Dementia awareness

A resource reference for Personal Care Workers

Person-centred
Supportive
Evidence-based
Respectful

Dementia awareness
Introduction

The Department of Veterans’ Affairs (DVA) is focused on promoting a person-centred approach across all programs delivering services to veterans and their families. By ‘person-centred’, I mean care that is determined by the needs of the veteran, or entitled family member. DVA is committed to assisting Community Nurses and Personal Care Workers deliver the very best person-centred care. I trust this resource will support you in the delivery of community nursing services and thank you for your care of our veterans and their family members.

Dr Trish Batchelor
Deputy Chief Health Officer
Department of Veterans’ Affairs

The Department of Veterans’ Affairs (DVA) requires community nursing and support services for entitled persons to be driven by person-centred approaches. By ‘person-centred’, we mean care that is determined by the needs of the person, rather than the needs of the health service provider.

As a DVA community nursing Personal Care Worker (PCW)*, it is likely you are supporting one or more people who are living with dementia. This resource is designed to build upon your existing knowledge of dementia. It also describes how the person-centred approach can be applied in supporting the person through communication, activities, and managing behaviours.

Fifty years ago, people showing early signs of dementia were often placed straight into residential care. However, medical pioneers like Professor Tom Kitwood showed that dementia is a medical condition that can be managed in a more compassionate way. The goal of person-centred care is to enable people living with dementia maintain their abilities, identity, preferences, and values for as long as possible. Supporting a person living with dementia in their own home has improved outcomes for the person, their family and the community. This is why DVA provides community nursing and personal care for people living with dementia, even those with high support needs.

In your role, you will often be the first person to notice changes in a person with dementia. If you have any concerns about the person, or your own safety, always report this immediately to your nursing supervisor. If a situation is escalating rapidly, follow your organisation’s policy on incident management. See the ‘behaviour management’ section of this resource for more information.

Supporting a person living with dementia can be challenging, but by understanding more about their condition and their individual experience, you will find it easier to anticipate needs and manage support. By following person-centred principles, you can also be confident you are helping maintain or even improve the persons quality of life.

* The term ‘Personal Care Worker’ includes Nursing Support Staff (NSS), Assistants in Nursing (AINs), Health or Home Care Assistants (HCAs), PCAs (Personal Care Assistants), Care Services Employees (CSEs) and Personal Care Employees (PCEs).
About dementia

Dementia describes a cluster of symptoms that includes a progressive loss of cognitive (thinking/processing) function and changes in behaviour and mood.

It is a broad term used to describe a loss of memory, intellect, rationality, social skills, and physical and sensory functioning over time.

There are many types of dementia. The most common is Alzheimer’s disease, followed by vascular dementia. Less common are conditions like frontotemporal dementia and Lewy body disease. The main types of dementia are described on page 5 of this resource.

Dementia can happen to anybody, but it is more common after the age of 65. One in 10 people over 65 years old have dementia, and this number rises to three in 10 over 85 years of age. ‘Younger onset’ dementia occurs before the age of 65 and can be diagnosed as early as 30 years of age.1

While older people might complain about being forgetful or unable to remember, this is not necessarily dementia. The next table explains the differences between a person living with dementia and an older person without the condition.

The progress of dementia varies greatly from person to person, but it has been shown that quality, person-centred care and support can greatly reduce the duration, impact and severity of symptoms.

Table 1

<table>
<thead>
<tr>
<th>Description</th>
<th>Person with dementia</th>
<th>Older person without dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Events</td>
<td>May forget all or part of an event</td>
<td>Memory may sometimes be vague</td>
</tr>
<tr>
<td>Words or names for things or objects</td>
<td>Progressively forgets</td>
<td>Sometimes may forget; words or names are on the ‘tip of the tongue’</td>
</tr>
<tr>
<td>Written and verbal directions</td>
<td>Increasingly unable to follow</td>
<td>Able to follow</td>
</tr>
<tr>
<td>Stories on TV, movies or book</td>
<td>Progressively loses ability to follow</td>
<td>Able to follow</td>
</tr>
<tr>
<td>Stored knowledge</td>
<td>Over time loses known information</td>
<td>Recall may be slower, but information essentially retained</td>
</tr>
<tr>
<td>Everyday skills e.g. cooking, dressing</td>
<td>Progressively loses capacity to perform tasks</td>
<td>Retains ability unless physically impaired</td>
</tr>
</tbody>
</table>

Source: Dementia Australia

Dementia Awareness

Diagnosis and impact

Diagnosis

Dementia can happen to anyone, but its incidence increases with age. Health and lifestyle factors can place someone at higher risk, including untreated high blood pressure, obesity, diabetes, smoking, alcohol intake, social isolation, hearing loss, and being less physically and mentally active. Only a few rare forms are genetic, but a family history of dementia does increase a person’s risk of developing it.

