

Why you should read this article:

- To enhance your understanding of how therapeutic communication can reduce levels of distress as well as behaviour that challenges among people with dementia
- To be aware of the common, but often ignored, communication strategy of lie telling with people who have dementia and its associated moral, ethical and professional dilemmas
- To count towards revalidation as part of your 35 hours of CPD, or you may wish to write a reflective account (UK readers)
- To contribute towards your professional development and local registration renewal requirements (non-UK readers)

Extending the Newcastle Model: how therapeutic communication can reduce distress in people with dementia

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Citation

Jackman L (2020) Extending the Newcastle Model: how therapeutic communication can reduce distress in people with dementia. *Nursing Older People*. doi: 10.7748/nop.2020.e1206

Peer review

This article has been subject to external double-blind peer review and has been checked for plagiarism using automated software

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Conflict of interest

None declared

Accepted

14 August 2019

Published online

January 2020

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Abstract

This article identifies the importance of effective communication in delivering care to people living with dementia when their understanding of the situation may differ to ours. The Newcastle Model's biopsychosocial framework is revisited to understand the context in which caregiving takes place, and the article goes on to consider the importance of communication to person-centred care delivery. The special case of lie telling or 'therapeutic untruths' as a communication tool is considered as an often essential way to join with the person's reality, and the practical and ethical dilemmas this poses are considered.

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Keywords

active listening, Alzheimer's disease, communication, dementia, ethical issues, mental capacity, mental health, neurology, nurse-patient relations, older people, psychology

Aim and intended learning outcomes

The aim of this article is to provide an update on ideas and concerns about working in dementia care settings with people expressing behaviour that challenges. It extends the concepts explained in a previous article, which introduced an approach to working with people expressing behaviour that challenges based on psychological formulation – the Newcastle Model (Jackman and Beatty 2015). The article identifies the importance of effective communication when interacting with people who have dementia and aims to raise awareness about the common, but often ignored, communication strategy of lie telling.

The success of the Newcastle Model often relies on the ability of nurses and clinical support staff to change their responses when

a person is distressed or angry. The article outlines a training approach to improve staff's communication skills and explores lie telling as an example of a communication strategy. The ethics and practicalities of embedding lie telling in formal intervention strategies to avoid distress and behaviour that challenges are considered.

While the article is aimed at nurses and clinical support staff working in long-term care settings, many of the concepts and issues raised may apply to people caring for friends or relatives at home, or formal home carers. The article advocates a structured approach to communication and deciding to withhold the whole truth from someone with dementia. It recommends that such an approach should be considered only as part of a planned

intervention based on what is known about the person, their understanding of their world and their present or predicted level of distress.

After reading this article and completing the time out activities, you should be able to:

- » Recognise examples of ineffective communication in your work environment and how they affect people's behaviour.
- » Reflect on examples of your emotional and behavioural responses to a challenging episode, and how these responses might relate to the way you could or do communicate.
- » Consider the case that telling lies or 'untruths' (Kirtley and Williamson 2016) can sometimes be a positive intervention strategy.
- » Develop care plans with colleagues that include 'therapeutic lying' as part of a planned intervention.

The Newcastle Model

The Newcastle Model has been developed over several years as an intervention to address behaviour that challenges in people with dementia (James 2011). The model is a structure (visual format for gathering assessment materials) and a process (assessment, formulation, care planning, and review). Clinicians using the Newcastle Model are often part of small specialist teams working with care home staff and carrying relatively small caseloads. The clinicians complete an approximately 12-week intervention including: assessing the behaviour that challenges; gathering information from staff, friends and family; and observing alongside staff in the care setting. They then draw up a 'formulation' or hypothesis of the person's challenges, which is presented to staff in a shared session.

The information gathered by clinicians reflects Kitwood's (1997) supposition that the person's experience of dementia and subsequent behaviour is influenced by multiple factors, not only their cognitive impairment. Kitwood (1997) suggests the equation $D=NI+PH+B+MSP$, where D = dementia, NI = neurological impairment, PH = physical health, B = biography and MSP = malignant social psychology. Malignant social psychology describes the social context of the person's experience of dementia, particularly the ways in which caregiver interactions can affect the person's psychological well-being. An example is 'outpacing' where the caregiver does not respond to the person's slower processing speed and therefore provides them with no time to respond to requests or carry out actions such as getting dressed.

