“Getting to Know Me”

Supporting people with dementia in general hospitals

Manual for Trainers

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Contents

Introduction

This manual for trainers is designed to provide guidance for the delivery of the "Getting to Know Me" training programme. To deliver this training effectively, it is recommended that you have a good understanding of dementia and person-centred practice, and the confidence and skills to facilitate a training session. This manual will take you step by step through the process of delivering the "Getting to Know Me" training sessions. It is to be used alongside other materials in the training pack.

The "Getting to Know Me" training programme can be targeted at staff of all grades who have regular contact with hospital patients who may have dementia. It is anticipated that the staff that you train will have had little – or no – previous training in dementia care, and as such it provides a foundation of knowledge and skills.

Pack contents

The resources in this pack will help you to plan and deliver the "Getting to Know Me" training sessions. The pack contents are:

- Disc 1. DVD containing six PowerPoint presentations, video clips (WMV and MP4 formats), PDFs of the materials contained in the training pack, and disc instructions
- Disc 2. DVD containing video clips (to play on a computer with a DVD drive or a DVD movie player)
- Communication skills mini-guide
- "Getting to Know Me" card
- "Getting to Know Me": Manual for Trainers
- "Getting to Know Me": Booklet for Staff
- Evaluation form

The pack contents will provide most of the materials you require for the delivery of the training. Additional items are recommended for Part 5 (see page 41).

Preparation

Preparation is everything! Familiarise yourself with all the materials, the video clips, the PowerPoint presentations, and trainer notes in this guide. Where there are references to other materials, try to familiarise yourself with these also.

"Getting to Know Me" card

The "Getting to Know Me" card is a key tool which:

- Enables the person living with dementia and/or their relative to share important information with staff
- Can be kept in an accessible place near the bedside where staff can have easy access to it
- Contains information such as the person's likes/dislikes/preferred name/ hobbies and interests/place of birth
- Can provide helpful information to stimulate conversation or to help staff understand the person's unique needs and perspective

The "Getting to Know Me" card can be printed and used by your organisation. Alternatively, your organisation may use a similar leaflet which you can incorporate into this training programme (see parts 5 and 6). The Alzheimer's Society and the Royal College of Nursing (RCN) also produce a leaflet called "This is Me" which you may also choose to use. This is available for free download from **www.alzheimers.org.uk**

Video clips

Disc 1 and disc 2 each contain an identical series of interview clips with people with dementia and a relative, and an additional clip on communication. You can use whichever format is most compatible with your IT equipment (please see instructions on the discs to assist you with this). It is possible to embed the video clips into the PowerPoint presentations if you wish to do so.

Flexible delivery

The "Getting to Know Me" training programme is divided into six parts. These can be delivered together in one full day or you may wish to separate them and run the training over a number of sessions. There is a space to make notes at the end of each section in this manual.

The approximate length of the training is six hours. Timings are indicated below, but these may vary according to the particular needs of the training group. If you are able to offer more time to expand any part(s) of the training, so much the better.

Contents		**Approximate duration**
Part 1:	Dementia: an introduction	**1 hour**
Part 2:	Seeing the whole person	**1 hour 20 mins**
Part 3:	Communication	**1 hour**
Part 4:	The impact of the hospital environment	**40 mins**
Part 5:	Knowing the person	**1 hour**
Part 6:	A person-centred understanding of behaviour that challenges	**1 hour**
		Total: 6 hours

Delivering the training

The training comprises:

- PowerPoint slides which as a facilitator you will need to present
- A series of six interview clips with people with dementia and a relative, and an additional video clip
- Group exercises
- Discussion

In addition to the structure outlined in this manual, you will also need to be flexible in order to create opportunities for discussion in response to the specific needs of your training group.

If you are delivering training to a small group of people you might find it practical to sit around a laptop to watch the video clips and view the PowerPoint slides. For larger groups you will need a projector and, if possible, a flip chart/wipeboard and marker pens.

How to use this manual

Much of the guidance within this manual for trainers is divided into the following sections:

Aim

Detailing what you are aiming to achieve in each part of the training.

Input

Describing what you need to do.

Key messages

The key messages help to ensure that you convey the most important information to staff and they help to guide you when summarising ideas from exercises or discussions.

Indicates an exercise

Indicates approximate length of activity

Indicates when you need to show a video clip

Indicates sources of further information

Part 1: Dementia: an introduction

Outline

Overview of the "Getting to Know Me" programme and introduction to the session	5 mins
The experience of being in hospital	15 mins
Facts and figures	5 mins
What is dementia?	15 mins
Identifying dementia in the hospital setting	10 mins
Video clip	10 mins
Total	**1 hour**

Materials you will need

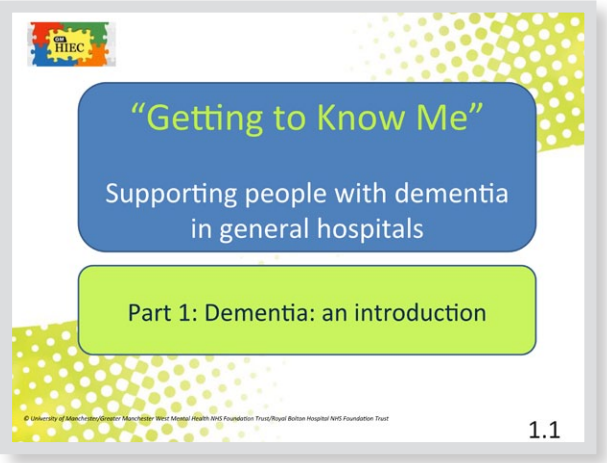
- "Getting to Know Me" Part 1 PowerPoint slides
- "Getting to Know Me" video clips
- Flip chart and marker pens (or A4 paper and pens)

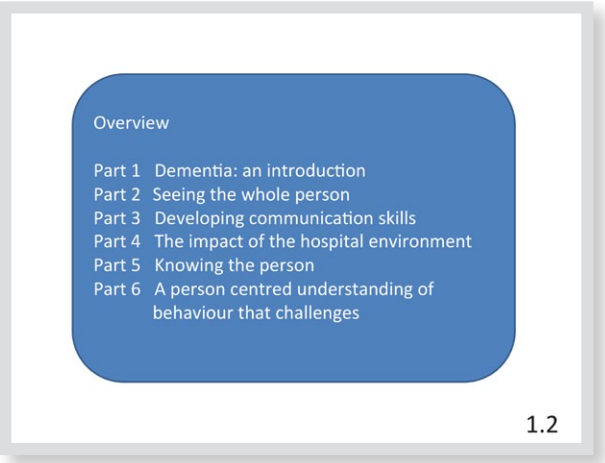
Overview of the "Getting to Know Me" programme and introduction to the session

5 mins

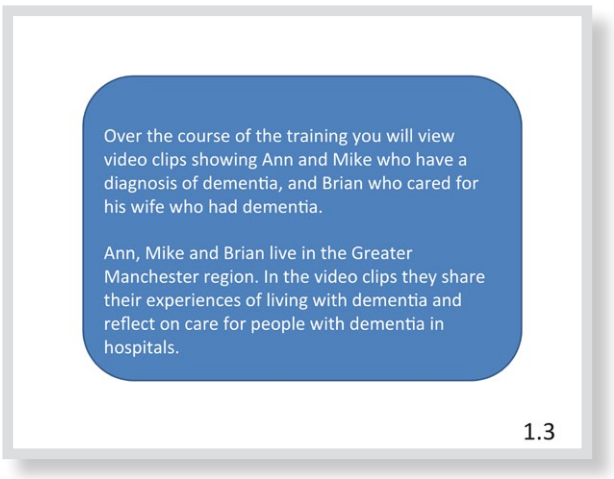
Begin the session with a general introduction to the programme and an outline of each part.

Introduce yourself and ask participants to introduce themselves, including their role and area of work.

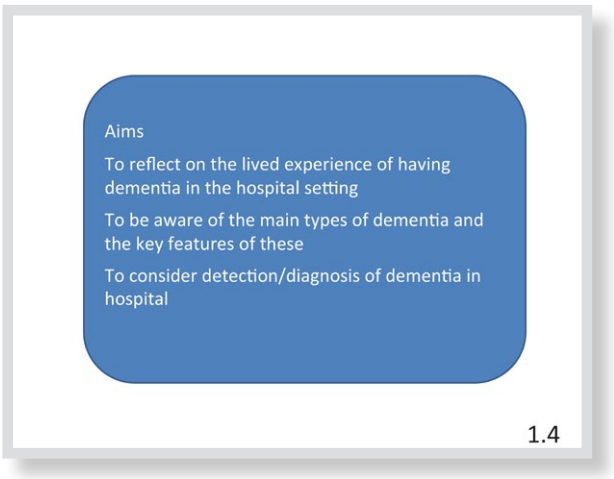




Inform the participants about the interview material you will be showing. The video clips feature Ann, Mike and Brian who are from the Greater Manchester area. Brian cared for his wife who had dementia; Ann and Mike both have a diagnosis of Alzheimer's disease. Ann, Mike and Brian talk about their experiences of dementia and their experiences of hospital care. You will be showing six short interview clips throughout the course of the training.



Share the aims of Part 1 with the participants (PowerPoint slide 1.4).



The experience of being in hospital

15 mins

Aim

To encourage participants to think about the feelings they might experience if they were in a similar situation to a person with dementia on a hospital ward.

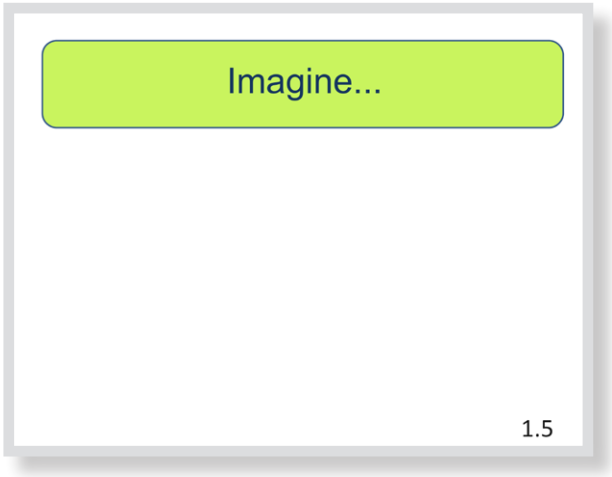
Input

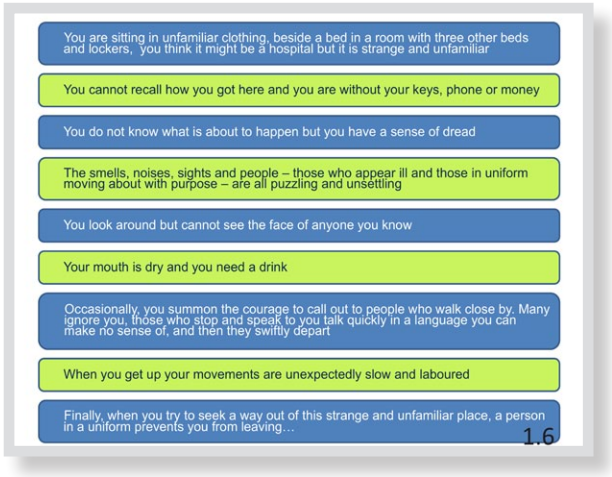
This is a slightly adapted version of an exercise devised by the Bradford Dementia Group[1]. Beginning with PowerPoint slide 1.5, ask participants to really "think" themselves into this situation and imagine they are experiencing the sensations you are about to describe. Slowly read through the scenario on slide 1.6. Follow this with a moment or two for participants to reflect. Proceed with the next slide (1.7).

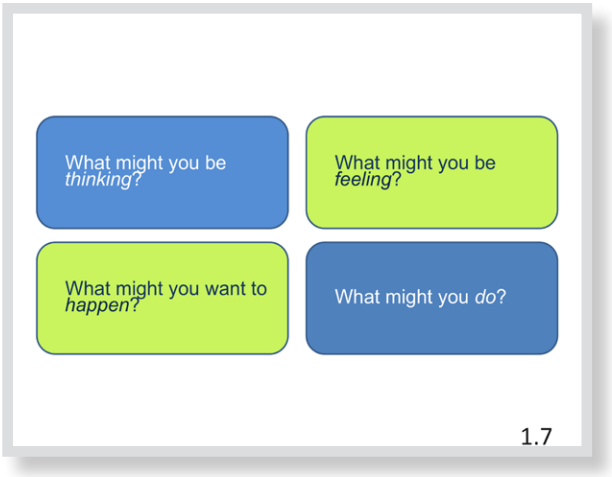
After each question facilitate feedback/discussion.

It is important for participants to consider what they would be thinking and feeling, what or who they would want in that situation, and what their actions might be.

Prompt participants to think about how a person with dementia might feel in such a situation.







1 Brooker, D., & Surr, C. (2005). *Dementia Care Mapping: Principles and Practice*. University of Bradford: Bradford Dementia Group.

Key messages

Having dementia and being in hospital is likely to give rise to powerful feelings which in turn will result in actions. These feelings and actions are entirely understandable given the gravity of the situation a person might perceive themselves to be in. For example, a person who feels lost and frightened may seek security and familiarity - a place (home?) or a familiar face (a family member?). This may lead to the person trying to leave the hospital ward with a sense of urgency in search of that source of comfort, familiarity or safety. Failure to recognise and be sensitive to these powerful needs and emotions may cause staff to act in ways that serve only to exacerbate feelings of fear and desperation. You could ask participants how they would feel if they were repeatedly escorted back to a hospital bed every time they attempted to get home to see their children, family or friends.

