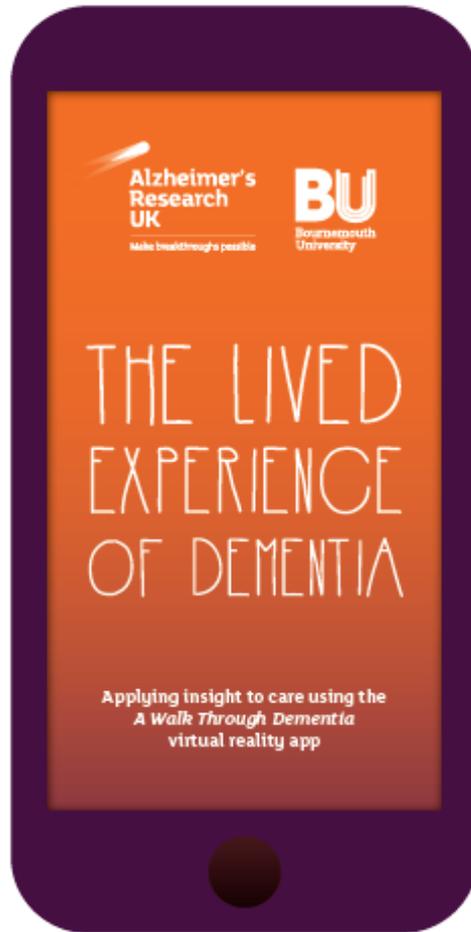


The Lived Experience of Dementia

A new resource for the health and social care workforce

The Alzheimer's Show, Olympia London
7th June

Dr Michele Board Principal Academic Nursing Older People
Professor Jane Murphy and Rebecca Mitchell
Bournemouth University
Dr Laura Phipps and Iain Fossey
Alzheimer's Research UK



The back cover of the workbook is displayed on a purple smartphone frame. The background is a gradient of orange and red. The title 'CONTENTS' is at the top in large, bold, dark letters. Below it is a table of contents listing sections and page numbers.

Introduction	01
What is dementia?	01
How was this workbook developed?	02
How to use the workbook	02
Learning outcomes	03
Section 1: Getting started	04
Introduction to a humanised approach to care	05
How to set up the app	08
Section 2: At the supermarket	09
Section 3: On the road	15
Section 4: At home	21
Test your knowledge	27
NMC revalidation	29
Certificate and evaluation	30
Appendix	
Content mapped against the Dementia Training Standards Framework 2018	31



A WALK THROUGH DEMENTIA
Alzheimer's
Research
UK

Alzheimer's
Research
UK
Alma Millane

A Walk Through Dementia



https://www.youtube.com/watch?v=R-Rcbj_qR4g



1. To deliver training session, mapped against Skills for Health Tier 2 learning outcomes, to undergraduate health care students and nursing home staff.
2. To evaluate via questionnaire participants perspective on the value of the app in understanding the lived experience of dementia.
3. To conduct focus groups with the participant after a period of time in practice to see if viewing the app influenced the care they offered to patients, and in a humanised way.





This relates to signs and symptoms of dementia, the research and evidence.



This relates to the lived experience of dementia, understanding more about what it might feel like.



This relates to how care is delivered, skills and attitudes.



Participants said they had learnt more about the symptoms of dementia.



Participants said they were able to put themselves into the shoes of a person with dementia.



Participants said the experience gave them greater empathy, understanding, patience and compassion for those with dementia.





'Having dementia is more than having difficulty with your memory. You're also unable to process information as well or sequence things. The app really helped us have a wider understanding of dementia.'



'It has influenced me and looking at the app to remind me of what it felt like emotionally and to be more empathetic and give people with dementia more time.'

'You have to put yourself in the patient's position, how they're feeling and how you respond to them.'



'I had a patient last week and he got down on the floor, there was a big black mark on the floor, a stain. And he got down on the floor. Everyone said get up, but I could see he was nervous so I stayed with him and reassured him'

'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



'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 Nursing Home

Conclusion: Did it make a difference?



head

Increased understanding of signs and symptoms dementia.



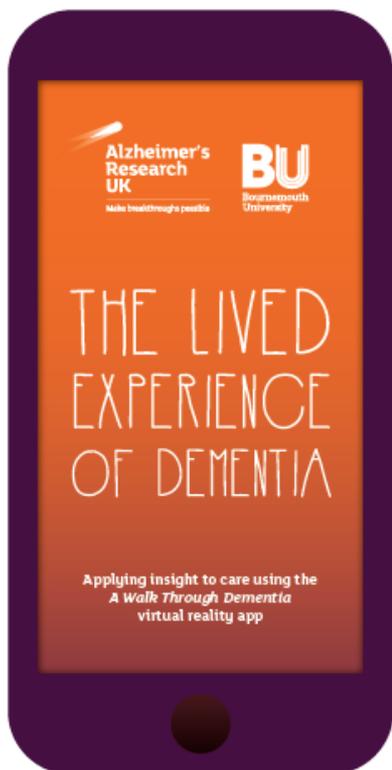
heart

Better understanding of the experience of dementia and therefore empathy.



hand

Real examples of how this learning influenced practice.



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 Knowledge Council (NMC) discussion 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 refers to patients, service users and residents.

03

SECTION 2 AT THE SUPERMARKET

Open the app, select user 'Ann' and choose item 1 at the supermarket. In this scenario Ann will go to the shop, go to the shop.

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

Complete the following questions, making notes if necessary.

a) How do you think Ann is feeling? **f) What did you notice about the supermarket environment?**

b) What is she finding difficult? **g) What did Joe comment on with regards to her shopping?**

c) How do you think that might feel? **h) How did the cashier communicate with Ann and how did it make her feel?**

d) Should people with dementia go shopping on their own?

e) What did you notice about the list? **i) How can understanding Ann's experience influence our practice when caring for people with dementia?**

Please photocopy this page and share with your team

09

Next steps

- Dissemination of the workbook
- Online training programme
- Evaluate learning on patient experience

Bournemouth University

*Dr Michele Board
Rebecca Mitchell
Prof Jane Murphy*

Alzheimer's Research UK

*Dr Laura Phipps
Iain Fossey*