

IMPROVING COMMUNICATION IN HUNTINGTON DISEASE (HD)

Huntington disease (HD) is a genetic neurodegenerative disorder that affects communication. The process of communication is a complex mix of muscle control, thinking, emotions and breathing. The ability to communicate can be affected early on in the disease, but especially in the later stages of HD.

HD affects communication in the following ways:

- People with HD can generally understand what you say, but the process of understanding what is said slows down. If too much information is being shared at once, this can become overwhelming for the person with HD.
- The ability to find words and give an answer is affected. Someone with HD may take more time when asked for information, and you may have difficulty understanding.
- The ability to start a conversation is also affected. The person may not 'strike up' a conversation but may enjoy the discussion if it is started by someone else.
- With oral and facial muscles also affected, speech can be difficult to understand and facial expressions may be difficult to read accurately.
- Speech patterns may be unpredictable.

Other factors that can also affect a person's ability to communicate include distractions or noises in the surrounding environment, fatigue, hunger/thirst, pain, a person's mood (e.g., anxious or depressed) and emotions such as anger or joy, his/her state of health, and the reaction of other people.

Who can help with communication?

Speech-language pathologists (SLPs) are health professionals who identify, diagnose and treat communication and swallowing disorders.

What do SLPs do?

SLPs can help with:

- the ability to speak and communicate as HD progresses
- challenges with swallowing and feeding due to symptoms of HD
- social communication skills and problem solving communication barriers

When do you reach out to a SLP?

An SLP should carry out an assessment early in the HD process to establish a baseline of the individual's skills in verbal communication. The SLP can evaluate if other means of communication need to be put in place. Individuals may consider using communication aids (e.g., letter boards, word boards, picture boards, flash cards, talking mats, computerized speech devices, tablets) if they are helpful. It can be easier to learn to use these tools if introduced in early stages.

Simple and clear communication tricks, such as giving a thumbs up or thumbs down (as a yes/no), can also be introduced early on so they are easier to use in the later stages of HD. The SLP can do regular reassessments to help with new strategies as HD progresses.

The person with HD often needs to rely on cues and guidance from the carer/family member to achieve communication. It is also important to realize that while the carer/ family member accepts the responsibility for the exchange, they must not control the conversation. While performing caregiving tasks, continue to provide information but keep it short and simple.

Helpful strategies in communication as HD progresses:

- Introduce routines as they give the person a sense of control and safety.
- Offer choices and allow the person with HD to make decisions where possible. This helps to maintain a sense of autonomy and independence.
- Educate and inform caregiving staff about the individual's likes, dislikes, expressions and non-verbal cues (e.g., eye gazes and other subtle movements). This may provide important information about how the person is feeling and what they need. Creating a life book (connect with your Family Services team member for more information on these) can help the staff get to know the person with HD. It can also be used as a communication aid.
- Slow down when speaking.
- Repeat/rephrase the message using different words back to the person.
- Say the main word.
- Spell or write the word (verbal or written spelling or letter board).
- Simplify the message and use short sentences and choices (e.g., "Would you like to go to the park or to the mall?").
- Use yes/no questions and include use of non-verbal communication when possible (e.g., gestures, thumbs-up or down).
- Ask for clarification. Wait for a response (several seconds, up to 60 for some) and allow plenty of time for the communication.

Helpful strategies in communication as HD progresses (cont'd):

- Do not repeat the message while waiting for a response.
- Ask for permission and then reduce distractions in the room during the conversation (e.g., turn off TV and radio).
- Refocus the conversation if there is a distraction.
- Reduce the number of times you change topics during a conversation.
- 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.
- Monitor repetitious behaviour. Let the person know when they are stuck on a topic and encourage a new topic. "Let's talk about _____ now".

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 Carer's Guide for Huntington Disease.](#)

HSC educational modules (especially Responsive Behaviours, Caregiver Overview, Thinking Module). Connect with the regional Resource Centre Director (RCD) for a presentation based on these educational modules.

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.