Facts and figures

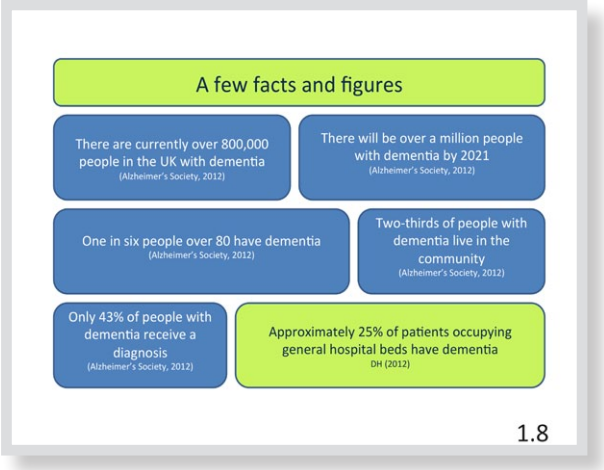
5 mins

Aim

To provide some key facts on the prevalence of dementia in the UK.

Input

Use slide 1.8 to illustrate the prevalence of dementia in general hospitals and also in the wider population.



What is dementia?

15 mins

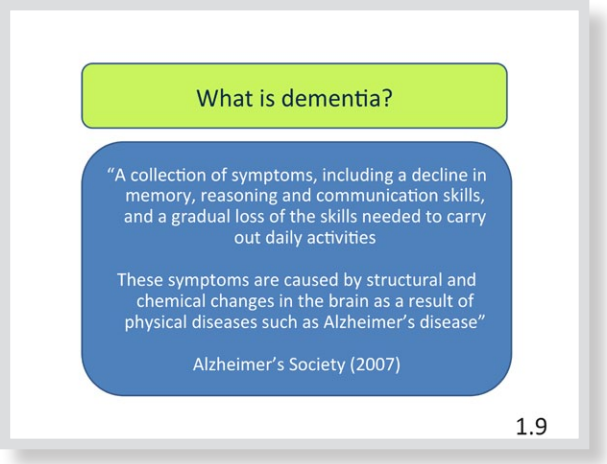
Aim

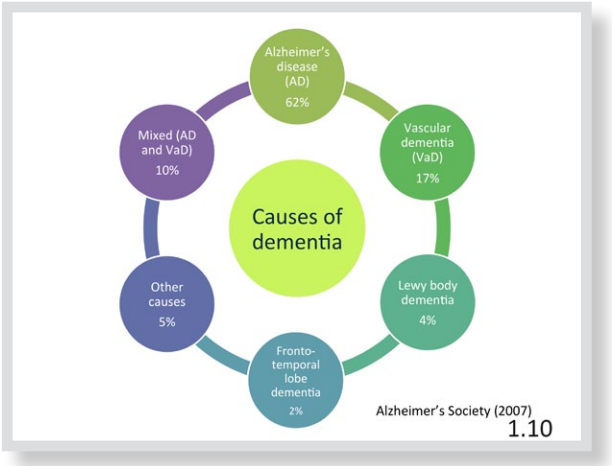
To give a definition of dementia and provide an overview of the main causes.

Input

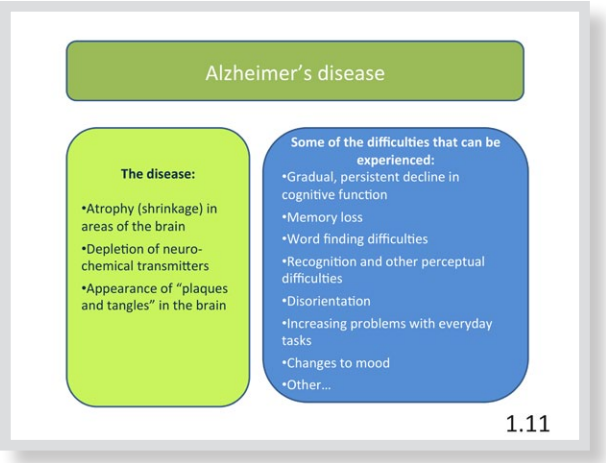
Ask participants how they would define what dementia is, and then show the definition on slide 1.9.

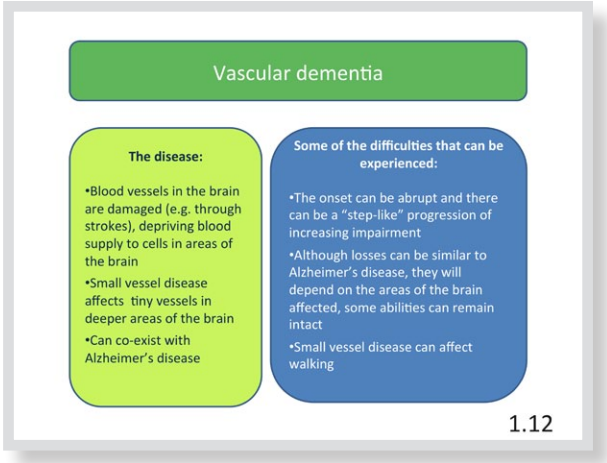
Clarify that the causes of dementia are physical and that they result in damage to areas of the brain. This damage is usually progressive and causes a range of cognitive impairments. Although there are many causes of dementia, the most common conditions are illustrated on slide 1.10.

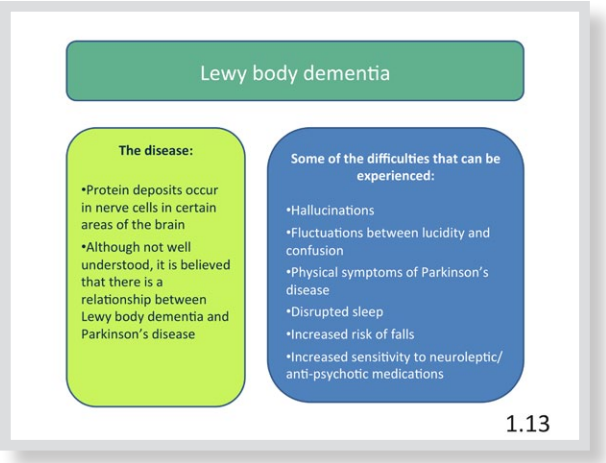


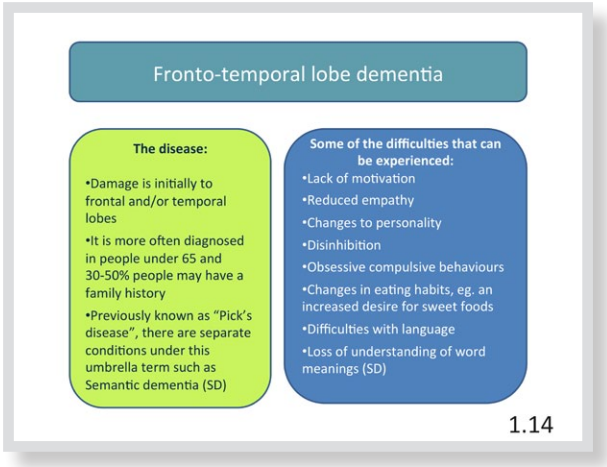


Slides 1.11 to 1.14 run through some of the key features of the four main causes of dementia.









Further Information

The Alzheimer's Society produces a range of helpful fact sheets. These can be downloaded from **www.alzheimers.org.uk**

Key messages

There are many causes of dementia.

Dementia can result in a variety of difficulties, and each person will be affected uniquely.

Identifying dementia in the hospital setting

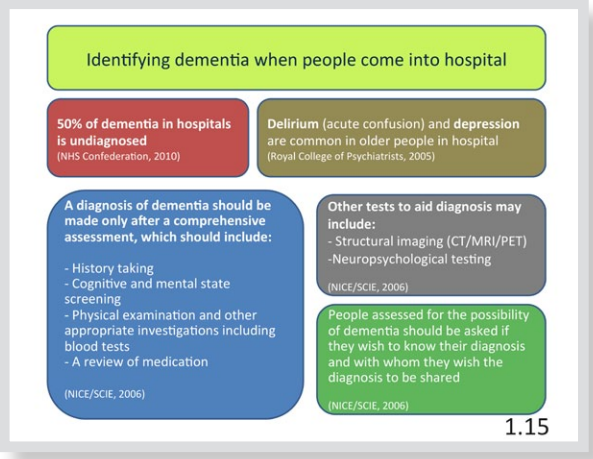
10 mins

Aim

To highlight issues concerning diagnosis, delirium and depression.

Input

Show slide 1.15 and talk through the issues that arise.



Key messages

Dementia is often poorly detected in general hospitals, so be aware of your organisation's guidelines regarding cognitive screening. If there are concerns about a person's cognitive abilties, an accurate diagnosis should be considered. A detailed history should be obtained, and other causes of confusion such as delirium or depression excluded.

Relatives and friends will frequently possess key information about the changes they may have observed in the person over a period of time.

The National Institute for Health and Care Excellence/Social Care Institute for Excellence (NICE/SCIE) Dementia guidelines on diagnosis are given on slide 1.15. People who are assessed for the possibility of dementia should be asked if they would wish to know their diagnosis and with whom they would wish this information to be shared.

Video clip

10 mins

Aim

To conclude with the *Introductions* video clip in which Ann, Mike and Brian introduce themselves.

Input

Introduce the clip: Ann and Mike both have a diagnosis of Alzheimer's disease and will be talking about their experiences, and Brian will be talking about his wife who had dementia.

After the clip, ask for reflections. Ask if people are surprised that Ann and Mike can talk so freely and eloquently about their dementia. If they are surprised, gently probe as to why this might be.

Remind participants that they will be seeing further clips of Ann, Mike and Brian throughout the "Getting to Know Me" training programme.

End the session with slide 1.16 by asking participants if they have any questions.

If Part 2 is going to take place on another day, ask participants to do the following prior to the next session: ask them to think back to the earlier exercise and place themselves in the shoes of a person with dementia in the setting in which they work. Ask them to reflect on what may make a person with dementia feel more or less anxious/confused whilst in hospital.

Further Information

The RCN has produced materials relating to the care of people with dementia in hospital settings including five videos and written material. You may wish to incorporate the videos into this training programme.

The RCN describe five principles to inform a shared commitment to improving care:

SPACE – supporting good dementia care

Staff who are skilled and have time to care
Partnership working with carers
Assessment and early identification
Care that is individualised
Environments that are dementia friendly

Royal College of Nursing (2013). *Dementia: Commitment to the care of people with dementia in hospital settings*. London: Royal College of Nursing.

www.rcn.org.uk/dementia

Notes

Part 2: Seeing the whole person

Outline

Introduction and video clip	10 mins
The holistic model of dementia	
Cognitive impairment	15 mins
Health	10 mins
Hospital environment	5 mins
Biography/life story	10 mins
Personality	5 mins
Social environment	15 mins
Concluding exercise	10 mins
Total	**1 hour 20 mins**

This is an important section of the training with a lot of content. If you have the capacity, you may wish to extend the length of this part to allow more time to cover the themes and exercises.

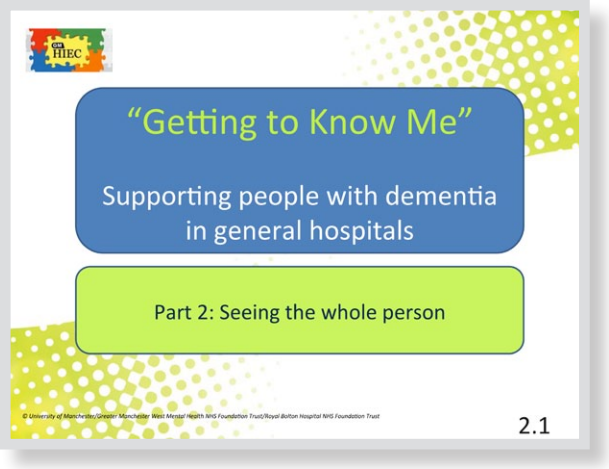
Materials you will need

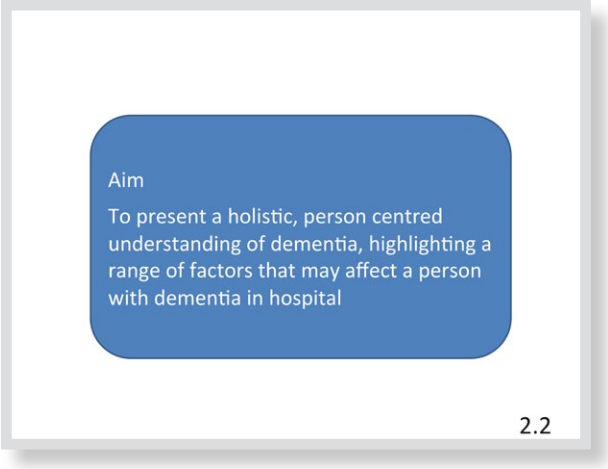
- "Getting to Know Me" Part 2 PowerPoint slides
- "Getting to Know Me" video clips
- Flip chart and marker pens (or A4 paper and pens)

Introduction and video clip

10 mins

Explain that this session is about understanding how the experience of living with dementia is influenced by many factors (not just damage to parts of the brain). A better understanding of what influences well-being in people with dementia in hospital should help us adapt and improve the care we provide in clinical settings.





Input

Show the *What is it like to have dementia?* video clip which features Ann talking about what it is like to have dementia.

Ask participants to reflect on Ann's description. Bring the discussion back to the emotional impact of being in hospital, as discussed in the first session.

Some people might say that they would not know Ann has dementia. This is a good point for discussion:

- Can we always easily identify who may have dementia?
- Might a person with dementia become much more confused and disorientated in hospital than they would have been at home - if so why?

The holistic model of dementia

Aim

To explore six factors that can impact on the experience of a person with dementia in a general hospital.

