

IS IT DEMENTIA?

TRANSPORT SERVICES | FACT SHEET

Your role requires you to transport passengers, some of whom will have issues such as dementia. This fact sheet is designed to give you information that will raise your awareness of the signs of dementia and provide you with considerations to support people with dementia. However it should not replace your organisational processes and procedures for response in regards to emergency situations.

What is dementia?

Dementia is a term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and what would be considered normal emotional reactions.

Signs of dementia

In the early stages the symptoms of dementia can be very subtle. However, it often begins with lapses in memory and difficulty in finding the right words for everyday objects. A person with dementia may experience one or more of the following symptoms:

- Forgetting recent events
- Difficulty with making decisions
- Difficulty with expressing their thoughts
- Confusion in understanding what others are saying
- Confusion about the day, time, where they live, where they have come from, what they have just been doing, or the actual situation they find themselves in
- Difficulty performing more complex tasks
- Difficulty managing finances
- Being anxious, crying or distressed
- Inappropriate behaviour or responses

People with dementia may differ in the patterns and type of problems they have, and the speed with which their abilities deteriorate. Their abilities may change from day to day, or even within the same day. However, what is certain is that the person's abilities will deteriorate, sometimes rapidly over a few months, in other cases more slowly over a number of years.

There are many conditions where people can exhibit signs similar to dementia such as forgetfulness or memory problems. It is best not to assume that someone has dementia just because some of the symptoms are present. Strokes, depression, alcoholism, infections, hormone disorders, nutritional deficiencies and brain tumours can all cause dementia-like symptoms.

Impact of dementia

When a person has dementia their ability to function can be compromised. For example their tolerance to stress may not be as good as it used to be. Being able to deal with uncertainties, crowds, pressure or noisy environments may cause them to become upset, angry or disoriented. Alternatively, a person may start to lose their social inhibitions, such as someone who has always taken pride in their dress, starting to dress carelessly, or doing and saying inappropriate things.

People close to the person with dementia are also affected. The nature of their relationship can change as the person with dementia may come to rely more heavily on them for support, especially family members. In turn the caring role may have an adverse effect on the wellbeing and health of the family members. Remember, when you interact with a member of the family, you may be faced with a very tired and frustrated person who will require gentle support.

Different Types of Dementia

Currently there are over 100 identified types of dementia. There are 5 common types which you will frequently encounter:

1. Alzheimer's disease is the most common type of dementia and will initially have an impact on someone's short term memory. Other changes can be experienced later as the disease progresses and may include communication and mobility difficulties, behavioural changes and eventually, loss of long term memory.
2. Vascular dementia is usually the result of ongoing mini stroke activity (transient ischaemic attacks or TIA's). The impact and presentation will vary depending on where in the brain the stroke activity has occurred.
3. A combination of Alzheimer's disease and Vascular dementia.
4. Lewy body disease is a form of dementia that can result in changes to movement, thinking and behaviour and is increasingly more common.
5. Fronto-temporal dementia where the signs may include significant behavioural and personality changes and loss of inhibition.

It is important to remember that all people present differently with dementia requiring an individualised approach.

Younger Onset Dementia

Dementia does not just happen to older people. People in their 30's, 40's and 50's can also experience dementia. Whilst less common, the incidence is increasing, with over 24,000 Australians living with younger onset dementia.

Signs to look out for

A person with dementia is likely to appear confused and disorientated or, they may lack insight or be stubborn about particular issues. There is no singular presentation as the disease exhibits across a range of domains, however the most common are memory loss and confusion. Repetitive questioning or the inability to follow simple instructions may be a first indication that something is 'not quite right' and the way you respond will have an affect on the outcome of the situation. Whilst not all people who present with these signs will have dementia you should take a moment to consider, 'is it dementia?' when interacting with passengers.

The person with dementia may not be able to distinguish between uniforms particularly if they have had experiences (negative or positive) with uniformed individuals in the past. Uniforms may signify ambulance, military, police, prison guards or street cleaners instead of transport support. They may make an attempt to rationalise or challenge what is happening as they are interacting with you. They might use resistive behaviour as they may connect the uniform with previous incidences from their life.

It is important to recognise that their response may seem abnormal to the situation or your experience, but to them it makes sense. Consider how you might respond if you had an experience as a prisoner of war – uniforms may make you feel uncomfortable, and in trouble.

Communication Considerations

Certain behaviours are easier to understand if you suspect or know the person has dementia and these considerations will help you explore situations further. It is important to try not to react to what someone with dementia may be saying as they may be unaware of the impact. Of course safety is paramount and your organisational processes and procedures should support your own and other passengers safety. Where possible, take a moment to consider if your interaction may be escalating the situation and if you can, choose alternative responses.

If possible be 'in the moment' and attempt to connect with the person through acknowledging their experience. This may be challenging within your environment and where possible moving to a quieter location with additional support is a good option. The following tips for communication may further assist you.

- Genuine and calm reassurance will potentially bring about better outcomes so where possible read the emotion, body language and tone of voice rather than the words used.
- Repeated questions from the person with dementia may be an indicator of increased confusion, stress or fear. The result may be someone asking for something that is not relevant within what is currently happening, such as asking for their

mother/husband/wife (even if deceased). This usually signifies a need for security and comfort. The response to this should be reassurance and validation of their emotions, even when you don't have the full information available.

- Reminiscence and diversion may assist to calm someone down and establish feelings of security. It can help someone to tell you about themselves and their life history and may also assist with distracting from their current point of focus.
- By using someone's name, it reminds them you know who they are and a connection has been established. You may need to continually reintroduce yourself and your purpose for being there and if so, do this calmly and reassuringly with as little frustration as possible. Model these behaviours for others to use.
- Look for signs that may indicate the person has dementia if you do not personally know them (e.g. Medic Alert bracelet, Companion Cards and other identifying materials). Some states have similar identification bracelets to the Medic Alert system which identify that a person has issues with their memory or dementia.
- Try not to react to what someone with dementia may be saying. If possible be 'in the moment' and connect with the person through acknowledging the insecurity felt.

Consider sharing information within your service if you have repeated incidences with a person who may have dementia to ensure there is awareness for others who might be interacting with that passenger. Flag the issues with your supervisor or call centre and consider putting a plan in place to support future interactions.

Consider the impact of environment on people with dementia. People with dementia work well in familiar and consistent environments and even minor changes to routine can cause anxiety and agitation. Your environment may be an additional stressor and anything you can do to support them will provide a positive outcome for both parties.

Consider accessing further specific advice from individual culturally and linguistically diverse or aboriginal communities where there is further complexity on the issues you are presented with.

Consider developing individual plans for your unit or team in the future for working with people with dementia - these could include dementia specific pathways

Final thoughts

Dementia is a terminal disease but it should be considered when we think about how our services support people with a disability. Where and whenever it is possible remember to consider:

- Your approach
- Your body language
- The language and words you use
- Environmental stressors (frantic/busy environments are distressing so move to a quieter area when practical)
- If possible nominate a contact person within your unit or team to support the person with dementia until further help arrives. This may involve calling supervisors or call centres for further support
- If a person with dementia is lost and you are unable to contact family members to support them please contact the police who will assist in supporting the person to return home.
- Consider developing individual plans for your unit or team in the future for working with people with dementia.

Where to from here?

For more information or support please contact the:

National Dementia Helpline 1800 100 500

The Helpline can assist you with locating additional supports or resources for your state or territory including:

- Statutory bodies for guardianship issues
- Public advocate
- Advocacy services
- Community support services

Additional information can be sourced at:

www.fightdementia.org.au