Clinicians using the Newcastle Model gather information about a person's present and

past physical and mental health, personality, biography, medication and communication. They ask staff to observe and record instances of behaviour that challenges in terms of what the person says (their thoughts), how they look (their feelings) and what they do (their behaviours). Clinicians are also interested in triggers to situations and what happens after a challenging incident occurs. This information allows them to understand the behaviour in terms of a cognitive behavioural framework – linking thoughts, feelings and behaviours – and the behavioural framework – antecedent, behaviour and consequence (Loddon Mallee Regional Dementia Management Strategy 2019) – that might be more familiar to nurses. This information is presented in the formulation session in a way that gives staff a framework for understanding the behaviour (Jackman et al 2014). Staff are then invited to debate and develop ideas for approaches to the person with dementia based on what needs the person is thought to be trying to meet (Jackman and Young 2013).

TIME OUT 1

Read the article on the Newcastle Model by Jackman and Beatty (2015) to provide a framework for your learning from this article

Communication

The success of any care intervention depends on how it is provided. In the author's work in dementia care settings it is clear that people can provide 'care' that the recipient experiences as unhelpful. This can lead to conflict, which can in turn open the way for behaviour that challenges and further provision of unhelpful care. As the behaviour of both parties escalates, those providing care may, in extreme situations, need to physically restrict or restrain the person with dementia. Case study 1 shows how this can occur in practice (a pseudonym has been used).

The trigger to the conflict described in Case study 1, and the subsequent aggression and restriction of Mrs Smith, was unthinking communication by the nurse that, while well intentioned, confronted Mrs Smith with a 'truth' with which she did not agree. Both parties were trying to make sense of, and react to, the situation they perceived themselves to be in.

Communication and Interaction Training

Training nurses and carers of people with dementia to identify and manage this type of spiralling miscommunication is at the heart of a programme developed by Ian James and

Key points

- When a person living with dementia does not share the same reality as you, that is, they might believe they are younger and still at work, keeping them safe and well can be challenging and can cause conflict, for example, if the person believes they are late for work and tries to leave a locked building
- Effective communication when providing care to people living with dementia is essential, especially in these circumstances. This begins with basic 'customer care', and sometimes needs an in-depth understanding of the possible causes of behaviour that challenges
- It is often difficult to manage challenging situations in this 'shifted reality' without telling the person something that is not true
- Telling a 'therapeutic untruth' may be an acceptable way of working if it is carefully thought through, in the person's best interests and there is no other option available

FURTHER RESOURCES

Teepa Snow’s Positive Approach to Care – Using Hand-under-Hand™ to Assist with Getting Dressed – Shirts and Coats

[youtube.com/watch?v=WnIOEfQtOow](https://www.youtube.com/watch?v=WnIOEfQtOow)

Mental Health Foundation– What is truth? An inquiry about truth and lying in dementia care

[tinyurl.com/MHF-dementia-care-inquiry](https://www.tinyurl.com/MHF-dementia-care-inquiry)

colleagues as a result of working with care homes to introduce the Newcastle Model. This programme is known as Communication and Interaction Training (CAIT) (James and Gibbons 2019).

A person with dementia often needs to be persuaded either to start a behaviour, such as washing, or stop a behaviour, such as leaving a building (James and Hope 2013). When nursing or care staff need to direct or prompt a behaviour, there is potential for conflict and behaviour that challenges to occur. The ability to communicate effectively with a person who has dementia is crucial, but few people working in dementia care settings receive formal teaching in this area.

CAIT is not designed to teach new skills to care staff, but to enhance their pre-existing communication skills. The CAIT programme is summarised in this article but more information can be found in James and Jackman (2017) and James and Gibbons (2019). The CAIT programme is delivered in modules. Module 1 covers core general

communication, or fundamental customer care skills. Respectful communication that shows the overall wish to be helpful is the minimum expectation. Simple ways to engage with ‘customers’ include:

- » Using the person with dementia’s name and introducing yourself to them by name.
- » Showing active listening through positioning and facial expression.
- » Using positive language, for example by avoiding saying ‘no’.
- » Having a plan for how the conversation will end.

Nurses and care staff should check that people’s glasses or hearing aids are available and working so that they can participate.

The second module relates to dementia-specific communication. Attendees gain awareness about how their own emotional state and that of the person with dementia can lead to misunderstandings and unhelpful responses, like the exchange shown in Case study 1. Links between thoughts and emotions are identified to show how easily miscommunication can arise. Table 1 shows examples of possible thoughts that may lie behind a person’s emotions. It also suggests that what people are thinking can be guessed from what they say.

Case study 1

A nurse approaches Mrs Smith (a pseudonym) because a member of someone else’s family has reported that she smells strongly of urine and there is a wet patch under her chair.

Nurse: ‘Come on Betty, time to go to the toilet.’

The nurse’s intention is to relieve Mrs Smith’s discomfort and ensure her skin remains intact.

Mrs Smith: ‘I don’t need the toilet.’