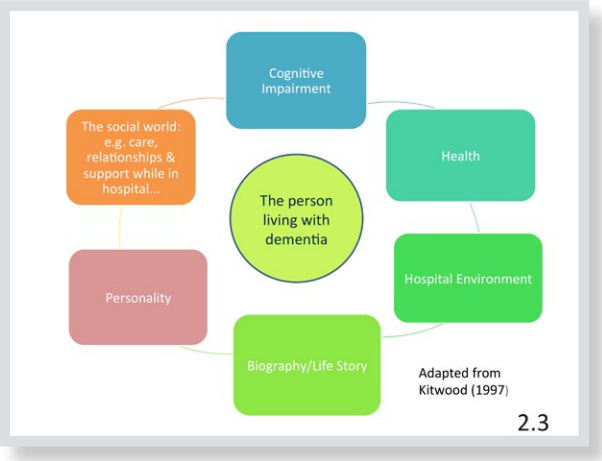
Input

Explain that in the 1990s the late Professor Tom Kitwood (1937 – 1998) challenged prevailing assumptions about dementia. His core "person-centred" message was that in supporting a person with dementia we must concern ourselves first and foremost with the *person* and not the dementia. Kitwood challenged the view that there was very little others could do to improve the well-being of people living with dementia.

The model depicted on slide 2.3 is adapted from work by Kitwood, and more recently May, Edwards and Brooker (2009).[2] The model can help us to see the range of influences that can impact on well-being.

Explain that you will briefly discuss how each of the six areas play an important part in influencing how dementia is experienced.

2 May, H., Edwards, P., & Brooker, D. (2009). *Enhanced care planning for people with dementia: A good practice guide*. London: Jessica Kingsley.



1. Cognitive impairment

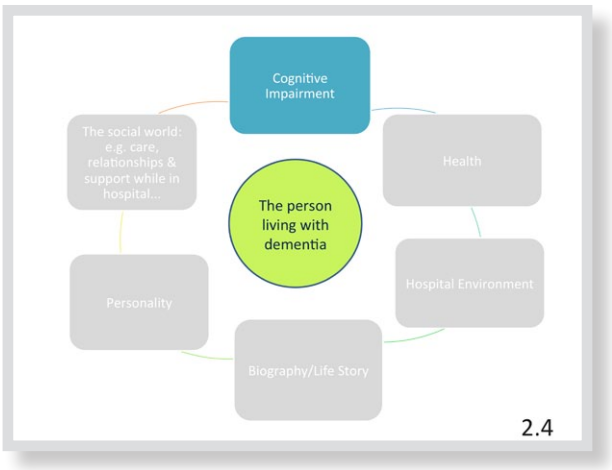
15 mins

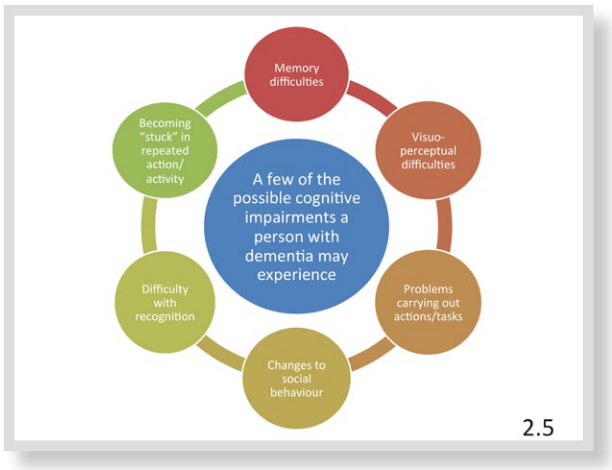
Aim

To outline how damage to areas of the brain can result in specific impairments to cognitive abilities such as memory, and how this can help us to understand some of the difficulties people may experience when they are in hospital.

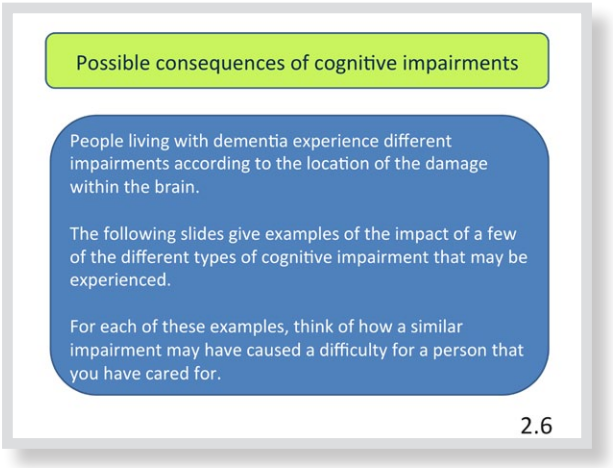
Input

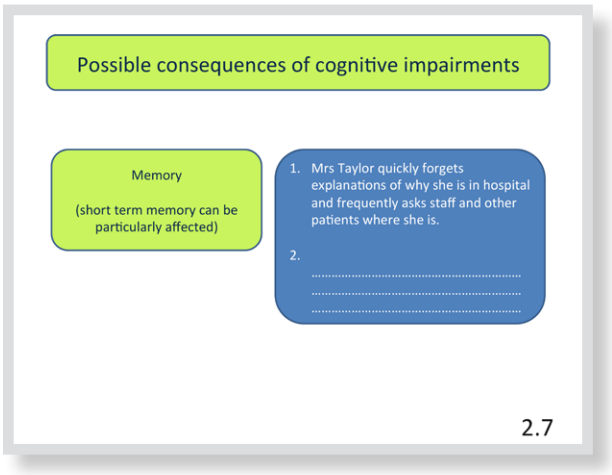
Begin by showing slides 2.4 and 2.5. Inform participants that the location of damage within the brain may give rise to specific areas of difficulty for the person with dementia.

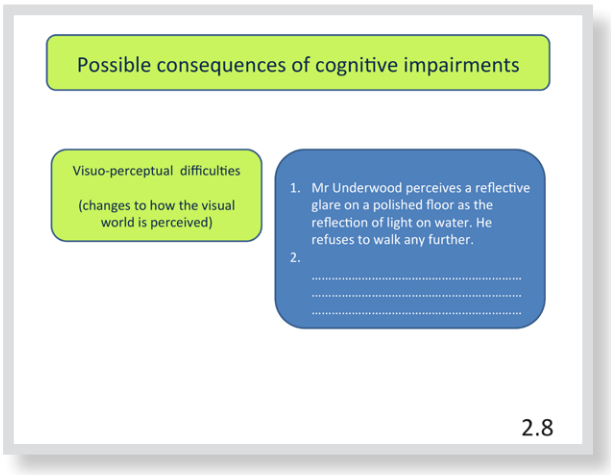


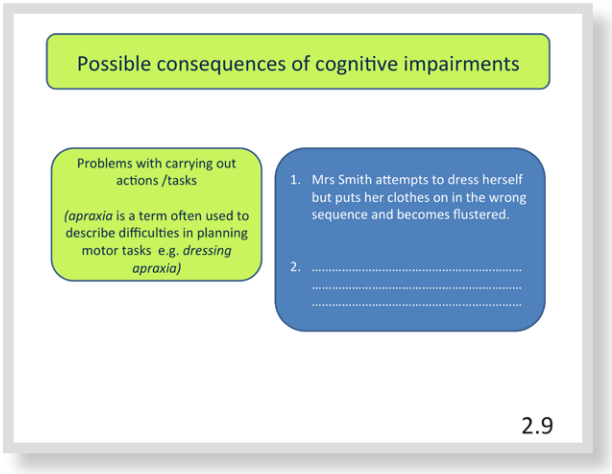


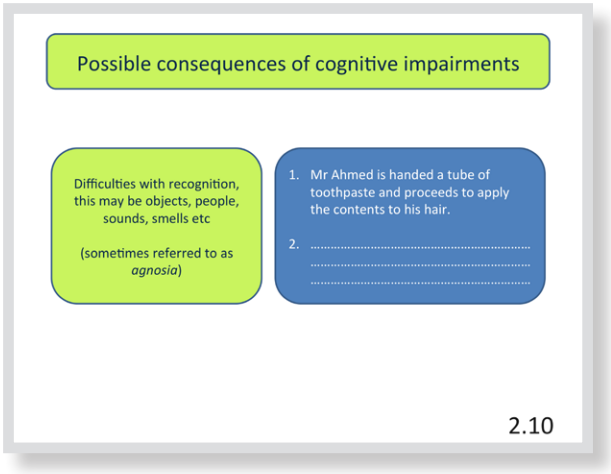
Using slide 2.6, explain that you will give examples of situations that may be encountered within a hospital setting, and ask participants to think about how cognitive damage may influence the experience of people with dementia in these situations. You will also be asking participants to think of examples from their own practice which similarly illustrate the impact of cognitive impairment. Work through slides 2.7-2.12.

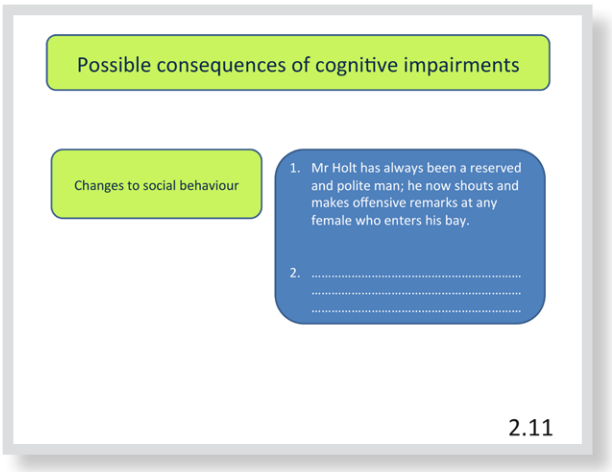


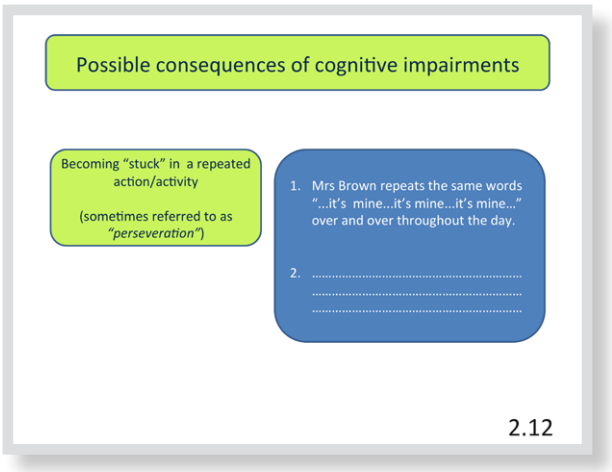












Key messages

People are likely to have a variety of strengths as well as difficulties. These can reflect which areas of the brain are working well and those that are affected by cognitive decline. Damage to similar areas of the brain will not affect everyone in the same way, therefore it is important to be flexible and creative when trying to understand a person's behaviour. Cognitive impairment is only one of many factors that will influence a person and their well-being whilst in hospital.

Further Information

You may find it helpful to refer to the Alzheimer's Society fact sheet 456: The Brain and Behaviour.

www.alzheimers.org.uk

2. Health

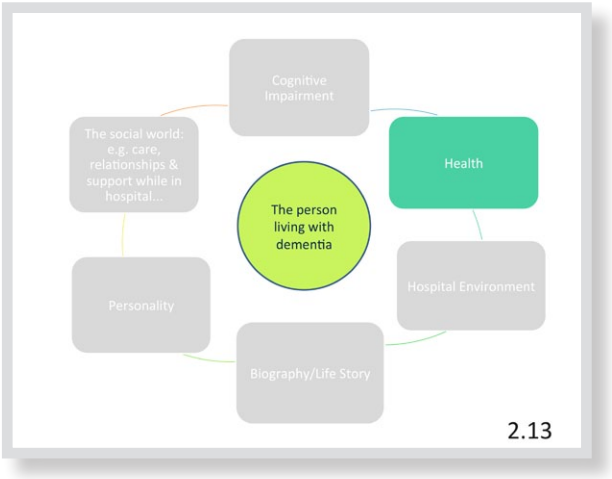
10 mins

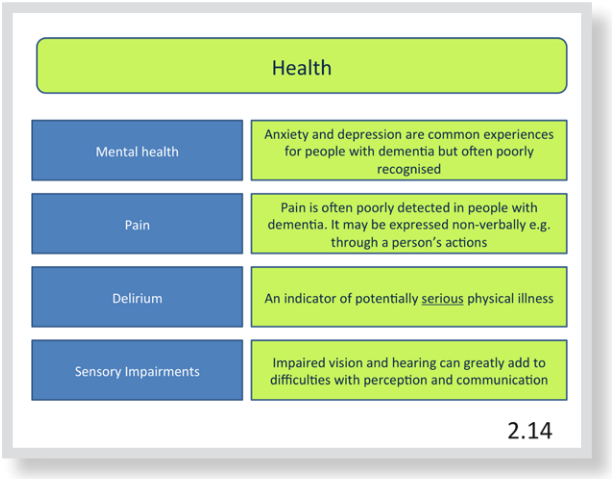
Aim

To give an overview of the impact of physical and mental health on a person's well-being.

Input

Show slides 2.13 and 2.14.





Explain that depression and anxiety are common experiences for people with dementia but they frequently go unrecognised. Depression can exacerbate a person's cognitive impairment, or sometimes a cognitive difficulty may be a result of depression and not dementia. It is important for low mood to be recognised and treated, so that an accurate understanding of a person's needs can be gained.

Discuss that pain is poorly detected in people with dementia. We need to be very aware that people with reduced communication skills may be experiencing pain which may manifest itself in many ways such as agitated or withdrawn behaviour.

