

## Nursing Practice

### Discussion

# Dementia

**Keywords:** Dementia/Nurse's role/  
Medication/Personal care/  
Multidisciplinary team  
● This article has been double-blind  
peer reviewed

How active listening, empathy and providing the right environment for people with dementia can help nurses build a therapeutic relationship and improve outcomes

DEMENTIA: PART 4 OF 4

# The nurse's role in caring for people with dementia

## In this article...

- › How communication skills can empower people with dementia
- › Understanding the behaviour of people with dementia
- › The nurse's role in caring for people with dementia

**Authors** Catharine Jenkins and Bernie Keenan are senior lecturers, School of Nursing, Midwifery and Social Work, Birmingham City University; Laura Ginesi is a lecturer in physiology, School of Health Sciences, University of East Anglia, Norwich.

**Abstract** Jenkins C et al (2016) Dementia 4: The nurse's role in caring for people with dementia. *Nursing Times*; 112: 27/28, 20-23. This final article in a four-part series on dementia focuses on the nurse's role in managing dementia and highlights the importance of communication skills in providing high-quality care. It also discusses treatment options, such as medication and ensuring the patient's nutritional needs are met, as well as the importance of dealing sensitively with behavioural problems that may mask pain or emotional difficulties. Finally, it explains how the care environment can make a huge difference to the lives of people with dementia, where aspects such as clear signage and assistive technology can contribute to dignity and quality of life.

Most of the 850,000 people who have dementia in the UK live at home with their families (Alzheimer's Society, 2014), and the difficulties associated with dementia mean nurses often respond to requests for support and advice from family carers. At the same time, nurses in all settings often have to manage patients' co-existing health problems and assist with personal care.

Although most people with dementia live independently or with minimal support, around a third live in care homes (Alzheimer's Society, 2014) and, while nurse education places high value on the attitudes

and skills needed for best practice, this has not always been reflected in the care provided on the ground. This series aims to provide an up-to-date guide to dementia and dementia care for nurses in any setting.

### A growing demographic

The risk of developing dementia increases with age, as does the risk of developing long-term conditions such as arthritis, diabetes and cerebrovascular or respiratory problems (Akushevich et al, 2013). 'Old age' occurs earlier for people with learning disabilities, and this group is particularly vulnerable to cognitive impairment (Glasson et al, 2013). People with dementia therefore often have co-existing problems, or comorbidities. At any time, 25% of patients in a general hospital may have dementia and this group is at higher risk of readmission and death than other patients admitted with the same conditions (Department of Health, 2013) – this means the identification and care of people with dementia is a crucial responsibility for nurses.

Responding to the complex combination of comorbidity and polypharmacy, particularly in environments that may be unfamiliar to the patient, means caring for people with dementia can be a challenge for the nurses aiming to provide high-quality care. Kitwood (1997), and more recently Brooker and Latham (2016), offer guidance on how nurses can respond to the needs of people living with dementia using a person-centred approach, which involves developing a therapeutic relationship and getting to know the individual's life story and preferences.

While the intention of treatment is to maximise wellbeing and aim for early discharge home, the experience of the person

## 5 key points

**1** Every intervention and interaction is an opportunity to build trust and rapport

**2** Nurses can tailor their communication skills and the environment to empower people with dementia

**3** Learning to understand behaviour can enable nurses to make people with dementia feel more comfortable and secure

**4** A strong nurse-patient relationship facilitates accurate assessment and improved outcomes

**5** The nurse is part of a multidisciplinary team that includes other health professionals, the person with dementia and their family carers



People with dementia experience short-term memory loss, which can be confusing

living with dementia is equally important. People with dementia have previously stated their priorities in a series of empowering statements for Dementia Action Alliance (2010), and all nurses in partnership with people with dementia, family carers and other members of the multidisciplinary team have a role in achieving these positive outcomes (see Box 1).

### Recognising dementia

An important aspect of the nurse's role is to observe and report any potential signs of underlying dementia. However, although early diagnosis leads to better treatment options and advance decision making, the condition is currently underdiagnosed (Jenkins et al, 2016).

