“Getting to know me”

Enhancing Skills in the Care of People with Dementia

Everyday, essential knowledge for the care and support of people with dementia

A booklet for staff

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Introduction

Dementia affects over 298,000 people in Australia. This figure continues to rise and is expected to be in excess of 900,000 by 2051\(^1\).

Caring for people with dementia can be a challenging experience. However, one might argue that the real challenges are the ones experienced by the people with dementia themselves.

Being in a strange environment can be an unsettling and disorientating experience for anyone. For a person with dementia it may be much worse. There is growing evidence that when compared with patients without dementia, patients with dementia in hospital are more likely to:

- experience poor nutrition and poor hydration
- develop delirium
- receive inadequate pain control
- experience lengthier hospital stays
- move from hospital into long term care

This booklet is designed to help you understand what dementia is, and offers straightforward and accessible advice on caring for people with dementia.

\(^1\) AIHW 2012. Dementia in Australia Cat. No Age 70 Canberra: AIHW
What is dementia?

Dementia can be described as:

“...a syndrome (a group of related symptoms) that is associated with an ongoing decline of the brain and its abilities. These include thinking, language, memory, understanding and judgement; the consequences are that people will be less able to care for themselves.”

Dementia can be caused by a number of different diseases:

- Alzheimer's disease (AD)
- Vascular dementia (VaD)
- Lewy body dementia
- Fronto-temporal lobe dementia
- Other causes

Figures taken from AIHW 2012

Dementia is an age-related condition. It occurs much more commonly in older people with 3 in 10 people over the age of 85 affected. However, dementia does also affect younger people, and there were 23,900 people diagnosed with dementia under the age of 65 in Australia in 2011.

2 The NHS Confederation (2010) Acute Awareness
3 AIHW 2012. Dementia in Australia Cat. No Age 70 Canberra: AIHW
4 AIHW 2012. Dementia in Australia Cat. No Age 70 Canberra: AIHW
What is Alzheimer’s disease?

Alzheimer’s disease is the most common cause of dementia. It is a progressive condition with gradual onset. There is a complex pathology in which neurones (brain cells) and the communication pathways of the brain are destroyed. Plaques and tangles develop in the structures of the brain, chemical messengers are affected, and areas of the brain decrease in size.

There are many features of Alzheimer’s disease and people are affected differently. Some of the changes a person may experience include:

• Memory loss – short term memory is usually affected first. Long term memory often remains intact initially, although this too may be affected over time
• Increasing difficulty with everyday skills
• Word finding difficulties
• Increasing difficulty understanding verbal or written communication
• Impaired reasoning
• Recognition problems – objects and people
• Disinhibited behaviour
• Difficulties with purposeful actions
• Changes in mood
• Visual-perceptual and spatial awareness difficulties
What is vascular dementia?

Vascular dementia is the second most common cause of dementia, and often co-exists with Alzheimer’s disease. It can be caused by disease affecting the larger vessels in the brain. A stroke, or series of strokes (called Multi Infarct Dementia), will prevent blood getting to areas of the brain. When deprived of blood, brain cells in affected areas can die, which can cause cognitive impairment.

Small vessel disease is the name given to another type of vascular dementia. This is when there is damage to the smaller vessels deeper in the brain structure.

The difficulties experienced with vascular dementia are similar to Alzheimer’s disease, but the following differences may also be apparent:

• The onset is often sudden (except in small vessel disease where symptoms develop more gradually)
• There may be periods where symptoms do not progress, followed by an episode of acute confusion often associated with a new “mini-stroke”. A series of “mini-strokes” and strokes can result in a “step-like” progression of impairments
• There is an increased likelihood of problems with unpredictable behaviour or changeable mood
• Some abilities may remain largely unaffected depending on which areas of the brain are undamaged
• In small vessel disease, symptoms tend to develop more gradually, mobility can be affected, and the person can appear “slower” in thought and action
What is dementia with Lewy bodies?

