

When Working with Individuals Affected by Huntington Disease

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

AUTONOMY

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

- Autonomy 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
- Always 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
- Expect significantly delayed responses and give enough time to respond
- Slow down, keep communication simple (There is a decreased ability for abstract thought)
- Keep in mind the reduced capacity using/reading body language and facial expressions
- Always expect that even severely affected people are aware of their surroundings

EFFECTIVE COMMUNICATION

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

- Take responsibility for effective communication: take time and slow down, focus and limit distractions, keep yourself and the environment calm, and be non-judgmental
- Maximize one-on-one communication settings as the greater the number of persons involved in the information exchange, the greater the challenge it may become
- Asking questions:
 - First ask an easy question...wait...No response does not mean no!
 - Rephrase the question as a multiple choice question...wait...if no response
 - Rephrase it as a yes/no question...wait...if no response
 - Excuse yourself and ask again later, starting low in the hierarchy

PERSEVERATION

Repeated responses need to be addressed as quickly as possible to avoid escalation to angry outbursts. Approach the individual as calmly as possible and get their attention, use a positive response. A refusal will not stop the perseveration.

- Avoid confrontation or ultimatums. Confrontations and ultimatums will not resolve the problem but might lead to an escalation
- You cannot convince, persuade or explain, to a person with HD, who is stuck on a specific idea or thought, a potential resolution. It is best to address the idea or thought and move on
- Not all conflicts or crisis can be avoided so:
 - Set realistic goals
 - 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 members and friends
 - Acknowledge how difficult the situation must be for the person affected by HD

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
- Routine can lessen short-term memory deficits, distractibility, difficulty initiating or sequencing task, impulsivity, aggression, obsessive or intrusive thoughts, anxiety, apathy

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.

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RESPONSIVE BEHAVIOUR

Responsive behaviour occurs when a person reacts in unusual ways 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 and when the coffee doesn't appear they may exhibit responsive behaviour by yelling or hitting. Remember, people with HD do not self-regulate well. Possible causes may include:

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

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 and determine the root of the issue and what the person is trying to communicate. Other areas to explore would be to observe, gather and share information:

- When does the challenging behaviour not occur?
- Where does the client have a good time? With whom?
- What conditions offer opportunities that seem to determine a "good time"?

IDENTIFY TRIGGERS

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

- When does the challenging behaviour occur? Where does it occur? What precedes it? What may have rewarded or supported it afterwards? 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 so future crisis can be avoided
- 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
- Spend time with a disruptive person during their good periods
- Acknowledge and reward non-disruptive behaviour
- Accept anger and frustration as valid expressions of feelings
- Allow "cooling off" time in a quiet environment so that person can regain control over feelings and behaviour

A NEW APPROACH

Always remember that physical, emotional and cognitive changes are not under the control of the person living with HD. Accept that sometimes the person with HD can only communicate through behaviour. Take on the challenge of responsive behaviour as the person with HD cannot simply try harder but we can understand the progression of the disease and manage accordingly.