The assessment process is complicated because of mixed factors – such as being in unfamiliar environments, having a high temperature or constipation (which can lead to delirium), and depression – have overlapping symptoms (Westerby and Howard, 2011), which can be easily misinterpreted. If a patient is withdrawn, anxious, seems lonely, has no appetite, is agitated and upset, and asks the same questions repeatedly, the signs could indicate delirium or depression as well as dementia. It is also possible to have more than one condition concurrently.

Accurate diagnosis of dementia, depression or delirium is the key to correct treatment, and nurses in any setting who are observant, empathetic and trusted by patients are ideally placed to identify problems (Table 1). People with dementia will feel safe with a trusted and familiar nurse, and be more able to:

- » Speak honestly about their concerns;
- » Allow the nurse to help them with personal care.

If a patient is diagnosed with delirium, the underlying physical problem must be addressed urgently (for example antibiotics to treat an infection). Patients who are depressed should be offered psychosocial interventions such as befriending, antidepressant medication and psychological therapy such as counselling (National Institute for Health and Care Excellence, 2009).

Similarly, if a patient has been diagnosed with a form of dementia they will usually be offered anti-dementia medication. The team should also make dementia-friendly adjustments to their approach and the environment – be they in a hospital or care home – to help them maintain a maximum level of functioning and quality of life. This can be done by ensuring:

- » Their bedspace is easily differentiated

**TABLE 1. DIFFERENTIATING BETWEEN LOW MOOD, DEMENTIA AND DELIRIUM**

Signs of low mood	Signs of dementia	Signs of delirium
Gradual onset	Usually gradual onset, though may worsen suddenly following a stroke	Quick onset, related to underlying deterioration in physical health
Feeling worse in the morning	Feeling worse in the afternoon	Pattern fluctuates
Self-blame; guilty feelings	Sometimes accusing others	Conversation difficult to understand; may refer to places and objects not present
Complaining of aches and pains	Behaviour may indicate pain	May not be able to communicate about pain
Inability to enjoy life	Can enjoy company, particularly of familiar people	May seem anxious or frightened but reassured by familiar faces
Poor sleep; early morning waking	Changes in sleep pattern; disorientation about time	May appear asleep for extended times of day and night; level of consciousness varies
Pessimistic in outlook; speech and responses may be slowed	Mood may change quickly; word-finding difficulties may make speech hard to follow	Speech disjointed and difficult to interpret; may seem unconnected to current reality, for example talk about 'seeing things' others cannot

from others through the use of colour or pictures;

- » Their bedspace is near a clearly signposted toilet;
- » Levels of light are good (Jenkins et al, 2016).

### Relationships, knowledge base and medication concordance

At present there are no cures for dementia, but there are four medications licensed in the UK that may slow its progress. It is part of the nurse's role to explain medications together with their side-effects to patients and family members; clear explanations aid decision making and are the basis of informed consent.

Nurses should also know where to find further information (for example, the *British National Formulary* online) and how to direct people to more information or support (for example, charities like Alzheimer's Society). As well as being familiar with online resources, they should also know about local agencies as not everyone has internet access.

Understanding how medicines work is extremely useful, particularly when responding to a patient or family member's questions. The cholinesterase inhibitors used to treat dementia (donepezil, rivastigmine and galantamine) work by preventing the breakdown of the neurotransmitter acetylcholine, which is needed for cognitive function (Neal, 2012). The drug memantine works differently, by disrupting the release of toxic levels of glutamate, which damages brain cells (Plosker, 2015).

People with dementia often have problems taking medicines due to poor

short-term memory, which means they may forget to take them or have already taken them and inadvertently take an additional dose. Asking to see a patient's tablets can help nurses gauge whether they are taking them appropriately; if they are, it is best not to interfere as they obviously have a system that works for them. However, if there are too many or too few tablets left in the packet compared with prescription dates, it may be useful to ask how they are coping with their medicines and suggest they consider a dosage system, such as a blister pack arranged by their local pharmacy, an assistive technology device or the help of a family member or carer.

People with diabetes who have managed that condition effectively for years may find doing so more difficult as they develop the memory problems associated with dementia. They may forget to eat properly or take their medication regularly, and may not recognise the signs of hypoglycaemia or communicate their needs effectively. Poorly controlled glucose levels can affect orientation and memory, while the risk of hypoglycaemia is greater if insulin is taken more often than prescribed (Hill, 2015). Assistive technology can be used to prompt injection times but, as time goes on people with both dementia and diabetes will need more support to manage their treatment (Sinclair et al, 2014).