This is true because Mrs Smith has already passed urine. She feels embarrassed and angry that she is being treated as if she is a child and worries what other people will think of her.

Nurse: ‘Come on now, don’t make a fuss, everyone is watching.’

The nurse offers her hand and, when this is rejected, feels hurt because her intention was to save Mrs Smith from further embarrassment. She takes Mrs Smith’s arm.

Mrs Smith: ‘Get off me!’

She pushes the nurse away and becomes aware of other people watching. She feels angry she is being stared at and says, ‘You can all go to hell!’ Other residents shout at her to be quiet and mind her language.

To manage her embarrassment and avoid further conflict, Mrs Smith pushes past the nurse to leave the room and knocks her over, causing her to hit her head on the door frame. Two other members of staff take Mrs Smith by the arms and lead her to a different room.

Link between emotions and thoughts

The link between emotions and thoughts is an essential part of the Newcastle Model. In a Newcastle Model formulation we look at the relationship between what someone is thinking, often by what they say; how they feel, often by their facial/non-verbal expressions; and their behaviour. CAIT extends this link by showing the potential for both parties in the interaction to contribute to escalating distress. The aim of the second module is for attendees to become mindful of where they could reduce emotions to a level where a conversation can take place.

Table 1. Links between a person’s emotions, thoughts and speech

Appearance/emotion	What thoughts might lie behind this emotion?	What might the person say that helps us guess their thoughts?
Depressed	The person may see no hope for the future and perceive themselves as worthless; they may believe the world to be an unfriendly place	‘What’s the point?’ ‘You lot don’t care!’ ‘I might as well be dead’
Anxious	The environment is threatening, the person feels unsafe, people are not predictable	‘Get her away from me!’ ‘Where are you going? Stay here!’ ‘I want my mum’
Angry	The person feels others are being unfair and that their rights are being infringed; they may think they are not being listened to or taken seriously	‘How dare you!’ ‘Who do you think you are?’ ‘F--k off!’

TIME OUT 2

In the exchange between the nurse and Mrs Smith in Case study 1 how could the nurse have managed the situation without Mrs Smith thinking that people were noticing her and that she was being treated like a child? If the nurse had taken a different approach, what might Mrs Smith think and feel?

CAIT’s third module focuses on activities of daily living (ADLs) such as personal care. Effective and sensitive communication is important here: having a stranger approach you for personal care can evoke feelings of shame and anger with consequent behavioural

responses such as hitting or pushing away.

Personal care requires physical touch and an invasion of a person's private space. This module introduces the work of Teepa Snow (Snow 2018) who trained as an occupational therapist (OT) in the US and has developed an approach to working with people with dementia that has been incorporated into CAIT. Teepa Snow advocates a three-stage approach to supporting people with dementia with their care:

- » Visual: ensure the person can see you approaching but pause while you establish eye contact.
- » Verbal: use the person's name and offer them formal physical contact through a handshake. Do not use overly complex language and accompany your conversation with gesture.
- » Touch: the technique developed by Teepa Snow is called Hand-under-Hand®, a supportive handhold that emerges from an initial handshake. The carer guides and supports the person's movements, leaving them with the sense they are completing the activity themselves.

It is important to understand which stage of dementia a person has reached and adapt approaches to their level of functioning. James and Jackman (2017) summarise different assessment tools for identifying a person's skill level and how best to provide support at the appropriate level. One tool is the Pool Activity Level scale (Pool 2002), which is commonly used by OTs in dementia care services. Understanding the level at which a person is functioning can change interactions with, and guide expectations of, the person.

The third CAIT module also promotes the need for preparation before offering personal care. This can be achieved by making sure the person is calm before you approach and preparing environments such as bathrooms to concentrate on interaction, not task, for example, by ensuring that towels are available.

The next time out shows how we can communicate with a person with dementia to encourage them to participate in personal care rather than imposing a task on them.

TIME OUT 3

Watch the video at [youtube.com/watch?v=Wn10EfQt0ow](https://www.youtube.com/watch?v=Wn10EfQt0ow), which illustrates the Hand-under-Hand® technique in action, and try it with a family member or friend. First, do the activity the way you would usually do it and then try it using the Hand-under-Hand® technique. Then ask someone to try it on you to see which you would prefer

The fourth and final module of CAIT represents approaches to managing people expressing behaviour that challenges. Further information can be found in Jackman and Beatty (2015) and James and Jackman (2017).

In Case study 1 there was a discrepancy between Mrs Smith's idea of what was happening and the nurse's understanding. There was a lack of agreement about the 'truth'. For people with dementia expressing behaviours that challenge, the use of lies or 'untruths' is one common but rarely discussed communication strategy for managing these different perceptions of truth.

