

Special Dementia Series

Article 3: The nurse's role in the care and treatment of people with dementia

Introduction

Most of the 850,000 people with dementia in the UK live at home with their families (Alzheimer's Society 2015). The difficulties associated with dementia, for example in understanding language and with self-expression, together with reasoning, memory, orientation and sequencing problems, mean that nurses frequently respond to requests for support and advice from family carers, while also providing care for coexisting health problems, assisting with personal care and meeting other dementia-related needs. Most people living with dementia live independently or with minimal support, but around a third live in care homes (Alzheimer's Society 2014). Modern nurse education places high value on the attitudes and skills needed for excellent dementia care, but this was not always the case. This article aims to guide nurses who may have learnt about dementia some time ago or who may be approaching this challenging and rewarding area of practice for the first time.

The risk of developing dementia increases with age, as does the risk of developing long-term conditions such as arthritis, diabetes and cerebrovascular and respiratory problems (Akushevich et al 2013). 'Old age' occurs earlier for people with learning disabilities and now that they are living longer, this group are particularly vulnerable to cognitive impairment (Glasson, Dye and Bittles 2013). Therefore people with dementia (with or without learning disabilities) often have co-existing problems, or 'co-morbidity', sometimes leading to a hospital admission or community referral for a complex mix of health issues. At any time 25% of patients in a general hospital may have dementia and this group is at higher risk of readmission and higher risk of death than other patients admitted with the same condition (Department of Health 2013). This means that the care of people with dementia is a crucial responsibility for nurses.

However, responding to the complex combination of co-morbidity and polypharmacy (taking four or more different medicines), particularly in environments that are unfamiliar to patients, makes the care-giving process challenging for both those living with dementia and the nurses aiming to provide high quality care. While the intention of treatment and care is to maximise well-being and aim for early discharge home, the experience of the person living with dementia is an equally important consideration. People with dementia have stated their priorities (Dementia Action Alliance 2010) in a series of empowering 'I statements':

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 going on which delivers a better life for me now and hope for the future.

Each nurse has a role to play (in partnership with their service users with dementia, family carers and multi-disciplinary team (MDT) colleagues) in achieving these positive outcomes.

The nurse's role in recognition of dementia

The term 'dementia' refers to a range of conditions including Alzheimer's disease, vascular dementia and Lewy Body disease. (Refer to articles 1 and 2 here). An important aspect of the nurse's role is to be observant and report pointers to possible underlying dementia. At present dementia is under-diagnosed, even though early diagnosis leads to better options for treatment and advance decision-making (Jenkins Ginesi and Keenan 2016). However, the assessment process is complicated because factors such as being in a strange place (think back to your first day on a ward!), having a high temperature or being constipated (which can lead to 'delirium'), or being very depressed, have overlapping symptoms (Westerby and Howard 2011) which can easily be misinterpreted by staff. If a person is withdrawn, anxious and seems lonely, has no appetite, or is agitated and upset and asks the same questions repeatedly, the signs could equally indicate delirium or depression as dementia. And of course it is possible to have more than one condition at a time!

Differentiating between low mood, dementia and delirium – some indications

Signs of low mood	Signs of dementia	Signs of delirium
Gradual onset	Usually gradual onset, though may worsen suddenly following a stroke (Cerebral Vascular Accident)	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	The person may not be able to communicate about pain
Not able to enjoy life	Can enjoy company, particularly that of familiar people	May seem anxious or frightened, reassured by familiar faces
Poor sleep – early morning wakening	Changes in sleep pattern, disorientation about time of day	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
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Accurate diagnosis dementia, depression or delirium (Refer to article 2) is the key to correct treatment and the nurse who is observant, empathetic and trusted by patients can make essential contributions to identifying problems accurately, as the person with dementia will feel safe both in speaking honestly about their concerns and allowing the nurse to help them with personal care, where further observations can be made. If a person is found to have delirium, the underlying physical problem will be addressed urgently (for example the person will be prescribed antibiotics if they have an infection). If a person is depressed, they could be offered psychosocial interventions, anti-depressant medication and a psychological intervention (NICE 2009). Similarly, if they have a form of dementia, they will usually be offered anti-dementia medication and the team will make 'dementia-friendly' adjustments to their approach and to the environment, to make it easier for the person with dementia to maintain a maximum level of functioning and quality of life (Jenkins Ginesi and Keenan 2016).

Relationships, knowledge base and medication concordance

At present there are no cures for dementia but there are four medications which slow down its progress and are licensed for the treatment of dementia in the UK (Please see table 1).