The early signs of dementia may not be obvious. Early signs can include memory loss that affects everyday function, difficulty performing familiar tasks, confusion about time and place, problems with language and abstract thinking, placing things in inappropriate places, poor or decreased judgement, lack of initiative and changes in behaviour and mood.

Where dementia is suspected, a GP can administer a screening test for impairment in personal orientation, attention, memory, and language (all 'cognitive' functions). Other tests include physical examinations, medical history, laboratory tests, brain imaging and psychiatric assessment.

Careful diagnosis is important, as other conditions can make a person appear to have signs of dementia. On average, it is three years between symptoms being first noticed by a person’s family and a medical diagnosis being made.

The impact of dementia

A diagnosis of dementia has different impacts on different people. Some may be devastated, while others might be relieved that what they are experiencing has a diagnosis. There are organisations that can offer advice and support to people living with dementia, their families and friends, including Dementia Australia.

For a person living with dementia, their abilities may change day to day, or even within the day. This may happen rapidly within a few months or over a period of years. As the disease progresses, different functions may be lost, but it’s important to remember that many will remain — these may be used to compensate for losses in other domains. Touch, hearing, and the ability to respond to emotion usually remain until the late stages of dementia.

The physical decline that comes with the progression of dementia limits the person’s ability to cope with infection and other diseases. This means that when someone dies of dementia, the actual death is often caused by another condition, like pneumonia. Dementia is currently the second leading cause of death of Australians, after coronary heart disease.2

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Types of dementia

**Alzheimer’s disease**
- Most common form of dementia, affecting up to 70% of all people with dementia³
- Brain has an abnormal build-up of proteins in and around brain cells
- Connections between brain cells are damaged, brain cells eventually die
- Affects memory, thinking, emotions, language, attention, behaviour and mood
- Symptoms start slowly, can be subtle
- Three stages: mild, moderate and severe (late stage).

**Vascular dementia**
- Second most common cause of dementia after Alzheimer’s disease⁴
- A broad term for dementia associated with problems of circulation of blood flow to the brain
- Usually caused by many small strokes (where blood supply to the brain is blocked temporarily), or other conditions reducing circulation
- Often occurs alongside Alzheimer’s or another brain disease, making symptoms of dementia worse
- Affects higher brain functions (‘executive’ functions), spatial processing and attention.

**Alcohol related dementia**
- Diagnosed when alcohol is the most likely cause of symptoms
- Affects memory, learning, reasoning, personality, mood and social skills
- May become stable.

**Lewy body disease**
- Abnormal build-up of protein in brain cells, in specific areas of the brain
- Causes changes in movement, thinking and behaviour, including hallucinations
- Depression can be severe
- Has some features in common with Parkinson’s disease.
- Diagnosis can be difficult; ‘younger onset’ is more common.

**Parkinson’s dementia**
- A person must have Parkinson’s disease to have Parkinson’s dementia
- Parkinson’s disease is a progressive disorder of the nervous system
- When a person with Parkinson’s disease develops cognitive impairment they may have Parkinson’s dementia.

**Frontotemporal dementia**
- Gradual damage to frontal and/or temporal lobes of brain
- Affects attention, judgement, planning and self-control
- Causes changes in personality, behaviour, mood and social ability
- Often causes behaviours affecting eating, e.g. cravings.

**Huntington’s dementia**
- Rare; caused by a defective gene
- Uncontrolled movements of arms, legs, head, face and upper body
- Decline in cognitive abilities
- Alterations in mood especially depression, anxiety, anger and irritability.

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Supporting the person living with dementia

Dementia is not a condition to be treated with restraint or control. It is a life-changing medical diagnosis that has a big emotional, social, psychological and practical impact on a person. Supporting a person living with dementia can be challenging, but by taking a person-centred approach, conflict and distress can be greatly reduced for the person, their family, and their carers.

Person-centred care is a set of guiding principles that underpin best practice in supporting people living with dementia.

The needs identified in the illustration are all equally important in supporting a person with dementia.

