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THE LIVED EXPERIENCE OF DEMENTIA

**Applying insight to care using the
A Walk Through Dementia
virtual reality app**

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A WALK THROUGH DEMENTIA

Introduction

Welcome to this workbook that aims to increase your understanding of the lived experience of dementia using *A Walk Through Dementia* – a virtual reality experience developed by the UK's leading dementia research charity, Alzheimer's Research UK.

Completing this workbook will help you develop enhanced relationships with the people you care for who have dementia.

What is dementia?

The word dementia is used to describe a group of symptoms – these include memory loss, confusion, mood changes and communication difficulties. Dementia is not a normal part of ageing but caused by diseases of the brain, of which Alzheimer's disease is the most common.

Dementia can affect how people feel, act and function as well as their health. Symptoms get worse over time until the person needs full time care. Currently around 850,000 people in the UK are affected by dementia.

What is A Walk Through Dementia?

A Walk through Dementia is the first time a smartphone app has been used to engage the public with a first-person experience of dementia. It can be viewed with or without a virtual reality headset using the smartphone app or online at:

www.awalkthroughdementia.org

Developed in partnership with people with dementia and their carers, the experience is designed to help the user think beyond memory loss to gain a fully immersive insight into the varied symptoms people with dementia can experience in everyday life.

The app contains three films, told from the perspective of a person we have named Ann. Each film uses a combination of computer-generated environments and 360° video sequences to illustrate in powerful detail how even the most everyday tasks can become challenging for someone with dementia.

As the user, you are placed in Ann's shoes, experiencing the symptoms and difficulties she faces when shopping, walking home from the supermarket and making a cup of tea at home.

How will this workbook help me?

This workbook is aimed at all staff working in health and social care settings. It provides a unique insight into the lived experience of dementia, increasing knowledge and understanding of the condition.

The workbook covers some of the learning outcomes from the Dementia Training Standards Framework and can support other learning materials covering Tier 2 standards. Staff working on the front line of care are often under enormous pressure, with increasing workloads and limited resources. These increasing demands can result in a focus on the tasks associated with care delivery rather than a more holistic approach.

Understanding the lived experience of dementia enables health and social care staff to develop a deeper appreciation of the challenges of living with dementia. A more humanised approach to dementia care, as proposed by Galvin and Todres (2013), focuses attention on the things that make us feel human. Treating others in a humanistic way can not only strengthen relationships with the people we care for, but also with those who we work alongside.

There are lots of educational materials on caring for people with dementia available, and if you are working for a health or social care organisation you may have already received some information. Or this may be the start of your caring career.

Either way, whether you work in an acute hospital, in the community or in a residential home setting, this workbook will help you to see beyond the diagnosis of dementia, increase your understanding of the lived experience of the condition and ultimately improve the quality of care you deliver.

To find out more, you can watch a film about the *A Walk through Dementia* project on YouTube:

<http://alzres.uk/awtd-launch-film>

How was this workbook developed?

The Alzheimer's Research UK *A Walk Through Dementia* app has been tested and evaluated at Bournemouth University with undergraduate students including operating department practitioners, physiotherapy, occupational therapy and adult, child and mental health nursing students.

The app has also been tested and evaluated with nursing home staff, and feedback from all of these groups has helped shape this workbook.

Feedback highlights

- 82% of students who used the app said that the experience had helped them learn more about the symptoms of dementia (n = 269).
- 93% of students who used the app said it gave them a greater insight into the challenges faced by people with dementia (n = 269).
- Participants felt the films were powerful and emotional, making it easier for them to relate to clients with dementia:

"I now have a very good understanding of what it is like to live with dementia and to look after an individual with dementia. I am able to understand their needs, and put my skills and knowledge into practice."

Undergraduate healthcare student

"When you feel it rather than see it, you understand it more."

Nursing home staff member

How to use the workbook

The workbook can be used for independent learning and can also be used as part of a facilitated group session to encourage further discussion, reflection on practice and suggestions to influence practice.

Each section should last a minimum of 30 minutes and include some reflection on practice. More time would be needed for group discussion and for further reading.

This workbook is split into four sections; an introduction to a 'humanised approach to care' which we will reference throughout this workbook, followed by three sections focusing on each of the films that make up *A Walk Through Dementia*.

We suggest you work through each section in turn.

Section 1: Getting started

Section 2: At the supermarket

Section 3: On the road

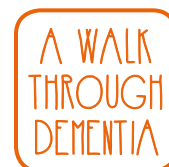
Section 4: At home

The workbook presents tasks, essential reading and links to further information, opportunities to reflect on your practice, and prompts on when to use the *A Walk Through Dementia* app.

KEY TO WORKBOOK



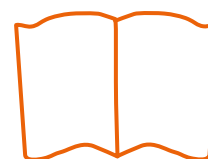
Do the tasks



View app



Reflection on
practice



Further reading



LEARNING OUTCOMES

By completing this workbook you will:

- Increase your understanding of the lived experience of a person with dementia.
- Enhance your understanding of the impact of dementia on day-to-day tasks.
- Consider how an increased understanding of the lived experience of dementia will impact upon practice.
- Consider how to adopt a more humanised approach to care delivery.
- Know where to find evidence-based information and resources.

The learning outcomes for this workbook have been mapped against the following Dementia Standards Training Framework subjects, (see appendix):

SUBJECT 1

Dementia awareness

SUBJECT 4

Person-centred dementia care

SUBJECT 5

Communication, interaction and behaviour in dementia care

SUBJECT 8

Living well with dementia and promoting independence



We recommend that the learning outcomes are discussed in a formal setting with your line manager – linked with performance review and Nursing Midwifery Council (NMC) revalidation for registered nurses.



Note the term client is being used to describe a person with dementia receiving care from health and social care professionals. This term relates to patients, service users and residents.



QUIZ

SECTION 1 GETTING STARTED

Answer these questions then work through the following sections.

You can test yourself again and check your answers on page 30.

- a) **Memory loss is the only symptom of dementia.**
a. True b. False
- b) **People with dementia should be supervised at all times.**
a. True b. False
- c) **People with dementia have no need to feel anxious.**
a. True b. False
- d) **People with dementia all have the same needs.**
a. True b. False
- e) **People with dementia lack capacity to make their own decisions.**
a. True b. False
- f) **The life story of a person with dementia shapes who they are.**
a. True b. False
- g) **People with dementia frequently exhibit unusual behaviours for no reason.**
a. True b. False
- h) **Imagine you or someone close to you has been diagnosed with dementia. Imagine what this might be like. Use the space below to reflect briefly on how you might feel.**

- i) Consider examples of when knowing more about a person's life story influenced the care you delivered. Use the space below to consider how this influenced your care and how it made you feel.

