Caring for a person with *Dementia*

Case study

Harry is an 85 year old man who has been brought to hospital following a fall from a ladder in his back yard. He lives with his wife, Alice, in their own home. He had been attempting to clean out the gutters following a storm. He is not sure how he got to hospital and is not good at providing other health or family history.

On a Mini Mental Status Examination he scored 17 out of 30, which is well under the cut-off score of 24. This indicates that he has possible cognitive impairment. His dislocated shoulder has been reduced under anaesthesia following two unsuccessful attempts at closed reduction.

Harry has not eaten or taken any fluids since returning to the ward. You become concerned that when his wife leaves after the evening meal, he becomes restless and begins to experience difficulty responding to directions.

The following information could help you nurse a patient like Harry.

What is dementia?

Dementia is the term used to describe the symptoms of a large group of illnesses that cause a progressive decline in a person's functioning. It is a broad term used to describe a loss of memory, intellect, rationality and social skills. It is estimated that dementia affects 6.5 per cent of all Australians aged 65 and over.

Symptoms and types of dementia

In the early stages of dementia, people function relatively normally with some support. As dementia progresses, more specific symptoms occur (such as difficulty with speech and language, poor judgement and lack of insight). Difficulty with personal care tasks (such as bathing) and other everyday tasks (such as cooking, shopping and managing money) may become apparent. Often there are enduring changes in personality and behaviour as well.

People with dementia can be perceived to be aggressive, uncooperative and unpredictable. They may also present with hallucinations and delusions. These 'behaviours of concern' and others can best be classified as 'behavioural and psychological symptoms of dementia'. All the signs and symptoms are a result of progressive damage to the brain. For example, damage to the limbic system is associated with memory dysfunction, unstable mood and personality changes. The behaviours are not the result of deliberate attempts to be difficult or to upset carers.

Dementia can be caused by a number of disease processes. Approximately 60 per cent of people with dementia have **Alzheimer's disease** and about 20

per cent have **vascular dementia**. Dementia related to **Parkinson's disease** is also common, and **excessive alcohol consumption** is another prevalent cause. Other illnesses (such as **multiple sclerosis, HIV/AIDS, Huntington's disease** and **Creutzfeldt-Jacob disease**) are less common causes.

Onset and course of dementia

In Alzheimer's disease, the onset is insidious, generally occurring after the age of 55 and increasing in frequency of occurrence with advancing age. Dementia is a terminal illness, and failing brain function and increasing physical disability lead to total dependence on others for all care. Palliative care measures towards the end of life are appropriate for people with dementia.

Difficulties in diagnosis

It is important to understand the difference between dementia, delirium and depression. Depression and delirium are treatable conditions that present similar to dementia. Remember that all three conditions can be present and that dementia increases the risk for delirium. Common precipitating factors for delirium include infection, medication interactions and surgery.

Differentiating between dementia, delirium and depression and (the three Ds) requires skilled assessment. The differences and similarities are outlined in Table 1. Be alert to co-morbid substance misuse as complex co-morbidities may mask substance misuse and the impact of co-occurring problems.

Table 1 *— The features of dementia, delirium and depression*

	Dementia	Delirium	Depression
Thoughts	• Repetitiveness of thought • Reduced interests • Difficulty making logical connections • Slow processing of thoughts	• Bizarre and vivid thoughts • Frightening thoughts and ideas • Often paranoid thoughts	• Often slowed thought processes • May be preoccupied by sadness and hopelessness • Negative thoughts about self • Reduced interest
Sleep	• Often a disturbed 24 hour clock mechanism (later in the disease process)	• Confusion disturbs sleep (may have a reverse sleep-wake cycle) • Nocturnal confusion • Vivid and disturbing nightmares	• Early morning waking or intermittent sleeping patterns (in atypical cases, too much sleep)
Orientation	• Increasingly impaired sense of time and place	• Fluctuating impairment of sense of time, place and person	• Usually normal
Onset	• Usually gradual, over several years • Insidious in nature	• Acute or subacute (hours or days)	• Usually over days or weeks • May coincide with life changes
Memory and Cognition	• Impaired recent memory • As disease progresses, long term memory also affected • Other cognitive deficits such as in word finding, judgement and abstract thinking	• Immediate memory impaired • Attention and concentration impaired	• Recent memory sometimes impaired • Long-term memory generally intact • Patchy memory loss • Poor attention
Duration	• Months or years and progressive degeneration	• Usually brief — hours to days (but can last months in some cases)	• At least two weeks (but can be several months to years)
Course throughout a day	• May be variable depending on type of dementia	• Fluctuates — usually worse at night in the dark • May have lucid periods	• Commonly worse in the morning with improvement as the day continues
Alertness	• Usually normal	• Fluctuates — lethargic or hypervigilant	• Normal
Other	• May be able to conceal or compensate for deficits (early)	• May occur as a consequence of a drug interaction or reaction, physical disease, psychological issue or environmental changes	• Often masked • May or may not have past history