- **Identity**: Respecting who the person is, who they were (their previous roles), and their name – including the name they like to be called by.
- **Inclusion**: Being together and being part of a group. Individuals need to be included and involved both in care and in life.
- **Attachment**: People with dementia need to feel attachment to objects, sensations and people, especially when they feel disoriented or confused by their surroundings.
- **Occupation**: More than simply being occupied; the person needs to be involved in past and current interests and sources of fulfilment and satisfaction.
- **Comfort**: Individuals need comfort or warmth to ‘remain in one piece’ when they may feel as though they are falling apart.
- **Love**: This includes loving someone and feeling loved. Love can be in other forms such as loving an activity or a favourite meal, to spiritual love and loving oneself.

Exactly how these needs will be felt, expressed and met is unique to each individual. Care is not just a person’s routine, their medication, and personal care; it is about understanding the whole person and meeting their needs.

Many of the behaviours that come with dementia are about unmet needs. Evidence shows us that person-centred care is better at meeting needs, with the result being that people living with dementia, their families, and carers, are faced with less confusion, upset, and misunderstandings.

The next few pages of this booklet explain some practical person-centred approaches in supporting the person with dementia.
Communication

Difficulties in communicating are one of the most frustrating experiences for people living with dementia. This frustration can trigger adverse behaviours, so it is important for carers to have effective communication strategies.

Different parts of the brain control different communication abilities. One person may find it hard to remember words, while another may use the wrong words for what they are describing.

As this chart shows, spoken language is only part of the way we communicate. Tone and pitch (the way we speak) and non-verbal communication (through body language and other cues) are what people respond to the most.

This means that for both you and the person, it may not be what is being said, but the way it is being said, that carries the most importance.

Validation

As dementia progresses, a person loses their memory. They also lose their ability to organise thoughts and express them. Losing recent memories sometimes means the past merges into the present, creating communication difficulties for family, friends and support workers.

Instead of bringing the person living with dementia into your reality, it can be more positive to enter into their reality. For example, if the person is worried about their parents (when their parents died a long time ago), trying to correct the person on this point may just create conflict and distress.

If appropriate, a person-centred approach would be to empathise with the person and reassure them about their parents. You may be concerned that you are lying to the person but remember that communication is not just about exchanging facts. Communication can also promote a sense of occupation, identity, comfort, attachment and inclusion (person-centred values).
Reality orientation

There will be times when the above approach is not appropriate, and you will want to let the person know of present and future actions and events. If this is the case, you can gently re-orient the person by reminding them of things that mean something to them, such as:

- “It’s a beautiful summer’s/winter’s day”
- “Let’s get ready for lunch/bedtime/dinner”
- What time it is, their routine, familiar events/occasions
- The relationships they have (“your son, Peter”).

Visual cues, body language, and other non-verbal techniques can also help.

Reassurance

A person with dementia may be afraid, anxious, upset and doubtful, or lack confidence. Be prepared to reassure them many times a day, paying attention to tone and volume of voice. Use reassuring words, body language and check surroundings. Appropriate touch can also be very reassuring.

Reminiscence

Remembering the person’s life and events is very important, because it validates their identity, opinions, beliefs and ideas. It also enhances the person’s competency, reminding them that they can contribute and are valued. Photo albums and other items can help with reminiscence.

Changes in communication & techniques

Changes in communication

Where someone has dementia, changes to different parts of the brain result in different communication issues. Some verbal changes might include:

- Difficulty finding a word
- Speaking fluently but not making sense
- Not understanding what you say or only understanding part of it
- Losing the idea of normal social conventions.

Remember that some other communication skills such as writing and reading may decline, but others will still be intact (eye gestures, eye contact, facial expression, hands), so pay close attention to these.
Your role in communication

It is important to monitor your own communication. Calm, gentle, matter-of-fact tone and body language are reassuring to the person.

Remember the Five S’s when communicating:

- **Slow** – slow down your rate of speech and wait for the person to respond, this can sometimes take a while, up to five times longer for a person with dementia.
- **Simple** – keep it simple, one idea or instruction at a time using short sentences.
- **Specific** – talk about specific people, objects or events; use names e.g. ‘John’ and ‘Mary’ instead of pronouns such as ‘she’ or ‘he’.
- **Show** – hand gestures, actions, pointing, body position, nodding, touching, holding, hugging, demonstrating e.g. drinking a cup of tea or eating.
- **Smile** – facial expressions can be understood long after verbal language is lost, a smile is one of the last cues that a person with dementia will respond to.