Truth and lying in dementia care

The success of the Newcastle Model depends on care staff contributing to the development of interventions and putting them into practice.

Once the formulation has been shared, some plans can be simple and intuitive. For example, if a person has been described as 'attention seeking' this is explored within a formulation framework.

The group is asked what needs the person may be expressing with their behaviour and would usually conclude that the person does not experience enough interaction any other way. The intuitive response would be to ensure that the person's need for interaction is met, often by structuring staff responses to ensure the person receives attention without needing to express behaviours that are considered challenging. Other interventions may be counterintuitive, however, and so cause ethical and professional dilemmas for staff. Even when the Newcastle Model is used the person with dementia sometimes continues to experience issues with understanding and adjusting to their environment.

Various approaches can be taken to interactions with a person with dementia who may be confused and feeling lost. Two of the most well-known approaches are reality orientation and the validation method (Feil 1993). In reality orientation, the person who is confused is reoriented to the present day and their circumstances. For example, someone wishing to leave to go to work would be reminded of their age and that they are living in a care home.

The validation method involves responding in an empathetic way to a person's behaviour without correcting them. Instead, the listener would comment on the feeling state of the person. For example, if a resident expressed a wish to leave to go to work, the nurse might say: 'It sounds like you're really missing work. What is it that you miss the most?'



Revalidation

Prepare for revalidation: read this CPD article, answer the questionnaire and write a reflective account.

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TIME OUT 4

You are visiting a nursing home where many of the doors are locked because most of the residents have dementia and would be at risk if they left the building unattended. As you leave, you are approached by a resident who looks confused and asks you to let them out because they want to go home. They are worried their mother does not know where they are. What would your response be?

A reality orientation approach could involve reminding the person that they are in a care home and people living there cannot leave without a member of staff. A validation approach could involve saying: 'You sound worried about your mum.' If you were the resident and were worried about your mother, which approach would you prefer? How could each approach affect what you think and make you feel, and how do you think you would respond?

Nurses and care staff will try to respond to the distressed person in as kind a way as possible. They are aware of the risks involved in, for example, allowing a resident to leave a care home and of the possibility that a 'reality check' can cause extra distress. However, in the absence of other options, it is common for care staff, visitors and family members to tell lies.

There has been much discussion about the term 'lying', with other, gentler, versions of not telling the truth being offered to describe it. For example, people may talk about 'going along with' something that a person with dementia has said, but which they know is untrue, such as talking about a dead parent as if they are still alive. The Mental Health Foundation advocates the term 'untruth' to indicate the lack of malicious intent behind the lie (Kirtley and Williamson 2016).

It is not only words that are used to deceive people with dementia. Changes to the environment, such as painting an exit door the same colour as the wall to disguise the route to leave, are also examples of deception, although they may be referred to as 'environmental modifications' (Remington et al 2006).

Should this practice be regarded as a form of 'treachery', as described by Kitwood (1997), and therefore a potential threat to someone's 'personhood'? Such questions divide thinking and, even among regulatory bodies, there is disagreement. For example, the Nursing and Midwifery Council (2018) and General Medical Council (2019) do not support the use of lies.

A Mental Health Foundation inquiry about truth and lying in dementia care (Kirtley and Williamson 2016) garnered opinion from a panel of experts, including people with dementia and carers. The inquiry report recognises the challenges of developing guidelines about the use of 'untruths' but accepts the practice within defined parameters

if it protects the well-being of a person with dementia. It also notes the dilemmas that arise from the terminology used to discuss the subject. The report notes that truth and lies are usually seen as being opposites, with truth being honourable and good, and lies dishonourable and bad. Consequently, those caring for a person with dementia who adopt strategies in which the truth is not being shared may feel they are not fulfilling their moral obligations to the person (Kirtley and Williamson 2016).

Several websites address the issue of lying to people with dementia and differentiate between lying and other approaches in which the truth is not shared. For example, the Alzheimer's Society (2019) refers to 'bending the truth' and gives an example of responding to an enquiry about a dead relative with 'don't worry, they are safe'. If the person did not have dementia, however, would this type of deceit be acceptable?

The Mental Health Foundation inquiry report acknowledges that lie telling and deceit occur as a matter of course in everyday life to protect ourselves or others from hurt (Kirtley and Williamson 2016). Lies may even be accepted or expected, for example by people seeking reassurance about their personal appearance; these may be described as 'white lies'. Ultimately, the decision about whether a lie to someone with dementia is acceptable or not depends on the intention of the lie, including that it must be perceived to be in the person's best interests. This is an area fraught with moral, ethical and professional dilemmas.

