

## Understanding Alzheimer's Disease

*THIS FACT SHEET discusses the nature of Alzheimer's disease, what we know about its cause, the symptoms and diagnosis. It offers suggestions on how to care for and communicate with someone who has the condition, and discusses ways to manage changes that may occur in their behaviour.*

### What is Alzheimer's Disease?

Alzheimer's disease is a progressive condition that affects the brain, resulting in impaired memory, thinking and behaviour. It is the most common form of dementia, which is the term used to describe a large group of illnesses that cause gradual decline in a person's functioning.

### What Causes Alzheimer's Disease?

As brain cells shrink or disappear, abnormal material builds up as "tangles" in the centre of the brain cells. Dense spots or "plaques" also build up outside the brain cells. These changes affect the vital connections between cells, disrupting messages within the brain. As areas of the brain become affected in this way, the functions or abilities controlled by that area, such as information recall, become limited or are lost.

### Who Develops Alzheimer's Disease?

Alzheimer's disease is most common in people over the age of 65, although it can affect people of any age. It is the most common form of dementia and accounts for between 50% and 70% of all cases.

### Symptoms

In the early stages, the symptoms of Alzheimer's disease can be very subtle. It often begins with lapses in memory and difficulty finding the right words for everyday objects.

Symptoms do vary however, and Alzheimer's disease progresses at a different pace according to the individual and the areas of brain that are affected.

A person's abilities may fluctuate from day to day, or even within one day, usually becoming worse in times of stress or ill health.

Symptoms may include:

- > Frequent, persistent memory difficulties, especially of recent events.
- > Repeating conversations or losing trails of thought.
- > Forgetting well-known people and places.
- > Loss of enthusiasm for previously enjoyed activities.
- > Taking longer to do routine tasks.
- > Inability to process questions and instructions.
- > Deterioration of social skills.
- > Emotional unpredictability.

### Diagnosis

There is no single test to identify Alzheimer's disease. The diagnosis is made after careful clinical consultation. The process usually requires the taking of a detailed medical history, a thorough physical and neurological examination, a test of intellectual function, and blood and urine tests.

After considering the symptoms and ordering various tests, a general practitioner may refer a person to a medical specialist, such as a neurologist (brain and nervous system specialist) or geriatrician (aged-care specialist) for further examination.

### Treatment

Currently, there is no cure for Alzheimer's disease. However some medications and alternative

treatments have been found to relieve some of the symptoms, for some people, for a period of time. Up to date information is available from Alzheimer's Australia Vic.

## What is the Outlook?

The rate at which Alzheimer's disease progresses is very different for each person but the condition gradually becomes worse over time. A person may live from three to 20 years, but the disease does lead eventually to complete dependence and finally to death, usually from complications associated with the condition.

## Caring for Someone with Alzheimer's Disease

Carers confront many challenges as this disease progresses. In particular, carers are likely to experience upsetting changes in a loved one's behaviour and a gradual loss of communication with them. As the person with Alzheimer's disease loses their independence, carers take on increasing responsibilities, such as planning daily activities for the person.

Carers need to pay special attention to their own health and wellbeing and learn to take time out for themselves.

The following strategies are a useful guide. Remember, Alzheimer's Australia Vic has a great deal of information and excellent support services to assist people with dementia, as well as their families and carers.

## Communicating Well

As the illness progresses, a person with Alzheimer's disease experiences a gradual lessening of their ability to communicate. This can be one of the most frustrating problems for everyone concerned. For example, the person may have trouble finding the right words, they may speak fluently but not make sense or they may not be able to grasp what you are saying. They often lose normal social conventions and begin to interrupt or ignore a speaker and may not respond when spoken to.

It is important to check that the person's sight and hearing are not impaired. Glasses or a hearing aid may help some people.

### Communication do's:

- > Remain calm and talk in a gentle, matter-of-fact way.
- > Keep sentences simple and focus on one idea at a time.
- > Allow plenty of time for what you say to be understood.
- > Avoid competing noises such as TV or radio.
- > Stay in the person's line of vision when talking to them.
- > Orientate names as much as possible: "Your son, Peter".
- > Maintain regular routines to help minimise confusion and assist communication.
- > A warm smile and laughter often says so much more than words.

### Communication don'ts:

- > Avoid arguing – it will only make the situation worse.
- > Try not to order the person around or tell them what they can or can't do.
- > Refrain from making condescending remarks.
- > Avoid negative body language – raised eyebrows, sighs, impatient foot tapping.
- > Try not to talk about someone with dementia in front of them, as if they are not there.

## Managing Changes in Behaviour

Changes in the behaviour of a person with Alzheimer's disease are very common. These changes may be related to changes in the brain, changes in the person's environment or it may be their health or medication that triggers certain behaviours. Understanding what triggers behaviours can give carers clues as to how to respond and cope.

Always discuss concerns about any changes in behaviour with your doctor. Your GP can check to

see if there is a physical illness or discomfort present, and provide advice.

Following are some of the common behaviour changes that may occur.

**Catastrophic reactions:** Sometimes a person with Alzheimer's disease will overreact to a trivial setback or minor criticism by screaming, shouting or making unreasonable accusations. This is called a catastrophic reaction and it is part of the disease. These can be brought on by a stressful situation, frustration due to communication difficulties or another underlying illness.

Keeping a diary of these reactions may help you to identify what circumstances trigger them.

**Hoarding:** People with Alzheimer's disease often search for something that they believe is missing and hoard things for safekeeping. Hoarding behaviours may be caused if a person feels alone or neglected or if they are experiencing feelings of loss or fear that may be associated with their present day or their memories.

Learn a person's usual hiding places and check there first for missing items. Also, provide a drawer full of odds and ends for the person to sort out – sometimes this can satisfy their need to be busy.

**Repetitive behaviour:** A person with Alzheimer's disease may often say or ask the same things over and over. They may also follow you everywhere and become very clinging. These behaviours can be upsetting and irritating. Distraction may help, such as going for a walk, making a cup of tea or suggesting a favourite activity.

**Coping:** Coping with changed behaviours can be very difficult. Always remember that the behaviour is not deliberate. It is out of the person's control and they may be quite frightened by it. They need reassurance, even though it may not appear that way.

## Planning Activities

Having Alzheimer's disease does not diminish a person's need for quality of life, which is very difficult to achieve without assistance from carers.

Activities should compensate for lost interests, promote self-esteem, maintain residual skills, not involve any new learning and provide opportunities for enjoyment and social contact.

These guidelines may help in planning daily activities.

- > Consider all that makes the person unique – their former lifestyle, hobbies, work and social interests.
- > Break down activities into simple steps, communicating one instruction at a time – allow plenty of time.
- > Encourage responsibilities, no matter how small, that make use of skills not yet forgotten, such as buttering bread, washing up, raking in the garden, folding clothes.
- > Enjoy outings together – it doesn't matter if they are forgotten – but avoid noisy, crowded places.
- > Because abilities can fluctuate from day to day, some activities may need to be adapted or tried another time if not successful or enjoyable.
- > Allow an emotional outlet – looking through old photos, discussing past events and listening to favourite, old songs can recall happy feelings and be deeply satisfying.
- > If reading skills have deteriorated, try audio books, picture books or magazines.

## Caring for Yourself

Caring for someone with Alzheimer's disease can be physically and emotionally draining and stressful. Taking a break from caring (called respite or respite care) is essential.

There are many respite-care services available that include in-home care, day care, weekend care and even overnight care.

Your loved one also needs opportunities to socialise and meet other people and to be reminded that there is something to look forward to.

It is common for people with Alzheimer's disease to feel anxious and unsettled in new environments, but planning ahead for a positive experience helps. Many families and carers have found it useful to start using regular respite care as early as possible. It's often best to start with smaller breaks and build up to longer ones.

Respite care services recommend that carers have at least two consecutive weeks in a break to allow time to relax fully and to gain maximum benefit. Fact Sheet 15: *Respite and Residential Care* tells you how to access these services.

Support groups are also an invaluable outlet, giving you a chance to mix with people who really understand what you are going through. Carers can also swap useful strategies.

(See Fact Sheet 19: *Coping with Stress*).

## Contact

Alzheimer's Australia Vic provides support, information, education and counselling for people with dementia, their families and carers.

### **Alzheimer's Australia Vic**

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### **National Dementia Helpline:**

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website: [www.alzheimers.org.au](http://www.alzheimers.org.au)

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