## 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.

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**Because no one should face Huntington's disease alone.**

Donate or get involved on
**huntingtonsaustralia.au**


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# Changes in behaviour and Huntington's disease



Huntington's Australia

## Behavioural changes in HD

People with Huntington's disease may experience changes in mood, behaviour, and how they relate to others—often before physical symptoms appear.

These changes are caused by damage to parts of the brain that affect emotion, judgement, and memory. While the behaviour may seem 'out of character', it is not intentional. This can be challenging for families and relationships, but support and strategies are available.

Behavioural symptoms may include depression, anxiety, irritability, impulsivity, outbursts, compulsive behaviours, aggression, disinhibition, withdrawal, rigid thinking, or paranoia. These are symptoms of the disease—not deliberate actions—and can often be managed with the right support.

## Supporting behavioural and emotional changes

**Creating Structure and Predictability**
A structured routine helps reduce confusion and distress. Predictable environments help the person feel safe and in control.

Tips:
- Create and stick to consistent daily and weekly routines where possible
- Build in quiet times to reduce overstimulation
- Break down tasks into small steps
- Avoid open-ended questions; offer clear choices
- Use visual prompts to support memory, like clocks, whiteboards and planners
- Reduce environmental stimuli where possible

**Withdrawal and Overwhelm**
If a person feels overstimulated, anxious or overwhelmed, a quiet space can help them settle.

Tips:
- Offer a calm space to retreat
- Use noise-cancelling headphones or calming music
- Dim lights or reduce background noise

## Managing emotional outbursts

HD can affect how a person controls emotions and movements. A raised voice or increased movement may not reflect anger or intention—it may be part of how they are processing their environment or a physical response to heightened emotion. It is easier to prevent escalation than to de-escalate a crisis. Anticipating needs and incorporating them into routines can help reduce distress. People with HD may also have difficulty waiting or processing rapid changes.

Tips:
- Stay calm and avoid raising your voice
- Acknowledge the person's feelings without arguing
- Meet the need if possible and practical
- Offer reassurance and redirect to a calming activity
- Ask the person to use alternative ways to gain your attention
- Prioritise safety—step away or request support

**Depression and Low Mood**
Depression is common and may be caused by brain changes as well as the emotional impact of living with HD. Thankfully, depression in HD often responds well to treatment. Talk to your healthcare professionals who understand the condition and review treatment regularly.

Support can include:
- Counselling or Psychology interventions
- Medication
- Connection to social supports



**Impulsivity and poor judgement**
HD can impair impulse control, leading to actions that are risky or socially inappropriate. This is a symptom of the disease—not intentional behaviour.

Tips :
- Supervision and support with decision-making
- Visual cues or reminders
- Reducing known triggers

**Repetitive thoughts or behaviours**
This may include repeated questions, rituals, or fixed routines. It is often a way for the person to maintain a sense of control.

Tips:
- Gently acknowledging and then redirecting
- Scheduling activities to allow time limits for repeated behaviours
- Supporting routines and reducing sudden changes

**Medical, environmental and personal triggers**
Sometimes behavioural symptoms are worsened by medical issues, including infection, unmanaged pain, discomfort, or even unmet needs. Other triggers may include sensory issues, hunger, medication side effects, fatigue, changes or stress. If behavioural changes occur, is it important to consult with your healthcare professionals to help identify causes and reduce escalation.

### 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.**