Introduction to a humanised approach to care



REFLECTION

Think about a time when you have worked with someone who has dementia. When that person's care was handed over to you, how were they described?

If you do not have any care experience, think about the language often used to describe people with dementia. Perhaps you have seen some newspaper headlines or you personally know someone with dementia.

Describe the language used:

Did the language used describe the person by their diagnosis first, such as 'dementia patient' or did you hear people described as a task to be completed? For example, 'has everyone in bay four been done?'. Were people with dementia considered to be all the same, a homogenous group, or were people's individual characteristics and contributions recognised?

We are all individuals with unique attributes, as are the people we care for. Avoiding the objectification and negative labelling of a person with dementia is central to both person-centred care and humanised care. In other words, seeing the person, not their diagnosis, and responding to individual unique human needs.

The language we use is an important part of the relationship between ourselves and our clients and can unwittingly affect the care we provide.

What is good care?

Good care is based upon genuine empathy from caregivers; this humanises care for clients by responding to the basic human need for:

- Security
- Meaning
- Feeling valued
- Respect
- Dignity
- Compassion

Good care is about enabling people with dementia to retain connections with others, maintain relationships and retain their unique sense of humanness. The Humanising Values Framework identifies eight dimensions of care for practice. These dimensions help us to unpack what it is to be human and how we can deliver a more humanised, person-centred approach to care. See 'Further reading' at the end of this section to find out more about the Humanising Values Framework.

Why is a humanising approach to care important?

If we have a better understanding of dementia and can put ourselves in the shoes of people with the condition, we can be more empathetic towards them. By responding to their unique emotional needs, we can enhance the compassionate care we give.

If the emotion experienced by a person with dementia is anxiety and distress, because they do not know where they are for example, we can help them make sense of what is happening by acknowledging their feelings and creating a sense of calmness.

A Walk Through Dementia provides an insight into what it might feel like to have dementia, so we, as care givers, can take steps to recognise where a person with dementia may be on their journey and give them the skills to maintain their independence.

In practice you may have come across the *This is me* document. *This is me* is a form that you can use to capture details about a person living with dementia. It provides an easy and practical way of recording who the person is, including details of their cultural and family background; events, people and places from their lives, as well as their preferences, routines and personality. Knowing more about a person and their life story can help care staff connect with them and understand their unique cultural and spiritual needs, their motivations and their behaviours. The role of family and friend carers is vital in capturing these important elements of an individual's life story.

Galvin and Todres (2013) suggest there are three different types of knowledge that come together to help us provide a humanised approach to care. As you use the *A Walk Through Dementia* app we will consider these three 'ways of knowing':

HEAD

Knowledge for the head includes facts, literature, research and policy



HEART

Knowledge for the heart includes feelings and experiential learning



HAND

Knowledge for the hand is what we do and how we do it; our skills and attitudes



NOTES



FURTHER READING

Barker, S, & Board, M 2012, *Dementia Care In Nursing*, n.p.: London : Learning Matters, 2012

Buckley, C., McCormack, B., Ryan, A., 2013. Valuing narrative in the care of older people: a framework of narrative practice for older adult residential care settings. *Journal of Clinical Nursing*, 23, 2565–2577.

Galvin, K, Sloan, C, Cowdell, F, Ellis Hill, C, Pound, C, Watson, R, Ersser, S, & Brooks, S 2018, 'Facilitating a dedicated focus on the human dimensions of care in practice settings: Development of a new humanised care assessment tool (HCAT) to sensitise care', *Nursing Inquiry*, 25, 3, p. 1.

Galvin, K. M. & Todres, L. 2013. *Caring and well-being: a lifeworld approach*. New York: Routledge, Taylor & Francis Group.

Hemingway, A, Scammell, J, & Heaslip, V 2012, 'Humanising nursing care: a theoretical model', *Nursing Times*, 108, 40, pp. 26–27,

Scammell, J 2015, 'Making a connection: the key to humanised care', *British Journal Of Nursing*, 24, 15, p. 786

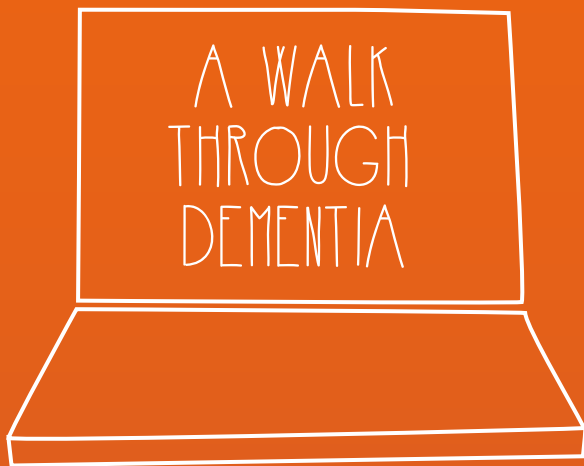
For more information about *This is me*, visit the Alzheimer's Society website
<https://www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me>

For more information about Life Story work, visit the Admiral Nurses website
<https://www.dementiauk.org/get-support/admiral-nursing/>

Please photocopy this page and share with your team

How to set up the app

Download *A Walk Through Dementia* to your smartphone from the App Store or Google Play store.



For anyone using an Apple device

The iOS version of the *A Walk Through Dementia* app **is no longer compatible with a cardboard headset**, or any other type of virtual reality headset.

Instead, anyone using an iPhone or iPad should hold the device at eye level.

Alternatively, you can watch all three videos online at

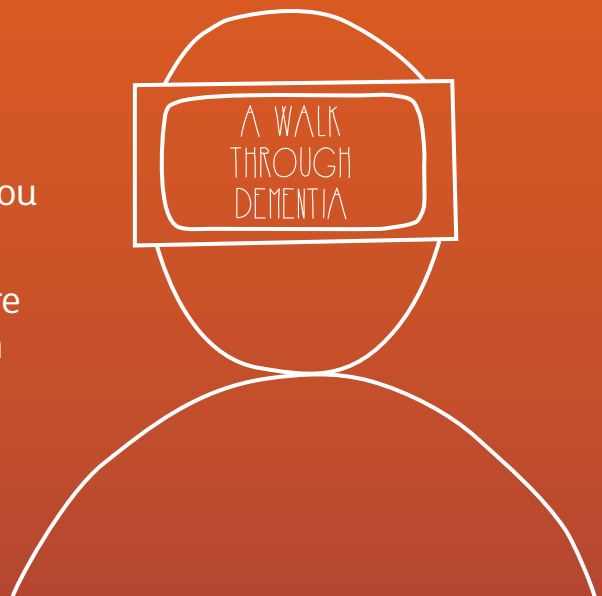
www.awalkthroughdementia.org

How to get started

Place your phone in the virtual reality headset and use headphones so that you can hear the audio clearly.