Drug name	Drug action	Therapeutic use	Drug side effects
Donepezil (<i>Aricept</i>)	Inactivation of cholinesterases, thus increases levels of acetylcholine and enhances cholinergic neurotransmission	Slows progress of dementia for some people, improves memory, communication and daily living skills. Used in early to middle stages of dementia, sometimes continuing into later stages.	Gastro-intestinal disturbances (poor appetite, nausea, vomiting), insomnia, tiredness
Rivastigmine (<i>Exelon</i>)			
Galantamine (<i>Reminyl</i>)			
Memantine (<i>Ebixa</i>)	N-methyl-D-aspartate receptor (NMDA) receptor antagonist so prevents toxic effects of glutamate over-	Usually used in later stages. May improve behavioural symptoms and delay progression of disease.	Dizziness, balance problems, constipation, headaches, raised blood pressure

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It is part of the nurse's role to explain medications and their side effects to patients and family members. Clear explanations help people to make understand the factors involved in decision-making and so are the basis of informed consent. The nurse should also know where to find further information (eg BNF online) and how to 'signpost' or direct people to more information or support (eg The Alzheimer's Society). It is useful to familiarise oneself with local agencies as well as online resources, as not everyone has internet access.

Understanding how medicines work is extremely useful for responding to a patient or family member's questions. The 'cholinesterase inhibitors' (Donepezil, Rivastigmine and Galantamine) work by preventing the breakdown of the neurotransmitter 'acetylcholine', which is needed (especially in the hippocampus) for cognitive function. Memantine works differently, by disrupting the release of toxic levels of glutamate, which damages brain cells (refer to article 1).

People living with dementia often have problems with taking medicines due to poor short term memory, which means they may forget to take them, or alternatively they forget that they did take them and inadvertently take more than one dose. Asking to see a person's tablets can help the nurse gauge whether a person is taking them accurately. If so it is best not to interfere as they have a system that works for them. However, if there are too many or too few left in the packets (when compared against prescription dates) it is useful to ask the person about how they cope with their medicines and ask them to consider a dosage system, either using a blister pack arranged by their local pharmacy, through an assistive technology device or the help of another person. People who have managed their own diabetes effectively for years may find it more difficult if they develop memory problems, as they may forget to eat or to take medication and may not be able to recognise signs of hypoglycaemia or communicate needs so effectively. Poorly controlled glucose levels can affect orientation and memory and the risk of hypoglycaemia (hypo) is greater if insulin is taken more often than prescribed. Assistive technology can be used to prompt with injection times. As time goes on a person with both dementia and diabetes will need more support with managing their treatment.

The nurse supports concordance with prescribed medication by collaborating with the patient and their family to ensure that they ensure they understand what the medicine is for, that they are prompted to take it if necessary, are able to get it out of the bottle or packet and are able to swallow it. Changing from a tablet or capsule to a dispersible tablet or liquid can help overcome swallowing difficulties but if the person is at end of life the team should consider whether it would be more beneficial to withdraw some medicines (Jenkins and McKay 2013).

Capacity and Medication concordance

Sometimes a person with dementia may refuse medicine that is essential for their well-being and if they have the capacity to make the decision this should be respected. To check capacity for this specific decision, guided by the Mental Capacity Act (2005) the nurse would have a conversation with the person who has an 'impairment of, or a disturbance in the functioning of, the mind or brain', in which the nurse assesses whether the person can understand the relevant information, retain it, weigh it up and communicate their decision (Department of Constitutional Affairs, 2005). If the person does not have capacity to make the decision to refuse the medicine, then a multidisciplinary team discussion, involving the nurse, doctor, pharmacist and family carer, would explore alternatives and make a decision in the person's best interests. In these circumstances the team might decide to give medication covertly, which involves disguising it in food or drink. This should only be done after advice from the pharmacist, who will be able to say if the process is safe and whether the medicine will remain effective.

Physical health of people who have dementia

The nurse can contribute by ensuring the person with dementia has plenty of fluids and nutrition, some exercise and is excreting normally, so that medication is metabolised effectively. In addition simple actions such as making sure the person has their hearing aid and spectacles can help them take part in conversations and maximise orientation and personal choice. As physical and emotional well-being are closely linked, any intervention to support one supports both. Pain in people with dementia is under-recognised, under-treated and leads to low mood (Flo, Gulla, and Husebo 2014) making it more difficult for a person to contribute to their own care. Sometimes pain leads to behaviour which is difficult for nurses to cope with, such as shouting or hitting out. If a person is unable to express pain verbally, they will probably express it through behaviour such as protecting their body, walking about, grimacing or groaning. If pain is suspected it is worth discussing its cause and prescription of analgesia with a member of the medical team, to see whether the person with dementia subsequently becomes more settled. Toothache can lead to reluctance to eat, in which case a referral to the dentist is required.

Nursing care and communication skills

The therapeutic relationship between the nurse and the patient is central to high quality nursing care. Communicating warmly, showing appreciation of the individuality of the person and recognising their strengths helps the person with dementia feel included and valued. Simple adjustments that the nurse can make to respond to short term memory issues include using short sentences, a familiar vocabulary, a warm tone and friendly smile. It is important to leave time for the person 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 nurse is aware that the patient is unlikely to know the answer. Instead, statements can foster inclusion while not being too demanding, (eg 'we'll all be happy when this cold weather is over!') In later stages of dementia a person may call for their mother or insist they must go home to cook their husband's tea. This can be upsetting for the nurse who is aware that the person their patient needs has died. Rather than being deceitful and implying the person will be back soon, it is

better to think about what the underlying emotion or need might be and to respond to that (Blackhall et al 2011). So, for example the sensitive nurse might say, 'I'm sorry, she's not here – but I am, you're safe and I'm going to be with you all evening' ... 'and I could really do with a hand folding these towels'. Use of touch is fine if sensitive and appropriate. If the person is not comfortable with a reassuring hand on their shoulder or touch to a hand, they will make this clear.

