

YOUNGER ONSET DEMENTIA

Dementia (also known as Neurocognitive Disorder) causes gradual deterioration in attention, decision-making, memory and learning, language, perception and /or social behaviour. It is often thought of as an older person's disease. However, about 5% of people who get dementia are under the age of 65; these people are referred to as having "younger onset", or sometimes, "early-onset", dementia. Because of the relative rarity, dementia symptoms in younger people are often missed or put down to something else (e.g. work stress, burnout or depression). Furthermore the proportion of people with the frontotemporal type of dementia (Information Sheet 10) is much greater than in older people with dementia. This is readily mistaken for psychiatric illness, another reason for the diagnosis to be delayed.

How is the diagnosis made?

The diagnosis is made the same way it is in older people. New Zealand GPs have access to *Cognitive Impairment Pathways* which guide them through the assessment of people who might have dementia.

Most important is the history of symptoms from the person and another informant, usually a family member. This will include information about how and when changes occurred and their progression, mental/ emotional symptoms, other illnesses, usual functioning, life stresses and family history.

Physical (including neurological) examination may detect abnormalities that suggest something else, possibly treatable, is causing confusion. The doctor will generally do cognitive screening on the first visit. The usual test is the Montreal Cognitive Assessment 30-question screen (MOCA).

Laboratory testing will check for other causes of memory loss and confusion and ensure that the person is in the best health possible. A CT scan, MRI or other special scans will be ordered as a standard procedure for people with younger onset cognitive impairment.

It is likely that the GP will refer a younger person for specialist assessment. This might be to a neurologist, psychiatrist, psychologist for more in-depth testing or a Memory Clinic if there is one available. If there is a strong family history a geneticist might be involved. Sometimes if it is difficult to make the diagnosis, e.g. if the person is also depressed, the doctor may try antidepressant treatment to see if it makes a difference to cognition and function.

What are the causes?

Dementia of any type can begin at a younger age. However, frontotemporal dementia is a common cause of younger-onset dementia.

Who gets it?

Some people have a family history of young onset dementia; rare familial forms of Alzheimers or frontotemporal dementia can afflict people in their 40s or 50s. Huntington's chorea, a genetic condition, often leads to young onset dementia. People with a history of head injury or Down syndrome are more prone to younger onset dementia. However, people with none of these risk factors can still, inexplicably, develop dementia before the age of 65.

What are the special needs of younger people with dementia?

People who develop dementia early in life are often still working and may be supporting the household, including children at home or through tertiary education. They are likely to be physically strong and socially active and have greater responsibility for others than older people.

Specific issues

Loss:

The person with dementia and their supporter lose a shared future that might have included travel and new activities later in life. There will be an unplanned loss of income as one or both of a couple has to retire. With loss of employment comes loss of purpose, self-esteem, social contact and structure to the day. The person may lose their role in the family, perhaps as carer for the younger or older generation. There are sometimes struggles with insurance companies who do not accept that a young person can have dementia.

Changes:

Supporters of people with dementia will have to take on additional tasks that their partner once performed. This might be managing the finances, raising children or helping older parents. As the dementia progresses spouses will be required to take on aspects of caregiving that make them feel more like a parent than an equal partner. This relationship change often impacts on a couple's sexual life. There are also likely to be changes in the person's social life. People in the younger age group might find it hard to accept or understand what is happening or tolerate changed behaviour, so that the person is increasingly excluded from his or her social life and friends fade away.

Children:

Children react differently depending on their personalities and age. Teenagers are already having to cope with a challenging life-stage; changes in the family and an unwell family member may cause embarrassment, resentment or withdrawal. They

may not want to worry the cognitively-intact parent with their feelings, but they need a chance to unburden about the situation. It could be important to inform the school about what is happening at home and to support the young person to find a suitable relative or counsellor to talk to.

Services:

Many Dementia NZ services host groups for people and with younger-onset dementia and their supporters. Sharing the difficult issues they face can be immensely reassuring and helpful. There are no particular residential services for people with younger-onset dementia making it difficult if people dislike being living with others who are 20-30 years older. Because younger people are physically stronger, this can make managing behavioural issue more of a challenge. Finally, there are differences in funding services for people who are under or over 65. Your caseworker will support you though the bureaucracy!

This publication provides a general summary only of the subject matter covered. People should seek professional advice about their specific case.

**Dementia New Zealand offers support, information and education.
Ring 0800 4 DEMENTIA or
0800 433 636.
Or visit our website at www.dementia.nz**