

Communication

It is very important to understand the communication difficulties experienced by people with Huntington's disease (HD) and how they cause distress and frustration.

1. Verbal communication

Huntington's disease makes it more difficult for the brain to control the muscles used for speech and breathing. This can lead to words sounding slurred and/or problems with volume control.

2. Non-verbal communication

The disease makes the use of non-verbal physical cues more difficult, for example:

- Facial expressions may not reflect how the person feels.
- It also affects posture and gestures, for example the person might look less interested than they actually are.
- Writing can become more difficult because of difficulties in holding a pen and/or cognitive difficulties that impact reading and processing information.

3. Cognitive changes

Impaired thinking processes can also have an impact, for example:

- Changes in the brain can make it more difficult for people with Huntington's disease to process information and think of a reply when asked a question.
- While people with the disease generally understand what is being said, they can find it difficult to put their own thoughts into words.

- Concentration and attention are affected, especially if there is a lot going on.
- Apathy might make it more difficult for someone with Huntington's disease to start a conversation.
- People with Huntington's disease can also become focused on a topic and find it difficult to move on from it. They might repeat something that is important to them.

4. Strategies to aid communication:

- Allow more time and wait for a response.
- Minimise distractions and provide a calm predictable environment.
- Discuss one thing at a time, don't overload with information.
- Initiate conversation.
- Break instructions or complex information down into small steps.
- Too much choice can make it difficult to find an answer. Consider using closed questions (usually requiring a simple yes or no answer) and visual prompts.
- As speech becomes more affected, it is useful to have life story books, photo albums, and information about likes, dislikes and interests.
- Don't pretend to understand what is being said if speech is not clear. Give time and encourage the person to repeat what they are saying. If this does not work, ask them to tell you one word or spell out an important word. You can also ask general closed questions to get a clue to the topic, for example, 'Is it about...?'
- Consider using communication aids such as number, letter or picture boards.
- Have important conversations when the person with Huntington's disease is not tired, hungry or stressed.

5. Who can help?

- A Speech and Language Therapist can offer strategies and help to develop communication aids.
- Your HD Specialist can help you and your family/carers to understand the communication difficulties caused by Huntington's disease and ways to manage them. They can also talk to you about future planning, such as making a Power of Attorney or discussing your wishes with your family/carer. This can help you to feel more in control of the future if it becomes more difficult to communicate your views.

Useful links

[Contact a Scottish Huntington's Association HD Specialist](#)

[National and Regional Care Frameworks for Huntington's Disease](#)

[Sign up for regular updates from Scottish Huntington's Association](#)

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