If you're not using a headset, make sure you're somewhere quiet where you can see and hear each film clearly.

Now you're ready to go!



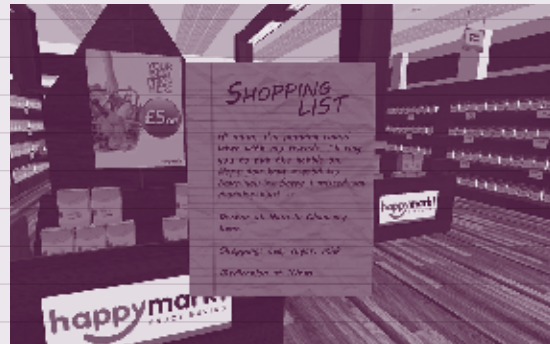
SECTION 2 AT THE SUPERMARKET

Open the app, select 360° tour and choose film 1: *At the supermarket*. In this animated film Ann and her son, Joe, go to the shop.

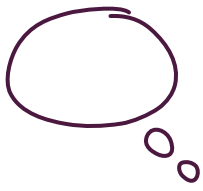
If you're viewing the film using a virtual reality headset, you'll need to choose items from the shelves. Either look at the item and press the button on your headset or hover over the item to select it automatically.



Consider the following questions, making notes if necessary.



- a) **How do you think Ann is feeling?**
- b) **What is she finding difficult?**
- c) **How do you think that might feel?**
- d) **Should people with dementia go shopping on their own?**
- e) **What did you notice about the list?**
- f) **What did you notice about the supermarket environment?**
- g) **What did Joe comment on with regards to her shopping?**
- h) **How did the cashier communicate with Ann and how did it make her feel?**
- i) **How can understanding Ann's experience influence our practice when caring for people with dementia?**



REFLECTION AND LEARNING

We will now reflect on what we've seen in the film, what we can learn and how this could relate to your clinical practice.



HEART

How do you think Ann is feeling?

As Ann enters the shop you are immediately struck by the **noise** and the constant beeping, which persists throughout the film.

Ann has her list to help her remember what to buy, but she **struggles to read the list**. There's also a lot of information not related to the shopping list on the piece of paper, which adds to her **confusion** – she says she *'can't quite make out'* what's on the list. So she tries to recall what she needs to buy, saying it *'will come to her when she sees things'*. She **anxiously** looks for Joe and her **breathing rate increases with her anxiety**.

Her **confidence grows** a little bit as she approaches the aisle to find the tea and sugar. But the shelves all look the same, as does the packaging on the shelves. Ann **anxiously** looks for the items she thinks she needs, no longer referring to the complex list.

Can you recall trying to find a specific item in a supermarket and how it's not always straightforward? Seemingly simple tasks such as choosing which milk to buy may not be easy for people with dementia as there are so many different types to choose from.

Ann meets Joe at the checkout and he seems frustrated because she has so many packets of biscuits. They weren't on the list because there is plenty of sweet stuff at home.

When challenged, Ann appears **muddled**, and when you look around, the layout of the shop appears to have changed. Sensing her disorientation, Joe reassures Ann and leaves her with the cashier.

The cashier puts pressure on Ann to be quick and asks more than one question at a time. Ann is **confused** and without the reassurance of Joe being around, becomes **anxious**. She wants to focus on one question at a time and responds saying, *'what do I have to pay?'*, but finding the correct money is very **confusing**. Ann **struggles** to count the change and the cashier's impatience increases Ann's **anxiety**. Joe returns and the payment is completed.



HEAD

What do we know about dementia?

Retaining independence is very important for maintaining identity and self-esteem.

Going to the shops to buy groceries is a familiar activity to many. It can be a social activity and helps people to remain part of the community. Choosing food can also help stimulate appetite and maintain nutritional status.

However, for someone with dementia, popping to the shops is not always an easy task. It requires planning, decision making, concentration, spatial navigation and calculation. All of these become harder for people with dementia.

Some people with visual forms of Alzheimer's disease can have real trouble reading words and following lines of text, such as those on a shopping list. This is caused by damage to the back of the brain which controls how we process our visual world.

We all feel the frustration when a supermarket changes its layout. Spatial memory and navigation problems mean that people with dementia can experience that feeling every time they go shopping.

Supermarkets are busy places and often very noisy, which can increase anxiety and confusion for people with dementia. In addition, information overload such as a complicated shopping list and being asked too many questions in quick succession can increase anxiety because of the difficulty in processing all this information.

People with dementia need time and patience when communicating. **Validate** their perspective of where they are and what is going on, respond to their **Emotion**, **Reassure** and introduce an **Activity** to distract if necessary (VERA Blackhall *et al* 2011).

Depending upon the type of dementia a person has, they may experience changes in their eating habits and food preferences. Food-related problems including lack of appetite and altered food preferences may cause significant weight loss and a subsequent increase in health problems.

A person with Alzheimer's disease may forget to eat and drink or forget that they have eaten. People with frontotemporal dementia in particular may crave sweet foods, or overeat. Those with dementia with Lewy bodies may also have eating problems associated with Parkinson's disease as their hands can shake and eating may become very tiring.

As the diseases that cause dementia progress, difficulties with eating and drinking generally worsen, and a person may need more help and support choosing, preparing and eating food.



HAND



How might this relate to practice?

Think about the environments in which you care for people with dementia. If you have time, sit and observe the environment, make notes and consider the following questions:

a) **What is going on?**

b) **What can you hear?**

c) **How many people are in that environment?**

d) **What are the noises in the environment?**

e) **Are people with dementia given written information to read?**

f) **Is there an element of frustration when a person with dementia takes their time to process information – how do staff react in those instances?**

g) **What can you observe in relation to how the person with dementia interacted with the environment?**

h) **What was positive about the environment and the interactions between the person with dementia and the staff, and what could be further developed?**

Suggestions for practice

Photocopy this page and keep it with you to remind you of what you've learnt.

