

Supporting people with dementia in hospital

Staff resource



Insight Dementia project

Contents

Foreground I

Chapter 1 - Holistic context..... 1-3

Care of people with dementia in hospital ... 1

Person-centred care in hospital 2

Chapter 2 - Insight Dementia virtual reality film..... 5-7

What is 'Insight Dementia'? 6

Technology in dementia education 6

Chapter 3 - Hospital environment..... 9-11

Creating a dementia-friendly ward environment..... 10

Chapter 4 - Holistic assessment..... 13-17

Definition of holistic assessment..... 14

Chapter 5 - Communication skills..... 19-25

Communication and interactions..... 20

Chapter 6 - Carer and staff support.... 27-28

Summary II

Foreground

This workbook has been designed to offer hospital staff a better understanding of how people with dementia might feel when they go into hospital. People with dementia and their carers spoke to us about their experiences and from these conversations we created a Virtual Reality (VR) film so that the viewer can be immersed for 3 minutes in those experiences and gain that 'insight into dementia' which will hopefully have a positive impact on care delivery.

In the first chapter, we will set the context of how many people with dementia might be in hospital and the importance of person-centred care. We will then invite you to view the film (chapter 2) either using a VR headset or on the screen. In chapter 3, we will consider what are the key principles of dementia-friendly environments (chapter 3) and the importance of assessing people with dementia holistically in chapter 4. We will then discuss key strategies for effective communication in chapter 5 and in chapter 6 we will offer suggestions how to support carers and the ward team when caring for someone with dementia.

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How to use this resource

This workbook is full of practical tips and information informed by research to help healthcare staff recognise and respond to the needs of patients with a dementia. It includes information, interactive activities and signposting, and makes recommendations on how to provide personalised care with tips on effective communication skills.

This resource is designed to be used as a tool alongside the "Insight Dementia: Going into hospital" virtual reality film. Each section includes the opportunity for reflection to encourage you to consider your own working practice in delivering good care for people living with dementia.



Chapter 1 - Holistic context

Emma Hall and Dr. Michele Board

Person-centred care in hospital

Approximately 982,000 people in the UK are living with a form of dementia. This figure is estimated to rise to 1.4 million people by 2040 (Alzheimer's Society, 2024). Dementia is NOT synonymous with ageing, albeit the risk of dementia increases with age. Risk factors for dementia are broad but include the same risk factors as heart disease, such as poor diet, insufficient exercise, alcohol intake and hypertension. Women are slightly more at risk of getting dementia than men.

Reflective activity

Discuss the following with your colleagues or make a few notes:

- In handover, how are people with dementia described?
- What words are used?
- How are you feeling when you go to look after a person with dementia?

Dementia is a condition characterised by the impairment of multiple cognitive functions to a degree that interferes with daily life, not due to a general medical condition or altered consciousness.

These cognitive deficits are associated with a progressive decline in the ability to perform activities of daily living (ADLs). Furthermore, this decline is linked with psychological symptoms and distress. The manifestation of distress is frequently (and incorrectly) referred to as 'challenging behaviours' – but consider who is challenging who? Causes of distress need to be assessed (see chapter 4 for more details).

If you felt confused, unsure where you were or who the people in uniform were, and then people were taking your blood pressure, trying to wash you – how would you feel? Would you feel afraid, anxious, lost, alone? Are these the words used to describe people at handover? Often a more negative dialogue is adopted, e.g. "Bob has been wandering all morning, calling out, aggressive, very challenging", which can then influence your thoughts and feelings as you approach a person with dementia who has really been agitated and distressed? Negative framing can affect your thoughts and emotions when caring for a person with dementia.

Putting yourself in the shoes of someone with dementia and understanding their perception of the world can offer unique insights into how to provide a more humanised, person-centred care approach to this client group.



Hospital care

At any one time, 1 in 4 hospital beds are occupied by people living with dementia. People with dementia stay in hospital on average 5 more days than patients admitted for the same reason. They have an increased risk of being transferred to a residential setting, increased risk of morbidity and mortality and, as a result of reduced mobility, the individual becomes deconditioned. Knowing these are risks for people with dementia, we need to work together to improve their outcomes.

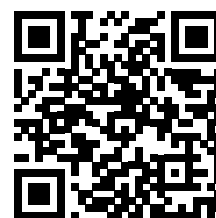
Numerous obstacles have been identified that hinder the delivery of quality dementia care in acute hospital settings. These include a lack of focus on those individual needs, poor leadership, insufficient training, challenges in assessing treatment risks and benefits, stigma, discrimination, inadequate staffing, unsafe environments, and suboptimal clinical pathways and policies (Featherstone et al., 2019).

Moreover, nursing staff face difficulties in providing person-centred dementia care in these settings due to institutional priorities such as routine, efficiency, and risk management (Featherstone et al., 2019).

Reflective activity

What does person-centred care look like? Think about what small steps you can take to provide a more person-centred approach to care. Consider this from your own perspective: What should people know about you if you were in hospital, how would you like to be spoken to, who and what is important to you that would influence the care you need?

Read the article: *The Fundamentals of Person-Centred Care for Individuals with Dementia* by Fazio et al. (2018), **scan the the QR** below.



Top tip: making notes on this could be a useful reflection for professional revalidation.

Based on Practice Recommendations for Person-Centred Care in Fazio et al.'s (2018) article, the following principles in **List 1** align well with the NHS's approach to person-centred dementia care, emphasising the importance of understanding the individual, involving family and carers, adapting care processes, training and expertise and liaising with either community and mental health teams when appropriate.

List 1

Know the person

Understanding the individual beyond their diagnosis, including their values, beliefs, interests, abilities, likes and dislikes, is crucial. This knowledge should inform every interaction and experience. Consider using "This Is Me" (Alzheimer's Society, 2010, reviewed 2024). This can be accessed at: www.alzheimers.org.uk/sites/default/files/2020-03/this_is_me_1553.pdf

Recognise and accept the person's reality

Seeing the world from the perspective of the individual living with dementia promotes effective and empathetic communication. It validates feelings and connects with the individual in their reality (see Chapter 5 for further suggestions).

Identify and support opportunities for meaningful engagement

Every experience and interaction can be an opportunity for engagement. Engagement should be meaningful, support interests and preferences, allow for choice and success, and recognise that the person can experience joy, comfort, and meaning in life, even when the dementia is most advanced.

