INTELLECTUAL DISABILITY AND DEMENTIA

People with intellectual disability (ID) are probably all more likely to develop dementia than others. However, there is a particularly strong link between Down syndrome and Alzheimers Disease.

Down syndrome (also known as *Down's* syndrome) is the commonest congenital cause of ID in New Zealand. It is caused by chromosomal abnormalities, usually a third copy of chromosome 21 rather than just two. It is associated with ID and characteristic physical features.

Alzheimers Disease causes deterioration in memory, reasoning, emotions and behaviour (see Information Sheet 7). The typical brain changes seen microscopically in this condition are amyloid plaques (protein laid down in response to damage) and neurofibrillary tangles (dying nerve cells). These changes can be seen in the brains of most people with Down syndrome by the age of 40, although they may not have developed symptoms. The average age of onset of dementia for people with Down syndrome is in the 50s, but even then, only 50% have dementia by the time they are 60. People with ID are living much longer than they used to and are more likely to develop dementia than others and at an earlier age.

Ageing and ID

People with ID are living longer because the physical and psychological abnormalities often associated with ID are better managed. It has been recognised that people with ID need good preventative medical care, including treatment of diabetes and high blood pressure, control of blood lipids (cholesterol) and avoidance of smoking. These treatments also reduce the risk of dementia. Other ways to reduce the dementia risk are: exercise, weight control, social and mental activity. Recognising and treating mental illness such as depression or psychosis and helping people with ID to cope with stress will improve quality of life and may help to prevent dementia.

Recognising dementia in people with ID

The signs and symptoms are similar to those seen in people without ID. Usually it is someone who has known the person for a long time who sees changes and a reduced level of function. The person may:

- Lose skills and not be able to function as well as previously e.g. have difficulty dressing, showering, catching the bus, setting the table.
- Develop memory problems e.g. forget names of people they usually know
- Get lost in familiar places
- Have trouble communicating or understanding what others tell them, bearing in mind the method of communication the person normally uses e.g. speech, talking mats, gesture, Makaton.
- Become apathetic or quieter than previously
- Not want to try out new things, have trouble learning and avoid new situations
- Change their sleep pattern
- Become easily upset or made anxious

Getting a diagnosis

If there are symptoms that suggest a person with ID may have dementia they should see their GP as soon as possible. It is important that someone who knows them well goes to the GP too, to explain what changes they have noticed. A history of gradual deterioration in memory, communication and living skills suggests dementia. In Down syndrome depression, poor hearing and hypothyroidism (underactive thyroid) can cause similar symptoms and are common. It is important to detect these problems since they are treatable. Unless the test has been done previously so that the doctor can see a decline, cognitive screens such as the MOCA are not very helpful in diagnosis. The GP will order routine blood tests, including for thyroid function and may request a CT head scan (very fast and usually tolerated). Occasionally the GP may need to refer the person to a specialist.

After the diagnosis

The physical and mental health of the person should be optimised. While there is no cure for dementia, the acetylcholinesterase inhibitors (donepezil, rivastigmine, galatamine) can be helpful in people with Down syndrome and possibly in others with ID and dementia.

Knowing the diagnosis helps people with ID and their carers prepared for the future. People working in the ID sector, including in residential situations are much more aware of dementia and can get specific advice and education from Dementia New Zealand. This would include how to manage difficult behaviours and the effects of dementia on family/ whānau and others in shared group homes. Dementia NZ may also help negotiate the tricky interface between intellectual disability and older people's services.

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

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