Dementia with Lewy bodies (DLB) accounts for approximately 5% of all cases of dementia (although some studies put this figure much higher). Lewy bodies are tiny spherical protein deposits found in nerve cells in the brain (they also occur in the brains of people with Parkinson’s disease). The condition shares some of the symptoms of both Alzheimer’s disease and Parkinson’s disease. The following are features which people may experience:

• Fluctuating episodes of lucidity and confusion
• Auditory and visual hallucinations are common
• Parkinsonian symptoms such as tremor, muscle stiffness, slowness, changes to voice tone and strength
• Risk of falls
• Disturbed nights with nightmares and hallucinations may be present
• Memory performance is often not affected to the extent it is in Alzheimer’s disease
• People with DLB may have a dangerous sensitivity to neuroleptic (sedative) medication
What is fronto-temporal dementia?

Fronto-temporal dementia (FTD) covers a range of related conditions that affect the frontal and temporal lobes of the brain. Although much rarer than the dementias previously described, it is one of the more common causes of dementia in people under 65.

Symptoms vary according to the specific type of FTD but can include:

- Changes to personality, including a lack of insight and ability to empathise with others
- Loss of inhibition. People with FTD may act spontaneously and in a way that other people might deem “inappropriate”
- Obsessive compulsive behaviours and repetitive behaviours
- Eating habits can change and it is not uncommon for people with FTD to develop a compulsive appetite for sweet foods
- Language can be affected in some forms of FTD
- In its later stages, FTD symptoms can be similar to Alzheimer’s disease as damage to the brain becomes more widespread
Delirium

Delirium and depression are highly prevalent conditions in older people admitted into hospital. Patients who have dementia are at a particularly high risk of also developing delirium\(^5\) and/or depression.

Delirium (or acute confusional state) is characterised by disturbed consciousness and cognitive function or perception, it often has a rapid onset and a fluctuating course. It may be caused by any acute physical illness (e.g. urine or chest infections) or drugs (e.g. opiates) and is a serious medical condition.

It is imperative to rapidly identify and treat the underlying cause.

Delirium is frequently a sign of acute – perhaps severe – illness.

Risk factors for delirium:

- Age 65 years or older
- Cognitive impairment (past or present) and/or dementia
- Current hip fracture
- Severe illness (a clinical condition that is deteriorating or is at risk of deterioration)\(^6\)

5 Royal College of Psychiatrists (2005) Who Cares Wins
6 NICE guidelines(2010) CG103 Delirium
Indicators of delirium: at presentation

Assess people at risk for recent (within hours or days) changes or fluctuations in behaviour. These may be reported by the person at risk, or a carer or relative. Be particularly vigilant for behaviour indicating hypoactive delirium (marked*). These behaviour changes may affect:

- Cognitive function: for example, worsened concentration*, slow responses*, confusion

- Perception: for example, visual or auditory hallucinations

- Physical function: for example, reduced mobility*, reduced movement*, restlessness, agitation, changes in appetite*, sleep disturbance

- Social behaviour: for example, lack of co-operation with reasonable requests, withdrawal*, or alterations in communication, mood and/or attitude

If any of these behaviour changes are present, a healthcare professional who is trained and competent in diagnosing delirium should carry out a clinical assessment to confirm the diagnosis.

7 NICE guidelines (2010) CG103 Delirium
WARNING:

In hospitals delirium can be missed because:

a) Although people experiencing delirium may be agitated and clearly confused (hyperactive delirium), this is not always the case – some people with delirium may also be quiet, withdrawn or drowsy (hypoactive delirium) and they may be easily missed. Some patients may show signs of both (mixed).

b) The person may have a known diagnosis of dementia. Where this is the case, altered behaviour may be assumed to be “normal” for that person and “part of the dementia” rather than the manifestation of an underlying (and treatable) cause.

In addition to the information above, the guidelines for providing person centred care for people with dementia which appear later in this booklet are also appropriate for providing care to people experiencing delirium.
Depression

Depression is a mood disorder and disturbs normal functioning. People can experience negative thoughts, low mood, forgetfulness and loss of interest. Depression can also be accompanied by physical symptoms such as fatigue, loss of appetite, difficulties sleeping, aches, pains, and sometimes delusions.

