

Behaviour

Behaviour changes in people with Huntington's disease (HD) can cause significant distress for both them and for their relatives/carers.

These changes, which are often most apparent at home, may not always be as obvious to other people who see the affected person less often. If the situation is grossly underestimated by professionals, it can be more difficult for a family member/carer to access support and explain the pressures they are under.

1. What behaviour changes will I notice?

Functions that may have been taken for granted, including planning, decision-making, organising, problem solving, initiating tasks and controlling feelings may be affected. The most common difficulties are:

- **Apathy (often regarded as depression)**
With Huntington's disease, there is a loss of initiative and drive. This can make you appear lazy when in fact you may be content to do very little and focus on the 'here and now'. It can be difficult or frustrating for your family/carer to understand this and it may be helpful to take advice about how it can be managed. You could also try to do more things together, find out about community groups or take up a hobby or activity.
- **A lack of sequential thinking**
Thinking ahead is about weighing up what is important and what isn't to help you reach a desired result. With Huntington's disease you may not be able to judge potential consequences, focusing instead only on what matters right now. This is not you being awkward; you are unable to think things through logically or anticipate the outcomes of certain actions or decisions. It may be helpful for people who know you to come back to the same situation later on as you may change your mind about a specific topic.

- **Mental inflexibility**

People with Huntington's disease can become very rigid in their thinking. You may be averse to trying new things, preferring instead to stick to set routines. It also means you are less able to consider other people's perspectives or points of view, which can make you appear selfish. Family and friends can help by introducing changes gradually rather than springing them on you out of the blue which could be difficult for you to cope with.
- **Attention problems**

Doing two things at once or making choices between two or more options can become difficult. This is because it becomes harder to switch your attention from one thing to another.
- **Memory**

Forgetting appointments or events can become commonplace. The use of diaries, calendars and planners can help so that everything is written down. A whiteboard is also an effective visual aid.
- **Loss of organisational skills**

With Huntington's disease, as connections to the frontal lobe become impaired, you might struggle with what used to be simple tasks. It might become difficult to prioritise and you can appear disorganised, which can lead to performance issues if you are still working. You haven't forgotten how to do your job, the difficulty is that you cannot organise as effectively as before.
- **Impulsivity**

How many times have you wanted something, and wanted it now? With Huntington's disease, it is virtually impossible to wait. You may get angry and want to lash out. Pre-empting your needs as much as possible is an effective way to avoid such situations.
- **Disinhibition**

You may say or do things that you would previously have found embarrassing. For example, you could have a complete lack of insight or awareness about a person or situation which, when challenged, leads to you swearing, slamming doors, hitting walls etc.

- **Managing emotions**

There are a number of emotional changes which can happen. You may appear volatile and lose your temper very easily for no apparent reason or over what most of us would consider trivial. **It is important to remember that there is always a reason for an outburst and what may be minor to most people will be very important to you.**

Demands placed on you could lead to anger or irritability simply because you are not able to cope with a given situation, for example, if it is too complicated.

2. How can I help myself?

- Try to recognise the triggers that make you angry or irritable e.g. hunger, fatigue, pain, excessive noise/distractions or if you are having problems communicating. This can make situations easier to deal with and reduce the frequency of outbursts and troubling behaviour. Gather as much information as possible e.g. when does the problem occur, who is involved and what was happening before the behaviour? This helps you to find out exactly what is going on and explore resolutions, if possible.
- Incorporate set routines or predictable schedules into your day. Let others plan things out for you if necessary.
- Let people suggest things to you and ask them to keep information limited to one thing at a time.
- Ask people to give you time to answer questions one at a time to avoid confusion, rather than jumping in to put the question in another way or asking additional questions.
- Consider using distraction if you become fixed on a topic and ask family members to remind you about topics that have already been discussed.
- Make a list of priorities and work out what you can compromise on.
- If applicable, discuss any performance issues with your employer.
- Talk to your GP or Consultant to consider medication, if appropriate.

Always remember that it is the disease causing the behaviour changes and you are not at fault. Losing the ability to control your feelings and thoughts does cause frustration and anger. To reduce the stress of coping with new

things in your life, it may be better for others to ‘plant a seed’ that helps you to gradually come to terms with suggested changes and offers you autonomy to make your own choices.

Useful links

[Contact a Scottish Huntington’s Association HD Specialist](#)

[National and Regional Care Frameworks for Huntington’s Disease](#)

[Sign up for regular updates from Scottish Huntington’s Association](#)

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