Build and nurture authentic, caring relationships

Individuals living with dementia should be part of relationships that treat them with dignity and respect, and where their individuality is always supported. This type of caring relationship is about being present and focusing on the interaction, rather than the task. It is about "doing with" rather than "doing for".

Create and maintain a supportive community

A supportive community provides comfort and creates opportunities for success. It values each person, respects individual differences, celebrates accomplishments and occasions, and provides access to and opportunities for autonomy, engagement, and shared experiences.

Person-centred care emphasises the individual's values, preferences, and needs (The Health Foundation, 2014). Furthermore, person-centred care has been positively associated with the ability of individuals with dementia to manage better in hospital settings (Scerri et al., 2020).

This is shown to improve patient outcomes, reduce agitation, alleviate depression symptoms, and enhance quality of life (Kim and Park, 2017).

1. **Understanding dementia:** Recognising the unique challenges faced by individuals with dementia, such as memory loss and difficulty communicating their needs
2. **Demonstrating empathy:** Connecting with patients on a deeper level to validate their feelings, which involves understanding and relating to their circumstances
3. **Respecting personhood:** Treating patients as autonomous individuals and involving them in care planning to ensure it reflects their needs
4. **Minimising disruption:** Maintaining routines to prevent worsening of cognitive decline symptoms and ensuring the person is as settled as possible
5. **Assessing people's needs:** Including their medical condition, personal history, abilities, interests, cultural background, preferences, and requirements
6. **Assisting with personal care, eating and drinking:** Offering tailored support for daily living activities and ensuring a comfortable environment during mealtimes
7. **Adding to the environment:** Making the physical environment dementia-friendly to promote patient safety, wellbeing, and independence
8. **Involving families and carers:** Involving families and carers in the care process can assist in getting to know the person better and provide additional support.

Healthcare professionals in general hospital wards should strive to provide person-centred care to patients living with dementia, working together with individuals, their loved ones and the wider interdisciplinary team.

With this in mind, once you have viewed the film, in the following chapters we will discuss and reflect on topics including dementia-friendly hospital environments, importance of holistic assessment, communication skills and how to best support yourself and others when engaging in person-centred dementia care.

For more information about dementia or person-centred care, **scan the QR code** below to view the reading list.





Chapter 2 - Insight Dementia **virtual reality film**

Rebecca Dew and Dr. Memory Taurigana

What is 'Insight Dementia'?

Insight Dementia is a short virtual reality film series which uses 360° video sequences to illustrate what it may feel like as a person living with dementia. Insight Dementia: Going into hospital was created to depict a first-person view point of a person with dementia going into hospital.

In a simulated ward setting, the video depicts a male living with dementia, who is being admitted into hospital following a fall. Throughout the video, an internal monologue is scripted and read aloud to illustrate how a person living with dementia may be feeling or thinking when being admitted into a busy hospital ward. This script was developed and informed by conversations with people living with dementia and carers about their experiences of going into hospital.

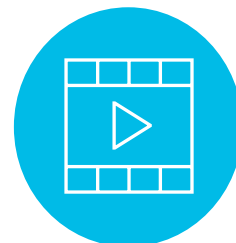
Technology in dementia education

Approaches to dementia education are constantly evolving, with technology becoming a useful tool for expanding different teaching and learning methods. By using virtual reality, Insight Dementia aims to provide an immersive learning experience.

1. Time to view the film

The film can be viewed in two ways. Either via a VR headset or by watching it on YouTube.

The most effective way is using a VR headset, which was supported by students and members of the public who viewed this as part of our evaluation. The film lasts just under 3 minutes. If viewing via a VR headset, we do not recommend that you walk around whilst watching the film.



2. How might a person view the film with a headset?

To view the film and instructions on the different ways to access the film, **scan the QR code** below:



Disclaimer: If viewing on a virtual reality headset, please refer to the specific guidance on how to use your headset from your provider.

Having viewed the film, chapter 3 will consider the impact of a hospital environment on people with dementia and suggestions for improving the environment.



Feedback about the film...

...from people living with dementia and their carers

1. "Having had feelings myself I understand the fear that can be felt and feeling of being lost in a strange place"
2. "Very realistic as it shows how confusing a totally new environment is, which would be so different from home"
3. **"A very valuable educational tool to raise awareness of how patients with dementia feel"**



....from students

1. "The film has really made me consider, when I'm in practice, how well I communicate my care and narrate my care."
2. **"I just feel that I've had a better understanding of how people can feel [...] It just made something else click...To understand where they're coming from a bit more"**
3. "As a learning tool, [it gives you] a better way of putting yourself into someone's shoes without just the imagination [...] it's a very good starting point for further discussion, further development."



Reflective activity

Either on your own or discuss with colleagues

- How did you feel watching this film?
- How do you think the person with dementia is feeling?
- What did you notice about the environment?
- What might be challenging?
- How do you think this could impact a person with dementia's experience of being in hospital?
- Why do you think they felt this way?
- Is there anything you think could help them?
- What did you notice about the nurse and patient interaction?
- How do you think this would make the patient feel?
- What could have helped to make them feel safer or reduce any anxiety?
- By putting yourself in the patient's position, how would this impact your approach to care?



Chapter 3 - Hospital environment

Helen Aldridge and Emma Hall

Hospitals were not originally designed with the needs of individuals with dementia in mind. However, there is now a growing movement towards creating “dementia-friendly” hospitals. While wayfinding and signage are often the primary focus, a genuinely dementia-friendly environment involves much more. It aims to reduce environmental stress, provide support, and create healthier, therapeutic spaces.

The design of acute hospitals is influenced by the need to balance meeting user requirements and maintaining core functionalities. Hence, it is vital to implement Universal Design principles that address the needs of individuals living with dementia.

Creating a dementia-friendly ward environment

Dementia-friendly wards represent a proactive approach to addressing the complex needs of those living with dementia, who at times may require hospital admission. These areas need to consider the unique requirements of this patient group. They should promote recognition of the individual's needs, promoting dignity and autonomy, whilst aiming to improve the overall hospital experience by incorporating features that address the cognitive, emotional and physical challenges faced.

Design and environment



Example of dementia-friendly ward design (The King's Fund, 2013). Used with permission.