Why do we need to tell lies or withhold the truth?

Discussions with those caring for people with dementia suggest that carers sometimes 'go along with' what a person with dementia says to them, knowing that to confront them with the truth could cause them distress, embarrassment, sorrow or anger. In this context, it is useful to consider the contributions of declining memory and thinking skills to the person with dementia's confusion about the truth. The 'time machine' analogy can be adopted to consider ways of joining the person in their reality.

In all dementias, memory issues occur as the condition progresses, with short-term memory being a problem in the early stages of Alzheimer's disease. Over time, a person's reference point can be to events further and further in the past: they may remember their wedding day or the birth of their children, but not who visited the day before or a conversation from an hour ago. This is because, as the brain changes, the hippocampus, which is the area of the brain thought to be responsible for forming new memories, is one of the first to be affected.

The hippocampus is less important for older memories, so it is easier for the person with dementia to access memories from long ago (Alzheimer's Society 2015).

Although reorienting a person with dementia to the 'facts' of a situation may work in the early stages of the condition, it requires the person to recognise and accept the facts being given to them as true. Memory is essential for this but so are other aspects of the brain's functioning, such as the ability to reason and to manage emotional arousal, which are also compromised in dementia. These are both associated with changes in the frontal lobes and other areas of the brain that contribute to executive functioning (Alzheimer's Society 2015).

One way of understanding the experience of a person with dementia is to imagine they have 'time-shifted'. In other words, their frame of reference is from another point in their lives. As part of the formulation process, it is often useful to draw a timeline of important events in the person's life and consider what their current frame of reference could be from information they give you. For example, a woman who says she is worried about who will pick her children up from school may believe she is still in her twenties or thirties. Where did she live then? Who else was in her life? This idea has been developed into an exercise known as the time machine (Mackenzie et al 2015), which is intended to support carers of people with dementia to appreciate the effect of time-shifting on the person's understanding and behaviour. Mackenzie et al (2015) present a visual representation of the timeline during a formulation session so that attendees can debate the most effective approach to managing the discrepancy between their own reality and that of the person with dementia.

If a person understands themselves to be young and with responsibilities, such as to collect children, go to work or let a parent know they are safe, but those around them tell them this is not true, a conflict can arise, and can escalate as each partner to the communication believes themselves to be the holder of 'fact'. Often in these situations the person with dementia may believe they are being lied to even when they are being told the truth.

What kinds of lies do we tell?

A study by Mills et al (2019) found that people tell lies, or withhold the truth, to put someone's mind at rest or fit in with their reality. However, some lies may be told to manage a potentially challenging situation or to get a job done. In this study, a group of professionals from specialist dementia services were asked what

lies they had heard in the course of their work and to speculate about the intention of each lie. The resulting statements were analysed and grouped into categories, which suggest that people see a difference between outright lying and manipulations of the truth, as reflected in the Mental Health Foundation inquiry report (Kirtley and Williamson 2016). Table 2 shows the categories and sub-categories of lies identified by Mills et al (2019).

There are times when lying is perceived to be in a person's best interests but other lies are related more to carer needs, as Case studies 2 and 3 show.

Table 2. Categories of lies

Category of lie	Subcategory	Explanation	Examples of lies	Perceived intention of type of lie
1. Non-client related: lies concerning actions or well-being of another person	1.1 Delayed fulfilment of request	Putting off requests by the client to see a person, who in many cases is deceased	'Your dad is coming to get you at 9.30am tomorrow'	Reducing immediate distress and managing subsequent behaviour that challenges
	1.2 Providing reassurance of well-being	Assuring client that a specific person, who may be deceased or now grown children, is safe	'The bairns are at school and will be home soon; they're safe'	Reducing distress by providing reassurance that the person in question is safe
	1.3 Explanation for absence	False account of where a relative, who in many cases is deceased, is	'Your mam's not at home at the moment, she's gone to the shops'	Reducing distress and managing behaviour that challenges, such as aggression. This type of lie involves a more direct but less reassuring mechanism for care staff to defuse a challenging situation
2. Client related: lies concerning activity or well-being of client	2.1 Enactment	Performing a false role or story to match the client's reality	Staff engage with toy cat as though it were real, for example by putting food out for it at a resident's request 'No need to go to work this morning, you're on holiday'	Meeting person with dementia's personal care needs, and reducing their anxiety and behaviours, such as wandering
	2.2 Fobbing off	Excuses for why something cannot happen	'You can't use the phone because it's broken'	Used for the benefit of others, rather than for the person with dementia, to reduce distress for visiting relatives

(Mills et al 2019)

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TIME OUT 5

In Case studies 2 and 3, which lie could be seen as 'fobbing off'? How would you describe the lie telling in the other case study (refer to Table 2)? What was the intention of the lie telling in Case studies 2 and 3? With a colleague consider the following: have you heard these type of lies in dementia care settings? Are either of these approaches acceptable and, if so, why? What are the dangers inherent in the deception used in both case studies?

