

Responsive Behaviours

The neurodegenerative nature of Huntington disease (HD) can cause cognitive changes to the brain, which can present as challenging behaviours. This fact sheet aims to help carers better understand the responsive behaviours in their loved ones, as part of their HD progression. With planning and setting realistic expectations, daily activities and routines can be more easily managed.

What are Responsive Behaviours?

Responsive behaviours are reactions meant to communicate a need usually by individuals who are losing the ability to think clearly and communicate verbally. Therefore, responsive behaviors occur in response to something and are unique to the person. At times, these responses can be challenging to manage.

Examples of responsive behaviours are:

- Perseveration – getting “stuck” on an idea or repeating a behaviour
- Irritability and impatience
- Defiance or stubbornness
- Yelling or physically striking out
- Withdrawing or seeming indifferent to others’ needs

Because of the damage to the brain, the intensity of these responses is not in the person’s control and trying to reason with them may not be effective.

Unfortunately, these challenging behaviours tend to be directed towards the people supporting the person with HD. This may cause the caregiver to feel that the behaviours are personal, resulting in increased frustration.

However, there are strategies to help manage some aspects of responsive behaviours.

Strategies for Supporting Individuals with HD

- Do not reason or rationalize – Avoid saying, “You’re doing this because of HD.”
- Slow down – Give them extra time to respond (10 to 60 seconds).
- Give simple choices – Ask “this or that” questions instead of open-ended ones.
- Avoid too much stimulation – Talk one-on-one and give one instruction or task at a time.
- Stick to a routine – Sudden changes can trigger behaviours.
- Give them space – If they’re upset, take a break and come back later.
- Be clear and specific – Say, “Let’s wash your face now” instead of “Do you want to wash your face?”
- Avoid power struggles – Ultimatums and confrontations tend to escalate behaviours.
- Check for unmet needs – Are they hungry, thirsty, in pain, or bored?
- Pay attention to triggers – Notice consistent time of day, activities, or situations that lead to more responsive behaviours.

It is important for caregivers to receive support when the person with HD is engaging in responsive behaviours. Here are some strategies for caregivers to help manage instances of responsive behaviours.

Caregiver Coping Strategies

- **Learn about HD:** Connect with your local Resource Centre Director (RCD), attend education sessions, and explore the HSC website.
- **Build a support circle:** Lean on friends, family, doctors, and other caregivers.
- **Join a support group:** Attend support groups where you can connect with other HD caregivers.
- **Take time for recharge:** Even a short break can help. It's okay to step away to look after yourself.
- **Use calming exercises:** Try deep breathing or mindfulness when you feel overwhelmed.
- **Book respite:** You may both need a break from each other, whether it's a few hours or a few days.
- **Celebrate small wins:** Focus on the positive and celebrate those moments, even if they're small.
- **Be kind to yourself:** Caring for someone with HD is hard; managing responsive behaviours is harder still.

When navigating responsive behaviours, it is important to note that these responses will change as the disease progresses.

You're not alone in your caring experience. The Huntington Society of Canada is available to provide support, advocacy, education and community referrals. Taking care of yourself is as important as taking care of the person with HD.

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