Over the past several decades, the detrimental impact that inadequately designed clinical environments can have on individuals living with dementia has been well-documented, highlighting the constraints imposed by clinical needs (Büter et al. 2017). While significant advancements have been made internationally and within UK hospitals, more work still needs to be done (Royal College of Psychiatrists, 2023).

The physical environment of dementia-friendly wards needs to be carefully planned to minimise confusion and agitation among these individuals.

Key design features include clear signage with symbols and colours that are easily identifiable, minimising the likelihood of patients becoming lost or disoriented. The use of contrasting colours helps patients distinguish between different areas and objects, which is crucial for those with visual-spatial difficulties common in dementia (Wiener and Pazzaglia, 2021).

For instructions on how to watch the film, scan the QR code below:



We know that the loud unfamiliar sounds of a busy ward or department can cause stress and anxiety in our patients, and this is especially true for those living with dementia.

Re-scan the QR code above and listen to the Insight Dementia video with your eyes closed. Did you pick up on all the noises on the ward? In our own familiar work environments, we may not notice how noisy it would appear to anyone who isn't familiar with a clinical environment, and perhaps even more alarming if you have a cognitive impairment.

Key considerations

Think about where you work. Is your environment dementia-friendly? Now take some time to reflect and consider how you can improve your ward or department so that it is more dementia-friendly. You may wish to take a walk around your work environment and consider it from a patient's perspective now that you have watched the video.

- What do you have control over and what do you need your department manager to support you with?
- Have you identified any changes that could be made, some may be very easy and quick to achieve, and some may require managerial and financial support?

Reflective activity

Have a think about the following requirements and how could they be achieved in your clinical environment. Make a list of things you and your team could achieve using the worksheet, accessed by scanning this QR code below:



Design Layout

1. **Clear signage and wayfinding:** Use simple, easily readable signs and visual cues to help patients navigate the ward
2. **Colour and contrast:** Use contrasting colours for walls, floors, and furniture to aid visibility and orientation
3. **Simple layout:** Minimise complexity and clutter to reduce confusion and agitation.

Safety Measures

1. **Fall prevention:** Ensure the environment is free of tripping hazards and install handrails where necessary
2. **Secure exits:** Implement measures to prevent patients from wandering out of the ward, such as alarms on doors
3. **Soft furnishings:** Use soft edges on furniture to minimise the risk of injury in case of falls.

Noise and distractions

1. **Reduce noise levels:** Minimise unnecessary noise and provide quiet areas for relaxation
2. **Limit distractions:** Avoid overcrowding and maintain a calm environment to prevent agitation.

Lighting

1. **Natural light:** Maximise access to natural light, which can help regulate sleep patterns and mood
2. **Adequate lighting:** Ensure consistent and sufficient lighting throughout the ward to reduce the risk of falls.

Additional considerations for a dementia- friendly environment

Assessment

An annual environmental assessment should take place in all areas that deliver healthcare using the **Patient-Led Assessment of the Care Environment (PLACE)** which is an assessment framework designed to put the person using our services at the centre of our care. More information on this can be found in the references and reading list linked at the end of this chapter.

Creating dementia-friendly hospital environments is crucial for improving the care and experience of patients with dementia. Some frequently recommended key principles and features include:

1. **Calm and comfortable spaces:** Design spaces to be calm and reduce noise levels. Comfortable seating areas and quiet rooms can help reduce anxiety and agitation
2. **Familiar and homely environment:** Incorporate familiar objects and homely touches in patient rooms and common areas to make the environment feel less clinical and more comforting
3. **Safe and accessible design:** Ensure the environment is safe and accessible, with features like non-slip flooring, handrails, and good lighting to prevent falls and injuries
4. **Personalised care plans:** Develop personalised care plans that consider the individual needs and preferences of patients with dementia. This includes involving family members in care decisions
5. **Staff training:** Provide comprehensive staff training on dementia care, focusing on person-centred approaches and effective communication strategies.

These principles aim to create an environment that supports the health, wellbeing and dignity of patients with dementia, helping them feel more secure and comfortable during their hospital stay.

Please refer to the reference list and further reading for this chapter, **scan the QR code** below:



In this chapter, we have considered the impact of a hospital environment on a person with dementia. In chapter 4, we will consider a more holistic understanding of a person with dementia.



Chapter 4 - Holistic assessment

Rebecca Dew, Adam Archer and Dr. Michele Board

Reflective activity

1. Without reading ahead, what does holistic assessment mean to you?
2. Why do we use it and why is it important?

Definition of holistic assessment

Holistic assessment is a valuable approach to providing high-quality care which meets a patient's individual needs. A holistic assessment should evaluate the overall wellbeing of the patient, including their physical, psychological, social and spiritual wellbeing. It is important to evaluate the person as a whole, and not by just their illness. This could mean considering their illness alongside their mental health, social support system, personal beliefs and other factors. There are a wide range of factors that may play a role in a patient's presentation, wellbeing and how they are feeling, many of which can be grouped into three key areas: biological, psychological and social.

The biopsychosocial model

The biopsychosocial model was first conceptualised by George Engel in 1977. The model suggests a more holistic approach to care to consider biological, psychological, social and environmental needs. See image below for more detail.

These factors are unique to each individual and no factor should be considered in isolation. This is especially true when a person has a dementia and may have difficulty expressing their needs and what is unique about themselves.



Adapted from:
www.selfloverainbow.com/the-biopsychosocial-model-for-mental-health/

Reflective activity

1. Consider a person you have met with dementia. How were they behaving?
2. What did you know about their holistic needs that might have influenced how they behaved and responded to your interventions?
3. View this reflection in light of the model, how does this influence your perception of that patient?

Case study

Mrs. Evelyn Green is an 82-year-old woman who was diagnosed with dementia, five years ago. She lives with her daughter, Laura, who is her primary caregiver. Evelyn's husband passed away ten years ago, and she has two other children who live in different parts of England. Evelyn is a retired primary school teacher and an active member of her community, enjoying gardening, reading, and participating in local events. Over the last few years, her condition has progressively worsened, affecting her cognitive abilities, memory, and daily functioning. Evelyn has been admitted to your ward after having a fall at home.

From this case study, what important areas would you need to know about Evelyn and how would that help with supporting Evelyn on your ward?