Discuss that delirium (acute confusion) is a potentially serious condition. It can be caused by a physical illness, for example, a urine infection. Cognitive function, consciousness, and perception may be affected. A person's presentation may have a rapid onset and may fluctuate. It is important to recognise that the person may be hypo-active as well as hyper-active. Delirium can be difficult to diagnose, particularly in people with dementia. A prompt diagnosis and treatment are very important.

Finally, remind people that impaired sight and hearing can also be detrimental to a person's functioning. They can exacerbate difficulties already experienced by people with dementia. Working/well fitted hearing aids and glasses are essential.

Further Information

Delirium

For further information and guidance on Delirium please consult the NICE Guideline CG103: Delirium available at: **http://guidance.nice.org.uk/CG103/NICEGuidance/**

3. Hospital environment

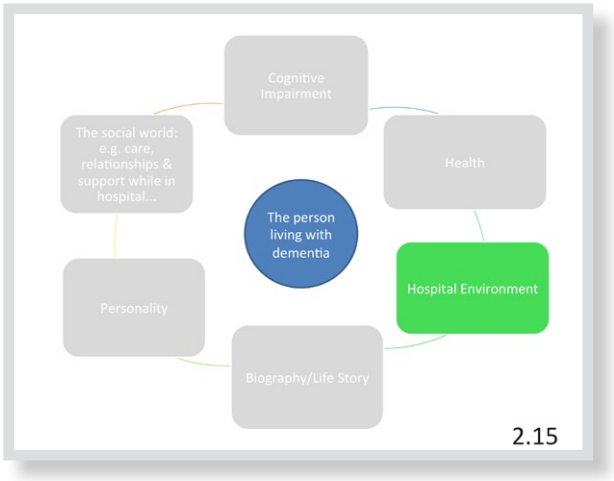
5 mins

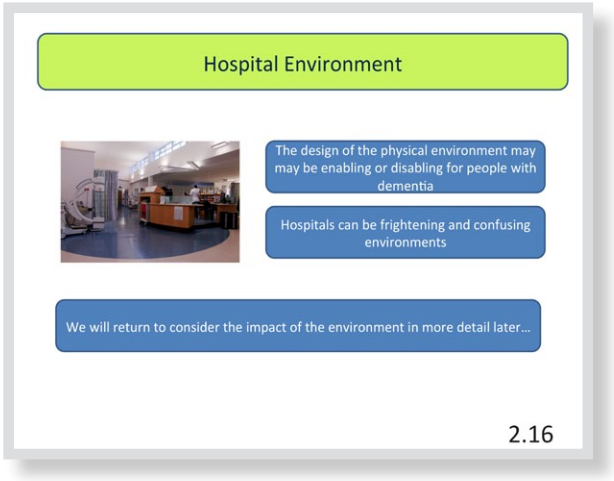
Aim

To inform participants that the physical environment of the hospital may have a significant impact on a person with dementia.

Input

Show slides 2.15 and 2.16 and briefly discuss the points on the slides. Inform participants that you will be focusing more on this topic in Part 4 of the training. If there is going to be a gap between this session and the session where you will be delivering Part 4, you may want to suggest that participants take time in-between to think about how the physical environment in which they work may positively or negatively impact on the experience of people with dementia.





4. Biography/life story

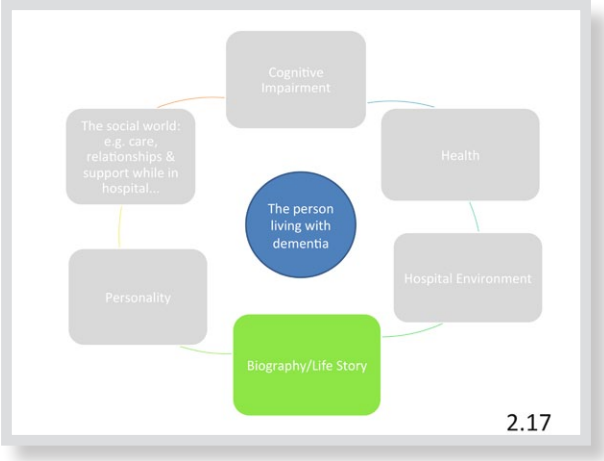
10 mins

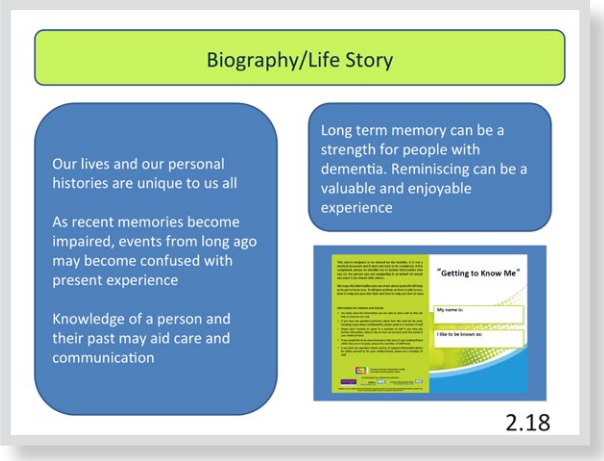
Aim

To outline that knowledge of a person with dementia can: i) help us to understand the person's specific needs; and ii) help staff to build a therapeutic and supportive relationship with the person during their stay in hospital.

Input

Show slides 2.17 and 2.18.





Discuss the reasons why people's life experiences can play an important part in how they experience life in the "here and now" on a hospital ward.

Ask participants to share examples of when understanding more about a person's life history has helped make sense of current behaviour. You may want to use an example from your own practice of how a person's behaviour was "labelled" as a symptom of dementia, but how deeper knowledge of the person and their past revealed a meaning behind the actions observed.

Discussing the past and long term memories can be a strength for people with dementia. This can create opportunities for mutually rewarding interactions, and can help to support a person's identity and sense of self. There will be a chance to focus more on reminiscence in Part 5 of the training.

At this point you may wish to introduce the importance of the "Getting to Know Me" card in facilitating the sharing of important biographical information (please note that, if applicable, you may wish to replace the graphic of the "Getting to Know Me" card on slide 2.18 with an image of the tool that you will be using within your own organisation). Participants will be exploring the use of the card in Parts 5 and 6.

5. Personality

5 mins

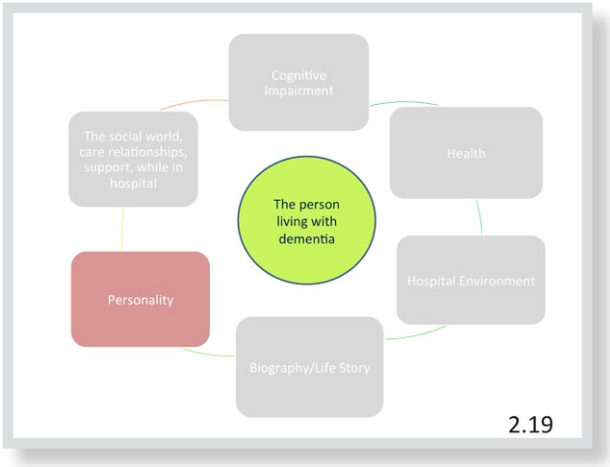
Aim

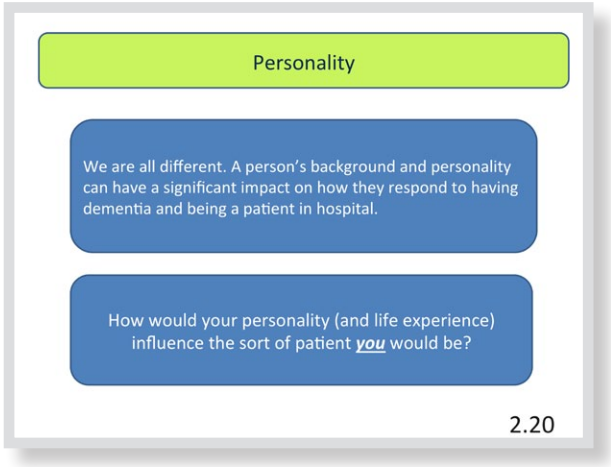
To discuss the impact of a person's personality on their experience in hospital.

Input

Using slides 2.19 and 2.20 ask participants how they feel our own personalities may affect experiences as a hospital patient. If answers are not forthcoming, enquire whether people think they would make a "good patient". Many will say no, and offer a variety of reasons, such as the need for privacy, dislike of hospital food, being the sort of person who likes to be in control, and dislike of sitting around for long periods.

People with dementia are no different to anyone else, but likes/dislikes and specific needs may be more difficult to convey.



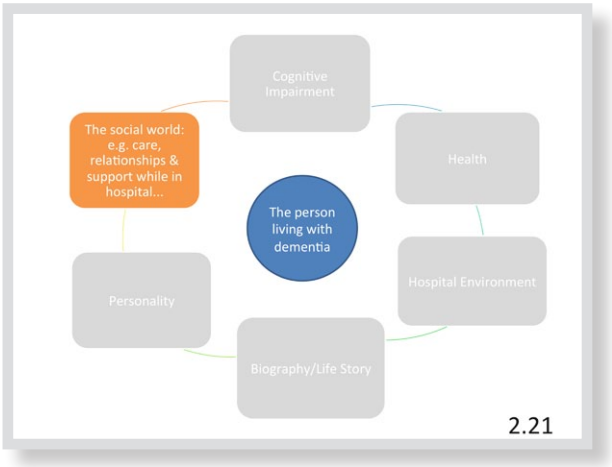


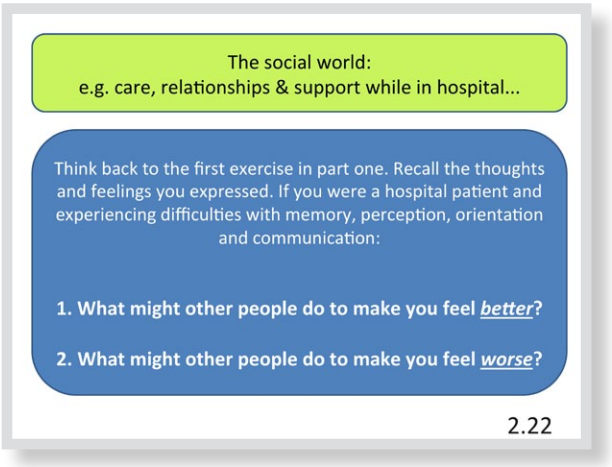
6. Social environment

15 mins

Aim

To highlight how relationships and the quality of care provided to a person with dementia can make a significant difference to a person's well-being.





Input

Using slide 2.22, ask participants to recall the thoughts and feelings that they expressed in the exercise in Part 1 of the training when they imagined themselves on a hospital ward experiencing cognitive and sensory impairments. Encourage people to think about what care and support would be important for them if they were a person with dementia on a hospital ward. Pose the questions on slide 2.22, and give time for participants to discuss their responses (if the group is large enough, this task can be done in small groups and fed back using a flipchart). Examples of the kinds of responses that the group may give are illustrated below.

What would make me feel better (emotionally)?

- *Having close family members present*
- *Being reminded of where I am*
- *To be told I may be going home soon*
- *To be able to walk about and get out of the ward*
- *Not have people crowding around my bedside talking about me and not to me*
- *Being able to pass the time doing something interesting*
- *Getting some fresh air*
- *Being free from pain*

What would make me feel worse ?

- Not being listened to
- Not being able to see family and friends
- People talking too quickly
- People not explaining what is going on
- Nothing to pass the time of day
- Not being able to sleep due to noise
- Other patients being noisy/disruptive
- Not having any privacy
- Being constantly brought back to my bed every time I try to leave the ward
- Pain

Concluding exercise

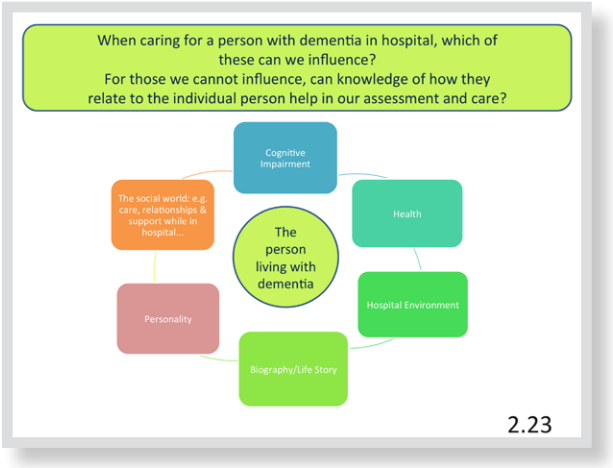
10 mins

Aim

To reinforce that the holistic model illustrates that there are many different factors that can influence the well-being of people with dementia in hospital, including the ways in which we provide care and support.

Input

Use the two questions on slide 2.23 to prompt a discussion about the ways in which we can make a positive difference. Even when we cannot directly make change (for example, we cannot change a person's level of cognitive impairment/their personality/their life experiences), knowledge and understanding of these areas can help to provide more informed and person-centred care.



To end the session, show slide 2.24 which presents Tom Kitwood's core concept of seeing the *person* rather than the dementia, and ask participants if they have any questions.