It can be the case that lie telling is the only acceptable way to support a distressed person, and perhaps this is the conclusion you drew from Case study 3. However, even lies told in a person's best interests can cause distress if the person concerned has more insight at that moment than was predicted. Case study 2 involves a person with dementia being 'fobbed off'. This can be a short-term solution, if the person is perceived to be at risk and is gently guided away, but in the scenario the person grew more frustrated every time she was given the wrong information, and did not stop her 'risky' behaviour of trying to enter the kitchen until her need for a drink was met.

The prevalence of lie telling in dementia care settings is identified in James et al's (2006)

Case study 2

A member of nursing staff on an older adult assessment ward for people with dementia is in an office close to a kitchen. The office door is open and the nurse can hear a patient, Beryl (a pseudonym), repeatedly trying to access the kitchen. Each time Beryl sees a member of staff she complains she cannot get in and asks for help. Over about half an hour, the nurse hears four different responses to Beryl:

'I don't have a key for that.'
'You don't need to go in there.'
'Nobody is allowed in there.'
'That isn't a kitchen. Let's go and sit down.'

Eventually, the nurse leaves the office and asks Beryl what she wants from the kitchen. Beryl tells her she is thirsty, so the nurse unlocks the door and pours her a glass of water from the tap.

Case study 3

Sadie (a pseudonym) is a 74-year-old woman with dementia. Her husband died six months ago and she is living in a care home now because she has no other family members who can support her. Since she moved in she has become confused and, if asked for her age, says she is in her thirties. On most days she forgets her husband has died and seeks him out occasionally, especially late in the afternoons when she would have expected him home from work. When she cannot find him, she gets increasingly upset.

On several occasions she has tried to leave the building, which is unsafe because she does not know the neighbourhood and cannot cross a road safely. She has also had a few falls. She has become aggressive towards staff who try to dissuade her from leaving. She has damaged a fire door and scratched a member of staff who tried to stop her leaving. Some members of staff are trying to manage the situation by telling Sadie that her husband is at the local allotment when she asks about his whereabouts. This sometimes calms her, which allows them to distract her with other activities.

Some members of staff have gone as far as inviting Sadie to make sandwiches in the kitchen to give her husband for his tea when he returns. However, there is disagreement between staff members about whether it is okay to 'lie' to Sadie about her husband's death, and some staff tell her the truth. Sadie often becomes upset and angry when she perceives them to be lying. She wonders if her husband is having an affair. At other times, the approach serves to remind Sadie about her husband's death and, although she is sad, she accepts it and moves on with her day.

programme of research into communication strategies. Recognising that lies are usually told to avoid or alleviate distress, they coined the phrase 'therapeutic lying' to describe lies that are told with a person's best interests at heart. These are different from lies told to prompt a person to behave in ways that make caring for them easier, such as saying their daughter is visiting to persuade them to get dressed before the early shift arrives. James et al (2006) recommend that lies are told only when other approaches have failed and that all approaches should be considered as part of a hierarchy of needs framework. Such a framework is described by James and Jackman (2017) and is suggested to form a protocol for managing challenging questions and requests. The suggested steps are:

1. Meet the request if possible.
2. Substitute the need or validate the person's thinking.
3. Distract the person and introduce a new need.
4. Meet the request using a therapeutic lie.

They also advocate that therapeutic lying should be based on a formulation of the person with dementia's understanding, past experiences and responses to truth telling; that is, it should be planned carefully and used consistently but as a last resort.

In Case study 3, care staff perceived that Sadie needed to know where her husband was. Attempts to meet this need by explaining the situation to her were unhelpful most of the time. Another approach would have been to validate her need, perhaps by recognising that she was worried and reassuring her there was nothing to worry about. Failing this, she could have been distracted from trying to find her husband.

It is not always possible or desirable to try each of these approaches until one works. Sadie could have seen them as further attempts to fob her off. Instead, people working with Sadie were encouraged to be aware of all the possible approaches and worked together to consider the signals Sadie was giving that one approach might work over another. Approaches were not seen as a hierarchy but as a toolkit, with the choice of tool driven by Sadie's apparent level of understanding at a particular time.

The Newcastle research group has developed several sets of guidelines about controversial practices including the use of therapeutic lies (James et al 2006, Mackenzie et al 2007). However, readers can access other material to inform their opinion about these practices. The Mental Health Foundation inquiry report (Kirtley and Williamson 2016) similarly suggests a continuum along which decisions

about telling lies or untruths to a person with dementia can be made.