Further helpful tips include:

- Maintain eye contact and stay in the person’s line of vision
- Don’t stand too close, or ‘stand over’ the person
- Include the person in conversations – try not to speak for them or complete their sentences, even if this takes more time
- Active listening – give the person time and really try to work out what they are trying to communicate
- Repeat and rephrase
- Use reminders throughout the conversation – key words
- Give options rather than orders
- Remove background distractions (noise, lights, television)
- Gently prompt if appropriate, or ‘role model’ what needs to happen
- Avoid sudden movements and tense facial expressions
- Use the person’s preferred name – this is their identity
- Avoid arguing – try distraction or gently changing the topic
- Focus on what the person can do, not what they can’t do
- In managing behaviours, don’t respond to the words – respond to the emotion behind them and identify the trigger.
Person-centred communication in practice

The following examples contrast non-person-centred versus person-centred communication. Which one would you prefer to hear?

<table>
<thead>
<tr>
<th>Not person-centred</th>
<th>Person-centred</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have to get dressed</td>
<td>Would you like to wear the blue dress today, or the red one? (eye contact, calm voice, points to dresses on hanger)</td>
</tr>
<tr>
<td>I don’t understand a word you are saying</td>
<td>You seem upset. Is it about Fran leaving early today?</td>
</tr>
</tbody>
</table>

Activities

In a person-centred approach, activities are not merely actions that fill in time. They must be meaningful to the person, and serve to:

- Maintain skills
- Maintain health
- Keep a sense of independence
- Establish routines.

Activities must also:

- Enable the person to use their existing skills
- Be culturally appropriate
- Give a sense of enjoyment and/or achievement
- Balance safety with independence and risk-taking
- Meet needs other than ‘being occupied’ – for example, inclusion, attachment and identity.

An effective activities program will take into consideration the type and stage of dementia, the person’s background, their concentration span, routine and the time of day that is best suited for them to do the activity.

Developing meaningful activities involves getting to know the person through communication and working with them to identify what they would like to do. The task is then to develop ways to make the activities safe and comfortable.

The more tailored an activities program is to the person, the greater the benefits. These include cognitive stimulation, emotional wellbeing, skill maintenance as well as new skills to compensate for lost function. Research shows that when activities are well-matched to a person, they may have more responsive behaviours.

When English is not a first language, it is important to ensure the person living with dementia can participate in activities in their preferred language. As cognitive ability declines, people can lose their English-speaking skills, making the experience of dementia more isolating.
Autonomy
Promoting autonomy (a sense of selfhood through action) is a major factor in planning activities. A person must feel they are in an environment where they can self-direct their actions while taking some risks.

Everyday activities
Eating, drinking, maintaining safety, mobilising, attending to personal hygiene, grooming, spiritual needs, expressing sexuality (e.g. through dress, grooming, safe/consensual activities), paying bills, shopping, preparing meals, climbing stairs, cooking, cleaning, laundry, travelling by public and private transport.

Other activities
Sport and leisure, craft and creative, socialising, reminiscing activities, spiritual activities, dancing, playing cards, gardening and walking.

Music
Music can reduce the feelings of isolation that come with the loss of verbal language. It can be used as formal therapy or for entertainment. Music may assist in reducing anxiety and to promote well-being and sociability. Individual and group music therapy have been shown to reduce adverse behaviours and distress among people living with dementia.

Behaviours

Behaviours
Dementia can lead to changes in behaviour. These changes can cause distress for the person living with dementia, as well as those who live with and care for them.

Understanding why someone is behaving the way they are can help family and carers to cope with the changes. In a person-centred approach, it’s important to ask yourself if the behaviours are of concern, or simply annoying to you. Do they distress the person? Are they causing damage? If not, then consider carefully if they need to be managed.

