

About Huntington's disease

Huntington's disease (HD) is a genetic, neurodegenerative disease that causes the progressive breakdown of nerve cells in the brain. This results in gradual changes in:

- Cognition – thinking and memory
- Movement and coordination
- Behaviour and emotions

Each person experiences HD differently, and progression is not linear. Symptoms vary in severity, and presentation and progression may differ even within the same family.

Symptoms often begin between the ages of 30 and 50 but can appear earlier or later. Cognition refers to how we think, focus, remember, problem-solve, and plan. HD causes gradual changes to areas of the brain responsible for these abilities.

There is currently no known treatment to stop, slow, or reverse the condition, but supportive therapies, routines, and medical care can make a significant difference in quality of life.

About Huntington's Australia

Huntington's Australia is the peak national body for Huntington's disease (HD) that works to improve the quality of life for individuals and families impacted by HD.

Because no one should face Huntington's disease alone.

Donate or get involved on
huntingtonsaustralia.au

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Huntington's disease and movement

Huntington's Australia

Movement changes in HD

HD affects both voluntary and involuntary movement. As the condition progresses, it can become more difficult to complete everyday tasks—such as dressing, operating equipment, speaking clearly, or eating safely.

Movement-related changes may include:

- Chorea – Involuntary jerking or twitching movements that may affect fingers, limbs, or the face. Chorea can interfere with speech, swallowing, and balance
- Rigidity – Muscle stiffness or tightness, sometimes resulting in 'freezing' in one position.
- Slowness and Poor Coordination – Movements become slower and less precise. Tasks like writing, using utensils, or operating devices may become more difficult.
- Walking and Balance Difficulties – Many people with HD develop a wide-based, unsteady gait. They may bump into objects, stumble, or experience spontaneous falls.

While there is currently no cure for HD, a variety of therapies and supports can help people adapt and maintain quality of life as a person's abilities change, and the condition progresses.





Therapies that support HD

Speech Therapy

As communication and swallowing become more difficult, Speech Pathologists offer valuable support. They can:

- Recommend communication strategies tailored to the person's needs
- Develop assistive tools such as communication boards or devices
- Help maintain oral motor function and support memory strategies
- Assess swallowing and suggest suitable food textures, feeding methods, positioning and frequency

Physical Therapy

Physiotherapists support movement and mobility at all stages of HD. They may:

- Design exercise programs to support strength, flexibility, and coordination
- Help manage fatigue, posture, and balance
- Recommend techniques or equipment to reduce falls and promote safer movement

Occupational Therapy

Occupational therapists assist people in staying independent and safe as abilities change. They can:

- Suggest assistive devices and home modifications
- Support daily routines through strategies for memory, focus, and task planning
- Recommend equipment such as wheelchairs, supportive seating, or bedding (Assistive Devices)
- Assess the person's living environment to enhance safety and comfort.

Dietitian

People with HD often require more calories than usual due to involuntary movements like chorea. At the same time, changes in muscle control can make eating more difficult — and it can also be tiring. This can affect a person's ability to get the nutrition they need.

A dietitian can offer advice on high-energy, easy-to-eat meals tailored to the person's needs and preferences. Smaller, more frequent meals may be recommended to help reduce fatigue and support consistent calorie intake. These strategies can help maintain nutrition and overall wellbeing as the condition progresses.

Medication

Medications may help reduce chorea, but should be prescribed by clinicians familiar with HD.

Final Thoughts

Physical changes in HD can be challenging, but support, patience and structure can make a real difference. Decisions should be made collaboratively with the person with HD, their support network and healthcare professionals who understand the condition.

Support is available for both the person living with HD and those who care for them.

It is important to know that you are not alone. The team at Huntington's Australia are here to help you.