You receive more information regarding Evelyn and learn that she struggles with short-term memory and often forgets recent events, such as what she had for breakfast leading to weight loss and malnutrition and she forgets if she has taken her medication. She has difficulty recognising family members, particularly her grandchildren, and sometimes forgets her own name. She has become more withdrawn and occasionally exhibits distressed behaviour, especially during personal care routines.

Evelyn's life story may contribute to how she might present on the ward. For example, she is used to being an active member of the community and engaging in a number of social activities - how might a busy ward make her feel? How many of the interactions Evelyn has on the ward are social, or are they all driven by care needs?

It is important to consider how personal history may influence how we all behave, this is especially true if we have a cognitive impairment.

Distressed behaviour

View this short clip 'Impact of Dementia on Family Relationships', accessed by scanning the QR code below:



Observe how distressed Finbar is and consider...

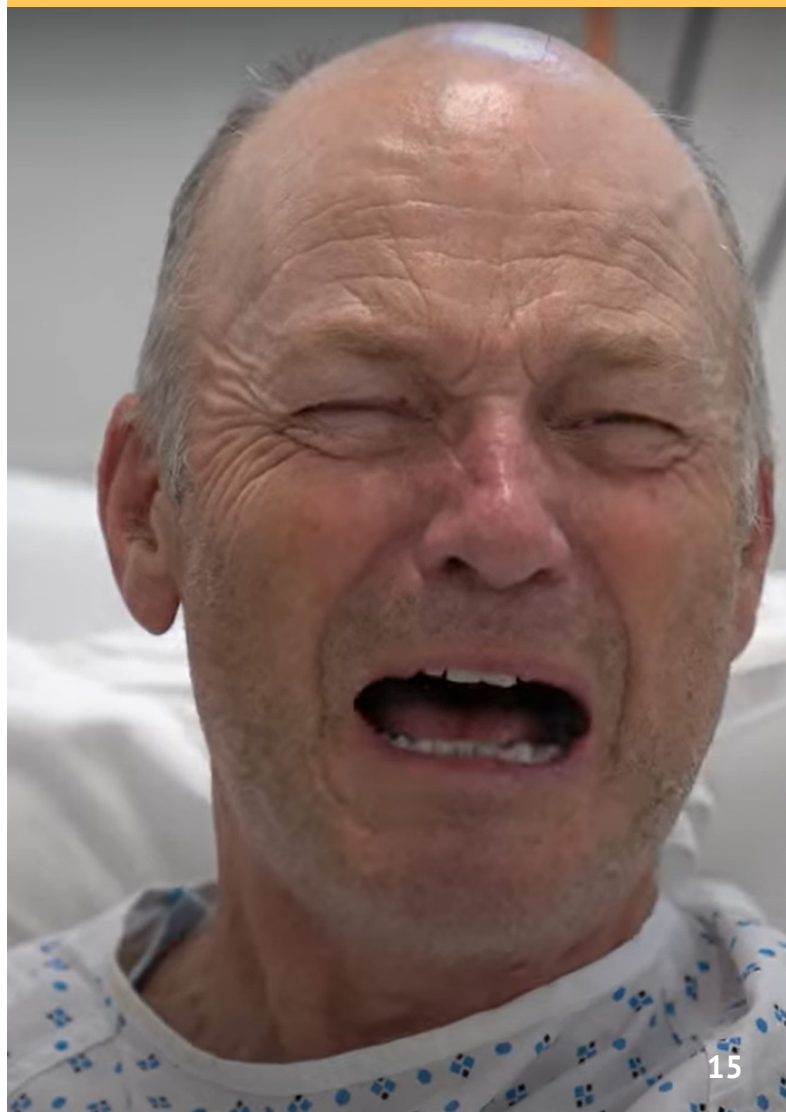
- What did you think as you viewed this clip?
- Did it feel like a familiar scenario?

When reflecting upon the causes of someone's distressed behaviour, Stokes and Goudie (1990) recommend an **ABC** approach. What were the **A**ntecedents - what preceded this distressed response? What was the **B**ehaviour - were there any clues in behaviour that might indicate a cause of the distress? What were the **C**onsequences of the behaviour - how was it resolved?

By exploring the potential cause of the distress, we might be able to ease that moving forward.

See chapter 5, for more guidance on communication skills.

The phrase 'challenging behaviour' is often used when describing a person's behaviour. However what we might be witnessing is distress and agitation, or an expression of an unmet need (Dewing, 2010). Assessing the cause of this distress should be holistic and comprehensive, requiring patience and skill. Read on to discover what a holistic assessment might entail.



A. Knowing the person

What can we do to better know the person? By doing this, we can avoid doing things that might cause further distress, and use this knowledge as a way of opening a conversation with that person, acknowledge what they are saying and how they might be feeling.

To provide holistic and individualised care, we must get to know the person we are caring for. By talking to the patient and family, also with the aid of tools such as **“This is Me”** documents (Alzheimer’s Society, 2024), we can develop a full holistic assessment.

By asking questions about what is important to that person and their sense of self, asking how they would prefer to be addressed, understanding their social connections and who knows them best, we can begin to see the person beyond their diagnosis of dementia. Furthermore, by understanding more about the patient’s personal story, their cultural beliefs, hobbies and previous occupation, we can build a human connection. Learning about an individual’s identity is important to assessing and knowing a patient. A person’s identity shapes their view of themselves and is influenced by their individual experiences and the world around them. Though a person with dementia might see the world differently, their experience is very real to them and will impact how they feel. Building good communication with a patient and their family, with verbal or non-verbal cues, can help us to better understand the patient and their needs. Effective communication can take many forms and there are many available tools which can help you develop skills in patient-centred communication. In the next chapter, we will discuss communication skills and how to link this to holistic assessment.

Remember the impact of a dementia:

- Loss or lapses of recent memory
- Mood changes or uncharacteristic behaviour (in later stages more pronounced)
- Poor concentration
- Difficulties in communicating (understanding what is being said to them, difficulties in word finding)
- Getting lost in familiar places (and hospitals are not familiar)
- Making mistakes in a previously learned skills (e.g. getting dressed in order)
- Problems telling the time or using money
- Changes in sleep patterns and appetite
- Personality changes
- Visio-spatial perception issues (i.e. the brain does not process images as normal).

What remains:

- Now, this moment!
- Response to the emotions of others
- Memories of self and relationships with others
- Your references and emotional responses to stimuli
- The defences you retreat into when you are stressed or anxious.