- Acknowledge the individual's feelings.
- Use the preferred name of the person with dementia.
- Create a sense of calmness in your approach and the environment if possible.
- Where you can, reduce the noise being created.
- Ensure the person knows you are speaking to them by using clear non-verbal communication; consider facial expression, gaze, gesture, body movement, posture, touch and spatial behaviour. Taking care over your non-verbal communication will show the person that you care and that you have time to listen to what they want to communicate.
- Avoid looking rushed – make that five-minute conversation your sole focus at that time.
- Make sure glasses are clean and hearing aids are in place and turned on.
- Is the individual comfortable? Are they thirsty, hungry or in pain? Addressing these needs can help reduce anxiety or distress.
- Good lighting can avoid shadows and decrease anxiety. You might want to cover mirrors if a person finds the image of themselves alarming or confusing.
- Involve the person with dementia and their family to identify effective communication strategies.
- See the person NOT the diagnosis.
- Avoid objectification, i.e. seeing people as a list of tasks to be completed as opposed to responding to individual needs.
- Offer visual choices if the person is having difficulty making verbal choices, for example offer two plates of food to see which they would prefer.
- Prompt the person about the topic of conversation if they go off track, for example 'you were just telling me about your daughter, Susan'.
- Value and recognise the humanness of the person, communicating respectfully and kindly.
- Avoid challenging their perception of what is happening or where they are. Instead, respond to the emotion they are expressing.
- Live in the present with that person and accept their reality. For example, if they are anxious, reassure them that they are safe, if they are they happy then laugh with them.
- Use distraction if necessary, for example, suggesting an activity that they like.
- If the person is living in their own home
 - Ask them if you can reduce external noises when you are talking to them, for example, turning down the TV or radio.
 - Discuss ways of maintaining independence, for example, would a local shop be more convenient than a large supermarket?
 - Suggest the use of a simple list, memo board, or clear calendar.
 - Consider looking at additional ways to maintain social engagement.
 - Find out if their local community is engaged with 'dementia friendly communities'.
- If the person is in an acute hospital setting
 - Consider reducing the noise in a busy environment. Could you introduce quiet time at some point during the day to ensure they can rest?
 - Provide care that is not solely technical or task-focused.
 - Provide information in visual as well as written format e.g. pictorial menus.
- If the person is in a residential setting
 - Help them maintain a normal routine such as the opportunity to shop, participate in 'chores' such as folding own clothes, involvement in cooking etc.
 - Again, consider reducing the noise in a busy environment and introducing quiet time.
 - Provide care that is not solely technical or task-focused.

What have you learnt?

Insights from people with dementia and their carers



PP I am sensitive to lots of noise. I don't like it. Things on TV, theatre, I get uncomfortable. Brightness and flashing lights... There's nothing obvious to say you have dementia, no sign, so people don't understand.

Trina, living with posterior cortical atrophy



PP So I went to the bank and the lady with a hand-held machine was walking around speaking to customers. It was too much information and the lady was very impatient and off-hand. I got really upset, cried and left.

Vicky, living with early-onset Alzheimer's disease



PP If we are out Trina picks up on other people's conversations and responds, and they are not talking to her. Her vision is impaired so she doesn't notice they are not speaking to her. It can make her feel embarrassed.

Graeme, Trina's husband



PP If we write something down, we highlight it, so Vicky can see that something is written and knows what she has to do.

Martin, Vicky's husband



Here are some insights from other learners.

PP Just last week, we had a new resident that came into our home and is living with dementia. She was very confused and scared. And then I was up in another resident's room and I could hear three TVs on and they were all on the same channel which made it really loud. And the lady's room is across the way from all these televisions.

It made me think of the film when she was going to the supermarket and all the noises. And I thought that probably doesn't help her fear and we turned the TVs down.

Student Nurse



PP I was getting really angry with the cashier, thinking... just give her a minute, you're confusing her and she's already confused.

Student Nurse



PP We have one resident here who struggles to vocalise his thoughts. And I think it was the second day he was in, I was on the dedicated dementia floor and he was just getting more and more anxious and upset because he couldn't vocalise.

I said to him, I understand your frustration, and he just came out, 'you don't understand my frustration'. And that really got to me. So I'm more careful about what I say.

Senior Health Care Assistant in a nursing home



PP If you just hear constant noise all the time then that affects your mood and if you don't understand it and you're trying to make sense of it then you might feel frightened and scared.

Health Care Assistant in a nursing home



Suggestions for practice

- Acknowledge the person with dementia's emotional response and respond calmly and with compassion.
- Take your time when communicating.
- Be conscious of the person with dementia's non-verbal cues when communicating.
- Be conscious of your own non-verbal cues when communicating.
- Consider the impact of a noisy, busy environment and try to create a calmer environment.
- Use visual cues as well as written signs to convey information.

NOTES



FURTHER READING

For more guidance about nutrition and dementia care and to access helpful information and resources, visit Bournemouth University's website

<http://www.bournemouth.ac.uk/nutrition-dementia>

Blackhall, A, Hawkes, D, Hingley, D, & Wood, S 2011, 'VERA framework: communicating with people who have dementia...Validation, Emotion, Reassure and Activity', *Nursing Standard*, 26, 10, pp. 35–39.

Killick, J, & Craig, C 2011, *Creativity And Communication In Persons With Dementia : A Practical Guide*, London: Jessica Kingsley Publishers.

Nazarko, L 2014, 'People living with dementia: components of communication', *British Journal Of Healthcare Assistants*, 8, 11, pp. 554–558.

O'Brien, R, Goldberg, S, Pilnick, A, Beeke, S, Schneider, J, Sartain, K, Thomson, L, Murray, M, Baxendale, B, & Harwood, R 2018, 'The VOICE study – A before and after study of a dementia communication skills training course', *Plos ONE*, 13, 6, pp. 1–16



SECTION 3 ON THE ROAD

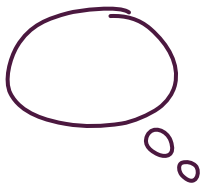


Open the app and select 360° tour and choose film 2: *On the road*. The film lasts 3 minutes 21 seconds and you can hear Ann's thoughts as she walks home from the supermarket with her son, Joe.



After you have watched the film consider the following questions, making notes if necessary.

- a) **How do you think Ann is feeling?**
- b) **What is she finding difficult?**
- c) **What could have been done to reduce her anxiety?**
- d) **Do you know what causes the difficulties she has with perception?**
- e) **What might happen if Ann was alone without her son? How might members of the public respond to her distress?**
- f) **What do you know about dementia friendly communities?**
- g) **How can understanding Ann's experience influence your practice when caring for people with dementia?**



REFLECTION AND LEARNING

We will now reflect on what we've seen in this film, what we can learn and how this could relate to your clinical practice. We will consider this using Galvin and Todres' three different types of knowledge.



HEART

How do you think Ann is feeling?

When Joe takes the telephone call, Ann decides to continue walking home. At first Ann appears to know where she is going and feels **confident** – she appears to recognise familiar objects and the colour of cars. But what she may not be able to process is that there may be several cars of the same colour.

Then Ann becomes **anxious** when she realises she has taken a wrong turn, saying:

'This isn't the right cut through, this isn't the alleyway, where does this go? This isn't the right way'.

You can hear her **breathing rate increase** and a change in the tone of her voice as she **anxiously** looks for Joe. Joe reaches her and is relieved that he has found her, saying 'I was so worried'.