One in four older people have symptoms of depression that require treatment. Physical illness, hospital admission and dementia are all risk factors.

If depression is suspected, consider referral to the hospital liaison team and make an immediate referral if a person expresses suicidal ideas.

20% - 25% of people with dementia also have symptoms of depression

Delirium and depression in people with dementia

Key messages:

• Do not assume that a person’s behaviour and confusion is necessarily a direct consequence of their dementia

• Dementia can become a “label” and obscure the identification of depression or delirium (and potentially serious underlying health concerns)

• Relatives will often be the most important source of information and may be able to inform you what is - and what is not - “normal” behaviour for that person

8 Factsheet: Management of depression in older people: why this is important in primary care (2011) Forum for mental health in primary care

Seeing the person

Providing good quality care for people with dementia is about providing care for the whole person. The hints and tips in the pages that follow are about looking beyond the diagnosis and seeing the person.

“Ask not what disease the person has, but rather what person the disease has”

William Osler

Good dementia care should be underpinned by the following principles:

• Stepping into the person’s world and asking:
How might the person be perceiving their situation? Is their perception of reality likely to be any different from my own? What might they be thinking? Does the person know who I am or where they are? What might they be feeling – physically and emotionally?

• Seeing and valuing the person:
We must be vigilant to ensure that dignity and respect underpin all our interactions with people with dementia. We need to see the person beyond the diagnosis. Knowledge of the person, for example their likes, dislikes, interests, cultural and spiritual needs etc can greatly inform the care we provide.

• Focus on feelings:
Having dementia and being in a strange environment will give rise to powerful emotions which might include fear, insecurity, abandonment, puzzlement, and frustration. Empathy is an essential pre-requisite in the care of people with dementia.
Case Example:

Judith became tense and agitated when helped to mobilise along the corridor and stammered “I can’t, I can’t, I can’t, it’s at sea, it’s all at sea...”. She did not appear to be in any obvious discomfort and staff assumed her “awkward” behaviour was simply “due to her dementia”. A healthcare assistant tried to “see” the difficulty from Judith’s perspective. When viewing the corridor floor she noted how reflective and shiny it was compared with the matt surface of the floor in the ward bay area. She wondered whether the glare might look to Judith like the reflection on the surface of water. Indeed it was subsequently noted that Judith could walk perfectly well on all surfaces that were not reflective. In perceiving the corridor to be flooded she was in fact behaving in a rational manner by refusing to walk any further!

“It was frightening, I felt - I think - out of control...”

“It is often not knowing what is going on, and what is expected of me as a patient...”
Communication

People with dementia often experience increasing difficulties with communication. This can be related to a growing difficulty in both expressing and understanding language.

As a consequence, we need to pay greater attention to try to interpret a person’s needs and feelings, and when we wish to express something to a person with dementia we need to adapt our usual style of communication to compensate for their difficulties.

“As we become more emotional and less cognitive, it’s the way you talk to us, not what you say that we will remember”  

Case Example:
Annie Winterton could no longer form words into sentences and she seemed to struggle to understand what was being said to her. Staff learned to communicate with her through actions. Rather than asking if she would like a cup of tea, the nurse would hold up an empty cup and mime taking a drink. This clearly worked for Annie, and it was evident from her facial expression whether she wanted a drink or not.

“Bear in mind it takes my mind sometimes a second or two to understand what is being said, so it’s important not to speak too quickly, to speak clearly and to leave a little space for me here and there...”

