

# Down syndrome and Alzheimer's disease

This help sheet explains the link between Down syndrome and Alzheimer's disease, as well as information about symptoms, treatment and where to find support.

## About Down syndrome

Down syndrome is a condition where someone is born with a third copy of chromosome 21, instead of the usual two copies. This genetic abnormality can cause developmental problems and health issues, and can affect learning, language and memory.

## About Alzheimer's disease

- Alzheimer's disease is the most common form of dementia.
- Alzheimer's disease is a physical brain condition resulting in impaired memory, thinking and behaviour.
- It disrupts the brain's neurons, affecting how they work and communicate with each other. A decrease of important chemicals stops messages travelling normally through the brain.
- People with Alzheimer's disease experience different challenges and changes throughout the progression of the condition.
- An individual's abilities deteriorate over time, although the progression varies from person to person.

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

People with Down syndrome have a much higher chance of developing Alzheimer's disease, and at a much earlier age, compared to the general population.

This is because people born with Down syndrome have an extra copy of chromosome 21. Chromosome 21 carries a gene that produces a specific protein called amyloid precursor protein (APP). When APP is broken down, beta amyloid forms. This clumps together in the brain plaques that characterise Alzheimer's disease.

People with Down syndrome make one and a half times as much APP as other people, and make more beta amyloid. Studies show that by the age of 40, almost all people with Down syndrome will have changes in the brain associated with Alzheimer's disease.

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However, not everyone with Down syndrome develops dementia.

Most studies report that around 50 per cent of people with Down syndrome will develop Alzheimer's disease by the age of 60 and that the average age when symptoms appear is in the early to mid-50s.

## **The early signs of dementia**

People living with Down syndrome may show symptoms in the early stages of dementia, or symptoms may be a further deterioration of existing difficulties, making them harder to recognise.

Common early signs include:

- decreased ability to accomplish tasks of daily living
- deterioration in short-term memory
- increased apathy and inactivity
- reduced interest in being sociable and a reduction in spontaneous communication and communication skills
- increased difficulties understanding language

- disorientation and confusion
- changes in night-time sleep patterns
- sadness, fearfulness or increased anxiety
- restlessness.

Someone experiencing symptoms may be unable to recognise any changes in themselves. Often a family member or friend of someone affected will observe changes in a person.

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

It is important to talk to a doctor when symptoms first appear.

If the symptoms are caused by dementia, an early diagnosis means early access to support, information and treatment. If symptoms are not caused by dementia, early diagnosis will be helpful to treat other conditions.

Seeking a diagnosis may take some time, because people with Down syndrome have pre-existing difficulties with thinking, memory and daily living skills.

It is important for the doctor to have a clear understanding of changes to the person's abilities. Family members and carers advising about the person's medical history can help separate pre-existing health problems from Alzheimer's disease symptoms.

Documenting the person's baseline functioning before the age of 35 can be helpful. Ongoing evaluation of intellectual, behavioural and social functioning may help in picking up early changes.

Currently there is no single test to diagnose Alzheimer's disease. A diagnosis is made after careful clinical consultation.

The assessment might include:

- a detailed medical history
- a physical examination
- blood and urine tests
- a psychiatric assessment
- neuropsychological tests (to assess memory and thinking abilities)
- brain scans.

## If Alzheimer's disease is diagnosed

At present there is no cure for Alzheimer's disease and no treatment that can stop the condition progressing. However, medications can help stabilise or slow the decline in memory and thinking abilities. 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 improve sleep.

## Seeking support

Someone with Down syndrome who receives a diagnosis of Alzheimer's disease may not understand what that means for them.

There are support services available for the person living with Down syndrome and Alzheimer's disease, as well as for their family and carers. This support can make a difference to learn more about Alzheimer's disease and living well with these conditions.

For people with Down syndrome living in residential care, Dementia Australia can help residential care homes and their staff to understand and respond to changes in memory, thinking and behaviour caused by Alzheimer's disease.

## Where to get help

### National Dementia Helpline

Learn about support services and education programs, including carer support groups, counselling, and services and programs.

Call: **1800 100 500**

### National Disability Insurance Scheme (NDIS)

Depending on eligibility, funding is available to support people living with dementia who are aged under 65.

Call: **1800 800 110**

Visit: [ndis.gov.au](https://www.ndis.gov.au)

**Dementia Behaviour Management Advisory Service** supports people living with dementia who experience changes in behaviour that impact their care or the carer.

Call: **1800 699 799**

## Additional reading and resources

- Down syndrome and Dementia: A Guide for Families, Down Syndrome Australia.  
Visit: [downsyndrome.org.au/wp-content/uploads/2020/01/DSA-DA-guide-for-families-May-2022.pdf](https://downsyndrome.org.au/wp-content/uploads/2020/01/DSA-DA-guide-for-families-May-2022.pdf)
- Dementia Australia library service  
Visit: [dementia.org.au/library](https://dementia.org.au/library)
- Dementia Australia support  
Visit: [dementia.org.au/support](https://dementia.org.au/support)
- Dementia Australia education  
Visit: [dementia.org.au/education](https://dementia.org.au/education)

### Further information

Dementia Australia offers support, information, education and counselling.

**National Dementia Helpline: 1800 100 500**

**For language assistance: 131 450**

**Visit our website: [dementia.org.au](https://dementia.org.au)**