Notes

Part 3 Communication

Outline

Introduction to communication	5 mins
Non-verbal communication	15 mins
Verbal communication	10 mins
Responding to different realities	20 mins
Video clip and conclusion	10 mins
Total	**1 hour**

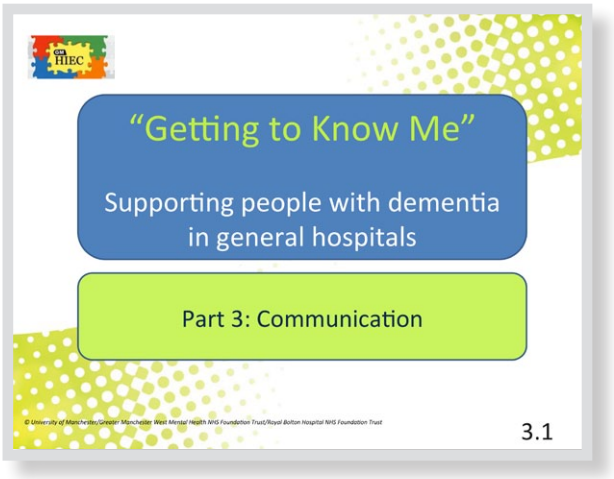
Materials you will need

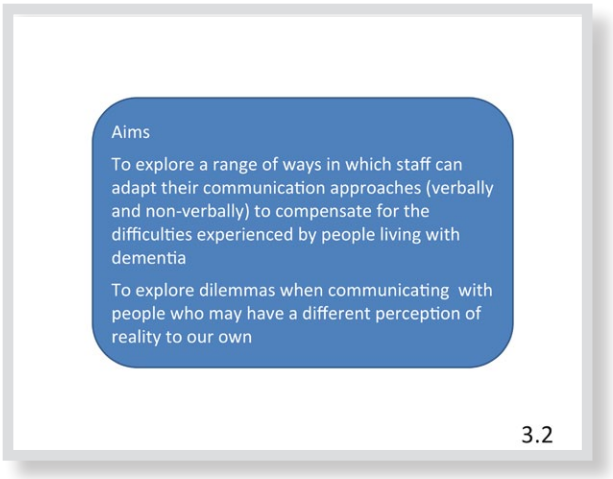
- "Getting to Know Me" Part 3 PowerPoint slides
- "Getting to Know Me" video clips
- Flip chart and marker pens (or A4 paper and pens)
- Copies of the communication skills mini-guide (if this is being used by your organisation)

Introduction to communication

5 mins

Explain the aims of this session as indicated on slide 3.2.





Non-verbal communication

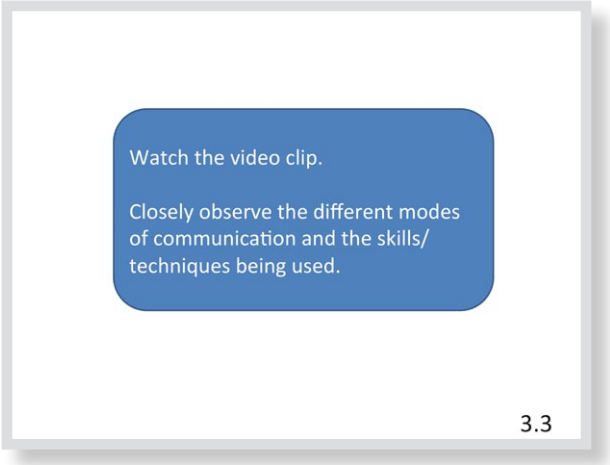
15 mins

Aim

To consider the importance of non-verbal communication and to focus on specific skills.

Input

Show slide 3.3 and encourage people to focus on the detail of the interaction that occurs between the two people in the video clip that you are about to show.



Show the RCN video clip (note, this is not a clip featuring Ann, Mike or Brian) and ask the group to identify the key aspects of communication that were revealed.

The following can all be identified in the clip. Discuss the value of each.

Communication Skills (non-verbal)

- Eye contact
- Reducing background stimuli
- Mirroring (words/actions)
- Active listening
- The value of not speaking!
- Physical touch
- Tone of voice
- Enabling the person to retain control of the exchange

Key messages

Over time, verbal communication can become more difficult for people with dementia.

Non-verbal communication is frequently an area of strength for people with moderate and more advanced dementia.

We need to pay great attention to our own non-verbal communication and that of the person with dementia.

Verbal communication

10 mins

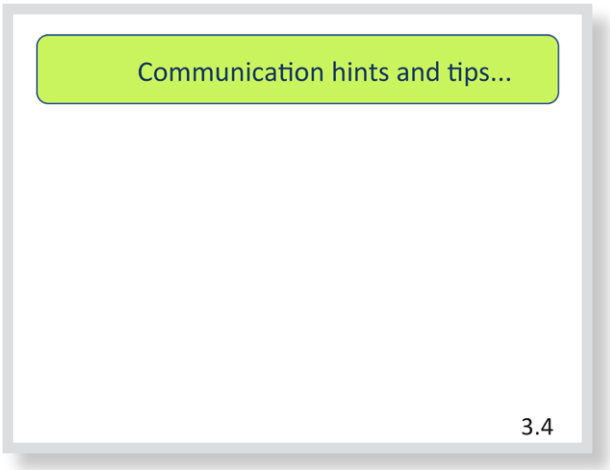
Aim

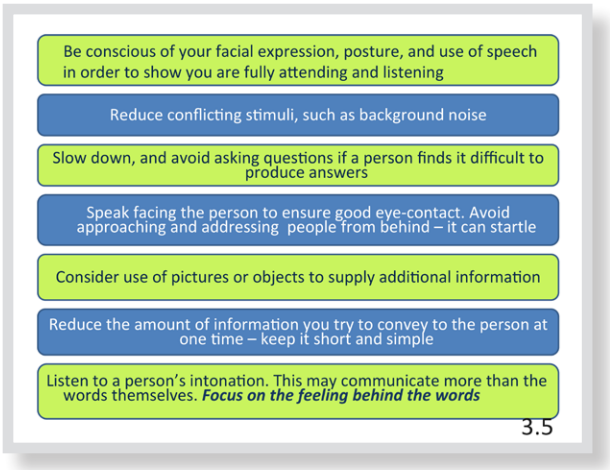
To briefly highlight a number of key principles in verbal communication, and to introduce participants to the communication skills mini-guide (if your organisation is choosing to use this).

Input

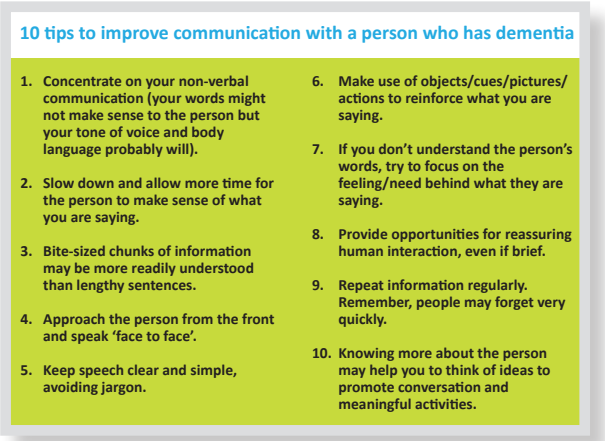
Run through the list of communication skills on slide 3.5 and discuss each in turn.

Clarify the understanding of the group and discuss issues that arise. Ask people how skilled they feel in these aspects of communication with people with dementia.





If applicable, introduce participants to the communication skills mini-guide (below). The card is designed to be carried in a pocket and lists ten tips to improve communication.



Responding to different realities

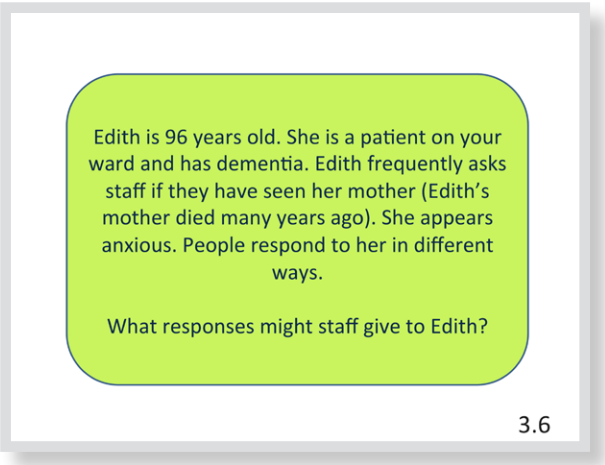
20 mins

Aim

To reflect on the issues that arise when a person with dementia has a different perception of reality to your own.

Input

This exercise raises issues regarding the use of deception in practice and highlights the importance of understanding the ways in which needs can underpin behaviour.



Show slide 3.6 and ask participants to consider the potential responses that Edith may be given. Write these on a flip chart.

Responses may include:

- Your mother has passed away
- How old are you...and how old would that make your mum?
- Would you like a cup of tea instead?
- I don't know where she is...
- What would you like to ask her?
- Is there anything I can do to help ?
- Everything is fine, your mum has just popped out and will be here later...
- I spoke to your mum earlier - she's fine

The group should identify a range of responses, including the "truth" (that Edith's mother has passed away) and "deception" (that mum will be along later).

There may be other responses such as: "What is bothering you Edith?", "What would you like to ask your mum?", or "Is there anything I can do for you?"

Discuss the arguments for and against the use of each of these approaches, highlighting the emotional impact they can have on the person. Can there be problems with "the truth" and can there be problems with "deception"?

Ask the group to think about what needs may be behind the words Edith is expressing. How effective would the responses on the flipchart be in the following scenarios?

- If Edith was in pain?
- If Edith was anxious and needing the comfort of her mother?
- If Edith needed to use the toilet?

Further Information

Elvish, R., James, I., & Milne, D. (2010). Lying in dementia care: An example of a culture that deceives in people's best interests. *Ageing and Mental Health, 14*(3), 255-262.

James, I. A., Wood-Mitchell, A. J., Waterworth, A. M., Mackenzie, L. E., & Cuningham, J. (2006). Lying to people with dementia: developing ethical guidelines for care settings. *International Journal of Geriatric Psychiatry, 21*, 800-801.

Walker, B. (2007). Communication: building up a toolkit of helpful responses. *Journal of Dementia Care, January/February,* 28-31.

Key Messages

This is a challenging area where there are no clear "rights" or "wrongs". Be aware that your response to a person's subjective reality may have a significant emotional impact. The needs and feelings underpinning a particular behaviour expressed by an individual may be different at various points in time. Standard responses may not be helpful, and it is important to think carefully about what might be behind a person's actions or words.

Video clip and conclusion

10 mins

Aim

To consider communication issues arising from the short video clip.

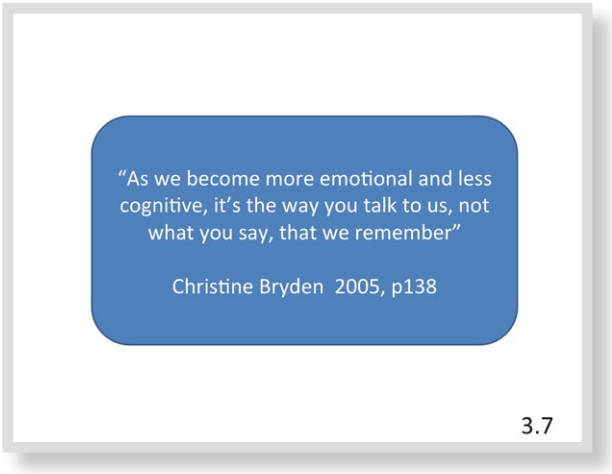
Input

Play the *Communication* video clip. Ann and Mike discuss what helps and hinders communication.

Briefly discuss the main points that arise from this.

Final reflections

Show slide 3.7. Explain that Christine Bryden is an Australian woman who has written two books on her experiences of living with Alzheimer's disease. Ask participants what they think Christine might be meaning here, and end the session with any questions (slide 3.8).



Notes

Part 4 The impact of the hospital environment

Outline

Introduction and video clip	10 mins
The impact of the environment	15 mins
Principles of enabling design	10 mins
Conclusion	5 mins
Total	**40 mins**

Materials you will need

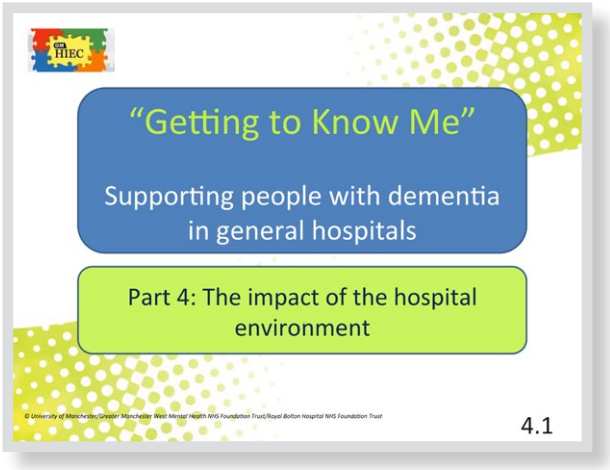
- "Getting to Know Me" Part 4 PowerPoint slides
- "Getting to Know Me" video clip
- Flip chart and marker pens (or A4 paper and pens)

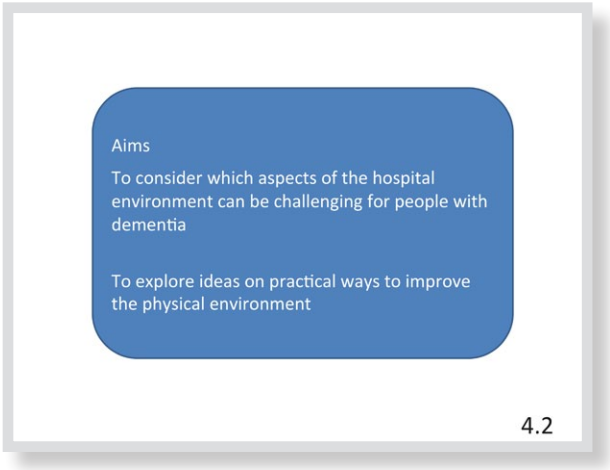
Introduction and video clip

10 mins

Show slides 4.1 and 4.2. Explain that this session will focus on the impact of the hospital environment and raise awareness of the disabling impact that this can have on people with dementia. It will also highlight the principles of enabling design that can help to promote well-being and independence for people with cognitive difficulties.

