

Responsive Behaviours in Huntington Disease

WHAT IS A RESPONSIVE BEHAVIOUR?

Responsive behaviours are not under the person's control and are simply "responses" to their environment and to the changes occurring within the brain due to the cell death.

Responsive behaviours may appear as Huntington Disease (HD) progresses, and as losses are experienced in the person's abilities and relationships. Sadly, these behaviours tend to be directed mostly towards people living and caring for the person with HD.

As a result, this remains one of the most challenging aspects of HD for both the individual and those around them. However, it is critical for individuals and families to share their concerns with their care team, and for direct care providers to seek consultation with HD specialists in order to try to understand, and reduce or manage these responsive behaviours as much as possible.

Each person with HD will have his/her own individual experience of these symptoms and they will vary within the course of the disease. Not all symptoms are present in one individual with HD at a specific time. Some traits become easier to manage with time, while others become more troublesome.

EXAMPLES OF RESPONSIVE BEHAVIOURS:

- Perseveration (persistent repetition of a word, phrase or gesture)
- Irritability, "short fused", impatience
- Resistance to care, refuses to have shower or change clothes
- Yelling/screaming, striking out (punching, hitting, kicking), pushing, grabbing, pinching
- Apathy (looks like the person affected with HD just "doesn't care" and doesn't engage in activities and relationships around them)
- Indifference, withdrawal, isolation, difficult to engage

WHAT ARE SOME REASONS FOR THE RESPONSIVE BEHAVIOURS?

Physical changes:

- The death of brain cells that help to regulate behaviour, mood, memory and social judgement
- Underlying medical condition or issue (e.g. hearing and/or vision loss, infection, tooth abscess, injury from fall)
- Physical needs being unmet (e.g. hunger, thirst, fatigue, unregulated body temperature too hot/too cold)
- Pain

Cognition changes:

- Impaired short term memory, difficulty retrieving information, slower response time
- Reduced attention span, feeling easily distracted and overwhelmed, difficulty multitasking
- Difficulty planning, organizing, sequencing (breaking task in small steps)
- Finding it difficult to adapt to new situations
- Loss of initiative and drive
- Loss of mental flexibility: getting stuck on ideas(perseveration), being repetitive and unable to switch attention to another topic
- Lack of self-awareness and unawareness of limitations
- Focused on immediate needs, seeking immediate gratification thus finding it difficult to forgo short-term rewards for longer-term goals (being reactive instead of proactive)



- Inability to foresee consequences of behaviour

Social changes:

- Loss of relationships, employment, independence
- Change of roles within the family
- Change in living environment
- Loss of ability to verbally communicate but is still aware of what is going on around them
- Isolation and/or boredom

Psychiatric concerns such as:

- Depression
- Anxiety
- Obsessive/compulsive thoughts and actions
- Psychotic symptoms such as hallucinations, delusions and/or paranoia

STRATEGIES:

Caregivers are encouraged to let go of the belief that they can reason with the individual with HD in an effort to enlist more responsible and insightful behaviour. Successful management of responsive behaviours usually require a variety of strategies that include:

- Remaining patient, staying calm and maintaining a non-judgmental approach
- Maintaining safety (for the person with HD, as well as caregivers), and providing a quiet retreat when a situation becomes overwhelming for the person with HD
- Helping to establish a routine that can be adapted as needs change
- Minimizing stress, identifying and reducing triggers
- Slowing down interactions and enhancing communication with the person with HD
- Using "I am sorry" when you cannot do what the person with HD is asking you to do or when you do not know why the person with HD is upset. Avoid unnecessary conflict.
- Helping the person find purpose and meaning in his/her day
- Knowing the person's likes and dislikes
- Helping establish and maintain social connections
- Ensuring basic physical needs are being met:
 - adequate caloric intake and hydration (these needs are high in HD: offer snacks and beverages regularly)
 - good sleep hygiene; assure sufficient periods of rest /breaks
 - physical activity
 - treat and monitor any other health condition, and monitor for any pain
- Ensuring spiritual needs are being met
- Attending (if possible) specialized Movement Disorder/HD clinic throughout the course of HD and accessing other members of the clinic team (i.e. Physiotherapy, occupational therapy, social work)
- Using medications as prescribed

These strategies will give the person with HD the best opportunities to be more authentically "him/herself."

It is important to:

- Know that for some people the cognitive and psychiatric impairments may appear long before the physical symptoms of HD, and they could impact relationships and employment.
- Remember that in the later stages of HD, responsive behaviours may be the only way the person is able to communicate with his/her caregivers
- Connect with Huntington Society of Canada and its Family Services team early on, and maintain this contact throughout the course of the disease. We will be here to guide you with support, advocacy, education and community referrals.