

Behavioural Changes with Huntington Disease

The basics:

- Behavioural and emotional changes in individuals with HD constitute an integral and inevitable part of the disorder
- The emergent social difficulties do NOT correspond with the severity of the movement disorder
- Behavioural patterns are NOT hereditary and the symptoms may differ dramatically between the affected relatives
- Not only do the alterations result from the psychological reaction to the presence of the disease but they are also a characteristic consequence of the disease process itself due to physical changes that take place in the brain's frontal lobes
- Since only certain areas of the brain are affected, the resultant changes are specific and predictable but variable in presentation
 - Unaffected areas of function: long term memory; well-learned skills; comprehension of speech;
 - Areas of function that could be affected to various degrees: verbal and non-verbal short term memory; orientation in space and time; ability to adapt to new environments; planning; judgement; decision making; self control (both physically and emotionally); awareness of one's mistakes; adaptability to change; depth of thought processes; verbal fluency

The four major characteristic behaviours:

- Loss of drive and initiative
- Mental inflexibility
- Lack of concern for one's appearance
- Decreased ability to empathize in the feelings and needs of others

Some key points to keep in mind:

- Behavioural and emotional changes are not under an individual with HD's control
- Changes vary between individuals with HD in their depth as well as course of progression
- Some emergent traits become easier to manage with time, while others become more troublesome
- Not all the symptoms are present in one individual with HD at a specific time – there are great differences among affected individuals in the time of onset and the identity of observed changes
- Some changes occur sporadically (i.e. depression), while others tend to follow progressive development (i.e. slightly decreased social awareness may develop into complete apathy)

Tips for the carers:

- Take some time off for yourself regularly
- Try different relaxation activities such as yoga
- Participate in activities that do not involve the individual with HD
- Find like-minded friends who are willing to listen without offering advice
- Practice having a positive attitude
- Acknowledge to yourself that you are grieving
- Recognize symptoms of overworking and chronic stress:
 - Irritability; depression; vague physical pain; insomnia; occasional dizziness; fears; tiredness
- Consider respite services to give yourself a break

SYMPTOM	REASON	GOOD TO KNOW	POSSIBLE SOLUTION
Lack of drive and initiative; Poor quality of performance	Impaired ability to self motivate and evaluate one's performance. Often the individual with HD is simply not aware of the errors that were made.	The individual with HD is still capable of carrying out the task but needs to be encouraged to get started.	Do not completely eliminate all responsibilities – the individual with HD still wants to feel useful and help. Joint participation allows the other person to serve as an external stimulator, thus encouraging the individuals with HD to take part in the activity. Accommodate for limitations by embarking on simpler tasks.
Inability to multitask and/or adapt to novel situations	Impaired ability to rapidly switch attention as well as process too much information at once.	The individual with HD is still capable of staying focused on a single task and can accomplish it.	Introduce structure into the day. Create a weekly schedule. The best approach is “one thing at a time”, thus breaking down complex activities into single steps.
Selfishness; Uncaring attitude;	Loss of mental flexibility, which leads to the inability to put oneself into another's shoes in an attempt to understand their point of view.	The individual with HD's own thought processes become less complex and more rigid, which results in a decreased capacity for sympathy and empathy for others.	Avoid direct confrontation about the issues on which there is disagreement. Investigate potential factors that can predispose the individuals with HD to unattainable demands and outbreak of emotions.
Lowered standards of hygiene; Impulsive behaviour Aggression	Impaired personal and social awareness leaves the individuals with HD unable to realize the social consequences of poor self-care and inappropriate behaviour.	The individual with HD has lost the feelings of guilt, shame and embarrassment, which would normally serve as strong motivators to keep one's appearance and actions under control.	Make self-cleaning a normal part of the daily routine. Let the individuals with HD make some decisions on a small scale, such as choosing the brand of the shampoo or the colour of a sweater. Place some written rules or “contractual agreements” on behaviour in places.
Denial; Anger	Slow process of realization or impaired insight into the reality: the nature of the disease and all the losses that it entails, such as one's job, friends, and relationships with family members. Frustration and grief as a result of decreased mobility and independence.	If the individual with HD's own current personal experience does not match with his/her perception of the disease, then he/she refuses to admit its presence. Occasional manifestations of symptoms at the early stages of onset may throw the individuals with HD off the emotional balance because he/she does not know how to deal with the changing reality.	Try to encourage the individual with HD to admit that he/she exhibits certain symptoms rather than telling them straight out of the presence of HD. It is easier to recognize one's difficulties one-step at a time, thus slowly arriving to the final diagnosis. However, when an individual with HD has shown by their behaviour the extent to which they are able to perform the activity, help them acknowledge here they need assistance to complete the task. Present this information in a dignified, respectful and factual way. If the individual with HD becomes upset acknowledge the loss and allow for grieving.