B. Physiological assessment

A useful acronym to consider in your assessment is **PINCH ME!**

Pain

- Use an observational pain tool to assess for pain, such as Abbey or Painad. Does the patient appear in pain? What might be causing that pain. Is pain relief required?
- Offer regular pain relief if required and monitor its effects

Infection

- Undertake urine analysis, record temperature, listen to their chest or observe for signs of a chest infection
- Don't assume it's a UTI, consider other sources of infection

Nutrition

- Assess appetite and nutritional intake. Use MUST tool to assess for signs of malnutrition
- Use a food chart if necessary, refer to a dietician if need be. Ask the patient and their family what their favourite foods are

Constipation (significant cause of confusion)

- Record bowel action, consider reporting using Bristol stool chart
- If constipated offer prescribed laxatives, suppositories and monitor their effects

Hydration

- Monitor fluid intake. Consider are we offering preferred drinks, is water stale and warm?
- Encourage fluid intake regularly

Medication

- Has there been a recent change in medication which has increased confusion? speak with pharmacist about drug interactions
- Discuss with the prescriber to consider if a review of medications is needed

Environment

- Hospitals are very stimulating, is this exacerbating distress?
- Try and create a calm environment in your clinical area, avoid loud noises, reduce phone volume, bins banging, staff calling out to each other.

Reflective activity

1. Think about these points, how do you assess these needs for a person with a dementia, what tools are there and what are your actions? Discuss with a colleague.
2. What might influence a person's behaviour? It's not straight forward, but by undertaking a holistic assessment we can begin to see past an individual's medical diagnosis to see them and try to assess what we can do to alleviate their distress.

Questions

1. Think about your previous patients, if you completed a full holistic assessment would the outcome be different?
2. Think about your take home message from this section, what might you do differently or what might you continue to do well?

Scan the QR code below to view the reference list:



Summary of factors influencing an individual's behaviour:

- **Complex situation**
- **Individuality – their own story**
- **Illness, such as delirium, pain, constipation**
- **Neuropsychological deficits**
- **Hospital environment**
- **Ineffective communication (in chapter 5 we will discuss communication skills).**



Chapter 5 - Communication skills

James Sansom and Emma Lucas

Communication and interactions

Understanding and supporting communication is essential for both the person with dementia and their caregivers. This guide aims to provide friends, family members, and caregivers with insights into the lived experience of individuals with dementia, focusing on how to communicate during times of calmness, distress, and when distress escalates into aggression. By understanding these different states and adopting appropriate communication techniques, we can enhance the quality of life for those affected by dementia and foster meaningful relationships.

Understanding communication and its importance in supporting people living with dementia means enabling self-expression, building relationships, and enhancing understanding. By doing so, caregivers can pass on positive emotions that have a lasting impact.

The three levels of communication

Living in a person's reality is about accepting and validating a person's feelings and emotional responses, which is an effective and helpful way to reduce anxiety.