Behaviours are always a response to something. If you can identify the trigger or reason that is prompting the behaviour, you may be able to resolve the issue and reduce the person’s distress.
Examples of behaviours include:

- Wandering
- Aggression
- Shadowing
- Being loud
- Agitation
- Resistance to care
- Withdrawal
- Sun-downing
- Hoarding
- Hallucinations
- Anxiety
- Disinhibition (e.g. taking clothes off)

Identifying and defining behaviours

The first step in supporting someone with their behaviours is to define the behaviour in a useful way. ‘Useful’ here means a way that describes exactly what the behaviour is, how often it occurs, and observed facts, not opinions about the behaviour. The STAR (Situation, Trigger, Action, Result) system is helpful for this. For example:

<table>
<thead>
<tr>
<th>Situation</th>
<th>Trigger</th>
<th>Action</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>At 10.00 am, I opened the curtains and Mrs Forbes shouted at me to ‘bloody stop it’.</td>
<td>I didn’t ask her if I could open the curtains. The room was dark and the sunlight was very bright.</td>
<td>I apologised and asked if I should close the curtains. She didn’t answer. I then asked Mrs Forbes if she would like to close them.</td>
<td>Mrs Forbes closed the curtains herself. She became much calmer. I asked if I could turn on the overhead light. She said yes.</td>
</tr>
</tbody>
</table>

Using the STAR system can provide information that is useful to you and others in supporting the person with dementia. If it becomes clear Mrs Forbes never likes her curtains opened suddenly, this can be added to her care plan and future distress avoided.
Behaviour management and delirium

Behaviour management

The aims of behaviour management are to:

• Keep people safe
• De-escalate behaviour
• Remove triggers
• Reduce the person's emotional trauma.

Managing behaviours

General management

Dementia research shows us that the more a person's needs are met, the less likely they are to have adverse responsive behaviours. By taking time to figure out what the triggers might be and taking steps to remove or modify those triggers, you can save a lot of distress for the person, and those around them.

General considerations include:

• Physical environment – is it too bright, too dark, too loud, too many people, unfamiliar?
• Immediate situation – has something upsetting happened? Something unexpected? Wrong language or tone used?
• Routine – is it working for them or is it just what suits others?
• Other – pain, medication changes, fatigue, dehydration, possible infection or illness.

Specific management

When behaviour escalates, you will need to respond quickly and calmly. Use the 7 R’s to respond to immediate needs:

1. **Remain calm** – communication: slow, simple, specific, show and smile
2. **Remove dangers to the person and yourself**
3. **Respond to feelings**
4. **Reassure and comfort** – keeping voice low and calm
5. **Respond to reasonable requests**
6. **Redirect or distraction when calm** – move onto another activity
7. **Report to your nursing supervisor** – seek support.

Try not to take the behaviour personally and debrief afterwards if necessary. Under no circumstances shout, restrain, lock out, grab, isolate or punish the person. This could lead to further distress and a chance of serious injury. If an incident occurs, document this in the progress notes and report to your nursing supervisor.
When strategies do not work

If the suggested strategies do not work, and a situation is continuing to escalate to a level where people's safety, including yours, is at risk, then a crisis management approach is required.

If there is a known pattern of behaviour, refer to the person’s care plan and follow the crisis management strategy given. If the behaviour is new or unknown, the first priority is your safety. Assess the situation for immediate and potential risks and take appropriate steps, including removing any items that could be used as a weapon. Ensure you can leave the situation quickly if you need to.

If you cannot resolve the situation using existing resources, contact your nursing supervisor and ask for assistance. If the situation is life-threatening, call emergency services on 000.

Delirium

Delirium is a medical emergency in which a person’s mental abilities are affected. It results in confused thinking and a reduced awareness of the environment. It comes on suddenly (often within hours). Delirium may have a single cause or more than one cause, including pain, infection, dehydration, lack of sleep, or a reaction to medication.

Delirium can result in serious harm, falls and death. For this reason, it is very important to recognise it early. Some signs of delirium are:

• A sudden change in the person’s personality or mood. For example, they are usually quiet, and become unreasonably loud
• Being far more disoriented or confused than usual
• Difficulties with perception (seeing, hearing what is around them)
• Hallucinations, delusions, being very agitated or aggressive
• Being quiet, drowsy or lethargic.

If you observe any sudden changes in the person, report them to your nursing supervisor immediately. Take note of any potential triggers (such as medication changes, dehydration, infection or lack of sleep), record them in the progress notes and notify your nursing supervisor as this could indicate a change in the person’s medical condition.
Contacts and other resources

DVA general enquiries  ☎ 1800 555 254

DVA provider enquiries  ☎ 1800 550 457

DVA community nursing  📧 nursing@dva.gov.au

Open Arms – Veterans and Families Counselling  ☎ 1800 011 046

Dementia Australia  ☎ 1800 100 500
                     ☑️ www.dementia.org.au

Carers Australia  ☑️ www.carersaustralia.org.au

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