with dementia may sometimes show signs of distress
- Explore behavioral & emotional aspects of dementia

@NHS_HealthEdEng

#DAAG

Objectives of the Unit:

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

Pause & Think: Video Presentation

What is the impact of dementia diagnosis on the person?

- "Getting to know the person with dementia – Impact of Diagnosis"
- After watching the video, please give brief comments about what you saw on the video.



Video clip
17 minutes

@NHS HealthEdEng

#DAAG

Pause & Think: Video presentation - "Getting to know the person with Dementia – Impact of Diagnosis"

(17:34 minute video)

The length of audience discussion: (3 minutes)

(20 minutes in total)

Facilitator explains: "This is a video that lasts for 17:34 minutes and it is from SCIE TV (Social Care Institute for Excellence) Television.

It presents the impact of diagnosis of dementia directly from the people who are experiencing it.

After 17 minutes, involve audience in a discussion about what they just viewed.

Any lessons learned?

NHS

Health Education England

How does dementia impact on the person?

- · Why do people with dementia sometimes get frustrated or agitated?
- · Emotional aspects of dementia:
- Acceptance of diagnosis
- Dealing with loss of memory (and sensory loss)
- · Increased dependency and becoming a 'burden'
- Loss of employment/social role/driving license
- · Confusion, anxiety and depression
- Communication issues
- · Some or all of the above may cause challenging behaviour

Many of these may also apply to carers

@NHS_HealthEdEng

#DAAG

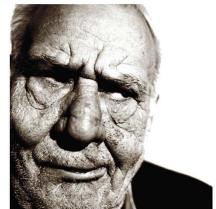
Notes:

If time permits, as the participants to think about some examples of how dementia has impacted on a person and other people around them.

Encourage the participants to think about what they learned in Unit 1 activity: "Your perceptions of people with dementia" and the Video that was shown in Unit 2, "Living with dementia".

Why might a person with dementia show signs of distress?

- It is not always the dementia that causes the distress.
- It is important to consider other potential causes
- They may be communicating an unmet physical, psychological, social or spiritual need.



@NHS HealthEdEng

4DAAG

Notes:

Present Slides 7 – 10 all focusing on the impact of dementia on the person with dementia

Facilitator to emphasise that after diagnosis, people with dementia go on a journey.

Each person's journey will be unique, which means that dementia will affect people differently

Facilitator to include reasons why people with dementia might show signs of distress

If time permits, engage in a developmental conversation about any experiences that the participants may have encountered.

Participants can make notes using the Unit 4 Activity Sheet if they wish.

Why might a person with dementia show signs of distress?

- Physically, they may be in pain or feeling tired feeling hungry &/or thirsty.
- Needing to go to the toilet.
- The distress may be also be triggered by environmental factors such as noise, heat, cold, darkness or bright lights.



@NHS_HealthEdEng

DAAG

Notes:

Present Slides 7 – 10 all focusing on the impact of dementia on the person with dementia

Facilitator to emphasise that after diagnosis, people with dementia go on a journey.

Each person's journey will be unique, which means that dementia will affect people differently

Facilitator to include reasons why people with dementia might show signs of distress

If time permits, engage in a developmental conversation about any experiences that the participants may have encountered. Ask the question:

"Can you think of examples when people with dementia have been in distress?"

Participants can make notes using the Unit 4 Activity Sheet if they wish.



What are the most common behavioural symptoms in dementia?

7 main challenges*:

- 1. Aggression
- 2. Anxiety and Agitation
- 3. Depression
- 4. Hallucinations or Delusions
- 5. Sleeplessness
- 6. Walking or being restless
- 7. Repeating the same conversation

*This list is not exhaustive (Adapted from James, 2015)



@NHS HealthEdEng #DAAG

Notes:

Present Slides 7 – 10 all focusing on the impact of dementia on the person with dementia

Facilitator to emphasise that after diagnosis, people with dementia go on a journey.

Each person's journey will be unique, which means that dementia will affect people differently

Facilitator to include reasons why people with dementia might show signs of distress

If time permits, engage in a developmental conversation about any experiences that the participants may have encountered. Ask the question:

"Can you think of examples when people with dementia have shown any of these behaviours?"

Participants can make notes using the Unit 4 Activity Sheet if they wish.

NHS

Health Education England

Emotional aspects of dementia on Carers

Carers for the person with dementia may experience:

- Denial
- Anger or resentment
- · Grief, loss or bereavement
- · A sense of relief
- Feeling overwhelmed or unable to cope
- Social isolation or loneliness
- Anxiety or fear about the future

There is a need to include the needs of carers in services/support

@NHS_HealthEdEng

#DAAG

Notes:

Present Slides 7 – 10 all focusing on the impact of dementia on the person with dementia

Facilitator to emphasise that after diagnosis, the carers of people with dementia also go on a journey.

Each carer's journey will be unique, which means that the dementia diagnosis will affect carers differently.

Facilitator to include reasons why carers of people with dementia might experience the emotions highlighted on this slide?

If time permits, engage in a developmental conversation about any experiences that the participants may have encountered. Ask the question:

"Can you think of examples when carers of people with dementia have experienced any of these emotions?"

Participants can make notes using the Unit 4 Activity Sheet if they wish.

For further learning, facilitators can signpost participants to www.heathtalkonline which features the experiences of a number of carers looking after a person with dementia.

Review of Unit 4

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

- · Explain the impact of dementia on people.
- Describe how some people may feel after being diagnosed with dementia.
- Discuss reasons why people with dementia may sometimes show signs of distress.
- State the behavioural & emotional aspects of dementia.

@NHS HealthEdEng

#DAAG

Review of Unit 4:

Facilitator to complete presentation & review objectives for Unit 4.

Obtain verbal feedback from participants. Ask participants to complete Tier 1 Dementia Training Evaluation Form.

Facilitator to give 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 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)



@NHS_HealthEdEng

#DAAG

NHS

Health Education England

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)

@NHS_HealthEdEng #

#DAAG





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/nerves-brain/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/

@NHS_HealthEdEng

#DAAG

Notes:

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

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

@NHS HealthEdEng #DAAG

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

Commissioners and Programme Leads

Health Education England Thames Valley

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

@NHS_HealthEdEng #DAAG