Day-to-day

Gentle communication strategies for everyday



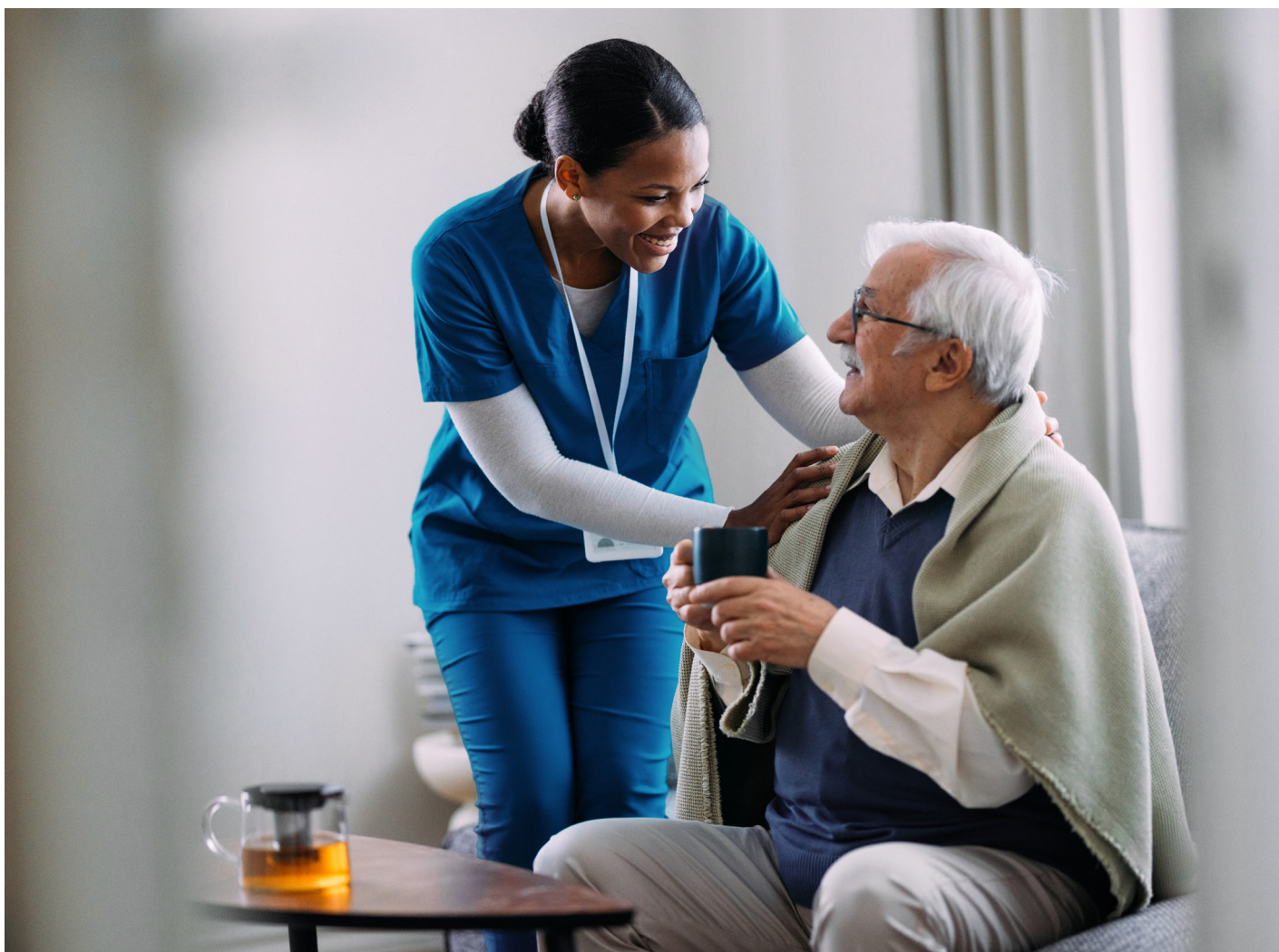
Signs of distress or agitation

Navigating escalating situations through effective communication



Distressed

Practical communication tips for distressful moments



Day-to-day

Gentle communication strategies for everyday

In everyday interactions, using calming communication strategies is essential to create a peaceful and supportive environment, which enhances understanding and reduces anxiety for both the person with dementia and their caregivers. Fredrickson's (1998) theory of positive emotions (Kunz et al., 2022) suggests that feeling good can help us come up with new and creative ideas. On the other hand, negative emotions can hold us back and make us less engaged. To encourage better communication, it's important to focus on positive feelings.

Memory issues and support strategies

Memory issues can make it hard for individuals to recall words and recognise names, often leading to social embarrassment.

To assist a person with dementia:

1. Use strategies and cues: Implement techniques that encourage independence
2. Reduce repeated words: Provide prompts to help them access information more easily.

Some common difficulties for a person with dementia when communicating:

- Struggling to find words
- Repeating themselves (Zeigarnik effect)
- Getting confused easily
- Difficulty organising thoughts
- Feeling upset or frustrated
- Trouble reading body language or tone
- Misinterpreting others
- Withdrawing from conversations
- Saying inappropriate things
- Lack of interest in talking or activities
- They may use a related or similar word (e.g. 'Book' for 'newspaper'), use substitutes for words (e.g. 'Thing to sit on' instead of 'chair') or may not find any words at all.

Best practices for communication while wearing face masks:

- Consider using a transparent face mask to improve communication compared to surgical masks
- Important! Recognise that some emotions cannot be accurately interpreted with facemasks.

Practise these two techniques to overcome communication difficulties. These can help to establish a sense of security and trust.

1. Actions

- Be patient and calm: Give the person time to respond without rushing
- Meet them in their reality: Accept their perspective and avoid correcting them
- Be sincere: Treat people with genuine care, as if they were family
- Use a gentle tone: Speak softly to reduce stress
- Minimise distractions: Ensure a quiet environment to help them focus
- Use appropriate touch: Sometimes a gentle touch, like a hand on the shoulder, can show empathy and support. Always consider the other person's comfort and cultural background before doing so.

2. Active listening

- Maintain eye contact: Show you're listening but avoid staring
- Provide simple, clear information: Keep your words straightforward and easy to follow
- Use positive body language: Smile and use gentle gestures to show empathy
- Repeat or rephrase when needed: Clarify things if they're confused
- Validate their feelings: Acknowledge their emotions, offering comfort and understanding.

These can help to establish a sense of security and trust.

For more strategies, **scan the QR code** below:



Signs of distress or agitation

Navigating escalating situations through effective communication

If you notice that a person with dementia is becoming distressed or agitated, it's important to de-escalate tensions to restore calm and wellbeing.

Caregivers should consider...

- The person with dementia may feel reassured by a friendly face **they know and feel comfortable with** (don't take it personally if that is not you)
- Remain calm themselves, avoiding frustration or impatience
- Redirecting attention to a different topic or activity
- Offering reassurance with comforting phrases like, "It's okay, you're safe here," and using non-verbal cues such as a gentle touch or soothing gestures
- Acknowledge and validate their emotions by saying, "I can see you're feeling upset. It's okay to feel that way," and then gently steer the conversation or activity toward something more positive, like looking at a photo album or listening to calming music.

It is important to notice any change in behaviour patterns, is this normal for this person to exhibit aggression, agitation, distress?

When caring for a person with dementia, it is important to meet them in their reality, recognising that they may not always be fully present in the moment. This means understanding that their perceptions and memories may differ from yours. In some cases, therapeutic lying (James & Jackman, 2017) - offering gentle, supportive responses that align with their reality - can be beneficial. This approach helps reduce confusion and anxiety by providing comfort rather than confronting them with facts that may be distressing. For example, if a person believes they are at a family gathering, it might be more soothing to engage with that narrative rather than correct them. By validating their feelings and experiences, you foster a sense of security and connection.

Using Resolution Therapy to understand confusion

Questions

1. Is there an unmet need that is causing the distress?
2. Is the person in pain?
3. Do they need the bathroom?
4. Are they hungry?

Resolution therapy focuses on understanding the hidden meanings in confusion, aiming to uncover the underlying anxiety that may be causing distress. By carefully listening and exploring the emotions behind the words, caregivers can gain insights into the person's feelings and concerns. This approach helps address the root of anxiety, fostering better communication and emotional support.

Actions

- Gently Investigate Distress: Use open questions to explore possible causes of distress, such as, "Can you tell me what's bothering you?"
- Respect Personal Space: Always ask if you can sit near someone to ensure they feel comfortable
- Use Simple Language: Communicate in straightforward terms without being patronising
- Avoid Speaking Too Quickly: Take your time when speaking to allow for better understanding
- Redirect Attention: Shift the focus to a calming activity or topic, such as, "Let's look at some pictures together"
- Involve Familiar Objects: Use items like photos or favourite belongings to spark positive memories and conversations
- Be Flexible: Adapt your approach based on the person's mood and responses, being open to changing the topic or activity as needed.

Active listening

- Non-Verbal Cues: Use reassuring gestures, such as a gentle smile or nodding, to show you're engaged and supportive
- Validate Feelings: Acknowledge their emotions by saying things like, "I can see this is upsetting for you"
- Maintain Patience: Give them time to express themselves without rushing or interrupting.

Distressed

Practical communication tips for distressful moments

When communication reaches a point of escalation* or crisis, caregivers must be prepared to respond effectively while prioritising safety and wellbeing. This may involve implementing specific crisis communication techniques, such as using simple and direct language, avoiding arguments or confrontation, and providing physical space if needed. It is crucial to remain patient, understanding, and compassionate, even in challenging situations, and to seek support from other caregivers or professionals when necessary.