Some aspects of design will be difficult and expensive to alter, other things may be much more achievable.





Input

Play the *What is it like to be in hospital?* video clip and discuss.
Highlight the issues which Ann raises that specifically relate to the ward environment.

The impact of the environment

15 mins

Aim

To think about how and why specific features of the hospital environment might cause difficulties for people with dementia.

Input

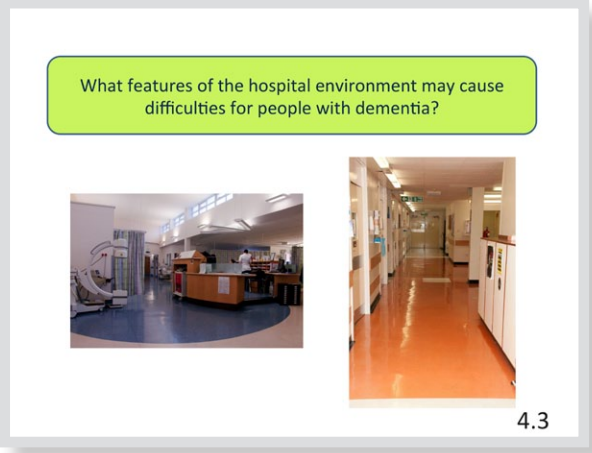
Ask participants to think back to the exercise in Part 1 of the training when they imagined themselves on a hospital ward experiencing cognitive and sensory impairments (guide them to use the additional knowledge that they have gained on how these impairments may affect a person).

Ask the following:

- What sense would you make of what you can see and hear from your immediate surroundings?
- How easy would it be for you to find: your bed; the toilet; a quiet space; something interesting to occupy you?
- How might the environment affect how you are feeling?

Encourage people to share and discuss their responses, and then ask people to identify and list particular features of the environment that might be problematic for people with dementia.

The images on slide 4.3 might help participants to think about some of the issues.



If people are finding it difficult to come up with responses, give some additional hints, and draw up a list with the group that may look something like this:

Problems with the environment:

- *Reflective flooring, giving the appearance of water*
- *Lack of privacy in ward bay areas*
- *All bays and corridors look similar with few distinguishing features*
- *Doors all look the same*
- *Confusing notices cover the walls*
- *Bathrooms are "cold" and clinical*
- *Noise levels are high*
- *Too much light at night*
- *No picture signage for toilets*
- *No day room for activities/quiet time*
- *Nowhere to "get away from it all"*
- *Lots of staff congregating at nursing station in view of one of the bays*
- *No access to a garden for fresh air and relaxation*

Key message

Our surroundings have a big impact on us. We “read” the environment for meaning; this will particularly be the case if we cannot draw on memory to make sense of where we are or how we came to be here. This will affect our thoughts, expectations and behaviour.

Principles of enabling design

10 mins

Aim

To consider aspects of "enabling" design.

Input

Slides 4.4 to 4.7 depict some key features of enabling design for people with dementia. Using these slides, explore the ways in which the environment can be adapted to better meet the needs of people with dementia.

Inevitably, some changes are easier to achieve than others. This is also a good point for debate.

Creating an "accessible" hospital environment for people living with dementia 1

Way-finding – what works?

- Signage that is clear/at an appropriate level, and uses pictures as well as words
- Objects/pictures/themes on walls that distinguish and identify areas
- Handrails with strong colour contrast to walls
- Walls and floors clearly distinguished by colour contrast

Noise – what works?

- Reduction in noise where possible, particularly at night
- Opportunity for patients to access quieter areas

4.4

Creating an "accessible" hospital environment for people living with dementia 2

Lighting – what works?

- Bright but avoiding glare
- Natural light where possible

Familiarity –what works?

- Avoid unnecessary moves within or between wards
- Familiar items from home for the bedside area
- Distinguishing features to help patients identify their own bed areas and bays
- Pictures of interest in communal areas

4.5

Creating an "accessible" hospital environment for people living with dementia 3

Flooring – what works?

- Flooring that does not reflect glare, and is of uniform colour e.g. avoiding patterns or abrupt changes in contrast

Occupation/relaxation – what works?

- Social areas that are homely, restful, and interesting
- Access to outdoor spaces and other facilities in the hospital e.g. shops/cafes
- Things of interest to look at e.g. pictures/murals/views from windows
- Books and interesting items

4.6

Creating an "accessible" hospital environment for people living with dementia 4

Mealtimes – what works?

- A calm and quiet environment
- The opportunity to eat with others if this is preferred (and possible)
- Contrasting colours for plates and cups against table surfaces

Toilets and bathrooms – what works?

- Warm, light and offering privacy
- Clearly signed
- As "non-clinical" as possible

Adapted from Dementia Service Development Centre (2009)

4.7

The images that are depicted on slides 4.8 to 4.11 are taken from The King's Fund Enhancing the Healing Environment project (see Further Information box). Use the slides to stimulate further discussion on enabling design.

The King's Fund Enhancing the Healing Environment Photo Library

4.8

The King's Fund Enhancing the Healing Environment Photo Library

4.9

The King's Fund Enhancing the Healing Environment Photo Library

4.10

The King's Fund Enhancing the Healing Environment Photo Library

4.11

Further Information

Visit The King's Fund Enhancing the Healing Environment (EHE) webpages for information on creating supporting hospital design for people with dementia:

http://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-in-dementia-care

Resources include:

- The EHE Assesment Tool "Is your ward dementia friendly?"
- Developing supportive design for people with dementia: design principles

You may wish to incorporate in this session the video "Environments that are Dementia Friendly" from the RCN's dementia project resources: ***www.rcn.org.uk/dementia***

Conclusion

5 mins

Show slide 4.12. End the session with participant reflections about the changes that can be made to make the environments in which we work more enabling for people with dementia.

4.12

Notes

Part 5 Knowing the person

Outline

Introduction and video clip	10 mins
Getting to know the person in your care	15 mins
Meaningful activity/occupation	10 mins
Being creative	15 mins
Involving and supporting families and friends	10 mins
Total	**1 hour**

Materials you will need

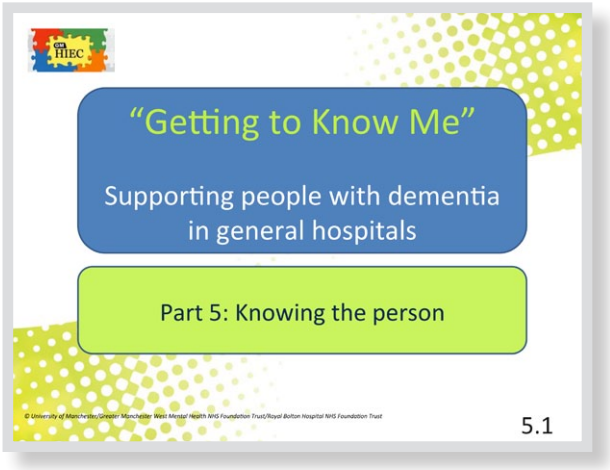
- "Getting to Know Me" Part 5 PowerPoint slides
- "Getting to Know Me" video clip
- Flip chart and marker pens (or A4 paper and pens)
- Copies of the "Getting to Know Me" card* (complete beforehand with information for the fictitious Mrs Atherton - see slide 5.4 and 5.5)
- A selection of interesting pictures, memorabilia, objects and illustrated books. If your organisation already uses activity boxes / reminiscence boxes / life story materials, you might wish to bring these to the session

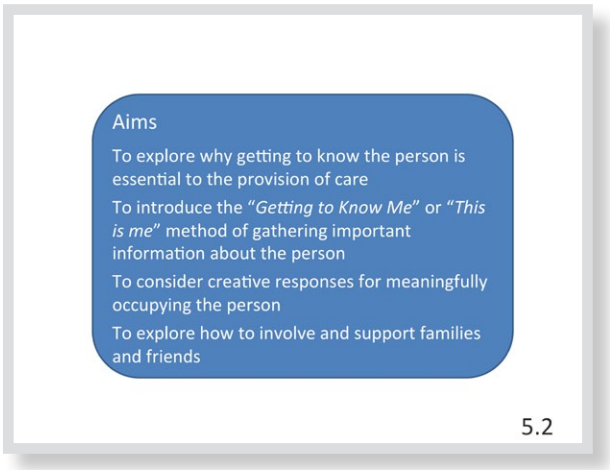
*If you are using the RCN/Alzheimer's Society "This is Me" booklet (or your organisation's own version of something similar), please complete some of these beforehand with information for the fictitious Mrs Atherton (see slides 5.4 and 5.5). Also bring some blank copies to the session.

Introduction and video clip

10 mins

Introduce the session by summarising the aims on slide 5.2.





Show the video clip *Supporting the person and their family* in which Ann talks about the needs of relatives and Brian talks about the importance of staff being aware of his wife's interests and achievements.

Ask participants how this kind of information can make a difference in providing support and care for people with dementia.

Getting to know the person in your care

15 mins

Aim

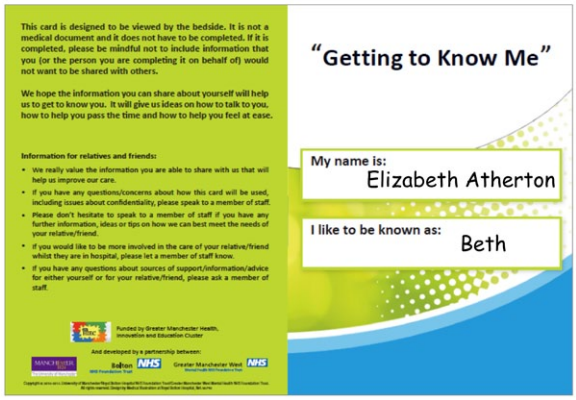
To explore the importance of getting to know the person. To experiment with the use of a booklet or card in which people with dementia can communicate important information about themselves.

Input

Show slide 5.3 and allow a few moments for participants to consider the situation described. Distribute the completed "Getting to Know Me" cards (or the version your organisation is using) with Mrs Atherton's information (using slides 5.4 and 5.5 here is optional). Show slide 5.6 and ask the group to consider the new information and ask them how this might inform the care and approach they would now take. This may be best done in pairs or groups, with responses recorded on paper or a flip chart.

Mrs Atherton continually appears distressed. She finds it difficult to communicate verbally, but can sometimes be heard calling the name “Joe”. When staff ask about Joe, Mrs Atherton is unable to say.

5.3



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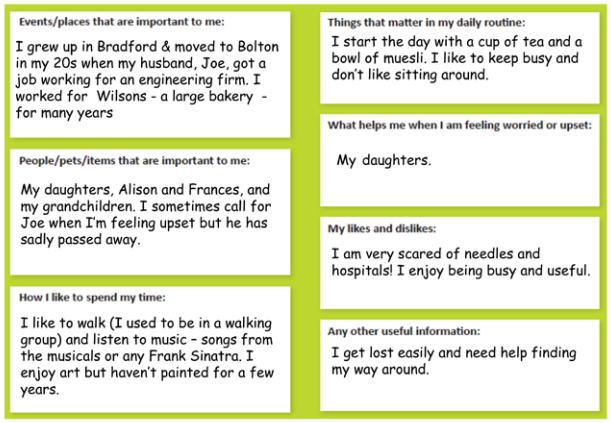


5.5

Knowing what you now do about Mrs Atherton, how might this information help inform how you interact with her?

5.6

Allow pairs/groups to formulate responses and record on a flip-chart. People may come up with ideas such as:

Caring for Beth - Ideas:

- Recognising how "Beth" likes to be known
- Conversations about Bradford and working at the bakery in Bolton
- Mentioning Beth's daughters when she is upset
- Being aware that Beth's deceased husband was called Joe
- Ensuring Beth's morning routine and breakfast are how she would like it
- Finding opportunities for exercise, such as asking Beth if she will accompany ward staff on tasks that require visits to other parts of the hospital and encouraging Beth's daughters to go on walks with her
- Encouraging Beth's daughters to bring in music or books with pictures of movie musicals/Frank Sinatra. A movie playing device (laptop/tablet etc if available)

Key messages

The more we know about a person, the better our chances of providing care that meets their needs.

Knowledge generates a rich potential for communication and for understanding what might be troubling a person.

Knowledge gives us ideas on how to introduce meaningful activities that may improve a person's well-being whilst in hospital.

Using a booklet or card to enable the person with dementia or their friends/family to share information about such things as likes/dislikes, hobbies, interests etc. can help to inform person-centred care.

Meaningful activity/occupation

10 mins

Aim

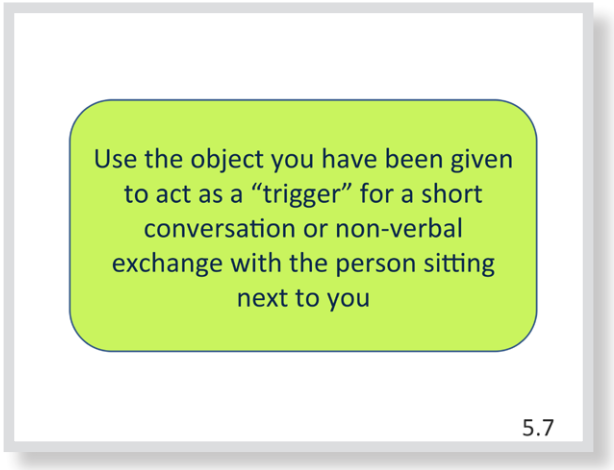
To explore the theme (that may have arisen in the previous exercise) of enabling people to engage in purposeful activity.

