

# Down syndrome and Alzheimer's disease

This Help Sheet explains what is currently known about the link between Down syndrome and Alzheimer's disease and provides information about where to find additional support.

## What is Down syndrome?

Down syndrome is a condition caused by the presence from conception of a third copy of chromosome 21, instead of the usual two copies. This genetic abnormality causes a collection of characteristics including intellectual impairment and some common physical traits.

## What is Alzheimer's disease?

Alzheimer's disease is a physical brain disease that causes dementia, resulting in impaired memory, thinking and behaviour. It is the most common form of dementia. Alzheimer's disease is characterised by specific changes in the brain that build up gradually and actually begin many years before symptoms of dementia occur. Eventually the damage becomes too great and brain function is affected resulting in dementia.

## The link between Down syndrome and Alzheimer's disease

Studies show that by the age of 40, almost 100% of people with Down syndrome will have the changes in the brain associated with Alzheimer's disease. Because these changes build up slowly, they don't all have the symptoms of dementia at this age, but they may develop in the future. Not everyone with Down syndrome develops dementia however.

The gene responsible for the amyloid precursor protein (APP) is located on chromosome 21. When APP is broken down, another protein called beta amyloid forms. Beta amyloid clumps together into the brain plaques that characterise Alzheimer's disease. Because people with Down syndrome have an extra copy of chromosome 21, they make 1.5 times as much APP as other people, and make more beta amyloid. This appears to cause earlier appearance of the brain changes typical of Alzheimer's disease.

People with Down syndrome therefore have a much higher chance of developing Alzheimer's disease dementia, and at a much earlier age, compared to the general population. Most studies report that around 50% of people with Down syndrome will develop

Alzheimer's disease dementia by the age of 60 years, and that the average onset age is in the early to mid 50s.

## Can dementia be prevented?

The average age of diagnosis of Alzheimer's disease in people with Down syndrome has been increasing, suggesting that improvements in health care, education and adult occupation may be having a positive effect on the brain. Research suggests that adopting a brain healthy lifestyle may reduce the risk of developing dementia. This involves:

- Maintaining good heart health – what is good for the heart is good for the brain – through healthy diet and exercise
- Managing cardiovascular risk factors including high cholesterol, diabetes and high blood pressure
- Maintaining social networks and activities
- Keeping the brain active – with music, art, drama, sport, reading, work, hobbies, etc.

For more information about dementia risk reduction visit [yourbrainmatters.org.au](http://yourbrainmatters.org.au)

## The early signs of dementia

It can be difficult to detect the early changes that occur as a result of dementia. Early signs of dementia in people with Down syndrome may be a further deterioration of existing difficulties, and so harder to recognise. Common early signs include:

- Decreased ability to accomplish tasks of daily living
- Deterioration in short term memory
- Increased apathy and inactivity
- Reduction in spontaneous communication and communication skills
- Increased difficulties understanding language
- Disorientation and confusion
- Changes in night time sleep patterns
- Increased wandering

National Dementia Helpline **1800 100 500**

[dementia.org.au](http://dementia.org.au)

If a person with Down syndrome exhibits some of these changes from their normal behaviour, they should have a thorough assessment to determine if the changes suggest dementia. The possibility that they are the result of other conditions also needs to be investigated. Treatment of these conditions can lead to great improvements in the person's functioning and well being. It is very important to get an early diagnosis so that the person can be given the right support as quickly as possible.

## Diagnosing Alzheimer's disease in someone with Down syndrome

The process of making a diagnosis of Alzheimer's disease in someone with Down syndrome is the same as for anyone else. Diagnosis is based on a detailed history of progressive change over time in thinking, memory and daily living skills, physical examination, tests of thinking and memory, and investigations (blood tests and brain scans) to rule out other possible causes of decline in functioning.

The difference for people with Down syndrome is that they have pre-existing difficulties with thinking, remembering and daily living skills. Therefore it is important for the clinician to have a very clear picture of the person's abilities before any change was noticed and how the person's abilities have progressively changed. Reports from family and carers about the person's medical history can help to separate pre-existing disabilities from the symptoms of Alzheimer's disease.

## If Alzheimer's disease is diagnosed

At present there is no cure for Alzheimer's disease and no treatment that can stop the disease progressing. However, there are medications available that can help stabilise or slow the decline in memory and thinking abilities for a time. People with Down syndrome may require smaller doses and may be more likely to develop side effects. Drugs may also be prescribed for secondary symptoms such as agitation or depression, or to help the person sleep better.

Activities and communication strategies may need to be modified to take into account the person's deteriorating memory and thinking skills. Some

people with Alzheimer's disease may develop behaviours that cause concern to families and carers. The principles of managing these behaviours are different from those which families and carers may be accustomed to, so specialised advice should always be sought about any changed behaviours.

Support services are available for the person with Down syndrome and Alzheimer's disease, their family and carers. This support can make a difference to managing these conditions. For people with Down syndrome who live in a residential setting, Dementia Australia can assist residential service providers to understand and manage the changes produced by Alzheimer's disease. Dementia Australia provides support, information, education and counselling for all people affected by dementia, their families and carers.

## Further Information on Down syndrome

Down Syndrome Australia is a network of state-based organisations providing support, encouragement, information and resources to people with Down syndrome, their families and the broader community. Contact the Down Syndrome Association in your State or Territory.

**Down syndrome and Alzheimer's disease** is a booklet providing more comprehensive information. It was produced by Dementia Australia, Down Syndrome Australia and the Centre for Developmental Disability Health Victoria, and is available from [downsyndromevictoria.org.au](http://downsyndromevictoria.org.au) or [dementia.org.au](http://dementia.org.au)

The Dementia Behaviour Management Advisory Service provides clinical support for people caring for someone with dementia who is demonstrating behavioural and psychological symptoms which are impacting on their care. Call the DBMAS Helpline on **1800 699 799** or visit [dbmas.org.au](http://dbmas.org.au)

## FURTHER INFORMATION

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at [dementia.org.au](http://dementia.org.au)



Interpreter

For language assistance phone the Translating and Interpreting Service on **131 450**