Her **anxiety increases** as she approaches the puddle in the road. Thinking it's a hole in the road, she warns Joe to 'take care'. He reassures her and tells her it's only a puddle and she then becomes **embarrassed**, saying:

'I'm sure everyone is looking at me'.

She's **relieved** to be home again, but as she approaches the steps to her front door the **fear** of going up the steps makes her heart race, as she thinks:

'I can't face these stairs today'.

Consider the following

- Have you ever been lost? As well as feeling anxious, do you remember feeling embarrassed that you got lost and a sense of relief when you arrived home? Feeling disorientated and getting lost even in familiar places is common in Alzheimer's disease and other forms of dementia. This may be attributed to problems with memory and/or spatial cognition.
- This film also highlights the anxiety carers can experience and the support they may need to enable them to continue to care for their loved one.

Focusing on how Ann is feeling is a good starting point in understanding how best to support her. Responding to that emotional reaction can also help us understand more about the impact of dementia on a person and increase our knowledge. While no two people are the same, we begin to recognise the difficulties a person with dementia may encounter and what we can do to help.



HEAD

What do we know about dementia?

In Alzheimer's disease, the most common form of dementia, people can experience problems with higher brain function as well as progressive memory loss. These can include:

- Geographical disorientation – getting lost in familiar places.
- Visual agnosia – difficulty recognising or interpreting visual information.
- Prosopagnosia – inability to recognise faces.

Ann was demonstrating some difficulties recognising her son Joe. This is associated with damage to the visual system of the brain found in the occipital and temporal lobes and can be common in Alzheimer's disease.

If there is damage in the parietal lobes of the brain, a person may have difficulty judging distances in three dimensions. We noticed this as Ann negotiated the steps to her front door. A combination of the damage to these two parts of the brain also meant that Ann saw a deep hole in the pavement and not a puddle.

Living in a person's reality and validating their emotional response rather than challenging their misperception is a helpful and effective way to reduce anxiety.

Carers may not fully understand the anxiety and distress their loved one can feel. Explaining the impact of dementia to them and how they can best support their loved one, as well as how they can look after themselves, is crucial.



HAND



How might this relate to practice?

Think about the environments in which you care for people with dementia. The difficulties we see in Ann are common and often made worse by unfamiliar environments such as a care home or hospital.

Some people with dementia may also have to move house and could be living in a new environment, which can also be very disorientating.

Having dementia can increase people's disorientation about where they are, even if it's a relatively familiar environment. It is therefore important to recognise and respond to the emotions of the individual.

Can you think about what you could do to support someone who is distressed because they do not recognise where they are or who they are with?

Use this space to make some notes, or talk about it with your colleagues

Suggestions for practice

Photocopy this page and keep it with you to remind you of what you've learnt.

→ Acknowledge the individual's feelings.

→ Communicate in a calm and reassuring way.

→ If the person agrees, make sure that they have some personal identification on them with an emergency contact number.

→ Do not challenge a person's misperception, instead respond to their emotion.

→ If the person is living in their own home and is happy for you to do so:

- Make their neighbours and local shop owners aware of their difficulties.
- Suggest the individual has an easy-to-use mobile phone.
- Discuss other potential assistive technologies such as a Global Positioning System (GPS).
- Do not recommend restricting an individual's physical activity by staying home. Exercise should be encouraged.

→ If the person is in an acute hospital setting

- Complete a 'This is me' form and ask family for a photograph.
- If the ward / hospital environment is not a 'dementia friendly environment' look up the key principles to improve accessibility and navigation.
- Allow next of kin to visit as much as they want (see John's campaign in the 'Further reading' section).

→ If the person is in a residential setting

- Follow guidance for an acute hospital setting.
- Create a more familiar homely environment with objects, textures and sounds familiar to the individual.
- Encourage involvement with the local community to maintain previous connections with friends, different age groups and pastimes.

→ Supporting carers

- Speak with carers to see how they are feeling and what additional support they may need.
- Direct carers to charities and other organisations that can provide them with more information about dementia and further support, such as Alzheimer's Research UK, Alzheimer's Society and Dementia UK (who can provide access to Admiral Nurses).
- What support services are available locally for carers? If appropriate, suggest that they could benefit from a carer's assessment from their GP.

What have you learnt?



Insights from people with dementia and their carers

☞ I hate large open spaces. Don't know which way to go. Too vast.

Vicky, living with early-onset Alzheimer's disease



☞ Keep going out. Try not to be frightened. Try to find people to help. A lot of people will help if you ask. Don't be ashamed to ask, it's not something to be ashamed about.

Trina, living with posterior cortical atrophy



☞ Vicky has difficulty with the stairs at home, when she comes to the last stair she still thinks there is a stair, she takes a step and it's not there...it's a real problem. So I've put tape down so she knows it's the last stair.

Martin, Vicky's husband



☞ Having the white stick helps Trina, as people know she has a disability. With dementia in general no one knows, so because Trina is now registered blind we use the white stick.

Graeme, Trina's husband



Here are some insights from other learners.

☞ You know when there's a carpet, sometimes residents would go around it. Because they see it and they think it's a black hole - that's what the puddle reminded me of and it made sense. Some people might avoid areas and I have seen residents that walk really close to walls and I've noticed that the carpet is a bit different there.

Student Nurse



☞ I think with the floor sensor mats, it makes sense for them to have bed sensor mats rather than the black sensor mats on the floor next to their bed. The mat might look like a hole and make someone feel anxious.

Night Care Assistant in a nursing home



☞ I understand that the health professionals are busy but you're the caring person. You've got to take a minute or two out if you're going to care properly, if you're going to deliver the proper care.

Student Nurse



☞ It gave me lots to think about, lots of things that I do know but actually seeing it is different. It gives a much clearer idea of what people with dementia may be visualising and what they're not visualising.

Registered Mental Health Nurse in a nursing home



To summarise

- The word dementia describes a set of symptoms that may include memory loss, difficulties with thinking, problem solving, language, spatial perception and orientation.
- Validate how that person is feeling. Doing so starts the journey towards a more person-centred, humanised approach to care.
- Work with the family to maintain the safety of the individual with dementia.
- In care environments, help create a sense of home to increase feelings of security.

NOTES



FURTHER READING

Visit the Alzheimer's Disease International website for examples of dementia friendly community projects
<https://www.alz.co.uk/dementia-friendly-communities/england>

Board M, McCormack B. 2018. Exploring the meaning of home and its implications for the care of older people. *Journal of Clinical Nursing*. Accepted 6th April 2018. DOI: 10.1111/jocn.14495

Brooker, D, & Latham, I 2016, Person-Centred Dementia Care. Making Services Better With The VIPS Framework, n.p.: London : Jessica Kingsley Publishers, 2016.