### Capacity and medication concordance

Nurses, particularly those working in the community, often support patients' adherence to prescribed medication by working with them and their family to ensure they:

## Nursing Practice Discussion

- » Understand what the medicine is for and are prompted to take it if necessary;
- » Are able to remove medication from the bottle or packet and swallow it.

Changing from tablets or capsules to dispersible tablets or liquids can help overcome swallowing difficulties but the team should consider whether it would be more beneficial to withdraw some medicines when people with dementia are nearing the end of life (Jenkins and McKay, 2013).

Sometimes people with dementia may refuse medicine that is essential for their wellbeing; in line with the Mental Capacity Act 2005 this decision should be respected if they have the capacity to make it. Assessing mental capacity means talking with the person considered or suspected to have an impairment of, or a disturbance in, the functioning of the mind or brain, and assessing whether they can understand and retain relevant information, weigh it up and communicate their decision.

If a patient is thought not to have capacity to make the decision to refuse medicine, a multidisciplinary team discussion – involving the nurse, doctor, pharmacist and family carer – would explore alternatives and make a decision in the patient's best interests. In these circumstances, the team might decide to administer the medication covertly, which usually involves disguising it in food or drink. This should only be done after advice from a pharmacist, who will be able to decide whether the process is safe and the medicine will still be effective.

### Physical health

Through good care planning and collaboration with secondary care colleagues, or by advising and supporting family carers in community settings, nurses can help to ensure people with dementia:

- » Receive adequate fluids and nutrition;
- » Take exercise;
- » Go to the toilet normally (this will also help to ensure medication is metabolised effectively).

By taking simple actions such as ensuring people with dementia take personal effects such as hearing aids and glasses into hospital or to appointments, nurses can help them take part in conversations and maximise their orientation and personal choice.

Physical and emotional wellbeing are closely linked and any intervention to support one will also affect the other. For example, pain in people with dementia is often under-recognised, under-treated and can lead to low mood (Flo et al, 2014), which will make it more difficult for them to contribute to their own care. Sometimes pain

### BOX 1. PEOPLE WITH DEMENTIA: PRIORITIES FOR CARE

- I have personal choice and control or influence over decisions about me
- I know that services are designed around me and my needs
- I have support that helps me live my life
- I have the knowledge and know-how to get what I need
- I live in an enabling and supportive environment where I feel valued and understood
- I have a sense of belonging and of being a valued part of family, community and civic life
- I know there is research being undertaken that delivers a better life for me now and hope for the future

leads to behaviour that can be difficult for nurses to cope with, such as shouting or hitting out. Inability to express pain verbally may mean it is expressed through behaviour such as protecting the body, wandering, grimacing or groaning.

If pain is suspected, it is worth discussing the cause and possible prescription of analgesia with a member of the medical team – if analgesia is prescribed, patients should be frequently reassessed to see if they become more settled. Toothache can often lead to a reluctance to eat, in which case a referral to the dentist would be required. The Pain Assessment in Advanced Dementia Scale ([Bit.ly/IowaPA-INAD](http://bit.ly/IowaPA-INAD)) relies on non-verbal indicators to assess pain levels and can be useful for patients with communication difficulties (Jenkins et al, 2016).

### Care and communication skills

The therapeutic relationship between nurse and patient is central to high-quality nursing care. Communicating warmly, showing appreciation of patients' individuality and recognising their strengths can help them feel included and valued. Simple adjustments that can help to improve communication with people who have short-term memory issues include:

- » Using short sentences;
- » Using familiar vocabulary;
- » Using a warm tone;
- » Smiling during conversation.

It is important to leave time for them to reply, and to listen carefully, responding to the emotion expressed if the content of speech is unclear (for example, "You sound happy/upset about that"). It is best to avoid

questions, especially if the patient is unlikely to know the answer; instead, statements can foster inclusion while not being too demanding (for example, "We will all be happy when this cold weather is over".)