Input

This is where the selection of books, pictures, objects, memorabilia etc. that you have brought to the session can be used.

Split the group into pairs. Show slide 5.7 and give a book/object to one person in each pair. Ask this person to use their item to initiate a brief interaction with the other participant (this may be verbal or non-verbal). After two minutes, ask the pair to switch roles to enable the other person to initiate another interaction using the item as a trigger/focal point.

Stop the activity after another minute or two, and ask for feedback. Was it easy or difficult? Did the prop help or hinder the exchange? What is the relevance here with regard to caring for people with dementia in hospital?



Key messages

Interactions with people with dementia can be meaningful, even if brief.
Objects and pictures can spark interest.
Objects may provide a focus for interaction.
Pictures/objects with reminiscence value (for example, prints of local scenes from several decades ago) can trigger memories.
Items of interest can also facilitate interactions when family and friends visit.

Being creative

15 mins

Aim

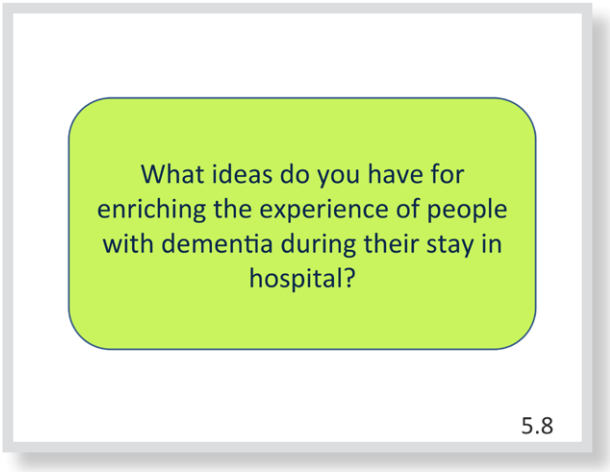
To encourage participants to think creatively about practical steps to provide greater opportunities for activity and occupation.

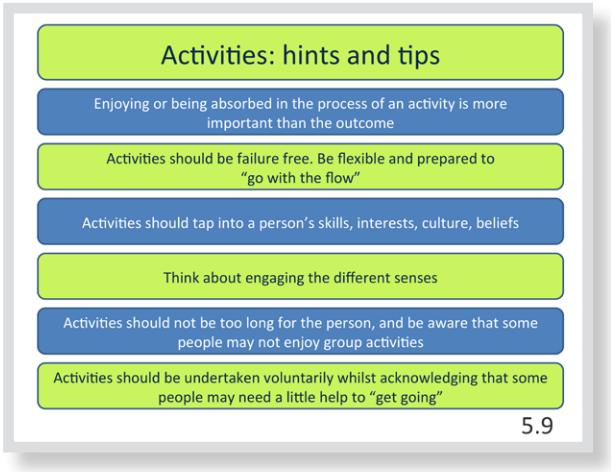
Input

Show slide 5.8 and invite participants to generate ideas for enriching the experience for patients in hospital wards. Pictures, themed walls, books, objects, reminiscence boxes, music etc. may be ideas to get people thinking.

Ask what barriers may exist (e.g. issues around hygiene/cross-infection) and how these can be overcome.

Following this discussion show slide 5.9 and summarise the hints and tips depicted. Discuss any issues that may arise.





Key messages

Finding ways to connect with people with dementia and facilitating opportunities in which individuals can be meaningfully occupied can make a significant contribution to well-being. This requires us to "see the person", to build relationships and to think creatively. It is also vital that we draw on the knowledge and expertise of family and friends.

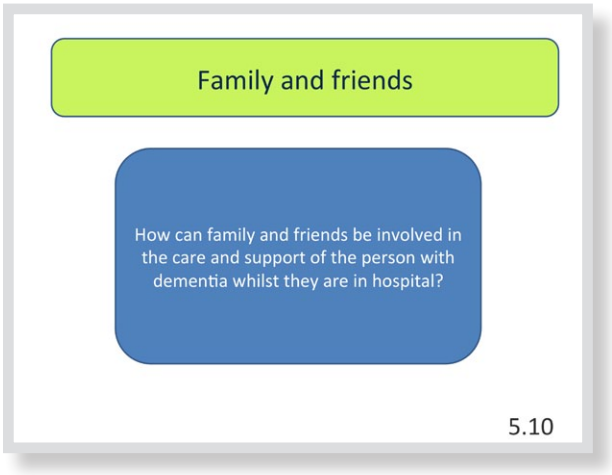
10 mins

Aim

To identify what families and friends have to offer, and to think about the needs of families and friends whilst relatives are in hospital.

Input

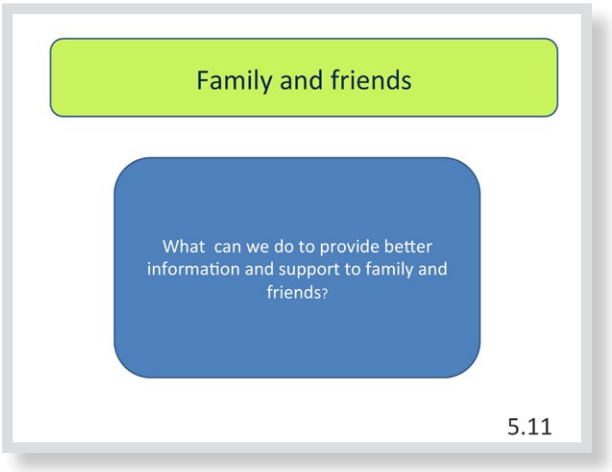
Show the question on slide 5.10. Drawing on some of the key ideas discussed in the training so far (for example, the emotional needs of people with dementia and the value of gathering important information about the person), ask participants to consider ways in which to facilitate the contribution that family and friends can make to the care of people with dementia in hospital.



Ideas may include:

- Encouraging sharing of information about the person e.g. through the use of the "Getting to Know Me" card
- Flexible visiting hours
- Better communication between the hospital and the family
- Involving family and friends in care planning and planning for discharge

Following this, show slide 5.11 and ask for ideas on better ways in which to provide information and support to meet the needs of family and friends.



Ideas may include:

- Providing literature on local and national sources of help
- Time to listen and respond to views and feelings of family/friends
- Providing educational materials

Key messages

Whilst many families and friends will choose to be actively involved in the care of the person with dementia whilst they are in hospital, not everyone will.

The mere presence of a familiar face may be reassuring to a person with dementia, and family/friends have a wealth of information about the person that may be vital to their care, treatment and well-being.

Families and friends also have a need for information and support. Make sure there are information leaflets and contacts for local/national support organisations.

End the session by asking participants if they have any questions.

Ideas for resources for your organisation

Books and magazines
Look for ones with interesting pictures that may stimulate conversations or memories, for example, with pictures of animals, buildings, gardens, landscapes, etc.

Objects
Try to find objects that are safe (no loose or small parts) and can be cleaned (infection control will be an issue that will need to be explored) but that are also interesting. All kinds of things can create interest; memorabilia, figurines, old-fashioned toys, shoes in a box with a cloth to polish them - anything that can be used or explored. Use your imagination.

Games
Jigsaws, dominoes, and other games can be fun. However, remember every person is different; what one person might find stimulating and rewarding, another might find difficult and frustrating.

Resources you can purchase
There are a number of websites specialising in memorabilia (including picture books, objects, signage, etc.). There are also organisations that produce specialist books for people with dementia. **www.atdementia.org.uk** is a useful starting point.

Notes

Part 6 A person-centred understanding of behaviour that challenges

Outline

Introduction	5 mins
Thinking about behaviours that challenge	10 mins
Case studies	25 mins
Action points and programme summary	15 mins
Concluding video clip	5 mins
Total	**1 hour**

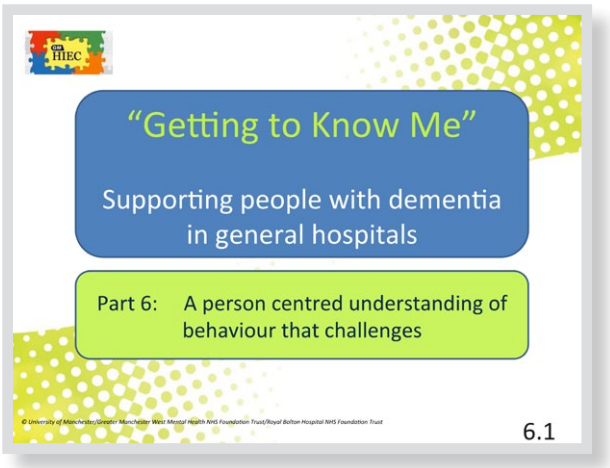
Materials you will need

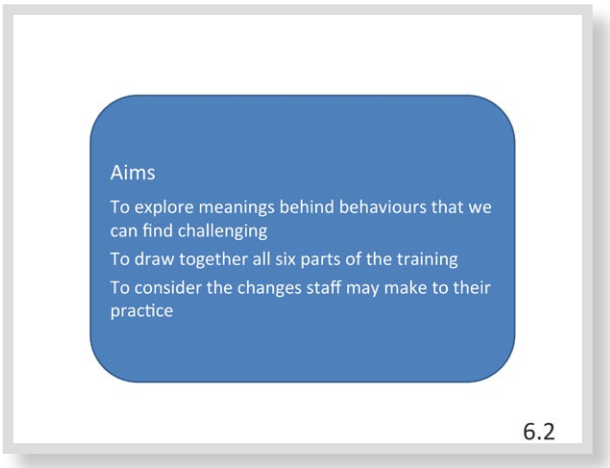
- "Getting to Know Me" Part 6 PowerPoint slides
- "Getting to Know Me" video clip
- Flip chart and marker pens (or A4 paper and pens)

Introduction

5 mins

Using slide 6.2, state the aims of the final part of the training.



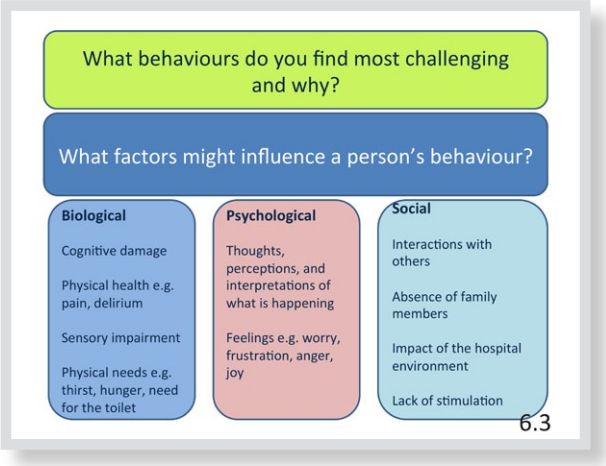


Thinking about behaviours that challenge

10 mins

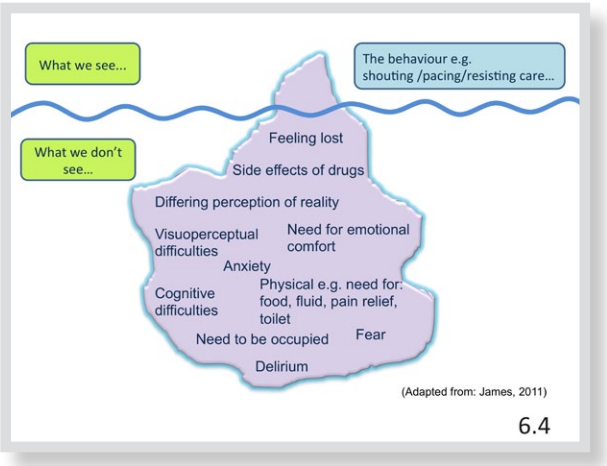
Show the first box on slide 6.3 and ask the group "what behaviours do you find most challenging and why?" Allow for a short discussion, highlighting some of the difficult situations staff might experience. Expect people to highlight issues such as: patients who are aggressive/shout repeatedly, or patients who cause disruption to other patients.

Show the second box on slide 6.3, and ask "what factors might influence a person's behaviour?" After a brief discussion, inform the group that you are going to build on their answers by discussing a framework containing a range of factors that can underpin behaviour. Read through the remaining three boxes to illustrate this.



Explore further by using the iceberg depicted on slide 6.4.[3] This represents the idea that when we see a behaviour, we do not necessarily think about the complexity of the different factors that may be underpinning that behaviour. This can lead to a person's behaviour being considered as a 'symptom' of dementia (that needs to be treated), rather than a means of communicating an unmet need that is unique to that particular person at a particular moment in time.

Discuss any issues that arise from this slide. This approach will be considered in the case studies that follow.



3 James, I. (2011). *Understanding behaviour in dementia that challenges: A guide to assessment and treatment*. London: Jessica Kingsley.

Input

There are two case studies presented on slides 6.5-6.15. You may choose to use one or both depending on the time available and the particular needs/issues of your group.

Case study 1
Show slides 6.5 and 6.6. Read through the short case study. Show the three headings (replicating the model introduced in slide 6.3): 'possible biological factors', 'possible psychological factors', and 'possible social factors'. Ask the group to suggest some potential factors that may be influencing Mrs Williams's behaviour that fall under these three headings. Because the group have very limited information about Mrs Williams, it will be difficult for them to be specific. Expect responses to be similar to the following:

Possible biological factors:
Physical discomfort?
Lack of oxygen?
Infection?
Thirst, hunger, need for the toilet?

Possible psychological factors:
Anxiety?
Curiosity?
Loneliness?

Possible social factors:
Searching for family members?
Looking for company?
Need to be occupied?