Dow, J. et al. (2018) 'How best to assess quality of life in informal carers of people with dementia; A systematic review of existing outcome measures', PLoS ONE, 13(3), pp. 1–18

Greenwood, N. et al. (2017) 'A qualitative study of carers' experiences of dementia cafés: a place to feel supported and be yourself', BMC Geriatrics, 17(1), p. 164

John's Campaign for the right to stay with people with dementia and to be supported by their family carers
<https://johnscampaign.org.uk>

The King's Fund – Developing supportive design for people with dementia
<https://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia>

Information from Alzheimer's Society on seeking support
<https://www.alzheimers.org.uk/get-support/help-dementia-care/getting-support>



After experiencing what it's like to go shopping and walk home, it's now time to watch the third film: *At home*.

Ann's daughter, Laura, phones her to say she is on her way over. She asks Ann to make a cup of tea for her and friends, Tim and Lloyd. The film lasts 2 minutes 49 seconds.



Watch the film and then consider the following questions, making notes if necessary.

- a) **How was the list of instructions given by Laura and interpreted by Ann?**

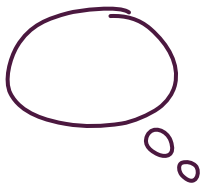
- b) **What is happening as Ann makes a cup of tea?**

- c) **How is she feeling?**

- d) **How does she respond to her daughter when she arrives?**

- e) **How would it feel to face these challenges every day?**

- f) **How can understanding Ann's experience influence your practice when caring for people with dementia?**



REFLECTION AND LEARNING

We will now reflect on what we've seen in the film, what we can learn and how this could relate to your clinical practice.



HEART

How do you think Ann is feeling?

Ann sounds **anxious** when she picks up the phone but is **reassured** when she hears it's her daughter, Laura. She **confidently** responds to Laura's request to put the kettle on but is **anxious** as she **tries to recall** the long list of instructions Laura gives her. Laura changes the subject and appears to test her mum's memory, saying 'you remember Tim and Lloyd don't you?' **Not wanting to appear forgetful** Ann **laughs nervously** and says of course she remembers them.

Would you recall that list of drinks? Ann is keen to present that all is well and **mask her symptoms**, which **increases her anxiety** as she tries to recall the list.

She **chastises herself** as she says 'Come on, it's not that difficult'. She also **struggles to locate** everything she needs to make the tea. She 'loses' the tea bags and thinks it's 'strange' when she comes across them - 'I'm sure they weren't here a minute ago' **she thinks suspiciously**. She has **forgotten** where the tea bags are kept. Then she spills some of the hot water on the counter and is **shocked**; 'Oh dear I didn't see that'.

Laura arrives and again Ann wants it to seem as if all is well. 'Make yourself comfortable' she says as she thinks about what she has to do next; 'Ahh yes put the cups on the tray'. She continues **to try to remember** how Tim likes his tea and she adds seven sugar lumps, losing count of how many she has put in.

She also **struggles to recall Tim's name**. When Tim drinks the tea he's horrified by how sweet it is, and Lloyd's tea has no milk in it. Laura decides not to confront her mum about the taste of the tea.



HEAD

What do we know about dementia?

While we often associate impairments in a person's memory with dementia, another significant area of cognition that may be affected is executive function. This is a broad term to cover higher-level cognitive processes that control everyday actions and thoughts. For someone with dementia, these higher-level tasks that involve planning, sequencing and inhibition, such as getting dressed, washing, and making a cup of tea, can become more difficult.

It is damage to the frontal lobes of the brain that impacts upon executive functioning, so completing everyday tasks in the correct order becomes harder.

For example, there are around 30 different steps to making a cup of tea and a breakdown in executive function can mean the water, milk and sugar are added in the incorrect order or forgotten completely. Remembering lists of instructions can also be hard, as a result of difficulties with working memory and sequencing.

If someone has a form of dementia that affects their vision, they may struggle to see things that are directly in front of them as a result of so-called 'blind spots'. Hand-eye coordination is controlled by an area at the top of the brain called the parietal lobe, which can be damaged by diseases such as Alzheimer's. This is what made Ann accidentally pour boiling water on the kitchen surface.

Safety and avoidance of risk is a key concern for health and social care professionals. Respect for autonomy should remain key and an individual assessment of risk and management should be tailored to meet the unique needs of each person with dementia. It's important to gauge risk based on the capacity of the individual rather than the diagnosis of dementia.

Obtaining a dementia diagnosis can take time and some of the delay can be associated with the stigma attached to dementia. There can also be a lack of awareness of the signs and symptoms of dementia. In some instances, the person with symptoms will do their best to mask them and cover up their memory lapses or disorganised thinking. They may be reluctant to get these symptoms investigated because they do not want to appear different to their old selves. It is often the family that notices changes in the person's condition that will prompt them to visit their doctor and begin an assessment.



How might this relate to practice?

- a) **Once people are aware of your interest in dementia they may start to talk to you about concerns they have about their memory or difficulties associated with activities of daily living. What would your advice to them be and why?**
- b) **Reflect on a time when you were caring for a person with dementia. What did you notice as they attended to their personal hygiene needs and got dressed? Also reflect upon how you intervened and how you were feeling. Make some reflective notes.**
- c) **Can you think of a time when your focus was on their diagnosis and not on whether they were able to do things themselves? If so, what could you have done differently?**

Suggestions for practice

Photocopy this page and keep it with you to remind you of what you've learnt.

When people express concerns about memory or difficulties associated with activities of daily living

- Acknowledge the individual's feelings and ask for more information about their concerns.
- Suggest that the person goes to the GP to investigate the causes of these symptoms. Seeking an early diagnosis is important to identify the causes as it may not be dementia. However, an early diagnosis ensures that appropriate planning and support can begin.

When supporting people with dementia with activities of daily living

- Adopt a humanised approach to care delivery.
- Take an interest in what a person with dementia tells you about how they like things done.
- Seek out flexibility in the system to respond to the priorities of a person with dementia, for example, do they want their bath in the evening or morning? If you are unable to accommodate their preferences, explain why.
- Assess what the person can do for themselves to maximise their independence.
- Avoid asking lots of questions at the same time.
- Give instructions in small steps.
- Offer a small number of choices rather than an open question such as 'what do you want to wear?'. Get to know their preferences and show selected options, asking which one they would like to wear.

- Write simple lists.
- Demonstrate what you mean.
- Avoid confrontation. If someone becomes distressed, stay calm and try to return when they are less agitated.
- Explore the use of assistive technologies, for example Alexa or sensor mats.