In the later stages of dementia when the memory has deteriorated further, patients may call for their mother or insist they go home to cook their husband's tea, for example; this can be difficult for nurses, especially if they know the parent or spouse has died. Rather than hiding the truth, however, it can be better to think about what the underlying emotion or need might be and respond to that – for example, "I'm sorry, she's not here, but I am. You're safe and I'm going to be with you all evening", followed by a distraction, such as "...and I could really do with a hand folding these towels") (Blackhall et al, 2011; Feil, 1993). Use of reassuring touch is acceptable where appropriate; patients will usually make it clear if they are not comfortable with a hand on their shoulder or their hand being held.

Nurses can also learn to "listen" to the behaviour of patients with dementia (for example, constantly walking may be due to pain, looking for someone or feeling bored or constrained). Imagining how these patients might be feeling – perhaps lost, alone and frightened – can help nurses to empathise and respond compassionately. Similarly, if they are unable to communicate verbally, their behaviour may provide clues about their feelings and needs. For example, interpreting behaviour perceived as challenging as an indication of distress is the first step in considering a response that might help people feel safe, comforted and included (Jenkins et al, 2016).

### Environmental adjustments

Hospital environments tend to be noisy and fast-paced and therefore difficult for people with dementia to cope with. However, the environment itself can be used to provide practical cues – for example, patients are more likely to remain continent if toilets are clearly labelled. Whether in the hospital or home, adjusting the surroundings can result in a more dementia-friendly environment. This includes:

- » Slowing and quietening the pace of life, for example through care planning, stopping to talk to patients and avoiding rushing when nearby;
- » Providing plenty of light;
- » Ensuring the decor conveys safety and comfort by using soft furnishings and muted colours;
- » Orientating patients via clear signs for toilets, bedrooms and kitchen areas. Design can also facilitate

independence: using contrasting colours to delineate door frames and separate areas will help patients move around a unit or home without risk. Similarly, placing personal items such as photographs at the bedside and using name signs on bedroom doors will help them to identify their own space. Assistive technology can also minimise unnecessary disturbance at night – for example enuresis detectors and automatic lights enable staff to respond when needed but otherwise allow patients and family carers to rest (Jenkins et al, 2016).

### Personal care

Most people would prefer not to be exposed in front of a stranger, yet people with dementia are asked to do this when being helped with personal care. This can be made easier if nurses use a warm, reassuring approach and ensure the patient's body is covered as far as possible. It is also important that staff members are allocated consistently so they become familiar to patients and gain an appreciation of their personal care preferences – for example, like whether they prefer their hair to be brushed in a certain way or have favourite clothes.

The Alzheimer's Society's (2016) *This is Me* document is useful for recording individuals' personal hygiene preferences and collecting information that can be used to build rapport; this could include hobbies, whether the person has or had any pets, and knowing which music they find distracting and relaxing.

### Carer support

Family carers often experience high levels of stress and neglect their own wellbeing while caring for a relative with dementia (de Oliveira et al, 2015). It is important to ask about their coping strategies and support network, and to work in partnership with them and the person with dementia (a "triangle of care") (Hannan, 2013).

Carers whose relative is admitted into hospital or a care home for respite might be having their first break for some time; nurses can take this opportunity to liaise with social services and voluntary organisations about providing an effective support package, which might also involve community nurse visits or further periods of respite care. This will also facilitate timely discharge. Under the 2014 Care Act the wellbeing of family carers is seen as equally important as that of patients.

### The multidisciplinary team

Members of the multidisciplinary team contribute in different ways to the wellbeing of people with dementia. As the

professionals who usually have the closest relationship with patients and the greatest understanding of their needs, nurses are central to referring to other colleagues for their expertise so need to know the best person to contact in each instance:

- » Doctors carry out assessments and decide treatments;
- » Pharmacists advise on medication prescription and management;
- » Physiotherapists design exercises to promote balance, rehabilitation and mobility, and make referrals for assistive technology;
- » Occupational therapists offer activities that promote independence and everyday skills;
- » Social workers assess support needs, design care packages and liaise with voluntary agencies and other services;
- » Home carers provide assistance with personal needs, for example, getting up in the morning, washing, dressing and having breakfast;
- » Community mental health nurses offer assessment support and advice, as do psychiatric liaison teams in hospitals;
- » Psychologists advise on specific problems such as practical measures to improve mood or providing counselling;
- » Admiral Nurses focus on supporting family carers.

