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.

Cognition changes in HD

Changes in cognition may be an early indicator of disease progression. These changes are not due to laziness or lack of effort—they are symptoms of the condition. With understanding, support, and structured routines, cognitive changes can often be managed.



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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Cognition and Huntington's disease



Huntington's Australia

Cognitive changes may include:

- Difficulty with multi-tasking, attention, and concentration
- Short-term memory loss and challenges with learning new information
- Trouble starting or completing tasks
- Repeating ideas or actions (perseveration)
- Reduced impulse control or increased risk-taking
- Emotional dysregulation, including irritability or frustration

Strategies to support cognitive changes

Focus, Attention, and Multi-tasking
People with HD may feel overwhelmed by distractions. Providing structure, reducing stimuli, and simplifying tasks can help.

Tips:

- Use short, clear sentences with one or two key points
- Break tasks into small, achievable steps
- Offer limited choices and avoid open-ended questions
- Use to-do lists, calendars, and visual schedules
- Keep daily routines consistent and predictable

Memory and New Learning
People with HD can still learn—but it may take more time and repetition, and spontaneous recall may be reduced.

Tips:

- Use prompts, visual cues, or reminder notes
- Allow adequate time to answer or respond
- Repeat key information in the same way
- Practice routines and skills regularly
- Label drawers, doors, or commonly used items

Starting and Finishing Tasks
Some individuals with HD may struggle with initiating or completing tasks. This may relate to changes in time awareness, planning, or processing speed.

Tips :

- Use structured daily routines
- Offer prompts and gentle reminders
- Break tasks into smaller time-bound steps
- Reduce pressure and allow extra time

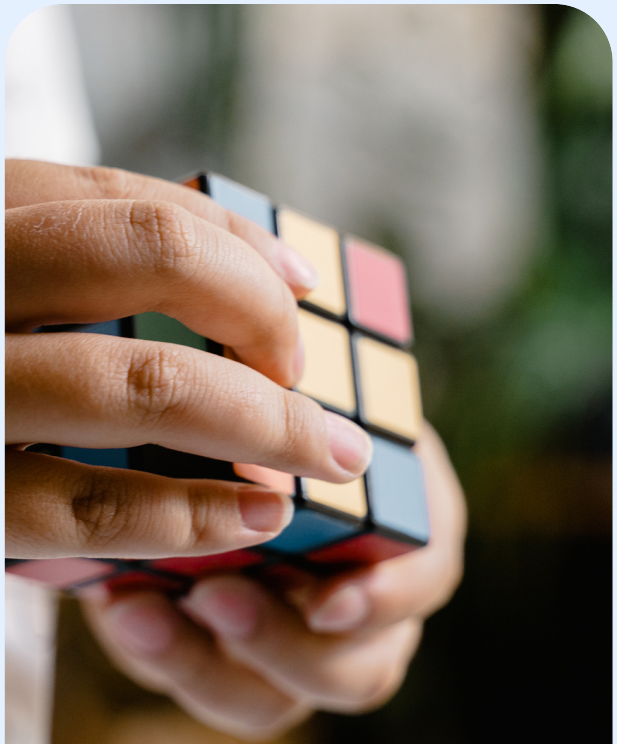
Perseveration (Repetition or Fixed Thinking)
People with HD may become 'stuck' on a thought or action. This can be frustrating for both the individual and those around them.

Tips:

- Let the person finish their thought
- Meet or address the need if possible
- Acknowledge what they've said
- Gently redirect or shift the conversation
- Schedule time-bound routines for repetitive tasks

Impulse control
Changes in impulse control can result in risky or socially inappropriate behaviour. This may include poor decision-making, disinhibition, or emotional outbursts.
Remember, this is a symptom of the condition and not a deliberate choice.

Medication, supervision, predictable routines, and reducing environmental triggers may help. Always consult your healthcare professionals who understand the condition when considering behavioural supports.



Irritability and emotional changes
Irritability is common and may be caused by the condition itself, or by fatigue, overstimulation, or underlying depression.

Tips:

- Identify and avoid known triggers
- Allow time for rest and recovery
- Build calming routines into the day
- Allow choice and address the persons underlying needs
- Speak in a calm, reassuring tone
- Consider discussing options with a medical professional

Visual and perceptual changes
HD can impact a person's ability to judge space and positioning, such as how close they are to furniture or doorways. This is in addition to changes in balance and involuntary movement.
Tips :

- Keep walkways clear and uncluttered
- Use corner protectors and remove loose rugs
- Move furniture against walls
- Use assistive devices (e.g. walkers, grab bars) as early as possible, before they are urgently needed

Early introduction of aids supports familiarity and confidence before they become essential.

Final Thoughts

Behavioural changes in HD can be difficult, but support, structure, and patience can help. These symptoms aren't the person's fault, though they can still be hard on families. Medication may assist with issues like depression or agitation. Decisions should involve the person with HD, their support network, and informed health professionals.

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.