

## **Reflective questions**

### **1 Introduction**

We introduce the idea of social inclusion early in the book because we feel that challenging it will improve the lives of people with dementia. Do you feel it is possible to challenge stigma and exclusion? How might you go about doing this either with individuals or within society as a whole?

### **2 The experiences of people with dementia**

Consider a memory or story about yourself that you enjoy re-living. What does this tell you about yourself and your identity? If this memory or story was lost, how might your sense of self be diminished? What are the implications of this insight?

### **3 Brain basics**

Make a list of brain regions or areas that you have heard of. Do you know what their function is thought to be? What might be the impact on the person if these brain regions were affected by dementia? Consider the extent to which you believe that better understanding of the brain can improve insight into dementia.

### **4 Progression of dementia**

Think about a person you know who has been diagnosed with dementia. What advice would you offer in the early period after diagnosis has been made? This is likely to be a long journey and when people families are affected by dementia it is hard not to become anxious about the situation. What coping strategies can you suggest at this stage? Justify your answer.

### **5 Alzheimer's disease**

Neuroscientists and other researchers do not know how to prevent Alzheimer's disease from occurring and there is currently no cure. Does this knowledge affect the kind of care you provide? What would you say to a person whose father had dementia and was worried that they are at risk of developing the disease and feels anxious?

### **6 Vascular dementia**

Carers sometimes report that people with vascular dementia struggle to interpret visual and non-visual clues. Can you explain why this might happen? How might the person with dementia react when they have difficulty? What strategies might you use to improve communication?

### **7 Less common forms of dementia**

There are more than 100 different forms of dementia. Choose one form with which you are unfamiliar. Carry out a simple literature search to find out more about the unfamiliar condition with the aim of identifying some information that will help you to change the ways you are currently doing things. Who might benefit from the change you have identified? In what way would people with dementia be affected if you were to implement this change? Plan how and when you could implement the change.

### **8 Younger people with dementia**

Consider a real or imaginary person recently diagnosed with early-onset dementia (EOD). What do you feel they might need most from someone in your role? How could you best provide this? What feelings might the situation provoke for you? How would you look after your own mental health during your time supporting a person with EOD?

### **9 People with learning disabilities and dementia**

Consider one of the problems identified in the chapter. How does the combination of learning disability and dementia exacerbate the problem?

### **10 Promoting health to reduce risk of dementia**

You are probably aware of health promotion campaigns, for example, for smoking cessation. There may be a campaign aimed at a health issue that you can relate to yourself. To what extent are you able to follow the advice given? What helps and hinders you in maintaining a healthy lifestyle? How could you apply this insight if designing an anti-dementia campaign?

### **11 Recognition and assessment**

Reflect on the fears that a person with slight memory problems might have about seeking assessment and diagnosis. What feelings might they have and how might these feelings drive the person's behaviour?

Consider whether you believe that an earlier diagnosis is always best. What are your reasons?

### **12 Post-diagnostic advice**

Think about an activity that you enjoy that others might consider risky (e.g. a sport, driving too fast, going out late). Reflect on the implications and feelings that would arise if you were restricted and unable to continue. What solutions might you suggest to enable a person like you to continue to have fun?

### **13 Signposting**

Consider the resources available in your local area that could be useful to people with dementia. Could you gather all these (e.g. links with a brief summary of what is offered) and add it to a Facebook page for local people, or offer it to the person managing a website for your locality?

### **14 Values**

On reading the chapter, what aspect of the discussion resonated most with you? Write about how this value could be upheld in a situation relevant to you.

### **15 The work of Tom Kitwood**

Note the needs of people with dementia, according to Kitwood. Then reflect upon how you have or could contribute to meeting these needs for a person with dementia that you know (or if you do not know anyone with dementia yet, anticipate for an imaginary person).

### **16 Cultural issues**

Consider the role of a 'sick' person within your family. What is a sick person expected to do? How could a health or social care professional adjust the care they offer to make it more culturally congruent and

acceptable for you? Then consider how sick people are expected to behave in a culture different from your own. How could you adjust the care you offer to make it culturally congruent and acceptable to a person from that culture?

### **17 Spirituality**

Reflect on what gives your own life meaning. How could someone support you to meet this need if you had dementia? Now consider someone with a completely different spiritual belief system to your own. How might you learn to do the same for them?

### **18 Communication**

Reflect on a recent conversation you have had with a person with dementia, focusing on one sentence or phrase that sticks in your mind. What was the person saying? How did their expression add to or contradict their message? Were emotions conveyed? How might what they said connect to an earlier part of their life? List and consider the many possible meanings of their interaction with you. What is the significance of what they were communicating?

### **19 Common dementia-related problems**

Sometimes the term 'challenging behaviour' is used to refer to some of the problems arising for people living with dementia and those around them. How does avoiding the use of this term benefit both people with and without dementia?

