

IMPROVING COMMUNICATION IN HUNTINGTON DISEASE (HD)

Huntington disease (HD) can affect how a person speaks, understands, and takes part in conversations. Changes in thinking, muscle control, emotions, and energy levels can make communication harder over time, even though understanding is often still there. These changes can be frustrating for both the person with HD and those supporting them. The information in this factsheet can help individuals with HD, families, and caregivers understand communication changes and learn practical ways to support clear, respectful communication at every stage of the disease.

How HD Affects Communication

Communication is complex and involves the brain, muscles, breathing, and emotions. HD can affect communication in several ways:

- Understanding what is said may take more time, especially if too much information is given at once
- Finding words and responding can be slower or harder
- Starting conversations may be difficult, even though the person may enjoy talking once a conversation begins
- Speech may be harder to understand due to changes in facial and mouth muscles
- Facial expressions may be harder to read
- Speech patterns may be unpredictable

People with HD often still understand what is being said — they just need more time and simpler information.

Other Factors that Can Affect Communication

Communication may be more difficult when a person is:

- Tired, hungry, thirsty, or in pain
- Feeling anxious, depressed, angry, or excited
- Unwell or stressed
- In a noisy or distracting environment
- Responding to how others communicate with them

Who Can Help?

Speech Language Pathologists (SLPs) are health professionals who help with:

- Speech and communication
- Swallowing and feeding concerns
- Finding ways to reduce communication barriers

When to Contact a Speech Language Pathologist

An SLP should be involved early to assess communication skills and set a baseline.

Early support makes it easier to:

- Learn new communication strategies
- Introduce tools before communication becomes more difficult

The SLP can reassess over time and adjust strategies as HD progresses.

Communication Tools that May Help

Some people find communication aids helpful, especially when introduced early. They include:

- Letter or word boards
- Picture boards or flash cards
- Thumbs up / thumbs down for yes/no
- Tablets or computerized communication devices

Simple tools are often easier to use later if they are learned early. It can be helpful to start practising using different tools with personal support systems early on. This allows decisions about what works for each person to be made at a comfortable pace.

Role of Family and Caregivers

People with HD often rely on support and cues from others to communicate. Caregivers can:

- Help guide communication, but should not take control of conversations
- Keep explanations short and clear while providing care
- Continue to talk respectfully and directly to the person

Helpful Communication Strategies for Communication Partners

How to Speak

- Slow down when speaking
- Use short sentences
- Focus on one topic at a time
- Say the most important word first
- Repeat or rephrase using different words
- Spell or write words if helpful

How to Ask Questions

- Use yes/no questions when possible
- Offer clear choices (for example: "Park or mall?")
- Allow plenty of time for a response (several seconds, sometimes longer)
- Do not repeat the question while waiting

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Using the Environment

- Reduce noise and distractions (TV, radio)
- Ask permission before changing the environment
- Refocus gently if the conversation gets off track

When Communication Is Hard

When communication becomes frustrating, connection can still be maintained in other meaningful ways:

- Ask for clarification instead of guessing
- Avoid pretending to understand
- If frustration increases, suggest a break and try again later
- Gently redirect repetitive conversations to a new topic
- Encourage non-verbal ways of connecting through shared, low-stress activities (e.g., quiet cooperative hobbies like art or puzzles)

Supporting Understanding and Connection

- Create routines to increase comfort and predictability
- Offer choices to support independence
- Share information with caregiving staff about:
 - Likes and dislikes
 - Facial expressions and body cues
- A life book can help others get to know the person and support communication (talk to your Family Services Team Member for guidance on building your own life book)

Factsheet developed by the HSC Family Services team. Reviewed by Tanya Greaser, BA, BSW, Registered Social Worker and Family Services Educator, and Jasmine Cload, BA, MSc, RSLP, S L P (C), Certified and Registered Speech Language Pathologist.

RESOURCES

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at hdsupport.ca

If you are ready to receive individual or group support from the Huntington Society of Canada, you can self-refer here: <http://contactme.cloud/form/huntingtonsociety>.

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

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at hdresources.ca