*Escalation in this context is behaviour that challenges –agitation, aggression, distress, and psychosis (NICE, 2015).

Developing coping strategies for when things go wrong.

The **DATA** method emphasises a compassionate approach to caregiving (James & Jackman, 2017).

Don't agitate

- Avoid actions or words that might provoke distress or anxiety. Stay calm and gentle in your interactions.

Tolerate

- Show patience and understanding. Recognise that the person may be experiencing confusion or frustration and respond with empathy rather than frustration.

Anticipate

- Try to foresee potential triggers for distress. Be aware of their environment and any changes that might affect their comfort or wellbeing. Preparing for these situations can help prevent escalation.

The **BANGS** method offers a helpful approach to managing challenging situations with individuals with dementia. James & Jackman, 2017.

Breathe

- Take a moment to pause and breathe deeply. This helps you remain calm and centred, allowing you to respond thoughtfully rather than react impulsively.

Access/accept/agree

- Access the situation by understanding the person's feelings and perspective. Accept their reality without judgment. Agree where possible to validate their feelings, even if their thoughts don't align with reality.

Never argue

- Avoid engaging in disputes over facts or reality. Arguing can escalate tensions and cause further distress. Instead, focus on understanding and supporting them.

Go/Let go

- If the situation becomes too heated or unproductive, it's okay to step back or let go of the topic. Redirect the conversation or activity to something more calming or enjoyable.

Say sorry

- If any misunderstanding occurs or if the person feels upset, acknowledge it by saying sorry. This can help rebuild trust and demonstrate empathy
- Attempt to remove what is upsetting them.

Scan the **QR code** below for further information on de-escalation techniques:



Reflective activity

1. In chapter 4, you reviewed a clip of Finbar feeling very distressed, how might the communication skills discussed in this chapter help to de-escalate his distress?



Additional communication strategies

To effectively de-escalate a tense situation, use mirroring techniques by subtly mimicking the other person's body language, tone, and pace of speech. Incorporate similar language and phrases to create a sense of connection, while actively listening and acknowledging their feelings to show empathy. Additionally, allowing pauses in the conversation can help both parties process their emotions, fostering a calmer atmosphere conducive to constructive communication.

Defusing situations through distraction

*e.g. "Look here is your favourite show on the TV!" Turning in the right direction - steering but not controlling - involves guiding a conversation without dominating it, encouraging a more positive mindset.

Communication strategies to support memory issues

- **Use the person's name and introduce yourself clearly.** For example, say, "Hello, [name of the person] I am the nurse caring for you this afternoon"
- **Talk directly to the person** with dementia, not just their carer, to respect their autonomy and acknowledge their presence
- **Display warmth in your tone and body language** to create a comfortable atmosphere, encouraging the speaker to express themselves more freely
- **Wear your name badge** as part of the #hellomynameiscampaign to promote familiarity and comfort
- **Be attentive** by actively listening to what the person is saying. Focus on both verbal and non-verbal cues to understand the full message and respond appropriately.

Creating positive moments through meaningful activities

Help a person with dementia to flourish by...

- Creating nurturing human connections through communication
- Initiating caring moments through storytelling, music, textiles, art, colours, patterns, photographs and images
- Involving family, friends and community
- Reminiscing with them, people with dementia prefer to talk about the past.
- Helping them to take part in familiar activities and skills (muscle memory often remains intact compared to words and verbal memories).

Scan the QR code below to view the reference list:



Reflective activity

Practice the following two techniques to improve communication if you notice that a person with dementia is becoming distressed or agitated to ensure a sense of security and trust. After applying these strategies, reflect on your experiences.

Part 1 – Actions

Gently investigate distress:

When you notice a person with dementia is upset, ask open-ended questions like, "Can you tell me what's bothering you?" or "How are you feeling right now?" without rushing or pressuring them.

Respect personal space:

When approaching a person with dementia, ask for permission to sit near them. For example, you can say, "Is it okay if I sit with you for a bit?" before taking a seat.

Redirect attention:

If the person becomes agitated, gently guide the conversation or activity to something soothing, such as, "Let's look at some pictures together" or "Would you like to hear a story?"

Part 2 – Active listening

Nonverbal cues:

While listening, use gestures like nodding, a gentle smile, or making eye contact to show engagement.

Validate feelings:

When someone shares something distressing, say phrases like, "I can see this is really upsetting for you" to acknowledge their emotions.

Maintain patience:

Allow the person time to express themselves fully without rushing them, even if it takes longer than expected. Avoid interrupting.

Time to now reflect...

...After applying the actions and active listening techniques, reflect on the following four points.

1. How did they respond?

- Did they seem more comfortable after you asked open-ended questions or allowed them to talk freely?

2. How did you feel while practicing the techniques?

- Did you feel more connected or compassionate while using non-verbal cues or validating their feelings?
- Was it challenging to maintain patience, or did it come naturally?

3. What worked well, and what might you adjust?

- Were certain actions or phrases more effective in building trust and security? Which ones worked best in calming or soothing the person?

4. Overall impact on communication?

- After practicing these techniques, did the conversation feel more collaborative or reassuring?
- Did the person express a sense of relief or comfort as a result of your communication approach?

Supporting a person with dementia requires great skill, compassion, kindness and patience, which is emotionally demanding. In the final chapter, we discuss a few strategies to support your own wellbeing.



are you ok?

Chapter 6 - Carer and staff support

Scott McEwan and Madison Ling

Caring for a person with dementia requires skill, compassion, knowledge and patience. Demonstrating these behaviours can be exhausting in a busy clinical environment or caring for a loved one at home. It is important to acknowledge the impact that caring for a person with dementia has on us as individuals. Recognising this, talking about it and sharing your experiences with others in your team can provide you with support. In this final chapter, we talk about looking after yourself as a caregiver. It involves creating strategies that promote emotional wellbeing, reduce stress, and enhance the quality of care. The information discussed in this chapter is not exhaustive and there are other methods that might work for

you better, but the idea is for you to start to think about them. These suggestions can also be offered to family caregivers as well.

