



YOUNGER PEOPLE WITH MEMORY LOSS

Many people assume that Alzheimers disease and other causes of dementia only affect older people. In fact, about one person in every 1000 below the age of 65 develops dementia. While rare, it can affect people in their 30's, 40's and 50's. Any dementia beginning before the age of 65 is known as younger onset dementia.

Obtaining a diagnosis

You need to ask your family doctor to refer you to a specialist such as a neurologist, geriatrician or psychogeriatrician for an accurate diagnosis. Sometimes general practitioners may not consider that you have Alzheimers disease or a related dementia because of your age and therefore be reluctant to refer you for specialist assessment. It may help if you take this leaflet with you and/or request support from your local Alzheimers organisation.

A complete medical and psychological assessment may identify an easily treatable condition, or it may confirm the presence of dementia. A detailed medical history, provided if possible by the person with the symptoms and a relative or friend will help to establish whether the symptoms have been slow or sudden, and the impact they are having on the affected person's life. An early diagnosis will allow for early planning, the early involvement of support services and perhaps medical treatment.

To help determine a diagnosis tests are likely to include blood samples, a CAT or MRI scan, and questions regarding memory, thinking and day-to-day functioning. In some places in New Zealand there are Memory Clinics where these tests can be undertaken in one place. It is not unusual for someone under 65 years to be referred to a service for older people.

It is not always possible to obtain a firm diagnosis and a review may be necessary 6 – 12 months later before a diagnosis can be confirmed.

Sharing the diagnosis

Accepting the diagnosis is an important step towards making the changes that will be necessary. People around you are already likely to be aware of changes and they will be concerned. People do tend to withhold the diagnosis from others. This can lead to embarrassment, isolation and lack of support and help. Sharing the diagnosis and talking about its implication allows you to move forward with support of others.

Talking to others in a similar situation might also help.

There may be a support group in your area for people with early stage dementia. Talking to staff at the Alzheimers Society or attending counselling sessions can be helpful. The more information and ideas you can learn to help you deal with your situation, the better.

Loss

The sense of loss for the person with younger onset dementia and their family can be enormous. Unplanned loss of income, if the person with dementia was earning an income, can be a major problem for the family. This can be made worse by the loss of the self-esteem and self-worth that usually comes with working, and the loss of a purpose in life. Future plans, perhaps for retirement and travel, or time with children or grandchildren may no longer be an option.

Different needs

Each person's experience of dementia is unique. Although the symptoms of dementia are similar whatever a person's age, younger people with dementia have different needs and their problems often require a different approach. They may:

- be in work at the time of diagnosis;
- have dependent children still living at home;
- have financial commitments;
- be physically fit and behave in ways that other people find challenging;
- be more aware of their disease in the early stages;
- find it hard to accept and cope with losing skills at such a young age.

Planning ahead

Planning ahead can make it easier for you and your family to manage your affairs. It means that you will be able to participate in planning for your future and make sure that your wishes are carried out.

You may have children, work or financial commitments. Seek advice and support about financial matters and arrange a Power of Attorney who can act on your behalf for your property and personal welfare. (Refer to Information sheet no. 13 on legal issues)

If you are still working it is important that you advise your employer as changes to your role and tasks may be necessary. There may be risks in continuing to work in your current job. If you are no longer able to work, financial support may be available through Work and Income New Zealand (WINZ).

You will need to consider your ability to drive. Sometimes people with dementia recognise their own limits and accept that they can no longer drive, whilst others may be more reluctant to do this. This may be due to an inability to fully understand the loss of skills they are experiencing. This problem cannot be ignored, even if driving is only for short trips to the shops. (Refer to LTSA Factsheet: Dementia and Driving)

What might help

- Having regular exercise to keep fit and active may help with restless behaviour and disturbed sleep. Walking, for instance, may have a calming effect.
- Maintain social activities and contacts for as long as you are able to.
- Keep structure and routine in your day.
- Use reminder notices or a diary to support your failing memory.

Advice for families and friends

A diagnosis of dementia may be hard to accept, particularly in a younger person. It is important that you seek support and information to assist you in coming to terms with the diagnosis.

As abilities decline carers should understand that the person with dementia may no longer be able to make even the simplest decision. This can be hard to accept for both the person and the family. In the best interests of the person with dementia someone who knows him or her well, usually the carer, may have to take over decision-making. Your local Alzheimers Society will be able to help with advice, if needed.

It may be necessary to consider that the primary carer may have to alter employment commitments or give up work as the disease progresses. These changes can be significant and unwanted.

Partnership

It is possible that intimacy and sexuality will also be affected by the early onset of dementia. Changes in behaviour may range from a complete withdrawal of physical contact to demanding physical behaviour. There are different strategies to enable you to cope with these changes.

Children

Children, especially young children, whose parent has been diagnosed with dementia, may have reactions varying from anger to feeling isolated, or become embarrassed and withdraw from their friends. They

may be afraid that they will also lose the other parent to illness or to inherit the disease themselves. Both parents need to make time to talk through this with their child. There are a number of books and videos available from the Alzheimers Society which focuses on the needs of children.

Down syndrome and Alzheimers disease

Research studies indicate that people with Down syndrome are predisposed to developing Alzheimers disease at an early age. This deterioration may be influenced by other factors such as residential conditions, diet, recreational opportunities and rehabilitation. Please contact your local Alzheimers Organisation for more information.

Other resources

There are many excellent books and information sheets available. Ask your local Alzheimers organisation staff for advice about which ones might be helpful.

An internet-based advocacy and support group can be a useful place to discuss issues: <http://www.dasinternational.org/>

Other sites on the internet provide information and the opportunity to communicate with others with early onset (email: alzchat@aol.com).

C.A.N.D.I.D. (Counselling and Diagnosis in Dementia) under "Links" at www.alnsw.asn.au offers support, information and education for anyone caring for a younger person with dementia.

You will also find more detailed information in the booklet "Just For You" available from your local Alzheimers organisation.

Alzheimers New Zealand has a range of information sheets and booklets available for people with dementia, their carers, families and whānau. Alzheimers member organisations located throughout New Zealand provide a variety of services and support to all people affected by dementia. Contact your local organisation on freephone 0800 004 001.

This information sheet provides a general summary only of the subject matter covered and is not a substitute for informed professional advice. Any person with dementia or their carer or family/whānau should seek professional advice about any individual case. Alzheimers New Zealand is not be liable for any error or omission in this publication, as a result of negligence or otherwise. This information sheet was produced in March 2010.

Alzheimers New Zealand – National Office Level 1, 4-12 Cruickshank Street, PO Box 14768, Kilbirnie, Wellington 6241
Phone 04 387 8264 **Facsimile** 04 387 8264 **Web** www.alzheimers.org.nz **Member** Alzheimer's Disease International
Contact your local organisation on freephone 0800 004 001 Charity registration CC21026