

HD Has Three Major Areas of Impact:

Movement

- Involuntary movements (chorea)
 - Legs, arms, torso and face are affected.
- Diminished coordination of voluntary movements
 - An unsteady gait and slurred speech can create an intoxicated appearance.
- Falls are a common risk for persons with HD. Persons with HD will eventually become unable to walk.
 - Physiotherapy or occupational therapy assessment or treatment can extend mobility and independence and decrease the risk of falls and injuries. Consider possible side effects of medications.
- Increased nutrition and hydration needs
 - Assure easy access to high caloric meals, drinks, supplements. Allow for sufficient time to support the person; if needed, provide several smaller meals; create a supportive environment (reduce disturbances, increase measures of comfort).
- Speech impairment
 - For most people affected by HD, it will become increasingly difficult to produce clear speech. Consult a speech language pathologist (SLP) in the early stages of the disease.
 - Take time to get to know the person and learn to better understand the individual's way of articulation
- Swallowing difficulties and risk of choking or aspiration pneumonia
 - Seek a swallowing assessment and ongoing consultation from a speech language pathologist.
- Disturbed sensation
 - Pain tolerance is often abnormally high (e.g. dental abscess/cigarette burn). Small changes in behaviour or appearance can be signs of serious illness.
- Incontinence
 - Possible unawareness of full bladder and bowel; impaired control of voluntary movements; regular toileting routine can be helpful.
- Altered perception of body temperature
 - Adjust room temperature and clothing to individual needs.
- Excessive perspiration
 - Respond to increased needs for personal care.

Emotion

- There are a number of psychiatric disorders induced through the physical changes in the brain that can affect a person with HD. It is important to consult a psychiatrist to discuss medications and possible treatment options available. The disorders could include the following:
 - Depression
 - Anxiety
 - Suicidal ideation
 - Psychosis
 - Obsessive compulsive disorder
 - Sexual disorders
 - Bipolar disorder
- Common emotional reactions when diagnosed with a chronic, incurable, terminal disease are:
 - Fear of possible abandonment, pain and suffering and grief
 - Loss of hopes and wishes for the future
 - Loss of abilities and competencies
 - Loss of control and independence

Emotion Continued

- These emotional reactions can be intensified and complicated through the genetic component of HD.
 - HD affects lives over generations
 - HD can overshadow childhood
 - People affected by HD might have more knowledge about what lies ahead than they might wish to have
 - Inherent risk for children and grandchildren
- Personality changes induced through the physical changes in the brain.
 - Low frustration tolerance and short temper
 - Impulsivity and irritability
 - Inflexibility and obsessive compulsive behaviour
 - Apathy, loss of drive and lack of initiative
 - Decreased ability to empathize with others' feelings

Thinking

- Cognitive Disorder and Impairment
 - Difficulty with short-term memory and retrieval; long-term memory stays intact
 - Difficulty understanding complex information and sequencing
 - Slow response time, short attention span (easily distracted)
 - Difficulty learning new things (but not impossible)
 - Lack of ability in problem-solving and reasoning, poor judgment skills
 - Altered visual-spatial sense and altered sense of time
 - Tendency for perseveration and repetition
 - A narrow focus on what is coming next
 - Lack of self-awareness and unaware of limitations and symptoms
- Communication Difficulties
 - Word-finding difficulties
 - Difficulties beginning conversations and staying on topic
 - Poor listening skills and concentration
 - Lack of spontaneous communication
 - Impaired facial expressions
 - Impaired reading and writing ability
- Sometimes responsive behaviour can be the most effective method or the only method of communication for a person with HD.
- An improvement of communication and comprehension can lead to a decrease of responsive behaviour.
- Caregivers need to take the responsibility for effective communication.
- Communication will be highly impaired in the advanced stages of HD.
- Be aware that the person with HD has comprehension of his or her whereabouts and of the situation, and can hear and see you.
- It is the ability to communicate that decreases, not the need.

Resources

For more information, visit our fact sheets:

[HSC Responsive Behaviours Fact Sheet](#)

[HSC Communication Strategies Fact Sheet](#)

Ongoing support, education and information is available from the Huntington Society of Canada (HSC). You can find a listing of our Family Services team members at www.huntingtonsociety.ca/family-services-team.