There may be difficult times where you feel exhausted, hopeless, or disappointed in yourself. This could be due to not being able to provide the care you wanted or felt the patient deserved, it could be you felt angry and frustrated at the patient or loved one and wanted to walk away. This can lead you to spiral to where you cannot see past the situation. By grounding yourself to the present this can help take you out of your spiral and bring you back to the moment

It is important to remember that it is human to have these feelings, and you need to remember to care for yourself too.

In moments of intense stress or frustration, stepping away, taking a deep breath, and remembering why you chose to work in healthcare can be really beneficial. This break helps you reset emotionally and refocus. You chose to work in healthcare likely to be a nurse because you wanted to help, you have a caring nature and want to give the best care possible. This is a great first step, as we can often forget why we have chosen our direction, which can add to the negative feelings when situations arise. Reconnecting with your purpose helps you reframe the situation and recognise your positive impact, even if it doesn't feel that way in the moment. It should help you to become more rational, logical, and clear-sighted.

Sometimes stressful situations make it harder for us to stick to how we want to be as carers, and we can often judge ourselves harshly later because of this. A good next step is the process of 'visualising' what you want to happen.

As healthcare professionals, we can visualise how a great colleague or carer would act in this situation. Perhaps this may be how we imagine a great role model to be, or perhaps we're thinking of a particular mentor who has inspired us in the past. Try to visualise what values or principles that colleague or carer would stick to, then visualise how they would act in order to keep to those values. We could focus on patience or compassion, for example, which gives us a map of behaviour to follow.

Breaking down the situation into its components and evaluating what went well and what could be improved helps you make more informed decisions and manage stress or anxiety. Setting short- and long-term goals can also help you to plan for returning to the patient.

When a situation occurs like the video has shown us, stress levels rise, and the feeling of hopelessness can start to set in. This makes it hard to stay focused on the fact that the person you are caring for needs your respect and empathy. There are many techniques that can help to ground or anchor you. These techniques need further training and in the heat of the moment we need to ask ourselves if they are the right thing to do.

Relatives and staff in crisis might not be open to trying mindfulness techniques, they might become more upset or "brush" you off. It is important to bring immediate support, by talking and listening, some of the communication skills from chapter 5 can be applied here. By using active listening and looking at non-verbal communication you can allow the staff or relative to "offload" their concerns in a controlled way.

The simple task of offering tea/coffee and letting them sit with you can make a difference. You might be able to pick up compassion fatigue from relatives and staff and be able to sign post and offer support.

By building rapport with relatives, you may notice recurring patterns and recognise when their mental/physical health is deteriorating through stress, compassion fatigue or emotional labour. Remember you are not a trained therapist, but you can signpost and listen. Wellbeing services for staff within the trust provide the opportunity to talk to trained professionals, they are able to offer therapists to explore how you are feeling and help you to discover useful strategies and anchoring techniques, or if you need some time away this through work leave or reallocation to a different ward or workplace for a short time.

For relatives, you can refer to the Alzheimer's Society for a wide range of support, including access to therapists, arranging respite, advice for taking next steps and helping with crucial family affairs.

Remember to **SELF CARE**

S

Sleep well

Prioritise rest and aim for 7-9 hours of sleep each night to recharge your body and mind

E

Eat nutritiously

Fuel your body with balanced meals rich in fruits, vegetables, whole grains, and lean proteins

L

Love yourself

Practise self-compassion, acknowledge your worth, and embrace positive self-talk

F

Find you

Engage in activities that bring you happiness and fulfilment, whether it's a hobby, sport, or spending time with loved ones

C

Connect with others

Build and maintain supportive relationships with friends, family, and your community

A

Actively move

Incorporate regular physical activity into your routine, whether it's walking, yoga, or any form of exercise you enjoy

R

Relax and unwind

Dedicate time to relax through mindfulness, meditation, or any activity that helps you to de-stress

E

Engage in growth

Continue learning and growing by pursuing new skills, knowledge, or personal development opportunities.

Summary

When a patient arrives in hospital, it can be a daunting experience. If a patient is cognitively impaired the hospital environment is even more frightening. Patients may feel isolated, disorientated, confused and in pain, but be unable to express these needs. The film and this resource is there to help you understand how that person may be feeling in an unfamiliar environment, and what role you can play to reduce their anxiety.

Taking time to know your patients beyond their medical diagnosis can help you to understand their thoughts, behaviours, challenges and even fears. By prioritising person-centred care, you can improve the quality – and sometimes efficiency – of care you give through additional knowledge.

Consider your hospital environment and how it can be made more dementia-friendly. This may be assessing a ward's layout, safety measures, lighting and possible noise or distractions. Taking appropriate measures, such as using contrasting colours to aid with visual misperception or making clearer signage, may help to minimise disorientation and confusion for patients living with dementia.

Knowing the person through holistic assessment can be just as important as physiological assessment. Asking a patient or carer to tell you more about them, for example using tools such as “This is Me” documents, can be very helpful.

Assess your interactions with each patient and ask yourself what they may be trying to communicate with you. Remember the traffic light system:

- **Day-to-day (green)**
- **Signs of distress and agitation (amber)**
- **Distressed (red).**

Interpret behaviour and communication and respond appropriately. Ask yourself if there are any warning signs or triggers for escalation. Remember strategies to de-escalate and manage each situation accordingly.

Providing good quality care can be demanding, taking care of yourself will positively impact the quality of care you can give.

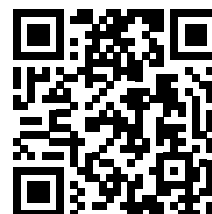
Take time to complete the reflective activities throughout the workbook to enhance your learning experience.

NMC revalidation

As part of a registered nurses revalidation this workbook can contribute to your CPD activity. Write a reflective account on your learning after completing the book.

Further guidance on completing your revalidation can be found via the following link:

www.nmc.org.uk/revalidation/



To view further resources and information, **scan the QR code** below:



Thank you for using Insight Dementia, a resource designed to support healthcare professionals working in hospitals understand and care for individuals living with dementia.

Your input would be incredibly valuable in helping us understand the impact of this resource for healthcare professionals and we would love to hear your feedback.

Please complete a short survey (designed to take no longer than 5 minutes to complete) on your experiences, **scan the QR code** below:



Contact us:

Email: **adrc@bournemouth.ac.uk**

X (Twitter): **@BournemouthADRC**

For more information on nutrition for people with dementia,
visit: **www.bournemouth.ac.uk/nutrition-dementia** or
scan the QR code below:

