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## Alzheimer's Disease and Dementia

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### What is Dementia?

Dementia is a general term that describes the syndrome of intellectual deterioration affecting memory, other cognitive functions and personality. It leads to confusion and the inability to cope with daily living until, in the terminal phase, the sufferer is completely dependent on others for basic care.

Dementia is a collection of symptoms resulting from the failure of the brain. The result is a progressive decline in the person's ability to think, remember and to reason. It may also affect behaviour and personality.

### Who does it affect?

An estimated 38,000 New Zealanders have dementia. It is currently estimated that 50% of people with dementia have Alzheimer's disease. Another 20% have vascular dementia, previously called multi-infarct

*Dementia is not a normal part of the ageing process. Younger people can develop it too.*

dementia (MID), and about 10% have a mixture of AD and MID. Other causes of dementia account for the remainder and include: brain tumours, severe head injury, AIDS, excessive use of alcohol over a long time, Parkinson's disease and other less common conditions. There is no single test for Alzheimer's Disease and diagnosis is generally reached as a process of elimination. Although a clinical diagnosis may be made, confirmation of Alzheimer's Disease can only be made by examination of brain tissue after death.

### Types of Dementia

#### Alzheimer's Disease

Alzheimer's disease is the most common form of dementia. It affects 1 in 10 over 60 years and 1 in 3 over 85 years but dementia is not part of the normal ageing process. Younger people can also develop it.

Alzheimer's disease is a progressive degenerative disease of the brain. Nerve cells die and are not replaced, which results in impaired memory, thinking and behaviour. Alzheimer's disease can affect anyone regardless of race, gender, social or economic status.

The changes in the brain can only be seen under a microscope. Neurofibrillary tangles composed of tau protein build up and kill the nerve cells. Plaques composed of a protein called  $\beta$  amyloid also build up. The more plaques and tangles there are the greater the dementia.

#### Vascular Dementia

Brain cells die i.e. infarct when small blood vessels either burst (haemorrhagic infarction) or are blocked by blood clots (thrombo-embolic infarction). Essentially dementia is caused progressively by more and more very small strokes. Unlike Alzheimer's patients deteriorate in a stepwise fashion. They remain at the same level and may even improve until their next infarct when they deteriorate a little bit more.

High blood pressure can damage the blood vessel walls in the brain. The vessels tend to bulge and blood leaking from it damages the surrounding brain tissue. Clots or thrombi may form within and block the blood vessel or parts of a clot in another area of the body may break off i.e. emboli and travel to the small blood vessels in the brain causing a blockage.

Vascular dementia cannot be reversed by drug treatment but the risk of further small blood vessel blockages may be reduced by regular low dose aspirin which prevents clot formation. High blood pressure is also a risk factor and can be reduced by regular exercise, no smoking, low salt intake and management of stress.

### Symptoms

The symptoms of dementia can vary widely with different people. There are three main phases of dementia with corresponding symptoms.

*In the first phase, the forgetful phase, the person may be:*

- Apathetic, less sparkle
- Less interested in hobbies, activities
- Less able to make decisions or plans
- Unwilling to try new things or adapt to change
- Slower to grasp complex ideas
- Ready to blame others for 'stealing' mislaid items
- Seeking the familiar
- More self-centred, less concerned with others and their feelings
- More forgetful of details of recent events
- Change of personality, more irritable or anxious
- More likely to repeat themselves, or forget their line of thought.

*In the second phase, the confusional phase, the person may:*

- Need assistance and supervision with many tasks
- Be forgetful of recent events, and the distant past may be forgotten or confused
- Be confused regarding time and place, and time of day - may go out shopping at midnight
- Rapidly become lost if out of familiar surroundings
- Forget names of friends or family, or confuse one family member with another
- Forget saucepans, kettles; may leave stove on
- Wander around streets, perhaps at night; sometimes becoming completely lost
- Behave inappropriately, e.g. going outdoors in nightwear
- Be confused with the completion of everyday tasks, e.g. putting underwear on last when dressing
- See or hear things that are not there
- Become very repetitive
- May feel safer at home and avoid visiting people
- Be neglectful of hygiene or eating, perhaps saying they had a bath or meal when they have not
- Become angry or upset or distressed very rapidly

*In the third phase, the dementia phase, the person may:*

- Be unable to find their way around
- Constantly repeat one or more phrases or sounds
- Be incontinent (urine and/or faeces)
- Show no recognition of friends or relatives
- Take their clothes off inappropriately
- Fail to recognise everyday objects
- Be unable to remember for even a few minutes what they have just done
- Need help or supervision with feeding, washing, bathing, using the toilet, dressing
- Have difficulty understanding what is said to them.
- Make little sense with their speech

## **Treatment**

Although no cure for Alzheimer's Disease is available at present, appropriate medication can lessen agitation, anxiety and unpredictable behaviour,

improve sleeping patterns and treat depression. Research into the cause and finding a cure is ongoing. There are new drugs that in some cases can slow down the progress of the disease, but these must be seen as complementary to good psychosocial care. The drugs are not subsidised.

## **How to Best Care for a Person with Dementia**

*In the home:*

- Look out for safety hazards in the home, install smoke detectors, hide matches, avoid clutter and rugs that could trip your caree, improve lighting in dark areas, install locks or alarms on doors.
- Keep the environment as familiar and as calm as possible.
- Encourage your caree to remember as best that they can. Have items connected with the past to maintain good quality of life and reassure your caree. Prepare a 'This is your Life' book.

*Maintain activities:*

- Encourage your caree to continue previous interests and lifestyle for as long as possible.
- Discourage driving or other potentially dangerous activities.
- Use praise and encouragement when possible to assist in maintaining independence and dignity for your caree, e.g. don't put sugar in tea if caree can add it on their own.
- Do not persist with the activity if your caree becomes frustrated or upset.
- Maintain consistency and establish routines.

*Their health:*

- Find out all you can about dementia.
- People with dementia suffer from the same illnesses that we all suffer from.
- Engage the support of family, friends and neighbours.
- Make use of adult day care which will provide motivation and companionship for your caree, while at the same time allowing you some free time to keep up your own interests.

*Your health:*

- Look after yourself, the carer, by eating well and taking regular breaks, e.g. walking, visiting a friend, reading. This is important if a carer is to continue in their caring role.
- Keep up your interests and maintain contact with your family and friends
- You're not alone. There are other people in the same situation you can talk to.
- Join a support group with other carers, as they may be able to give you practical advice.

## Practical Suggestions for Coping with Dementia

**Balance:** The more the person with dementia does for himself or herself, the less you have to do for them. A calm relaxed atmosphere will help the person to function as well as they are able.

**Communication:** People who have dementia often have difficulty in communicating. They may have trouble expressing what they wish to say, or they may have problems understanding what is being said. This can be frustrating and painful for all concerned.

*Remember - sight and hearing loss may make dementia seem worse than it really is.*

*Here are some ideas to think about for communicating with your caree who has dementia:*

- Eliminate distractions
- Make sure that you can be seen and heard
- Speak in clear, distinct tones on an adult level
- Use short, simple sentences and ask simple questions that can be answered with one word or a gesture
- Repeat or rephrase your message if there is no response
- Talking about past experiences can be easier than recent ones
- Keep conversation specific
- Use hand gestures and facial expressions to reinforce what you are saying
- Smile and use humour and affection – they can go a long way.
- Aid your caree's conversation by providing prompts
- Give your caree time to respond
- Reward your caree for correct responses with verbal praise, touch, smiles etc
- Reinforce what is real, and when dealing with rambling talk, tactfully correct conversation or change the subject and discuss something else
- Acknowledge any feelings that are expressed
- Be honest, encouraging and patient with your caree
- Touch gently if the person likes to be touched

Your approach is extremely important. Your feelings can be conveyed to the person by body tension or facial expression.

**Memory Aids:** These may be useful in the early stages. They may consist of lists, labels or regular patterns.

**Bathing and hygiene:** Many people with dementia may need a gentle reminder as they simply forget

whether they have washed. Some supervision may be required, from a safety point of view, for bathing.

**Dressing:** It may help if the clothes are laid out in order for them on the bed. Clothing can be simplified where necessary e.g. slip on shoes, front fastenings.

**Wandering:** A person with memory loss and confusion may wander from home and be unable to find their way back. Have locks that are unfamiliar to the person installed or try placing the lock where they are unlikely to look e.g. at the bottom of the door. It is also a good idea to have an identification bracelet.

**Safety:** Look out for safety hazards in the home, install smoke detectors, hide matches, avoid clutter and rugs that could trip your caree, improve lighting in dark areas, install locks or alarms on doors.

**Delusions and Hallucinations:** Some people with dementia can see or hear things. These are called hallucinations. Others have 'mistaken ideas' or delusions. Usually telling the person there is nothing there will be futile as the person is actually experiencing seeing something. Instead respond to their feelings "I can't see the creatures over there, but it must be really disturbing for you".

**Depression and Anxiety:** People who are depressed usually look depressed. They may be slowed down, moving, thinking and speaking more slowly or may be withdrawn and miserable. Ask your doctor in these circumstances to assess whether there is an element of depression that could be treated.

*Remember that difficult behaviour is not aimed at you personally.*

**Challenging Behaviour:** As people with dementia become more forgetful and insecure they become more agitated as they are unable to comprehend the 'disorganised' world around them. Agitated behaviour may also be due to illness or infection, the side effects of medication, dehydration or constipation. It is best to try and prevent it by not engaging in arguments. Sometimes a small degree of sedation may be necessary if the person is becoming more frustrated.

## **Where to go for Support**

### **Alzheimers Society**

The Alzheimers Society exists to alleviate the social and personal consequences of Alzheimer's Disease and related disorders, especially as they affect families and friends. Information and advice for caregivers, together with a wide range of written information, is available from the Alzheimers Society, including information sheets, booklets, videos and books to borrow, and newsletters. They not only provide support for people in the early stages of dementia, but also hold regular education meetings and support groups for caregivers and family members.

Volunteers are incorporated in a sitting service and a walkabout programme. For information on the services available in your area and how to access them contact the Alzheimer's Society at their Christchurch office at 314 Worcester Street or by phone on 03 379 2590.

### **Caring for Carers**

All too often the burden of caring for a person with dementia falls on one or two of the immediate family members and the emotional, physical and financial hardships involved can be difficult to cope with. Carers can get discouraged and lonely, angry and depressed. Someone they have loved gradually disintegrates as a person. The whole relationship changes and new demands are placed upon the carer.

As a carer, it is important to remember that you are an individual with needs of your own. Ensure that you take care of yourself by arranging your day so that you have some time for yourself. Meeting with other carers can also ease the loneliness that carers can often experience.

*Caring for Carers* has a Newsletter and several support meetings each month and ongoing telephone support. These services are provided to help make your job easier.

*Caring for Carers* is situated:

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221 Gloucester Street, Christchurch.  
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Phone: 377 8426  
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