TIME OUT 6

Read the Mental Health Foundation inquiry report on truth and lying in dementia care at www.mentalhealth.org.uk/publications/what-truth-inquiry-about-truth-and-lying-dementia-care and discuss the following questions with a colleague:

- » What are your feelings about the words 'lie' and 'untruth'?
- » Do you feel that the report advocates the same approach as that outlined by James and Jackman (2017)?
- » What are your personal beliefs about withholding the truth from a person with dementia?

In an article explaining the Newcastle Model structure and process, Jackman and Beatty (2015) refer to the importance of care planning for promoting consistency and monitoring strategies. It is vital that interventions that raise these ethical dilemmas are subject to discussion, agreement and care planning. This will ensure that managers and senior staff can monitor their effectiveness, and explain and justify their use to families, visitors and regulatory organisations such as the Care Quality Commission.

Conclusion

This article has summarised the Newcastle Model, which adopts a psychosocial approach to predict, prevent or work with people who have dementia and behaviour that challenges. The team that developed the model has also devised the CAIT programme for care staff to manage communication with people who have dementia and decrease the likelihood of

behaviour that challenges occurring. However, under some circumstances, more reactive strategies are required and, in care homes, one of these strategies is to tell a lie or withhold the truth from the person with dementia.

The negative connotations of lying mean this is a controversial practice. The Newcastle Model is a structure and a process and the use of lies or untruths is only recommended to care staff in the context of a structured formulation and care planning meeting and in the context of a person lacking capacity. Lie telling and deceit should only be used if the truth would cause distress to the person with dementia and is in their best interests. The prevalence of this practice, and the feelings of unease it can give care staff, families and professionals, have prompted research into why, when and how lie telling is appropriate or inappropriate, including an inquiry report by the Mental Health Foundation (Kirtley and Williamson 2016).

TIME OUT 7

Consider how therapeutic communication to reduce distress and behaviour that challenges among people with dementia relates to The Code: Professional Standards of Practice and Behaviour for Nurses, Midwives and Nursing Associates (Nursing and Midwifery Council 2018) or, for non-UK readers, the requirements of the regulatory body

TIME OUT 8

Now that you have completed the article, reflect on your practice in this area and consider writing a reflective account. Guidelines are at rcni.com/reflective-account

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References

- Alzheimer's Society (2015) Dementia and the Brain. alzheimers.org.uk/sites/default/files/migrate/downloads/factsheet_dementia_and_the_brain.pdf (Last accessed: 12 November 2019.)
- Alzheimer's Society (2019) Telling the Truth to People with Dementia. alzheimers.org.uk/get-support/daily-living/making-decisions-telling-truth (Last accessed: 10 October 2019.)
- Feil N (1993) The Validation Breakthrough: Simple Techniques for Communicating with People with 'Alzheimer's-type Dementia'. Health Professions Press, Baltimore MD.
- General Medical Council (2019) Good Medical Practice. gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice (Last accessed: 12 November 2019.)
- Jackman LJ, Young J (2013) Exploring 'unmet needs' in dementia care. *Journal of Dementia Care*, 21, 3, 32-34.
- Jackman L, Beatty A (2015) Using the Newcastle Model to understand people whose behaviour challenges in dementia care. *Nursing Older People*, 27, 2, 32-39. doi: 10.7748/nop.27.2.32.e666
- Jackman LJ, Wood-Mitchell A, James IA (2014) Micro-skills of group formulations in care settings. *Dementia*, 13, 1, 23-32. doi: 10.1177/1471301212442463
- James I (2011) Understanding Behaviour in Dementia that Challenges: A Guide to Assessment and Treatment. Jessica Kingsley, London.
- James IA, Hope A (2013) Relevance of emotions and beliefs in the treatment of behaviors that challenge in dementia patients. *Neurodegenerative Disease Management*, 3, 6, 575-588. doi: 10.2217/nmt.13.60
- James IA, Jackman L (2017) Understanding Behaviour in Dementia that Challenges: A Guide to Assessment and Treatment. Second edition. Jessica Kingsley, London.
- James IA, Gibbons L (2019) Communication Skills for Effective Dementia Care: A Practical Guide to Communication and Interaction Training (CAIT). Jessica Kingsley, London.
- James IA, Wood-Mitchell AJ, Waterworth AM et al (2006) Lying to people with dementia: developing ethical guidelines for care settings. *International Journal of Geriatric Psychiatry*, 21, 8, 800-801. doi: 10.1002/gps.1551
- Kirtley A, Williamson T (2016) What is Truth? An Inquiry about Truth and Lying in Dementia Care. Mental Health Foundation, London.
- Kitwood T (1997) Dementia Reconsidered: The Person Comes First. Open University Press, Buckingham.
- Loddon Mallee Regional Dementia Management Strategy (2019) ABC of Behaviour Management. dementiamanagementstrategy.com/Pages/ABC_of_behaviour_management.aspx (Last accessed: 12 November 2019.)
- Mackenzie L, Wood-Mitchell A, James I (2007) Guidelines on using dolls. *Journal of Dementia Care*, 15, 1, 26-27.
- Mackenzie L, Smith K, James I (2015) How a time machine concept aids dementia care. *Nursing Times*, 111, 17, 18-21.
- Mills R, Jackman L, Mahesh M et al (2019) Key dimensions of therapeutic lies in dementia care: a new taxonomy. *OBM Geriatrics*, 3, 1, 12. doi: 10.21926/obm.geriatr.1901032
- Nursing and Midwifery Council (2018) The Code: Professional Standards of Practice and Behaviour for Nurses, Midwives and Nursing Associates. NMC, London.
- Pool J (2002) The Pool Activity Level (PAL) Instrument for Occupational Profiling: A Practical Resource for Carers of People with Cognitive Impairment. Second edition. Jessica Kingsley, London.
- Remington R, Abdallah L, Melillo KD et al (2006) Managing problem behaviors associated with dementia. *Rehabilitation Nursing*, 31, 5, 186-192. doi: 10.1002/j.2048-7940.2006.tb00134.x
- Snow T (2018) Dementia Caregiver Guide: Teepa Snow's Positive Approach to Care Techniques for Caregiving, Alzheimer's, and other Forms of Dementia. Cedar Village Retirement Community, Ohio MO.