It is likely that the group will have highlighted that they need to know more about Mrs Williams. Run through slides 6.7-6.9 which depict further information, including the information in the "Getting to Know Me" card (if you are using this). Using the prompt questions on slide 6.10, encourage the group to explore the possible meanings of Mrs Williams's behaviour and the implications for her care and support. If the group is large enough, split into smaller groups or pairs for this part of the exercise and ask participants to write down their ideas.

Case study 1

Mrs Williams

6.5

Sylvia Williams is a 73 year old lady of Jamaican origin. She has a diagnosis of dementia and was admitted four days ago from a care home with a respiratory infection. Mrs Williams is responding well to antibiotics and oxygen via a nasal cannula, but is constantly "on the go". Mrs Williams walks around the ward, becoming breathless and disorientated. One day she left the ward and was discovered "lost" in the grounds of the hospital.

Possible biological factors?

Possible psychological factors?

Possible social factors?

6.6

Additional information

Health
Wears dentures and spectacles for long distance
Physical health improving after illness

Social
Receives visits in the evening by her daughter Angela, and friends from her church

Psychological
Becomes agitated when she is prevented from walking and escorted back to bed
Often heard asking for Angela or Edna

Getting to Know Me
Angela provides some additional information on her mother's "Getting to Know Me" card...

6.7

This card is designed to be viewed by the bedside. It is not a medical document and it does not have to be completed. If it is completed, please be mindful not to include information that you (or the person you are completing it on behalf of) would not want to be shared with others.

We hope the information you can share about yourself will help us to get to know you. It will give us ideas on how to talk to you, how to help you pass the time and how to help you feel at ease.

Information for relatives and friends:

- We really value the information you are able to share with us that will help us improve our care.
- If you have any questions/concerns about how this card will be used, including issues about confidentiality, please speak to a member of staff.
- Please don't hesitate to speak to a member of staff if you have any further information, ideas or tips on how we can best meet the needs of your relative/friend.
- If you would like to be more involved in the care of your relative/friend whilst they are in hospital, please let a member of staff know.
- If you have any questions about sources of support/information/advice for either yourself or for your relative/friend, please ask a member of staff.

Funded by Greater Manchester Health, Innovation and Education Cluster

And developed by a partnership between:

Bolton NHS Greater Manchester West NHS

"Getting to Know Me"

My name is: Sylvia Williams

I like to be known as: Mrs Williams

6.8

Events/places that are important to me:
I grew up in Kingston, Jamaica, and emigrated to England in 1962 with my late sister, Edna. I have lived in Manchester ever since. I worked for many years in a textile factory and have two children, Angela and Malcolm, and five wonderful grandchildren.

People/pets/items that are important to me:
My dear husband, Clifford, died twenty years ago but I treasure fond memories of him. I adore my children and grandchildren but cannot always remember their names. My friends from church are all important to me.

How I like to spend my time:
I like the company of children who bring joy to me. I enjoy flowers and gardens and used to arrange the flowers for our church. I am told I have a lovely voice and I like to sing. Angela takes me to church every Sunday.

Things that matter in my daily routine:
I eat cornflakes and fresh fruit for breakfast. At my care home "Meadow View". I get up 6.30 and always have a nap after lunch. Most days I like to spend some time in the garden.

What helps me when I am feeling worried or upset:
Angela is a great comfort to me, as are my friends. When I am worried and need comfort I sometimes like to pray.

My likes and dislikes:
I don't like too much noise, particularly people shouting and laughing noisily. I feel lost and frightened when there is no one around that I know.

Any other useful information:
I sometimes have problems finding the loo and worry that I might not get there in time.

6.9

With the additional information we now have on Mrs Williams:

1. What might be influencing the observed behaviours?

2. What care/interventions could we provide?

6.10

If you are using the second case study, repeat the above process using the material in slides 6.11-6.16.

Case study 2

Mr Samadi

6.11

Mr Samadi has advanced dementia. He has lost the ability to walk and to feed himself. As he sits in his chair or lies in bed he repeatedly calls out. This shouting annoys other patients in his bay. Mr Samadi's family inform you that the words he repeatedly shouts are not intelligible in English or Persian (his first language).

Possible biological factors?

Possible psychological factors?

Possible social factors?

6.12

Additional information

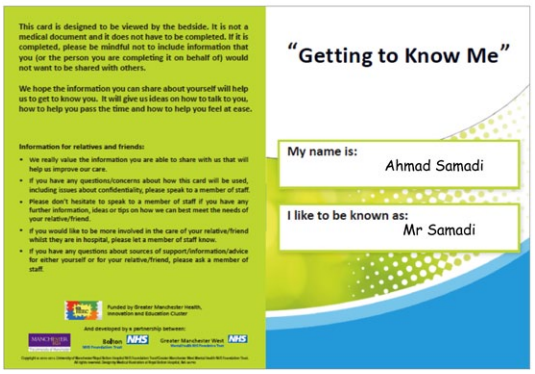
Health
Has an indwelling catheter
Manages a soft diet and thickened fluids
Pressure sore with dry dressing to left heel

Social Factors
Mrs Samadi visits every evening

Psychological
Sometimes seems unsettled
Appears a little calmer with physical contact e.g. holding of hand, particularly by his wife

Getting to Know Me
Mr Samadi's children have completed a "Getting to Know Me" card…

6.13



6.14

Events/places that are important to me:

Father was born in Iran in 1942. His family moved to London in the 1950s. He studied dentistry in Manchester in 1960 where he soon met and fell in love with our mum, Anne. Our father set up a successful dental practice in Sale. He has 4 children and 7grandchildren.

People/pets/items that are important to me:

Father is very close to all his family and has always been devoted to his grandchildren.

How I like to spend my time:

Our father's life-long passion has been for flying, he used to own and pilot a light aircraft. In more recent times he has enjoyed the company of his family and spending time in the garden.
Our father used to enjoy jazz and traditional Iranian classical music.

Things that matter in my daily routine:

Father no longer has routines but he still seems to like regular drinks of chai (sweetened tea made with condensed milk).

What helps me when I am feeling worried or upset:

When father is upset we talk to him, and massage his hand when he lets us do so. The sound of mother's voice often soothes him.

My likes and dislikes:

Father dislikes being alone. He will call out words none of us understand, but he often becomes calmer when we are around.

Any other useful information:

Father can no longer manage solid foods but likes regular sips of thickened chai. He often gets discomfort from the area around his catheter which makes him upset.

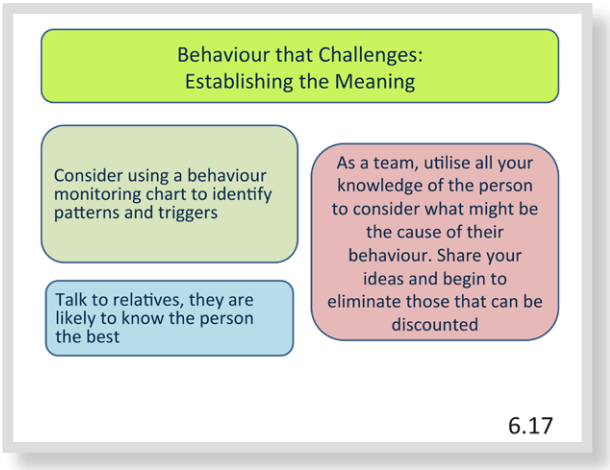
6.15

1. What might be influencing Mr Samadi's behaviour?

2. What care/interventions could we provide?

6.16

Slide 6.17 presents a number of discussion points to complete the exercise. Finish by showing slide 6.18 and asking for any questions.



Key messages

There may be multiple factors influencing a person's behaviour.

We need to try our best to establish the underlying need/meaning of a behaviour. This isn't always easy but a team approach and knowledge from relatives can help.

Trying to prevent a person from doing something can exacerbate problems; search for creative solutions (e.g. ways in which to occupy a person and refocus their attention).

Do not forget physical pain, discomfort or illness as possible causes of changes in behaviour.

Further Information

You may find the following publications helpful:

James, I. (2011). *Understanding behaviour in Dementia that Challenges: A guide to assessment and treatment.* London: Jessica Kingsley.

Stokes, G. (2008). *And Still the Music Plays: Stories of People with Dementia.* London: Hawker Publications.

Action points and programme summary

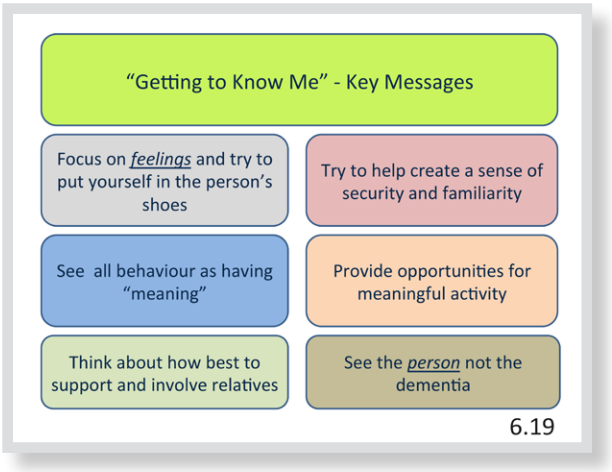
15 mins

Aim

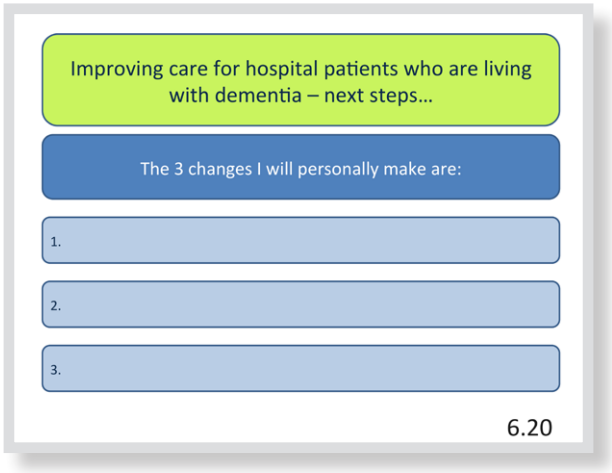
The remainder of the session is a summary/review of the training programme. It is an opportunity for people to identify what changes they intend to make to practice at an individual/team/ward level.

Input

Slide 6.19 will help staff to review key messages from the training programme. Read through the boxes, and facilitate discussion on any isues that arise.



Ask participants to reflect on what they have learned by thinking about or writing down reflections to the question depicted on slide 6.20. Following this, undertake a discussion to summarise what staff have learned across the programme.



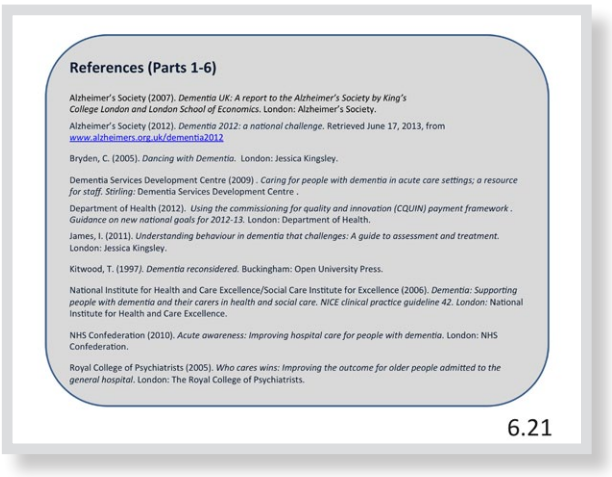
Ask what further training people feel they may need. These exercises may also be undertaken by participants completing an evaluation form, such as the one included in this pack.

Key message

Reinforce the message that has underpinned the training: caring for people with dementia in hospital is about, first and foremost, *seeing the person*.

Concluding video clip

Show the video clip *Final messages*, and ask participants to complete the evaluation form. This will complete the training programme.



Notes

Simon Burrow

Simon is the pathway lead for the MSc in Dementia Care at the Unversity of Manchester. Prior to this he set up and managed a dementia charity specialising in training and education in the East Midlands. Simon is a registered social worker and has also practiced as a registered nurse working in general hospitals.

Ruth Elvish

Ruth is a clinical psychologist. She works within the Dementia and Ageing Research Team at the University of Manchester and within Pennine Care NHS Foundation Trust. Her clinical work includes working with people with dementia and with people following a stroke, and she has an interest in neuropsychology and older people.

John Keady

John is a registered mental health nurse and completed his part-time PhD in 1999. Prior to this, he practised for several years as a community psychiatric nurse in dementia care, a position he held in North Wales. Since 2006 John has worked at the University of Manchester where he holds a joint position between the University and the Greater Manchester West Mental Health NHS Foundation Trust. John currently leads the inter-disciplinary Dementia and Ageing Research Team at the School of Nursing, Midwifery and Social Work.

Kathryn Harney

Kathryn is the Associate Director of Research at Greater Manchester West Mental Health NHS Foundation Trust and has worked in local and national NHS research management since 1996. She previously worked at Cranfield University on improving transport accessibility for people with physical, sensory or learning difficulties.

Credits and acknowledgements

The "Getting to Know Me" training programme has been developed with funding from the Greater Manchester Health Innovation and Education Cluster (GM-HIEC). The project took place during 2010-2013, and was a collaboration between the University of Manchester, Royal Bolton Hospital NHS Foundation Trust and Greater Manchester West Mental Health NHS Foundation Trust. The aim of the project was to pilot and evaluate dementia awareness training for staff working with people with dementia in general hospitals.

The following people have provided invaluable input into the development of the project:

Ruth Elvish, Simon Burrow, John Keady, Rosanne Cawley, Kati Edwards, Jenna King, Abi Tarran-Jones and Pamela Roach (University of Manchester).

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