

FACTSHEETS FOR HEALTHCARE PROFESSIONALS: Managing Behaviour in Huntington Disease

Because Huntington disease (HD) attacks specific parts of the brain, it can lead to a number of behavioural problems. These can be aggravated by the speech and memory problems that make it difficult for people with late-stage HD to communicate their needs and preferences.

Common impairments in HD that can cause challenging behaviours

- Apathy/lack of motivation
- Lack of impulse control
- Perseveration/compulsivity
- Difficulty dealing with distractions or adapting to new situations
- Low tolerance for frustration
- Lack of self-awareness
- Inability to reason and solve problems
- Inability to delay gratification of needs or desires

Occasionally you may also see:

- Aggression to self, objects and others
- Verbally inappropriate behaviour
- Sexually inappropriate behaviour

Assessing behaviour in HD

If communication is impaired, behaviour can become the most effective method of communication — or even the only method of communication — for someone with living with HD. If you observe a sudden change in behaviour or if the client exhibits challenging behaviours, keep in mind that it may often be an attempt to communicate something: infection, pain, frustration, anxiety, needs, or preferences, for example.

Consider keeping a systematic record of behaviour, working in close cooperation with the people who know the individual best — and have

known them in the past — such as caregivers or staff. Identify triggers for challenging behaviours:

- When does the behaviour occur?
- Where does it occur?
- What precedes it?
- Who is involved?
- What interventions help the person to calm down?
- What actions are counterproductive?

At the same time, track the positive:

- When does the challenging behaviour *not* occur?
- Where does your client have a good time?
- With whom?

Managing behaviour in HD

Identifying the conditions that encourage appropriate behaviour and the triggers that lead to challenging behaviour will help you adapt the environment, schedules, approaches and goals to create a supportive setting and avoid future crises. Routine is important to people with HD, however, so don't try to change too much at one time.

Keep in mind the “ABC” formula for behaviour:

A (antecedent) -> B (behaviour) -> C (consequence)

In Huntington disease, you have opportunities to change the antecedent or the consequence but not the behaviour itself. Identifying the root cause can help you to understand the behaviour and develop plans to support the individual and those around them.

Once you've made changes, keep tracking the person's behaviour to see what is working and what could be improved.

If the behaviour is a risk to self or others, consider referring the patient to a clinical psychologist or psychiatrist.

Tips for making life easier — for you and your client

- Provide a calm, predictable environment — establish a routine for the day that the individual is comfortable with
- Use short sentences, cues and pictures to communicate
- Give the individual with HD extra time to process what you say and then respond
- Use verbal or environmental prompts to deal with problems initiating actions
- Don't overload the person with information or stimulation
- Focus on one thing at a time
- Break things down into manageable tasks

- Use a consistent approach and establish helpful boundaries to reduce problems with perseveration

Always remember that physical, emotional and cognitive changes are not under the control of the person living with HD. We have to be flexible, adaptable and creative in the care we give. Accept the “unintentionally non-compliant” behaviour as an untreatable part of HD. Take on the challenge of challenging behaviour!

For more information

- *Behavioural Changes with Huntington Disease* (a Huntington Society of Canada factsheet for families)
- *Understanding Behaviour in Huntington Disease*, Dr. Jane Paulsen (a Huntington Society of Canada booklet for individuals, families and professionals)

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>