Communication: Hints and Tips

- Concentrate on your non-verbal communication (your words might not make sense to the person but your tone of voice and body language probably will)
- Slow down speech (do not out-pace) and reduce the length of your sentences. Bite sized chunks of information may be more readily understood than lengthy sentences
- Approach the person from the front and speak face to face with good eye contact
- Keep speech clear and simple, avoiding both jargon and figurative phrases such as “it’s raining cats and dogs”
- Make use of objects/cues/pictures to back up what you are saying. Even when the spoken word is not recognised, it may be that an image or object representing the word or phrase is understood
- Concentrate on the feeling/need behind what a person is saying. For example, if a person is asking for their mother, think why this might be. Are they feeling anxious or lost and needing comfort? Are they experiencing pain? Do they need to go to the toilet?
- Try to provide opportunities for reassuring human contact. Stop and share a few moments when you can. Encourage flexible visiting where possible
- Talk through procedures clearly as you do them to try to reduce any fears
- Repeat information regularly, for example, who you are and where the person is. Remember, short term memory is often affected in people with dementia, this can mean people may forget information in a matter of moments
Coping in a strange environment

People with dementia may have impaired memory, reasoning, spatial awareness and communication. This makes it all the more difficult for them to make sense of their surroundings and to feel safe, secure and orientated.

Put yourself in the shoes of a person with dementia. If you were in a strange and disturbing place and your short-term memory was so poor that you couldn’t retain information...

- What or who might help you to feel more safe and secure?
- What would help you find your way around?

Case Example:

When Roger is in an unfamiliar situation or when he is unsure what is expected of him, he often becomes anxious. As a consequence he can become agitated and sometimes aggressive. On a recent occasion Roger attended a clinic for a procedure under local anaesthetic. Roger’s wife, Joan, was discouraged from entering the theatre with him. Mid-way into the procedure Roger became anxious and agitated, and the procedure had to be abandoned. Both he and Joan were left feeling very distressed by the experience. Joan feels this could have been avoided had she simply been permitted to be at his side to re-assure him. Now when Roger is in hospital, Joan has requested to be with him during procedures (eg scans) whenever possible.
Improving the physical environment: Hints and Tips

- Use prominent clocks, calendars and pictures on walls to help orientation
- Keep signage simple and uncluttered. Use images as well as words (for example, an image of a toilet on a toilet door)
- Consider drawing attention to toilets/bathrooms with colours that help define these areas (reds are effective)
- Try to “soften” the appearance of bathrooms to create a domestic and unthreatening space
- Ensure adequate lighting but avoid glare
- Avoid reflective, highly polished floors that reflect glare
- Control noise as far as possible
- Create areas of interest/talking points such as interesting pictures on walls, some of which might have reminiscence value
- Create spaces for interesting activity where possible eg: activity table/day room

“It was the simple things which gave me a problem, like: Where is the toilet? How do I get there? How do I get back?”
Discovering ways to meaningfully occupy people with dementia

Like everyone else, people with dementia have a need to be active, occupied and purposeful.

All too often there is very little to occupy people and focus attention. For a person with dementia this lack of occupation may lead to that person behaving in ways that cause difficulties for themselves and others. Alternatively, it can also lead to a person withdrawing into themselves and losing all motivation.

Case Example:

Mr Rhodes had lost the ability to communicate verbally, and he appeared anxious when his family were not around. His brother had completed his “Getting to Know Me” card and this contained lots of useful information that helped staff gain a fuller picture of Mr Rhodes - as a person with a rich and interesting past. It contained information revealing that Mr Rhodes had been an art historian and had taught evening classes. Art books and magazines were brought into hospital and these became well thumbed by Mr Rhodes who drew particular satisfaction from looking at them in an “educative” role in the company of another.

“If (the staff) were aware for example that my wife was a former ladies fencing champion, she liked hiking and she used to play the piano, they could talk to her about them...”
Meaningful activities: Hints and Tips

- Use of the Alzheimer’s Society / RCN “This is Me” booklet\(^{11}\) or a similar initiative such as “Getting to Know Me” card (both pictured) can help to enable staff to “see” the person beyond their dementia and aid the generation of ideas for interactions and purposeful activity with the person.

