

Huntington disease (HD) is a hereditary, neurodegenerative disorder with physical, cognitive and emotional symptoms.

This fact sheet aims to help individuals better understand and support those who experience cognitive changes as part of their HD progression.

Cognitive Skills (Thinking Abilities)

Cognitive skills (thinking abilities) affected may include:

- Learning and memory
- Perception
- Executive efficiency or functioning
- Language

Learning and Memory

- Long-term memory and the ability of a person with HD to recount past experiences can remain relatively intact
- Short-term memory loss occurs. This could look like forgetting recent conversations or what a person ate for lunch
- Implicit memories include the set of skills and coordinated movements that allow a person to drive a car, ride a bike, or know how to chew and swallow. These memories are impacted in varying degrees. Skills learned in the past and automatic actions or behaviours are not lost right away. If an individual has been working in a particular job for many years and are in the very early stages of HD, they may be able to perform the tasks required for the job
- Recall is decreased (this might look like forgetting your words). A person with HD will can identify a cup, look at it and know it is used for drinking, but they may be unable to remember the word “cup”
- Learning new tasks or information is a challenge and requires more time and practice

Perception

- A person with HD may have trouble accurately identifying and understanding 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
- Spatial perception (meaning how a person moves his or her body in space) is also impacted. This can result in falls and accidents
- Smell identification (the ability to identify a smell) is not as accurate
- A person with HD may not be aware of feelings, actions, and consequences of choices. Insight is affected.

Executive Efficiency or Function

- Speed of cognitive processing is slower. It will take more time to think about things and respond
- Figuring out new situations is hard
- Problems with maintaining focus; difficulty multi-tasking and problem-solving
- Trouble with planning and prioritizing one's day
- Initiation (starting a task) and motivation are decreased
- Repeating things and getting "stuck" on thoughts is common
- Inability to control impulses

Language

- Difficulty finding the right word
- The person affected by HD may have trouble saying what they are thinking but will understand what is being said

Strategies to Assist with Cognitive Decline

- Routine is key - establish and maintain daily routines
- Use checklists and simple, written reminders (e.g., sticky notes, dry eraser boards, calendars, schedules)
- Focus on one task at a time
- Allow more time to complete tasks; reduce rushing
- Technology aids may help. Consider text messages and alarm reminders
- Thinking will take longer; allow enough time for the person to answer
- Offer only two choices, yes/no questions or thumbs up/thumbs down as a response
- Access a speech and language pathologist, occupational therapist, or social worker for support
- Reduce distractions (extra talking, external and background noise, or movements)
- To support communication with a person with HD offer cues, hints, or missing words
- Ensure the person with HD is well rested; being tired impacts the ability to think clearly
- Keep activities short and take breaks as needed
- Sometimes medications for emotional challenges or dysregulation can improve quality of life and improve cognitive thinking

Things to Remember

It is important to remember that the presentation of symptoms of HD will differ in each person, even within the same family. Sometimes symptoms related to thinking or cognition appear many months or years before any physical symptoms are present. People experience symptoms in their own way.

RESOURCES

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at www.huntingtonsociety.ca/family-services-team-list/

Informational fact sheets for family and friends impacted by HD are available to view, print and download at www.hdfactsheets.ca

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at www.huntingtonsociety.ca/hd-booklets-and-publications/