In any inpatient environment used by people with dementia, receptionists, domestic workers and porters all contribute to patient wellbeing and should be offered training in how to deal with people with dementia so they can form part of the multidisciplinary team.

### Conclusion

Working with people who have dementia is challenging and fulfilling. As the population ages, providing effective person-centred care in a range of specialist fields for people with dementia will become essential for nurses. The ageing demographic means dementia care skills have become core skills. However, managing people with dementia requires patience, empathy, sensitivity and dedication; as such, it is important that nurses look after themselves and each other via peer support and mentoring, and extend this support to multidisciplinary colleagues (Jenkins et al, 2016).

The skills nurses develop while caring for people with dementia, such as sensitivity, compassion and empathy, are core qualities that all nurses should value as professional strengths. Similarly, the ability to listen and communicate effectively, provide care that meets patients' needs while recognising their individuality, and support

family carers, are central to the wellbeing of people with dementia. **NT**

### References

- Akushevich I et al (2013) Time trends of incidence of age-associated diseases in the US elderly population: medicare-based analysis. *Age and Ageing*; 42: 4, 494-500.
- Alzheimer's Society (2016) *This is Me*. alzheimers.org.uk/thisisme
- Alzheimer's Society (2014) *Dementia UK: Update*. alzheimers.org.uk/dementiauk
- Blackhall A et al (2011) VERA framework: communicating with people who have dementia. *Nursing Standard*; 26: 10, 35-39.
- Brooker D, Latham I (2016) *Person-Centred Dementia Care. Making Services Better with the VIPS Framework*. London: Jessica Kingsley.
- Dementia Action Alliance (2010) *National Dementia Declaration*. Bit.ly/DAADementiaDeclaration
- de Oliveira DC et al (2015) Ageing and quality of life in family carers of people with dementia being cared for at home: a literature review. *Quality in Primary Care*; 23: 1, 18-30.
- Department of Health (2013) *Dementia: A State of the Nation Report on Dementia Care and Support in England*. Bit.ly/DHDementia2013
- Feil N, de Klerk-Rubin V (1993) *The Validation Breakthrough*. Baltimore, MD: Health Professions Press.
- Flo E et al (2014) Effective pain management in patients with dementia: benefits beyond pain? *Drugs and Aging*; 31: 12, 863-871.
- Glasson EJ et al (2013) The triple challenges associated with age-related comorbidities in Down syndrome. *Journal of Intellectual Disability Research*; 58: 4, 393-398.
- Hannan R (2013) The Triangle of Care: carers included. *Journal of Public Mental Health*; 12: 3, 171-172.
- Hill J (2015) Diabetes and dementia: The implications for diabetes nursing. *Journal of Diabetes Nursing*; 19: 148-151.
- Jenkins C, McKay A (2013) Collaborative health promotion in middle and later stages of dementia. *Nursing Standard*; 27: 37, 49-56.
- Jenkins C et al (2016) *Dementia Care at a Glance*. Oxford: Wiley Blackwell.
- Kitwood T (1997) *Dementia Reconsidered: The Person Comes First*. Buckingham: Open University Press.
- National Institute for Health and Care Excellence (2009) *Depression in Adults: Recognition and Management*. nice.org.uk/cg90
- Neal MJ (2012) *Medical Pharmacology at a Glance*. Chichester: Wiley Blackwell.
- Plosker GL (2015) Memantine extended release (28mg once daily): a review of its use in Alzheimer's disease. *Drugs*; 75: 8, 887-897.
- Sinclair AJ et al (2014) Diabetes and dementia in older people: a best clinical practice statement by a multidisciplinary national expert group. *Diabetic Medicine*; 31: 9, 1024-1031.
- Westerby R, Howard S (2011) Early recognition and diagnosis. *Practice Nurse*; 41: 16, 42-47.

### ARTICLES IN THE SERIES

- Part 1: How dementia differs from normal ageing: 15 June
- Part 2: New approaches to understanding dementia: 22 June
- Part 3: Preventing and diagnosing dementia: 29 June

### For more on this topic go online...

- » Low-cost strategies to improve dementia care
- » [Bit.ly/NTDementiaStrategies](http://Bit.ly/NTDementiaStrategies)