### **20 Depression in people with dementia**

Consider a person with dementia that you know, or if you do not know anyone with dementia yet, create an imaginary person. How could you do simple things to raise their self-esteem?

### **21 Delirium in dementia**

Think back to a time when you woke up in the middle of the night and were not sure where you were or what day it was. How did this feel, even if only for a few seconds? What might it be like for a person with dementia who is also delirious? How could other people respond so as to reassure someone in this situation?

### **22 Psychosis in people with dementia**

Consider a person with dementia who holds a delusionary belief (e.g. that they need to collect their children from school). How might the belief connect to the needs of people with dementia that Kitwood identified? What else might the delusion mean in relation to the person's history and identity? How might you respond to the person, showing empathy for their experience?

### **23 Sensory impairment**

Think about the needs of an individual with dementia who has a sensory impairment. In what way are his/her needs different from another person who has dementia? What, if anything, would you do differently and why?

### **24 Falls**

People at high risk of falling are often advised frequently to 'sit down'. Imagine someone telling you to sit down – how does it make you feel? What emotional and physical needs are met by getting up and walking about?

### **25 Nutrition**

Reflect on the tastiest and most enjoyable meal you have ever had. What made it so special? Could any of these characteristics be recreated for a person with dementia who needs assistance with meeting nutritional needs?

### **26 Protecting and caring for skin**

Think about a time when your skin was broken or very dry. What steps did you take to alleviate the problem? How did it feel afterwards? Can you use this insight to consider your approach to skin care for people with dementia?

### **27 Continence**

Do you remember a time at nursery school when you or a classmate wet their knickers/pants? What were the consequences? How does it make you feel now, looking back? Can you use this memory to imagine the experience of a person with dementia and continence problems and to consider what a suitable response should involve?

### **28 Constipation**

Next time you go to a public toilet, as an experiment, 'forget' to lock the door. Are you able to urinate or defecate? How would you explain this response?

### **29 Exercise and dementia**

Think about a time when you were feeling fed-up and had to do some housework or walk from one place to another. Did the activity change your mood? If so, in what way? Are there simple things that you could involve a person with dementia in which would involve movement and could lift mood at the same time?<Author: Please check the sentence 'Are there simple things that you could involve a person with dementia in which would involve movement and could lift mood at the same time?' for clarity.>

### **30 Dementia-friendly communities**

Consider a small area near to where you live or work. What features are dementia-friendly and why? If nothing seems dementia friendly, what would you suggest that would make a difference?

### **31 Medication for dementia-related problems**

Reflect upon the many different ways, apart from through speech, that a person with dementia could show or communicate that they are in pain. Consider how you could become more alert to these forms of communication and what you would do as a result.

### **32 Anti-dementia medication**

Anti-dementia medication offers hope to those with dementia and to future generations. However, they do not work for everyone and do not work indefinitely. How would you support a person with dementia or a family carer through the process of coming off one of these medications?

### **33 Medication management**

The terms 'compliance' and 'concordance' are sometimes used to describe the extent to which a patient goes along with the treatment plan. What do you feel are the differences in meanings between the two terms? Which do you feel is best? What are your reasons?

### **34 Cognitive interventions**

Consider what the term 'failure-free' means and illustrate it with examples. How could you adjust an activity that stimulates thinking to ensure it becomes 'failure-free'?

### **35 Activities for people with dementia**

Think of a time when you last played a game – maybe a game of cards with other people or a board game or jigsaw with some children. How did it feel while you were playing? What was different from 'normal' life? Can you think of ways to recreate this type of experience for people with dementia?

### **36 Creativity and people with dementia**

Identify a creative activity that allows you to lose yourself in the flow. What feelings are created? How could you adjust the activity to include a person with dementia?

### **37 Music therapy**

Tap out the rhythm of a song you learnt as a small child, then hum or sing it. Can you remember the words? What emotions arise? Does the music evoke a particular time, place or relationship? Consider the advantages and disadvantages of using music from a person's past for reminiscence or relaxation.

### **38 Reminiscence**

Find an old photograph from your childhood. Write about the feelings this evokes. If you were telling your best friend about the time, what would you say? How would talking about the photograph with a caring person affect you? How might this insight influence your practice when using reminiscence with a service user?

### **39 Life stories and memory boxes**

Consider a minority group that you belong to or include people living near to you. If you were making a community memory box, what would you put in it? If you do not know, how could you find out and where would you gather the items from? What emotions would you anticipate might arise from using a memory box with people from the group, and how might you support participants?

### **40 Reality orientation**

Read about the pros and cons of reality orientation. If you had dementia, would you prefer those around you to take an orientating approach or a validating approach? What does this answer reveal about you?

#### **41 Validation**

Think about a person who has severe dementia and is unable to communicate verbally. How might you convey empathy in your responses and show that you are trying to understand their feelings?

