Strategies for Supporting Someone with Huntington Disease (HD)

Huntington disease (HD) is a genetic brain disorder that affects movement, thinking, and emotions. This factsheet is for anyone who supports a person with HD—whether you're a healthcare worker, family member, friend, home care provider, or staff in long-term care. These strategies can help you better understand HD and feel more confident when giving care.

Helping the Person Stay Independent

One important goal is to help the person stay independent for as long as possible. This means letting them do things on their own when it's safe and possible.

- Independence gets harder in the later stages of the disease, but early on, many people can still do things for themselves with support.
- Try not to take over tasks right away. Let the person try first, then help only when needed.
- Give choices whenever possible. This helps the person feel more in control of their life. For example, ask, "Would you like to wear the blue shirt or the red one?"
- Talk with the person during care tasks (like bathing or dressing) and include them in decisions so they feel respected and involved.

Communicating Effectively

As HD progresses, it can be harder for the person to understand and respond to others. You can help by using simple and clear communication.

- Speak slowly, use short sentences, and keep your tone calm and friendly. Try to limit noise and distractions during conversations. ***Give them time to respond.***
- One-on-one conversations usually work best. Too many people talking at once can be overwhelming.
- If they don't answer a question, try again using this method:
  1. Start with an easy, simple question (e.g., "What would you like to eat?") and wait.
  2. If no answer, offer two choices (e.g., "Would you like soup or a sandwich?").
  3. If still no answer, ask a yes/no question (e.g., "Do you want soup?"), and offer simple gesture like thumbs up/down.
  4. If there's still no answer, step away and try again later.
- People with HD may not understand body language or tone of voice, so clear words are important.
- Their own expressions may seem blank or hard to read, and movements may seem stiff or jerky. Try not to assume how a person with HD is feeling just by looking at them.
- Even when they can't speak, many people with HD can still understand what's being said. Always speak with respect.

Understanding Perseveration (Getting Stuck on Thoughts or Actions)

Perseveration is when someone with HD repeats a word, idea, or action many times and has trouble moving on.

- If they seem stuck, allow a few minutes to talk about it, then gently change the topic to something more positive or calming.
- Show that you hear them. For example, say, “I understand you’re worried about missing your appointment,” before guiding the conversation elsewhere.
- You may need to try different things to help. What works one day might not work the next. That’s okay—keep trying.
- Involve others—like family, care team members, or friends—who may have helpful ideas.
- Avoid arguing, correcting, or giving ultimatums. These will not help and may make the person more upset.

Creating and Keeping Routines

Routines help people with HD feel more comfortable and less confused. Doing the same things at the same time each day creates a sense of order and calm.

- Start simple routines early—such as waking up, eating, bathing, and bedtime—and keep them going daily.
- Routines help manage problems like forgetfulness, getting distracted, strong emotions, trouble starting tasks, and anxiety.
- Doing things in the same order and at the same time each day can give a sense of control and safety for both the person and the caregiver. For example: “First breakfast, then a walk, then quiet time.”

Responding to Behaviour

Sometimes, people with HD may act in ways that seem out of place, like yelling, getting upset, or walking away suddenly. These actions are often their way of showing they need something but can’t say it.

Possible causes include:
- Trouble speaking or being understood
- Not knowing how their actions affect others
- Boredom or being asked to do something too hard
- Loud noises, changes in routine, or too much going on
- Feelings of sadness, worry, or frustration
- Hunger, thirst, pain, tiredness, or feeling too hot or cold
- The disease progressing

Responding to Behaviour continued:

If a behaviour comes up suddenly, try to find out why.
- Watch what's happening before, during, and after the behaviour.
- Ask yourself: Is something hurting them? Are they overwhelmed or tired?
- Write down patterns you notice. This helps you and others know what works.
- Talk to family or team members who know them well.
- If the person seems upset, try moving to a quiet space with fewer distractions.

Note: People with HD may not respond well to "behaviour contracts" or rules like, "If you do this, then you get that." Their brain may not process the cause and effect in this way.

Supporting Through Understanding

It's important to remember that the changes in the brain caused by Huntington disease are not the person's fault. They may not be able to control what they do or say or explain how they feel. As a caregiver, you play a big part in helping the person feel safe, respected, and understood. The more you know about them—their likes, dislikes, daily routines, and past experiences—the better support you can give. Challenging behaviour is often the result of being unable to communicate well, so it helps to stay calm, kind, and patient. You are not alone—work with others, share what you notice, and ask for help when you need it.

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RESOURCES

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

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at www.huntingtonsociety.ca/family-services-team-list/

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

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at www.huntingtonsociety.ca/hd-booklets-and-publications/ on:
- 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