(NSW Department of Health, 2006)

A perspective on being the partner of a person with dementia

‘My wife’s dementia was insidious. It snuck up on us slowly and then took over every aspect of our life, requiring her to be cared for in a nursing home. She became extremely scared and anxious and everyday when I left the nursing home she would cry out “don’t leave me.” It was heartwrenching to leave her but even more distressing to know that ten minutes after leaving, she wouldn’t even remember that I had been there with her. I felt helpless watching her decline.’

Some reported reactions to people with dementia

Nurses who have worked with people with dementia have reported the following reactions:

Frustration and helplessness — This results from lack of improvement in a person with irreversible symptoms, as well as the constant need to repeat instructions, break down tasks step-by-step and answer repetitive questions.

Impatience — Nurses report decreased patience and tolerance in providing care when people with dementia are negative, hostile, impulsive or slow to respond.

Anger — People with dementia may show little insight into their loss of ability, and this can be interpreted as choosing not to accept help or being resistive to care. This can lead to feelings of anger in nurses.

Goals for nursing a person with dementia

Appropriate goals for caring for a person with dementia in a community or hospital setting include:

- Develop a relationship with the person based on empathy and trust.
- Provide an environment that supports a flexible but predictable routine.
- Maintain a safe environment for the person, yourself and other staff.
- Promote the person’s engagement with their social and support network.
- Ensure effective collaboration with other relevant service providers, through development of effective working relationships and communication.
- Support and promote self care activities for families and carers of the person with dementia.

Guidelines for responding to a person with dementia

The following guidelines will assist in nursing a person with dementia.

- Arrange for a review of the person’s medication and an initial or follow-up psychiatric assessment if their care plan needs reviewing. A mental health assessment may be appropriate to undertake — see the MIND Essentials resource ‘What is a mental health assessment?’.
- A person’s cultural background can influence the way symptoms of mental illness are expressed or understood. It is essential to take this into account when formulating diagnosis and care plans. Indigenous mental health workers or multicultural mental health coordinators and the Transcultural Clinical Consultation Service from Queensland Transcultural Mental Health Centre are available for advice and assistance in understanding these issues. For further information please visit www.health.qld.gov.au/pahospital/qtmhc/default.asp

- Explain to the person who you are, what you want to do and why.
- Smile — the person is likely to take cues from you, and will mirror your relaxed and positive body language and tone of voice.
- Move slowly, you may have a lot to do and be in a hurry, but the person is not. Imagine how you would feel if someone came into your bedroom, pulled back your blankets and started pulling you out of bed without even giving you time to wake up properly.
- If the person is resistant or aggressive but is not causing harm, leave him or her alone. Give the person time to settle down and approach the task later.
- Distract the person by talking about things he or she enjoyed in the past, and by giving him or her a face washer or something to hold while you are providing care.
- Do not argue with the person. The brain of a person with dementia tells the person that he or she cannot be wrong.
- If the person is agitated, maintain a quiet environment. Check noise levels regularly and reduce them if necessary by turning off the radio and television.
- Provide orientating cues such as a clock and calendar.
- Give the person a comfortable space. Any activity that involves invasion of personal space increases the risk of assault and aggression.
- Always provide care from the side (not the front) of the person. If you stand in front, you are easily hit or kicked if the person becomes aggressive.
- Be vigilant if the person is climbing out of bed. Refer to your workplace policy on restraint. If you cannot work out a reason for this behaviour, you might walk with the person or engage him or her in an activity. This helps to maintain his or her mobility, and eventually he or she may tire and go back to bed. Encourage family or volunteers to help with this.
- Monitor compliance with medication and general physical health (including nutrition, weight, blood pressure, etc).
- Monitor food and fluid intake and elimination — dehydration or constipation can exacerbate confusion.
- People with dementia are at increased risk of developing delirium, so be aware of risk factors for delirium (such as medication interactions, infection and the postoperative period).
- Provide family members and carers with information about the illness if appropriate, as well as reassure and validate their experiences with the person. Encourage family members and carers to look after themselves and seek support if required.
- Be aware of your own feelings when nursing a patient with dementia. Arrange for debriefing for yourself or any colleague who may need support or assistance — this may occur with a clinical supervisor or an Employee Assistance Service counsellor.