Therapeutic communication for people with dementia

TEST YOUR KNOWLEDGE BY COMPLETING THIS MULTIPLE-CHOICE QUIZ

1. The Communication and Interaction Training programme is designed to:

- a) Develop caregivers' resilience
- b) Improve communication with people with dementia
- c) Tell lies to people with dementia
- d) Increase the activity levels of people with dementia

2. Which of the following is not a feature of respectful communication?

- a) Showing active listening
- b) Introducing yourself to the person
- c) Planning how the conversation might end
- d) Saying no

3. Who developed the Hand-under-Hand® technique to support people with dementia?

- a) Tom Kitwood
- b) Murna Downs
- c) Teepa Snow
- d) John Hardy

4. Which of the following factors could influence a person with dementia's behaviour?

- a) Neurological impairment
- b) Physical health
- c) Biography
- d) Any of the above

5. What emotion is most likely being expressed by a person with dementia who says: 'Where are you going? Stay here!?'

- a) Anxiety
- b) Depression
- c) Anger
- d) Contentment

6. It is important to assess and understand a person with dementia's emotions to:

- a) Avoid behaviour that challenges
- b) Reduce the person's distress
- c) Understand the person
- d) All of the above

7. What is a useful tool to assess a person with dementia's skill level?

- a) Confusion Assessment Method
- b) Pool Activity Level scale
- c) DisDAT
- d) Traffic Light Assessment

8. Which approach involves responding in an empathetic way to a person who may be confused without correcting or lying to them?

- a) Reality orientation
- b) Therapeutic lying
- c) Validation
- d) Distraction

9. Which of the following reasons for lying to a person with dementia is most likely to be adopted for the benefit of others?

- a) Delayed fulfilment of request to see a deceased relative
- b) Providing reassurance of another's well-being
- c) Fobbing off
- d) Enactment

10. A helpful way to manage a challenging request from a person with dementia may be to:

- a) Tell the person you cannot help
- b) Ignore the person
- c) Say no
- d) Distract the person

How to complete this assessment

This multiple-choice quiz will help you test your knowledge. It comprises ten multiple choice questions broadly linked to the previous article. There is one correct answer to each question.

You can read the article before answering the questions or attempt the questions first, then read the article and see if you would answer them differently.

You may want to write a reflective account. Visit rcni.com/reflective-account

Go online to complete this multiple-choice quiz and you can save it to your RCNi portfolio to help meet your revalidation requirements. Go to rcni.com/cpd/test-your-knowledge

This multiple-choice quiz was compiled by **Sonia Shepherd**
The answers to this quiz are:

1 b 2 d 3 c 4 d 5 a 6 b
7 b 8 c 9 c 10 d

This activity has taken me ___ minutes/hours to complete. Now that I have read this article and completed this assessment, I think my knowledge is:

Excellent Good Satisfactory Unsatisfactory Poor

As a result of this I intend to: _____

