

Huntington disease (HD) is a progressive neurological disease that causes physical, emotional and cognitive impairments. Communication can be affected early on in the disease and will be highly impaired in the later stages of HD. In most cases, a person in the advanced stages of HD will not be able to respond to questions in a way that is understandable. Unlike other forms of dementia, however, long-term memories can remain intact in individuals living with HD. The process of communication is a complex integration of thought (cognitive processing), muscle control and breathing. HD affects these functions in the following ways:

Language (Cognitive Processing) is Affected:

- People with HD can generally understand what you say, but the process of comprehension slows down. If too much information is being shared at once, this can become overwhelming.
- Retrieval of vocabulary is affected. Someone with HD may take longer to answer a question or give information, and you may have difficulty understanding the message.
- Decreased ability to organize outgoing and incoming information (language) can result in miscommunication.
- Initiation of conversation is also affected. The person may not 'strike up' a conversation spontaneously but may enjoy the discussion if it is started by someone else.

Lack of Muscle Control and Breathing Affects Articulation:

- Faulty coordination of breathing and voice affects the volume and pace of speech.
- Coordination of the larynx is impaired, affecting vocal pitch.
- Reduced coordination of oral and facial muscles affects speech sounds and facial expressions, so it may be difficult to 'read someone's face' accurately.
- Speech patterns may be unpredictable.

Other factors that can also affect a person's ability to communicate include distractions in the surrounding environment, fatigue, hunger/thirst, a person's mood, his/her state of health and the reaction of other people.

Assessing Communication

A speech language pathologist or an occupational therapist should carry out an assessment early in the disease process to establish a baseline of the individual's skills in verbal communication and evaluate whether other means of communication need to be put in place. It is still possible for people with HD to learn new skills, but it requires more time and support and is best started in the early stages. Early training in how to use assistive devices or tools is very important. Simple communication systems, such as giving a thumbs up or thumbs down to indicate yes/no, also need to be introduced early on so that they can be used in the later stages of HD. Regular reassessments should be made over the course of the disease.

When Communication is Minimal

- Remember that people with HD can understand what you are saying – even though two-way communication is no longer possible. Continue to provide information while performing caregiving tasks, but keep it short and simple.
- Remember what the person had previously asked for and continue to provide that. Ongoing written documentation of individual needs and wishes will help caregivers respect and accommodate personal preferences.

When Communication is Minimal (Continued)

- Introduce daily (and even hourly) routines as early as possible to give the person a sense of control and safety.
- Offer choices and allow the person to make decisions where possible to maintain a sense of autonomy and independence in the person with HD.

Strategies and Tips to Enhance Communication

Since communication becomes more challenging when people have HD, it is important to create an effective way of expressing needs, feelings and thoughts. It is very important to remember that HD affects communication skills and abilities, but people still have the need and desire to communicate. People with HD will understand the messages but may not be able to respond as quickly or accurately as they have in the past. Here are tips for the person with HD, caregivers and family members to help with communicating effectively. As the disease progresses, modifications may be needed.

Person with HD

- Slow down when speaking.
- Repeat/rephrase the message using different words.
- Say the main word.
- Spell the word (verbal or written spelling or letter board).
- Write the word (even just a few letters).

Caregiver

- Rephrase the main message back to the person.
- Simplify the message using short sentences and closed ended or multiple choice questions first (e.g. "Would you like to go to the park, the mall or the restaurant?").
- If closed ended questions become difficult, try using yes/no questions.
- Use non-verbal communication when possible (e.g. gestures, thumbs-up or down).
- Ask for clarification and feedback.
- Wait for a response (several minutes at least) and allow plenty of time for the communication.
- Do not repeat the message while waiting for a response.
- Reduce distractions in the room during the conversation (e.g. turn off TV and radio). Let the person with HD know why you are doing this or ask for permission first.
- Refocus the conversation if there is a distraction.
- Avoid pretending to understand if you don't. If the person is getting frustrated, suggest taking a break and coming back later to try again.
- Ask for help from others. Speech language pathologists can provide support on adapting communication techniques.
- Consider using communication aids (e.g. letter boards, word boards, picture boards, flash cards, talking mats, computerized speech devices, tablets) if they are helpful and if introduced in early stages.
- Monitor perseverative (repetitious) behaviour and provide feedback. Let the person know when they are stuck on a topic and encourage a new topic. "Let's talk about ____ now".
- Reduce the number of times you change topics during a conversation.

Family Members

- Help to educate and inform caregiving staff about your loved one’s likes, dislikes, expressions and non-verbal cues (eye gazes, other subtle movements) that may provide important information about how a person is feeling and what he/she needs. This may help to decrease the number of frustrating events for the person with HD and reduce responsive behaviours.
- Initiation of conversations also becomes impaired as the disease progresses. The caregivers will need to start conversations more frequently as the person’s communication skills become affected.
- Create a life book or memory book (scrapbooks that allow a person with HD to share his/her life story) so staff can get to know the person with HD. It can also be used as a communication aid.
- Try to avoid situations which will trigger frustration, and provide diversions when possible.

The basic guideline in achieving effective communication is for the caregiver/family member to consciously accept the responsibility for the conversation exchange. The person with HD often needs to rely on external cues and guidance from the caregiver/family member to achieve communication. It is also important to realize that while the caregiver/family member accepts the responsibility for the exchange, he/she must not control the conversation.

RESOURCES

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.

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

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

[A Caregiver’s Handbook for Advanced-Stage Huntington Disease](#)

HSC educational modules (especially Responsive Behaviours, Caregiver Overview, Thinking Module)

Fact sheets on a variety of other topics including Cognitive Changes in HD, Have you Met HD?, Responsive Behaviours, Tips When Working with Individuals with HD are available at www.hdfactsheets.ca.