
FACTSHEETS FOR HEALTHCARE PROFESSIONALS:
Improving Communication in Huntington Disease

Communication problems in HD

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 stage of HD will not be able to respond to questions in a way that is comprehensible. While long-term memories can remain intact in individuals living with HD, unlike with other forms of dementia, communicating this information can be challenging.

Language processing:

- People with HD can generally understand what you say, but the process of comprehension slows down. This affects the memory of the message, so “information overload” happens more easily.
- Retrieval of vocabulary is impaired. Someone with HD may take longer to answer a question or give information, and the words they use may not be accurate.

Articulation:

- Faulty co-ordination of breathing and voice affects the volume and pacing of speech.
- Co-ordination of the larynx is impaired, affecting vocal pitch.
- Reduced co-ordination of oral and facial muscles affects speech sounds and facial expressions.
- Speech patterns may be unpredictable.

Several other factors can also affect a person’s ability to communicate:

- Distractions in the surrounding environment
- Fatigue
- Mood
- State of health
- The reaction of other people

Assessing communication

A speech and language therapist should carry out an assessment early in the disease process to establish the individual’s skills in verbal communication and evaluate whether other means of communication need to be put in place. It is not impossible for people with HD to learn new tasks, but it requires more time and support.

Early training in how to use assistive devices or tools is of utmost importance. Simple communication systems, such as touching the hand 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.

Managing communication

Basic strategies:

- Reduce distractions.
- Ask the person to repeat themselves if you have difficulty understanding what they say.
- Speak slower and make the message simple to avoid “information overload.”
- Use yes/no questions.
- Use non-verbal communication when appropriate.
- Keep in mind that people with HD have limited muscle control, so their facial expressions can be misleading.

Useful tools:

- Activity charts or weekly planners
- Communication boards or charts with symbols the person with HD can point to
- Flash cards
- Life books or memory books (essentially scrapbooks that allow people with HD to share their life story)
- “Talking mats” (textured mats with movable picture symbols)
- Computerized speech devices

When communication is minimal

- Don’t assume that people with HD can’t understand what you are saying just because they can no longer communicate. Continue to keep them informed and involved and focus on them while performing caregiving tasks.

- 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.
- 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 as sense of autonomy and independence in the person with HD.

For more information

- *Strategies to Enhance Communication* (a Huntington Society of Canada factsheet for families)

Adapted from: *Huntington’s Disease Association’s Standards of Care*, Huntington’s Disease Association / St. Andrew’s Healthcare
<http://www.hda.org.uk/download/fact-sheets/HD-Standards-Of-Care.pdf>