- Encourage families to share anything that may help to keep the person occupied

- Be creative! Books, photos, bags with items to rummage through may all help

- Provide opportunities for exercise and walks whenever possible

- Think of creative ways to help a person to feel useful, purposeful and valued

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Promoting eating and drinking

A person with dementia may look like they are perfectly able to eat and drink without assistance, but they may in fact need help.

Physical discomfort, loss of appetite and sensory impairment can prevent anyone from eating well. In addition to these problems, a person with dementia may have specific problems such as:

- **Difficulty initiating** an action (for example picking up a fork or spoon to eat)
- **Difficulty recognising** food, drinks or cutlery for what they are (agnosia)
- **Difficulty with spatial awareness**, making seeing the food more difficult
- **Problems with memory** – actually remembering to eat and drink
- **Experiencing anxiety** and other emotions that may affect appetite. This may be exacerbated by the distractions (noise, appearance, smells) of the ward environment
Promoting eating and drinking: Hints and Tips

- Try appropriate prompting
- Consider the presentation of the food – does it look appetising, are foods in containers or packaging that requires removal?
- Consider whether the person may have visuo-perceptual problems. Can they see the food clearly? Do they recognise it as food and realise it is for them to eat?
- Can the eating environment be made quieter and stress free? Too much noise and distraction do not encourage eating
- Some people with dementia prefer to eat little and often rather than at the set mealtimes
- Be aware of personal preferences and special dietary needs

Case Example:

Enid, Reginald and Margaret all had some difficulties eating their main meals. The ward decided to create a “dining club”. A dining area was created at lunch times in the small day room. A table would be appropriately set for four people and at lunch times a member of staff would sit to have a meal with Enid, Reginald and Margaret. In the quiet and calm, away from the distractions of the busy ward bays, and with appropriate prompts and cues, meals were regularly enjoyed.
Relatives and friends: offering support and valuing their expertise

Being a relative or “carer” of a person with dementia can carry emotional, physical and financial stresses. People do not always get the necessary information and support they need.

Relatives/carers can also be a vital resource in caring for the person. They are frequently the most important source of information about the person with dementia and their very presence can bring the familiarity and emotional security that people with dementia often need.

As such, families and friends need to feel that they can be involved in the person’s care. Equally, they may need support, advice and information themselves.

“Once you are in the system everything is fine, but it is knowing how to get into the system. My wife and I have been very fortunate, in that we have had some excellent carers and excellent help from other organisations; it has helped me, it has helped her, but until you find out where those organisations are and how to get in touch with them you might just as well bash your head against a brick wall...”
Involving and supporting relatives and friends: Hints and Tips

- Relatives may be able to suggest what actions/responses are likely to make a person more distressed, and conversely, what may help a person feel more secure if they are already in a distressed state.
- Relatives might be able to provide insight and explanations of behaviours you find puzzling.
- Make sure valuable information is recorded and shared across the care team.
- Encourage use of the “Getting to Know Me” card. This will provide a valuable resource to staff and is a concrete way of enabling relatives to contribute to the person’s care and wellbeing.
- Family members should be made to feel that they can be actively involved in the person’s care to the extent they wish.
- Information on dementia and services outside of the hospital should always be available.

Case Example:

Clifford is reluctant to drink fluids despite the best attempts of nursing staff. When a relative is asked if they have any ideas, they point out that Clifford is an avid tea drinker but he only drinks it at home from a particular mug. This is brought in and Clifford’s tea consumption returns to normal!
Providing pain relief

There is evidence to suggest that people with dementia are likely to experience less pain relief than people who do not have dementia, and this becomes a greater problem the more severe their cognitive impairment\(^\text{12}\). Hence, the more confused and disoriented a person is, the less likely they are to receive effective pain control.

Behaviour such as shouting, aggression, agitation and pacing/walking may be triggered by pain. Too often anti-psychotic medication is prescribed for people with these behaviours rather than pain relief.