#### **42 Sensory environments**

It can be difficult to provide sensory rooms in every environment. Consider how you could promote sensory pleasure within your own home or work environment and how you would be able to tell whether this has been effective.

#### **43 Pets: animals as therapy**

Think back to your first pet or memory of interacting with an animal. Try to recall all the different feelings this evoked. Reflect on how re-experiencing these types of feelings could be positive or negative for a person with dementia.

#### **44 Assistive technology**

Sometimes assistive technology is spoken about as surveillance and control. How would you balance rights and risk when using a specific technology? Are you in favour of the use of assistive technology? If so, make an argument against it. If against, consider the points in its favour. Compare notes with a colleague – what do your arguments tell you about your beliefs about people with dementia?

#### **45 Design for dementia**

Think about your favourite café or bar. How could it be made more 'dementia-friendly' using the principles outlined in the chapter? How might these changes affect the character of the place? Do you think that character and dementia-friendly design can co-exist, and if so, how?

#### **46 Relationships and dementia**

Think about the relationship that you have with the person who is closest to you. What do they do for you that others do not? Imagine if they stopped, or were not able to do so any more. What emotions might you feel? How might you cope with these feelings and what support might help you?

#### **47 Sex and sexuality**

What do you feel about people with dementia having sex? What does this tell you about your attitudes and beliefs about the autonomy of people with dementia? How could you assist a person with dementia in meeting sexual needs? If a person with dementia had the capacity to make the decision to pay for sex, would you feel it right to facilitate this?

#### **48 Carers' issues and carer support**

Consider all that a person gives up to be the main carer for a person with dementia. What are the benefits for a person with dementia in being cared for by a loved one? Do you feel it is right that a large part of one person's well-being is put to one side for the sake of another's? What could you do within your role to support and empower a carer so that their own quality of life remains good?

## **49 Reducing stress levels for family carers**

Read about resilience in this chapter. Reflect upon the protective factors that enhance your own resilience and consider how you could develop these further.

## **50 Having difficult conversations**

What particular 'difficult conversation' do you find the most challenging? Consider what the reasons for this might be. What advice would you give someone in your position in working out what to say and how to behave?

## **51 The multi-disciplinary team**

How many different professionals might someone with dementia meet in the course of their 'dementia journey'? (You may be aware of more than are mentioned in the chapter.) How could you support them to make sense of and cope with this experience?

## **52 Care planning**

Think about a person you know who has dementia. How could you use what you know about their personality and life history to make their care plan more person-centred and effective?

## **53 Personal care**

Think about what you know about the rules about washing and dressing in a culture different from your own, then imagine being assisted to wash or dress by a person from that culture who does not know about your norms. What might happen and how might you feel? Can you use this insight to guide how you approach the care of people with dementia, all of whom have their own norms?

## **54 Resistance to care**

Ask a friend to help you with an exercise in which they either brush your teeth for you or feed you yoghurt. How soon do you want to ask them to stop? What feelings arise? What makes the exercise easier or more difficult?

## **55 Sundowning syndrome and sleep**

Think of a time you awoke from a very vivid dream. What feelings did you have? How long did they last for? What helped you shift them? Can you imagine how this experience might be similar and different for a person with dementia?

## **56 Transitions**

What are the factors that make transitions difficult for people with dementia? Consider what you could do to make a difficult change of location less stressful for a person with dementia.

## **57 Walking**

This behaviour associated with later stages of dementia used to be known as 'wandering'. What are the implications of each term? Which do you feel is best, or can you come up with a better alternative? If so explain your choice.

## **58 End-of-life care**

It can be difficult to talk about end of life, or death. Are there any factors that might make it difficult or easier for you? How can people make it less challenging to discuss this topic?

## **59 Abuse, neglect and safeguarding**

Imagine that a person with dementia makes an allegation against one of your team. You find it hard to believe the allegation. Think about how you would feel, how you would manage your own emotions and what you should do next.

## **60 Ethical issues**

What do you feel about the term 'therapeutic lie'? What ethical principle supports this approach? and which could be undermined? What do you feel would be the right approach to this type of dilemma and why?

## **61 Advocacy**

Consider a situation where the autonomy and wishes of a person with dementia may be over-ruled. How might you be able to stand up for the person? What feelings might you have? and how would you manage them? How would you manage the consequences?

## **62 Mental capacity**

How would you go about incorporating a person's life history into a decision made in their best interests? Give an example and consider what the benefits of this approach might be.

## **63 Leadership issues**

Everyone can be a leader by influencing others. What would you want to change within your own sphere of influence in the field of dementia care? How could you take on leadership characteristics and practices so as to make this change happen?

## **64 Research**

It is considered very important to involve people with dementia and family carers in the design and development of research programmes. What do you feel are the reasons for this? How could this be facilitated?

## **65 Conclusion**

Reflect on a time when you might anticipate that you could be at risk of developing dementia. What do you hope will be in place by then? How could you contribute to making this a reality?