The nurse can also learn to 'listen to behaviour'. Perhaps the person who is constantly walking is in pain, or looking for someone or something, feeling bored or constrained. Imagining how the person with dementia might be feeling – perhaps lost, alone and frightened - can prompt empathy and a compassionate response. If a person with dementia is not able to communicate verbally their behaviour may give clues about their feelings and needs. Interpreting behaviour perceived as 'challenging' as an indication of distress or need is the first step in considering a response that can help the person to feel safe, comforted and included.

Environmental adjustments

The environment itself gives clues and cues to a person with dementia. People with dementia in hospital environments are much more likely to remain continent if they can see the toilet and it is clearly labelled. Hospital environments tend to be noisy and fast-paced, and so difficult for people living with dementia. Enabling adjustments that result in a 'dementia-friendly' environment include making the pace of life slower and quieter, providing plenty of light, ensuring décor conveys safety and comfort while orientating the person to knowledge of where they are, whether hospital or home. Design should facilitate independence, so for example contrasting colours show door frames. If possible the person should be able to walk about without risk. Personal items and a large name sign by the person's room or bed shows them which is their space. Assistive technology can minimise unnecessary disturbance at night, for example enuresis detectors and automatic lights enable staff to respond when needed but otherwise to allow people with dementia and family carers to rest.

Personal care

Most of us would prefer not to be naked in front of a stranger, yet this is what nurses ask when assisting with personal care. This can be made easier by using a warm, reassuring approach and ensuring the person is covered as far as possible, that staff are allocated consistently so that they get to know the person they are assisting and their patient's preferences for personal care are known. The 'This is me' document from the Alzheimer's Society is very useful for recording personal hygiene preferences and information that staff can use to build rapport, for example about hobbies and pets. Background music (that the person likes) can be pleasantly distracting and relaxing.

Carer support

Family carers experience high levels of stress and often neglect their own well-being while caring for a relative with dementia (de Oliveira, Vass and Aubeeluck 2015). It is important to

ask family carers about their coping strategies, support network and needs and to work in partnership (or a 'triangle of care') with both family carers and people with dementia (Hannan 2013). Carers may not have been able to have any breaks until their relative came into hospital or a care home for respite, so the nurse can take this opportunity to liaise with local social services staff and voluntary organisations about provision of an effective support package. This will also facilitate timely discharge. Under the Care Act (2014) the well-being of family carers is seen as equally important as that of the person for whom they care.

The MDT

The multi-disciplinary team contribute in different ways to the well-being of people with dementia in hospital or at home in the community. As the person who usually has the closest relationship with the patient and greatest understanding of their needs, the nurse is central in referring to colleagues to take advantage of their clinical expertise. Doctors carry out assessments and decide upon treatments, pharmacists provide advice on medication prescription and management and physiotherapists design exercises to promote balance, rehabilitation and mobility and make referrals for suitable assistive technology. Occupational therapists offer a range of activities that promote independence and everyday skills. The social worker will assess the person's needs for support, design a care package and liaise with or signpost to agencies and services. Home carers provide assistance with personal needs at home, for example, getting up, washed and dressed and having breakfast. Community mental health nurses provide assessment support and advice, as do psychiatric liaison teams in acute hospitals. Psychologists advise on specific problems, while Admiral Nurses focus on supporting family carers. In a care environment that is used by people with dementia, receptionists, domestic workers and porters all contribute to patient well-being, so should all be offered training as part of the team.

The rewards of being skilled in care of people with dementia

Working with people with dementia is challenging and fulfilling. As the population ages confidence in dementia care will become an essential feature of competent nurses providing high quality care within a range of specialist nursing fields. Dementia care skills are now core skills. However, caring for people with dementia requires patience, empathy, sensitivity and dedication. It is not always easy! It is important for nurses to look after themselves and support each other and their MDT colleagues.

The skills that nurses develop while caring for people with dementia are transferable to other aspects of their roles. Sensitivity, compassion and empathy are core qualities which nurses should value as professional strengths. The ability to listen and communicate effectively, to provide care that meets a person's needs while recognising their individuality and to support family carers all contribute to the priorities that people with dementia have identified as central to their well-being.

Five Key Points:

- Every intervention and interaction is an opportunity to build trust and rapport

- Nurses can adjust their communication skills and the environment to empower people with dementia in their care
- Behaviour is a form of communication. Learning to understand it can enable nurses to make people with dementia in their care feel more comfortable and secure
- A strong nurse-patient relationship facilitates accurate assessments and better care outcomes
- The nurse is part of a team which includes the person with dementia, their family carer and the multi-disciplinary team. All have their part to play in promoting the well-being of the person with dementia and in supporting each other

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