

The nature of Huntington disease (HD) means that a person living with the disease will experience a wide range of changes in movement, emotions and thinking. These changes can affect multiple aspects of a person's life. The following tips can help manage the complexities of HD.

Independence

The objective of the caregiver is to help the individual maintain independence as long as possible.

- Independence becomes more difficult to maintain in the later stage of the disease.
- Attempt to allow the person to act independently to the fullest extent possible for as long as possible.
- Try to instill a sense of control in the person you support: offer choices, allow decision making where possible.
- Keep the person informed and involved; focus on the person while performing caregiving tasks.

Effective Communication

Communication becomes increasingly difficult as the individual progresses with HD. The following tips can help to manage the communication process throughout the disease:

- Take responsibility for effective communication: take time and slow down; keep it simple; focus and limit distractions; keep yourself and the environment calm, and be non-judgmental.
- Limit the number of persons in the communication process; one-on-one is most effective.
- Expect delayed responses and use these steps for asking questions:
 - First, ask an easy question and wait. No response does not mean no.
 - Secondly, rephrase the question as a multiple choice question and wait. If no response, move to the third step.
 - Rephrase it as a yes/no question and wait.
 - If there is still no response, excuse yourself and ask again later, starting at the beginning of the process.
- Keep in mind that individuals with HD lose the ability to read body language and facial expressions and may not notice another person's mood or emotions.
- It is also difficult to 'read' the facial expressions and body language of a person with HD (there may be a flat facial expression, sometimes referred to as the 'HD mask').
- Most importantly, always remember that persons in the later stages of HD are aware of the surroundings and still understand what is being said even if responses can't be made.

Perseveration

When a person with HD perseverates, it means that he or she is 'stuck' or fixated on an idea and tends to repeat that same idea over and over again.

Caregivers will want to address the repeated responses quickly to avoid escalation to angry outbursts. A calm approach and positive response is recommended. Refusals, attempts to persuade and explanations are generally ineffective.

- Honour a specific amount of time (e.g. 5 minutes) for the topic discussion and take responsibility for switching topics to something that generates a desired mood and/or captures answers to information requests.
- Avoid confrontation or ultimatums. Confrontations and ultimatums will not resolve the problem but might lead to an escalation.
- Not all conflict or confrontation can be avoided, so try the following ideas:
 - Acknowledge how difficult the situation must be for the person affected by HD.
 - Be flexible and ready to try several strategies; trial and error processes may be necessary.
 - Don't carry the burden alone; involve all members of the multidisciplinary team, family and friends.

Routines

Routines can help manage the disease and expectations of the individual affected by HD and the caregiver.

- Introduce daily, almost hourly routines that meet the individual needs of the person as early as possible.
- Establishing routine can help with the following challenges: short-term memory deficits, distractibility, impulsivity, aggression, obsessive or intrusive thoughts, anxiety, apathy, difficulty with initiating tasks and difficulty with being able to follow a sequence of events to complete a task.
- Routines provide a sense of control and safety. Consistency comes from doing the same thing, in the same order, at the same time, in the same way, every day.

Responsive Behaviour

Responsive behaviour occurs when a person reacts to a situation that does not warrant the response (such as yelling or hitting). This is the person's way of communicating with us. For example, an individual with HD may want a coffee. When the coffee doesn't appear, he/she may exhibit responsive behaviour by yelling or hitting because self-regulation is not easily accomplished by someone with HD.

Possible causes of the responsive behaviour may include the following:

- Inability to communicate
- Unawareness of limitations and/or needs of others
- Boredom or feeling overwhelmed by difficult tasks
- Change in routine and/or noise
- Feelings such as frustration, fear and/or grief
- Progression of the disease
- Inability to self-regulate when experiencing discomfort (e.g. pain, hunger, thirst, feeling tired, hot or cold)

If you observe a sudden change in behaviour, consider that the person with HD might not be able to successfully communicate the experience of discomfort, feelings, wishes and/or needs. In this case it is best to re-evaluate, reassess and support. Try to determine the root cause of the issue and what the person is trying to communicate by observing the person's behaviour.

Although negotiating a behavioural contract may work with some people in other situations, the practice of making a contract with a person with HD to help encourage self-regulation and decrease responsive behaviours generally will not work.

Identify Triggers

The more you can observe, gather and share information, the more support you can provide.

- When and where does the challenging behaviour occur? What happened before? Who is involved? What emotion was expressed?
- What intervention supported the person in calming down?
- Identifying both the positive exceptions and the triggers for challenging behaviours will allow you to adapt environments, time frames, schedules, approaches and goals in ways that provide the most supportive conditions.
- Work in close cooperation with all caregivers and staff involved; use journals and share observations.
- Talk to family and others who know the individual well for effective problem-solving strategies.
- Spend time with the person to get to know him/her.
- Accept anger and frustration as valid expressions of feelings.
- Allow "cooling off" time in a quiet environment, so the person can regain control over feelings and behaviour.

A New Approach

Remember that physical, emotional and cognitive changes are not under the control of the person living with HD. Caregivers can help by understanding the progression of the disease and accepting that sometimes the person with HD can only communicate through behaviour as verbal skills are continuously lost.

Resources

Ongoing support, education and information about HD is available from the HSC. You can find a listing of our Family Services team members at www.huntingtonsociety.ca/family-services-team.

Fact sheets on Responsive Behaviour and Improving Communication: www.hdfactsheets.ca.

Understanding Behaviour in HD: A Guide for Professionals: https://www.huntingtonsociety.ca/wp-content/uploads/2013/10/HSC_UnderstandingBehaviour_3rdEdition.pdf