

# YOUNGER ONSET DEMENTIA

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This Help Sheet discusses younger onset dementia, sometimes called early onset dementia. It emphasises the importance of a correct diagnosis and some aspects of caring for someone with younger onset dementia.

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's mind. It is a broad term which describes a loss of memory, intellect, rationality, social skills and normal emotional reactions, as well as speech and behaviour change. The term 'younger onset dementia' is usually used to describe any form of dementia diagnosed in people under the age of 65.

Dementia in younger people is much less common than dementia occurring after the age of 65, and has been diagnosed in people in their 50's, 40's and even in their 30's. For this reason, it can be difficult to diagnose, and its incidence in the community is still not clear.

## **A correct diagnosis is important.**

Consulting a doctor to obtain a diagnosis is critical at an early stage. It may be however that diagnosis in a younger person may take some time as doctors must eliminate other possible causes of symptoms. A complete medical and psychological assessment may identify a treatable condition, or it may confirm the presence of dementia.

A diagnostic evaluation might include:

- A detailed medical history, provided if possible by the person with the symptoms and a close relative or friend. This helps to establish whether there is a slow or sudden onset and its progressions.
- A thorough physical and neurological examination, including tests of the senses and movements. This is to rule out other conditions, and to identify possible medical illnesses which may worsen the confusion associated with dementia.
- Laboratory tests including a variety of blood and urine tests (sometimes called a "dementia screen") to test for a variety of possible illnesses which could be responsible for the symptoms. The dementia screen is available through a doctor. Other specialised tests including a chest x-ray, ECG and CT scan may be recommended.
- Mental status test to evaluate the range of intellectual functions such as memory, the ability to read, write and calculate which are often affected by dementia.
- Psychiatric assessment to identify treatable disorders such as depression, which can mimic dementia, and to manage any psychiatric symptoms such as anxiety or delusions which may occur in conjunction with dementia.
- Neuro-psychological testing to identify retained abilities and specific problems in areas such as comprehension, insight and judgement.

## Are the needs of people with younger onset dementia different?

A person with younger onset dementia will need extra consideration because the dementia appears at an earlier stage of their life when they are likely to be more physically and socially active.

When diagnosed they may be:

- In full time employment Actively raising a family
- Financially responsible for the family
- Physically strong and healthy

Changed behaviours that are associated with dementia may be more difficult to accept and manage in a younger person.

For the family member who is caring for someone with younger onset dementia there are a number of issues that may arise:

### 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 self-esteem that comes if employment ceases, and the loss of a purpose in life. Future plans, perhaps for travel and retirement, or time with children or grandchildren may no longer be viable.

### Changes

Carers who are partners may have double the responsibility of caring for the person with dementia as well as raising children and managing finances. Sometimes families and carers must reduce or give up work altogether to care for the person with dementia. These changes can be significant.

### Attitudes

An added difficulty can be the attitude of other people. It can be difficult to accept that a younger person can have dementia, particularly when no obvious physical changes can be seen. It may appear that no-one else in the family or carer's age group understands what is happening. Most people affected by the illness find that friendships may fade as the dementia progresses, but a younger person's friends may break away even earlier.

### Children

Children may react differently to the disease, but are likely to have strong reactions. At a time when they are trying to cope with their own growing up, they find that they also have to cope with a family member who is unwell.

They may become angry, resentful and withdrawn. Some young people may have problems talking with their parents because they don't want to worry them or are afraid of making them sad, or of being an extra burden. They may prefer to talk to people their own age or to a counsellor.

### Remember

#### **You are not alone**

Dementia New Zealand can also put family and carers in touch with other family and carers of people with younger onset dementia and provide links to support groups.

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This publication provides a general summary only of the subject matter covered. People should seek professional advice about their specific case. The content was adapted from Alzheimer's Australia who have generously consented to their work being used. Written and peer reviewed: 2017 by Dr Chris Perkins and Dr Richard Worrall, Psychiatrists of Old Age. Reviewed by Dr Tina Crownshaw, Psychiatrist of Old Age 2023.

Dementia New Zealand offers support, information and education.

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