

Huntington disease (HD) is a hereditary, neurodegenerative illness with physical, cognitive and psychiatric symptoms. This means that a person with HD will experience changes in motor abilities, thinking abilities (called cognitive functioning) and emotions. This fact sheet focuses on the cognitive changes in HD and on strategies for managing the changes.

## Cognition (Thinking Abilities)

According to research data and personal stories, the changes in thinking (known as 'cognition') and behavioural changes are the most disabling part of HD. The cognitive skills affected include learning and memory, perceptual skills, executive efficiency or functioning (the primary thinking processes in the brain) and language. However, it is important to mention that many cognitive functions remain relatively unaffected in HD.

The long-term memory and the ability of a person with HD to recount past experiences can remain relatively intact. Skills learned in the past and automatic actions or behaviours are not lost. If an individual has been working in a particular job for many years, he or she will usually be able, in the very early stages of HD, to continue to carry out the tasks required in the job. However, this does become a problem if new skills are introduced, and the person with HD is expected to learn new information. Some common cognitive changes include:

## Learning and Memory Difficulties

- Short term memory loss — such as forgetting recent conversations or what a person ate for lunch.
- Implicit memory is affected. Implicit memories are the set of skills and coordinated movements that allow a person to drive a car or ride a bike or know how to chew and swallow.
- Difficulty bringing back information from memory (e.g. word finding difficulties). A person with HD will be able to look at a cup and know that it's a cup and know that it's used for drinking. He/she may not be able to remember the word cup, however.
- Difficulty learning new tasks or information.

## Perceptual Problems

- A person is unable to accurately identify and understand the feelings of others.
- Perception or sense of time is affected - which may mean that a person who was always on time now tends to be late for appointments. A person may have trouble waiting for things.
- Spatial perception (meaning how a person moves his or her body in space) is also affected. This can result in falls and accidents.
- Smell identification – the ability to identify a smell is affected.
- Not being aware of one's feelings, actions and consequences of choices, lack of insight.

## Executive Efficiency or Function

- Speed of cognitive (mental) processing is slower. It will take more time to think about things and more time to respond.
- Attention and Higher Order Thinking: figuring out new situations is hard.
- Problems with paying attention; difficulty multi-tasking and problem solving.
- Trouble with planning one's day.
- Initiation (starting a task) and motivation is affected.
- Repeating things and getting "stuck" on thoughts is common.
- Inability to control impulses and responsive behaviours.

## Language

- Difficulty with finding the right word.
- Someone may have trouble saying what they are thinking but will understand what is being said.

## Communication and Cognition

At some point, communication and speech difficulties will impact a person’s level of function. A person with HD often relies on external cues and guidance from others to achieve communication.

A person with HD usually does not have trouble understanding the message that is being communicated - even until quite late in the illness; however, responding to the message will take longer and require lots of energy.

## Emotion and Cognition

Emotions can affect our thinking ability, and the way we think can affect our emotions (or the way we feel). Common emotional changes in HD include depression, anxiety, apathy or loss of interest, and irritability. Reducing emotional symptoms can help improve thinking abilities.

## Strategies to Assist with Cognitive Decline

- Routine is key - establish and maintain daily routines
- Use check lists & simple written reminders (e.g. sticky notes, dry eraser boards)
- Use memory aids such as calendars, schedules, notes
- Focus on one task at a time
- Break down tasks into small steps
- Allow more time to complete tasks, reduce rushing
- Technology aids may help to make life easier such as text messages, alarm reminders
- Try counselling to help with feelings of stress and frustration related to changes
- Gently guide behaviours, but try again later if answer is “no”
- Thinking will take longer; allow enough time for the person to answer
- Offer only two choices or only yes/no questions
- Reduce distractions (extra talking, external and background noise or movements)
- Offer cues, hints or missing words
- Establish communication or memory aids early on—yes/no signs or thumbs up or down
- Stay well rested; being tired lessens our ability to think clearly
- Keep activities short and take breaks as needed
- Speak to your doctor about mood changes or sleeping difficulties
- Sometimes medications for emotional issues can improve quality of life and improve cognitive thinking

## Things to Remember

It is important to remember that in HD, the decrease in thinking ability and the movement disorder will not be the same. If one person has a lot of memory problems and not many movements, that doesn’t mean that other family members will have the same problems or symptoms. Each person experiences symptoms in his/her own way. Sometimes, the thinking symptoms may appear many months or years before any physical symptoms are present.

## Resources

[Understanding Behaviour in Huntington Disease: A Guide for Professionals \(Third Edition\)](#)

[A Physician’s Guide to the Management of Huntington Disease \(Third Edition\)](#)

A listing of our Family Services team members can be found at: [www.huntingtonsociety.ca/family-services-team](http://www.huntingtonsociety.ca/family-services-team).