

INTELLECTUAL DISABILITY AND DEMENTIA

What is Dementia?

Dementia is the umbrella term for a number of diseases and causes of problems with thinking and memory that are severe enough to make managing day to day life more difficult to achieve. Signs and Symptoms can vary considerably but may include memory loss, poor concentration, difficulties with planning and organising, and disorientation problems.

The relationship between intellectual disability and dementia

Alzheimer's disease is a cause of dementia that is often identified by plaques and tangles:

- **Plaques** are Beta Amyloid proteins that build up in the spaces between the nerve cells, hindering the transmission of messages between the cells.
- **Tangles** are fibres of Tau, a protein that builds up inside the cells. They damage the connections between the cells and eventually causes the brain to die. This causes the brain to shrink.
- The changes in the brain associated with plaques and tangles, found in Alzheimer's Disease, are also found in some people with intellectual disability, especially those with Down Syndrome. This puts people living with Down Syndrome at a higher risk of developing dementia in adulthood, especially since they now have a much longer life expectancy, due to the great improvements in health care over recent years.
- Despite the longer life expectancy for everyone, the natural progression of the dementia process in people with Down Syndrome is similar to anyone else with Alzheimer's Disease, except that it starts approximately 20 years earlier in people with Down Syndrome.
- Down Syndrome, (Trisomy21) is a genetic condition where a person is born with an additional copy of chromosome 21. This causes several developmental and health challenges.
- Not all people with Down Syndrome show the symptoms of Alzheimer's Disease, however, on autopsy most older adults with Down Syndrome show the characteristic plaques and tangles of Alzheimer's Disease.
- Other factors that increase the risk of people living with intellectual disability developing dementia are health factors such as mental illness, epilepsy and heart problems
- Changes to the brain may occur many years prior, but at a certain point the brain is unable to compensate for the changes making it unable to function properly, affecting their day to day living.

Diagnosing Dementia in People with Intellectual Disability

Work has been done to develop criteria for a diagnosis of dementia, however this is not always applicable for adults with an intellectual disability, due to pre-existing cognitive impairment. It is very important, therefore, that any symptoms that are suggestive of dementia are discussed with the GP as soon as possible. As always with dementia, it is best if someone who knows the person well enough to notice changes goes with them to the Doctor. The Doctor will be able to carry out tests to rule out other conditions. If necessary, they can also refer the person to a specialist for further consultation.

What you might see with Alzheimer's Disease in a person with Intellectual Disability

- **Cognitive problems** that occur over and above their normal level of functioning, including increased confusion, poor focus/ concentration, problems with visual spatial relations and memory loss, especially recent memory. Questions may be repeated several times.
- **Struggles with carrying out day to day activities** that they have been able to manage in the past, such as dressing or making day to day decisions.
- **Communication problems** may become evident, with whatever form of communication they are familiar with.

- **Disorientation** may cause the person to get lost themselves or lose/ misplace things and to forget the names of people they are familiar with. They may also be disorientated to time. They may think they are living at a different time than now, usually a time prior to now.
- **Changes in social behaviour / personality** may occur causing an outgoing person to become more subdued or withdrawn and a quiet person to display more irritated or angry behaviour. Problems such as depression and lack of lack of motivation may occur. Longstanding habits/ behavioural traits may become more exaggerated. They may be emotionally labile.
- **Struggles in new situations.**
- **Struggles to learn new things.**
- **Psychological issues** such as delusions or hallucinations may also be present. Changes can appear subtle at the beginning, so initially, it may be difficult to identify problems. Memory problems can occur early in the process. Progression can be very gradual.
- **Later in the illness**, issues such as incontinence, mobility problems, swallowing difficulties and seizures may occur.

Things That You Can Do That May Help.

- **Make sure your GP is involved with the care.** Medication may help for a time, so it is important to monitor any changes. This is especially important when medications are introduced, or changes made to the dose. It is helpful to keep a folder to keep medical conversations and information sheets together. It is also helpful to write down your list of questions or things you want to discuss with the doctor before you visit.
- **Contact your local Dementia New Zealand affiliate for support.** The team at Dementia New Zealand are always willing to help with a listening ear and support.
- **Establish a workable routine**, so that there are not too many surprises. It may be helpful to plan to do activities the person enjoys at the same time each day to help maintain routine.
- **Make dementia friendly changes to your home environment.** Often very small changes can make life easier for a person with dementia, that in turn make it easier for all members of the family.
- **Continue to offer choices on all aspects of daily life.** A diagnosis of Alzheimer's Disease does not diminish a person's desire to have their own thoughts, opinions, feelings and wishes. Continuing to offer people choices helps to maintain dignity, respect, and a sense of wellbeing.
- **Support family members to maintain relationships.** Relationships with family members can change after a person is diagnosed with dementia. It may be necessary to support family members by offering reasons for the changes and encouragement to keep working at the relationship.
- **Reminiscing** is a good way to maintain relationships as a person with Alzheimer's disease often still has some long-term memory intact
- **Validate any feelings that are expressed.** This will help the person with dementia feel that they are being heard, creating a better sense of wellbeing.
- **Use Strategies to promote ongoing communication.** Use the positive communication fact sheet to help develop strategies to enhance good communication.
- **Encourage regular washing/showering routines.** This may involve help from community care organisations.
- **Offer healthy food choices.** Offer more whole foods such as fresh fruit and vegetables rather than processed foods.

Other helpful articles/websites

- <https://alzheimers.org.nz/get-support/supporting-someone-with-dementia>
- <https://www.alzheimers.gov/life-with-dementia/tips-caregiver>
- <https://www.alz.org/alzheimers-dementia/what-is-alzheimers>
- [dementia-care-97-dementia-in-adults-with-intellectual-disabilities.pdf](#) (alz.org)

- [Intellectual disability and dementia \(nzdementia.org\)](http://nzdementia.org)
- [New insight on why people with Down syndrome | EurekAlert!](#)
- The British Journal of Psychiatry , Volume 191 , Issue 2 , August 2007 , pp. 150 - 157
- DOI: <https://doi.org/10.1192/bjp.bp.106.028845>
- [Dementia and mild cognitive impairment in adults with intellectual disability: Issues of diagnosis - Krinsky-McHale - 2013 - Developmental Disabilities Research Reviews - Wiley Online Library](#)
- [Dementia and intellectual disabilities \(alzint.org\)](http://alzint.org)
- [Dementia in people with Down syndrome: What does the research tell us? - New Zealand Down Syndrome Association \(NZDSA\)](#)
- [Learning disabilities and dementia \(pkc.gov.uk\)](http://pkc.gov.uk)

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