Hints and Tips:

- Regularly ask people with dementia if they are in discomfort
- Use appropriate pain assessment scales, particularly if verbal communication skills are reduced
- Observe for behavioural, physiological and body language changes in individuals to guide assessment of pain
- Consider requesting “by the clock” medication for some patients rather than “as required”\(^\text{13}\)

Case Example:

Mr Mamoon shouted out repeatedly, but his words could not be identified by staff, interpreters or his family. A chart to monitor his behaviour was commenced but revealed no pattern. Unable to identify what was troubling Mr Mamoon, regular – round the clock – analgesia was prescribed. Mr Mamoon’s shouting became significantly less frequent and less pronounced. The nursing and medical team were able to assume that his behaviour was likely to be related to pain, they could then focus attention on identifying its specific origin.


Behaviours and what they may mean

A person’s behaviour may at times be challenging for staff and others. A person with dementia may, for example, shout-out persistently and repetitively, regularly try to walk off or perhaps interfere with other people’s belongings or equipment.

What we need to acknowledge first and foremost however, is that all behaviour has meaning and that behaviour usually communicates a need or a feeling.

Behaviour may indicate many things, here are just a few possibilities:

- Underlying illness (delirium)
- Pain or discomfort
- Feeling afraid
- Feeling lost
- Being overwhelmed by too much noise or activity
- Boredom - not having enough meaningful activity to feel occupied
- Trying to express a need – hunger, thirst, the need for the toilet
- Effects of medication
- Trying to find someone or something familiar
- It may be an action connected with a person’s past (for example, a former doctor may be inclined to attend to the patients!)

**WARNING:**

a) A sedative when used to control behaviour will not meet any of the underlying needs described above.

b) People with dementia who are quiet and withdrawn are at risk of receiving less care and reduced communication than those whose behaviours are more obviously demanding.
Responding to behaviours that challenge: Hints and Tips

• As a team, utilise all your knowledge of the person to consider what might be the cause of their behaviour. Pool your ideas and begin to eliminate those that are least likely

• Consider using a behaviour monitoring chart to observe for patterns that may be clues to triggers for behaviours

• Talk to relatives, they are likely to know the person best

• Always consider delirium/underlying physical illness

• Try to put yourself in the person’s shoes to consider their perspective. Remember their view of reality may be different from your own

• Be aware that sometimes the trigger for the behaviour may be the unlikeliest of causes (for example, a person not recognising their own reflection in a mirror when alone in a bathroom becoming frightened and agitated)

• Be aware that aggressive behaviour is often a resistance to the actions of others that are mistakenly perceived as threats

• If a person is aggressive, avoid invading their personal space if possible

• Where possible give a person the space and the opportunity to calm down

• Seek support but avoid crowding the person

• Use a calm and even tone of voice

• Maintain your own safety and that of others
Case Example:

Millie created problems for ward staff by continually needing to be on the move. Nurses would regularly escort Millie back to her bedside, much to her annoyance and frustration. Following a discussion with her husband, Tom, it was decided to give Millie more opportunities for “purposeful walking”. Tom was encouraged to walk Millie to the cafe and WRVS shop whenever he (or any other relative) visited. Staff also began to regularly ask Millie if she would like to help them when they went off the ward for a specific purpose, for example, to collect medicines from pharmacy. This practice seemed to give Millie a renewed sense of purpose, and staff began to experience fewer challenging episodes with Millie on the ward.

“I can look at a flannel and think: Yeah, okay, what is that? So it is the simple things that I need help with”
Sources of help and support

Dementia Training Study Centres – Vic & Tas Training, Innovation, Mentoring and Education (TIME) for Dementia: an overview
www.dtse.com.au

Alzheimer’s Australia professional, family and community education www.fightdementia.org.au

RDNS – Two day workshop ‘Dementia in focus’ Phone: 9536 5251
www.rdns.com.au

University of Wollongong Dementia Training Study Centre provides online dementia education resources designed to provide a flexible opportunity to improve knowledge and skills in working with people who have dementia and their family carers.
Acknowledgements

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“If only more people knew how easy it is to talk about dementia and how important it is to talk about it... it is by talking that we feel much more comfortable with our problem”

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