Suggestions for practice on managing risk

- Recognise that each person with dementia is unique and the progression of the illness is uniquely experienced.
- Get to know the person's life story – understanding this narrative is essential in understanding their behaviours.
- Support the person to maintain their independence.
- Removing one risk may create another. For example, you may prevent someone from falling if they are sat down all the time, but immobility increases the risk of pressure sores, urinary tract infection, constipation, chest infection and muscle wasting (sarcopenia).
- Risk management is a complex decision but should always be patient-centred.
- See 'Further reading' section for more information on managing risk.

What have you learnt?



Insights from people with dementia and their carers

☞ We ought to talk about dementia – we've got to talk about it and accept it is the way it is. We should talk about it all the time...it's just part of life. We shouldn't make people with dementia feel like they're another being.

Trina, living with posterior cortical atrophy



☞ Using technology can help. We use 'Alexa' at home, and Trina can just call out and it will respond, so she can say 'Phone Graeme' and it will.

Graeme, Trina's husband



☞ Too many options isn't good. So if we go out for a meal, I now know to read only a few choices of things I know she likes.

Martin, Vicky's husband



☞ You can end up eating things you don't like which is embarrassing.

Trina



Here are some insights from other learners.

☞ Her daughter was saying on the phone 'you need to do this and that, make this tea and that tea' and it's the same in practice. Something I picked up from the film is that you don't want to be overloading people who have dementia.

Take one thing at a time. Give simple instructions to help them to understand what they need to do so they can try to do it themselves.

Student Nurse



☞ It's about trying to be able to identify that they do need more time as part of their care. You need a care plan for them to make sure that person doesn't get flustered and doesn't get anxious, because otherwise, people get labelled as being difficult to deal with but actually it's us that's causing it.

Student Nurse



☞ Sometimes you offer people too many choices like, do you want tea, coffee, orange juice? If you say it too quickly they can't understand it either because it's too quick. So it's about pace as well, for that total understanding.

Registered General Nurse in a nursing home



☞ You look at their life histories and you look at their careers and when you get to know that person, you can see exactly why that person doesn't want to sit. Instead that person wants to be climbing chairs and taking shelves off the wall all day because that's what they've done all their life.

Support worker in a nursing home



To summarise

- Take your time to listen to and observe a person with dementia so that you know if they are understanding what you are trying to communicate.
- Avoid a long list of instructions.
- Encourage those who have worries about their memory to seek assessment from their GP.
- Knowing the person with dementia's life story is essential.
- Assess the capacity of the individual to be independent rather being led by their diagnosis of a dementia.

NOTES



FURTHER READING

Alzheimer's Society provides advice about supporting people with washing, safety and risk management, as well as different types of assistive technology available

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

The SCIE web pages provide some useful information on dementia friendly environments

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

Bunn, F, Goodman, C, Sworn, K, Rait, G, Brayne, C, Robinson, L, McNeilly, E, & Iliffe, S 2012, 'Psychosocial Factors That Shape Patient and Carer Experiences of Dementia Diagnosis and Treatment: A Systematic Review of Qualitative Studies', PLoS Medicine, vol. 9, no. 10, pp. 1–12.

Buckley, C., McCormack, B., Ryan, A., 2013. Valuing narrative in the care of older people: a framework of narrative practice for older adult residential care settings. *Journal of Clinical Nursing*, 23, 2565–2577.

Dickins, M, Goeman, D, O'Keefe, F, Iliffe, S, & Pond, D 2018, 'Understanding the conceptualisation of risk in the context of community dementia care', *Social Science & Medicine*, 208, pp. 72–79

Hsu, M I., McCormack, B., 2011. Using narrative inquiry with older people to inform practice and service developments. *Journal of Clinical Nursing*, 21, 841–849.

Karlsson, E., Axelsson, S., Zingmark, K., 2014. Stories about life narrated by people with Alzheimer's disease. *Journal of Advanced Nursing* 70(12), 2791–2799.

Manthorpe, J., Moriarty, J., 2010. *Nothing Ventured, Nothing Gained; Risk Guidance for People with Dementia*. Department of Health, London.



QUIZ

TEST YOUR KNOWLEDGE

Retake the quiz to check your understanding.

Compare with your answers on page 04.

a) **Memory loss is the only symptom of dementia.**

a. True b. False

e) **People with dementia lack capacity to make their own decisions.**

a. True b. False

b) **People with dementia should be supervised at all times.**

a. True b. False

f) **The life story of a person with dementia shapes who they are.**

a. True b. False

c) **People with dementia have no need to feel anxious.**

a. True b. False

g) **People with dementia frequently exhibit unusual behaviours for no reason.**

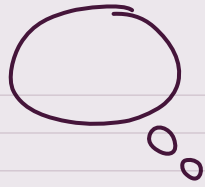
a. True b. False

d) **People with dementia all have the same needs.**

a. True b. False

The answers are found on page 30

Please photocopy this page and share with your team



REFLECT

on what you have learnt

h) **Imagine you or someone close to you has been diagnosed with dementia. Imagine what this might be like. Use the space below to briefly reflect on how you might feel.**

i) **How has completing this work book influenced your perspective?**

Consider examples of when knowing more about a person's life story influenced the care you delivered. Use the space below to consider how this influenced your care and how it made you feel.

j) **Reflect upon how completing this workbook will impact upon your practice.**

REFLECTIVE ACCOUNTS FORM

You must use this form to record five written reflective accounts on your CPD and/or practice-related feedback and/or an event or experience in your practice and how this relates to the Code. Please fill in a page for each of your reflective accounts, making sure you do not include any information that might identify a specific patient, service user or colleague. Please refer to our guidance on preserving anonymity in the section on non-identifiable information in **How to revalidate with the NMC**.

Reflective account:

What was the nature of the CPD activity and/or practice-related feedback and/or event or experience in your practice?

What did you learn from the CPD activity and/or feedback and/or event or experience in your practice?

How did you change or improve your practice as a result?

How is this relevant to the Code?