The Employee Assistance Service provides confidential, short-term counselling free-of-charge to Queensland Health staff to assist them to resolve personal and work related problems. For more information visit http://qheps.health.qld.gov.au/eap/home.htm

Treatment for dementia

In general, non-pharmacological approaches are first-line treatment for behavioural and psychological symptoms of dementia. If symptoms are moderate to severe and impact on the person's (or the carer's) quality of life or functioning, medication may be needed, often in conjunction with non-pharmacological interventions.

The person with dementia, as well as his or her family and carers, will need support, education and counselling to help them understand and cope with what can be a devastating illness. A problem-solving approach that is preventative rather than reactive may help to identify situations that trigger a particular behaviour, which can then be avoided or modified.

Non-pharmacological strategies

Non-pharmacological strategies need to be based on an understanding of the individual's strengths and deficits. A 'catastrophic reaction' may result when the person's ability to cope is exceeded by the demands of the caregiver. This may be in the form of aggression or other distressed behaviour.

Communication strategies should include using clear, plain language and short sentences that convey one idea at a time. Use of gestures, pictures and body language can enhance the effectiveness of the message.

It is helpful to use the 'ABC' model. This looks at the:

- activating event
- behaviour
- consequences.

Documenting these can provide clues to patterns and the triggers of behaviour.

Pharmacological strategies

Currently there is no cure for dementia, but drugs such as cholinesterase inhibitors (for example, donepezil, galantamine and/or rivastigmine) may help to slow the progress of the disease in the early stages. Memantine, which inhibits the release of glutamate (a neurotransmitter), is indicated for more advanced disease and may be used in conjunction with a cholinesterase inhibitor.

Antipsychotic medication is most effective in the treatment of psychotic symptoms (such as hallucinations and delusions) and behavioural symptoms (such as physical aggression). Newer antipsychotic medications appear to be at least as effective as conventional neuroleptics, but have fewer side effects. Those with strong extrapyramidal effects (such as muscle rigidity, tremor and Parkinsonism) may be avoided in favour of those with sedating qualities.

When the person is severely agitated, and as a result, distressed or representing a danger to himself, herself or others, sedation (a waking calm) is indicated. However, care needs to be taken to avoid oversedation (drowsiness), which ironically increases confusion and exposes the person to other risks such as falls, immobility, hypotension and reduced engagement. Benzodiazepines with lower toxicity and shorter half-life (for example, temazepam, and/or oxazepam) are preferred to longer-acting agents (for example, diazepam, and/or nitrazepam).

Antidepressant medications are underused in people with dementia, despite the common occurrence of depression in dementia and the documented therapeutic value of these drugs. Some people may present as agitated when suffering a depressive disorder.

Discharge planning

Discuss referral options with the person and carer and consider referrals to the following:

- GP
- Aged Care Assessment Teams (ACAT): http://qheps.health.qld.gov.au/acat/home.htm
- Older Persons Mental Health Services
- Private service providers

To access the contact numbers and details of your local services use QFinder (available on QHEPS) or call 13HEALTH (13 43 25 84).

Further reading

For more information, contact:

- Dementia Behavioural Management Advisory Service — 1800 699 799
- Carers Queensland — 1800 242 636
- Commonwealth Carer Respite Centre — 1800 059 059
- Alzheimer's Australia: www.alzheimers.org.au

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