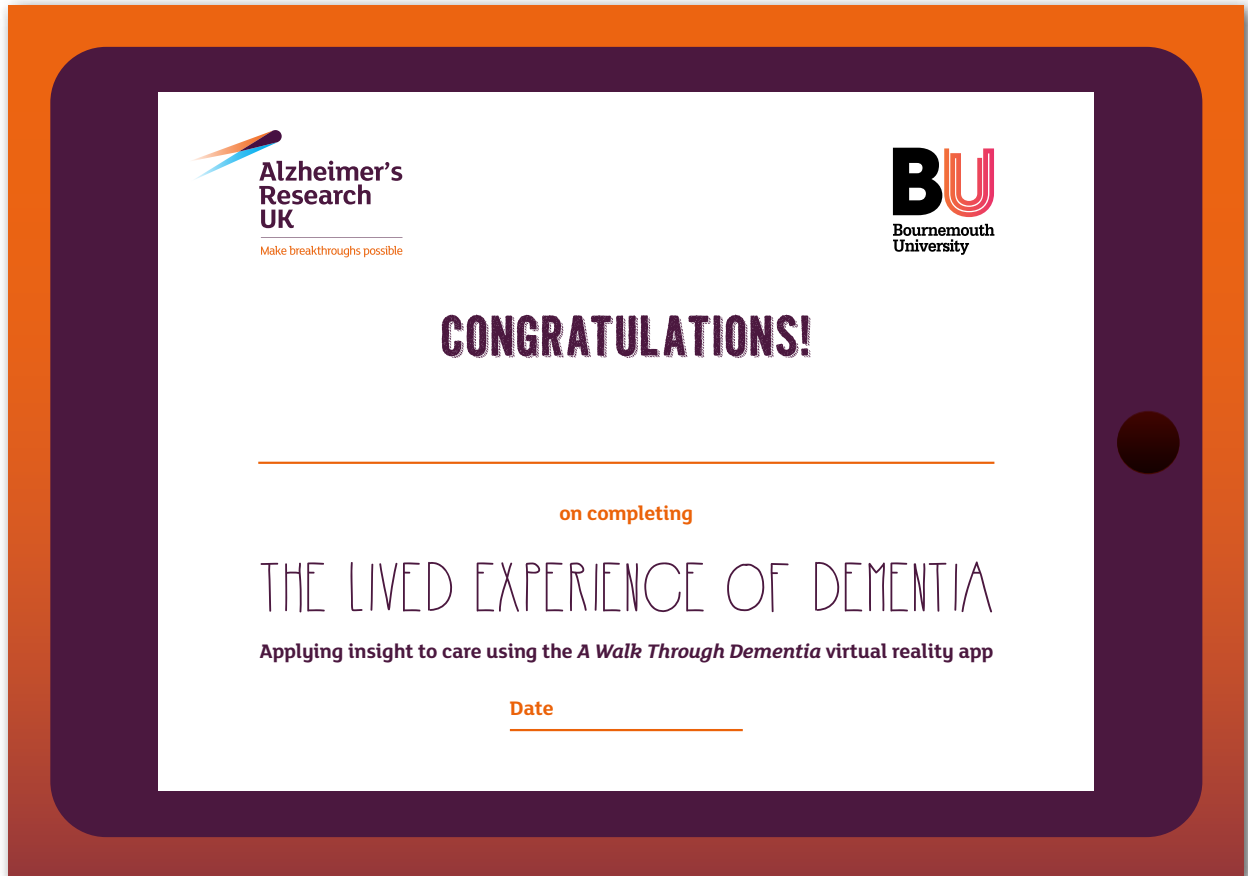
Select one or more themes: Prioritise people – Practise effectively – Preserve safety – Promote professionalism and trust

CERTIFICATE AND EVALUATION

We would like to receive your feedback on this workbook and the impact it has had on your understanding, behaviour and practice.

To download and print a certificate as proof of your completion of the workbook, complete the following short quiz and evaluation survey.

<http://alzres.uk/lived-experience-certificate>



Quiz answers

Correct answers are highlighted in bold.

- A) Dementia is just about memory loss.
a. True **b. False**
- B) People with dementia should be supervised at all times.
a. True **b. False**
- C) People with dementia have no need to feel anxious.
a. True **b. False**
- D) People with dementia have the same needs.
a. True **b. False**
- E) People with dementia lack capacity to make their own decisions.
a. True **b. False**
- F) The life story of a person with dementia shapes who they are.
a. True b. False
- G) People with dementia frequently exhibit unusual behaviours for 'no reason'.
a. True **b. False**

APPENDIX

Content mapped against the Dementia Training Standards Framework 2018.

Learning outcomes

Subject 1: Dementia awareness

- a) Know what is meant by the term dementia.
- f) Know the actions that people affected by dementia can take in order to live as well as possible after diagnosis.
- g) Understand the importance of recognising a person with dementia as a unique individual.
- h) Be aware of the impact of dementia on individuals, families and society.
- i) Be aware of the central role that their home, housing conditions and immediate community play in enabling a person with dementia to live well.
- j) Be able to communicate effectively and compassionately with individuals who have dementia.
- k) Understand reasons why a person with dementia may exhibit signs of distress and how behaviours seen in people with dementia may be a means for communicating unmet needs.

- l) Be able to signpost individuals, families and carers to dementia advice, support and information.

Subject 4: Person-centred dementia care

- 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.
- 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.
- c) Understand the role of family and carers in person-centred care and support of people with dementia.
- f) Know how to adapt the physical environment to meet the changing needs of people with dementia.

Subject		Learning outcome															
		a	b	c	d	e	f	g	h	i	j	k	l	m	n	o	p
1	Dementia Awareness	✓					✓	✓	✓	✓	✓	✓					
4	Person-centred dementia care	✓	✓	✓			✓	✓		✓							
5	Communication, interaction and behaviour in dementia care	✓	✓	✓		✓	✓	✓			✓	✓	✓	✓	✓	✓	✓
8	Living well with dementia and promoting independence	✓	✓	✓	✓						✓	✓	✓	✓			

- g) Understand the significance of a person's background, culture and experiences when providing their care.
- 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.

Subject 5: Communication, interaction and behaviour in dementia care

- a) Understand the importance of effective communication in dementia care.
- b) Understand the impact of memory and language difficulties on communication.
- c) Be able to demonstrate active listening skills.
- e) Understand the importance of speaking clearly, calmly and with patience.
- f) Know how to adapt the environment to minimise sensory difficulties experienced by an individual with dementia.
- 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.
- j) Be able to adapt communication techniques according to the different abilities and preferences of people with dementia.
- k) Be aware of the importance of non-verbal communication e.g. body language, visual images and the appropriate use of touch.
- 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.
- m) Understand how a person's feelings and perception may affect their behaviour.
- n) Understand how the behaviour of others might affect a person with dementia.
- o) Understand common causes of distressed behaviour by people with dementia.
- p) Be able to recognise distressed behaviour and provide a range of responses to comfort or reassure the person with dementia.

Subject 8: Living well with dementia and promoting independence

- a) Understand the importance of physical activity (including access to outside space) in maintaining a person's independence and abilities.
- b) Be able to support individuals to meet their daily living needs.
- c) Be able to support individuals to continue their interests, social life and community involvement and know why this is important.
- d) Know about community initiatives such as the development of dementia friendly environments.
- j) Be able to develop strategies to reduce the struggle with unfamiliar environments.
- k) Be aware of ways to adapt the physical environment to promote independence, privacy, orientation and safety (e.g. to reduce risk of falls).
- 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.
- m) Understand the importance of food-related activities to stimulate appetite and support engagement and independence in food preparation, eating and drinking.

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