



Huntington's Disease and Behaviour

Who can help?

The main source of support regarding mood and behavior will be a psychiatrist, ideally someone who specializes in neurological conditions. You should ask for a referral from your GP or HD Specialist Nurse for a neuropsychiatrist or neuropsychologist or failing that a generic mental health doctor highlighting the fact that you have HD. Ideally you, and your family, should be aware of the potential issues surrounding mood and behaviour from early on in the disease. This will allow you to foresee and hopefully avoid some common problems and come to terms with the changes which may develop. You should also seek a referral to a neurologist who should work closely with your mental health team.

If you need help or support please contact HDANI info@hdani.org.uk and one of our Family Support Workers will be in touch.

Common Problems

- Depression
- Apathy (lack of interest/motivation/engagement)
- Mood swings
- Anxiety
- Difficulty processing or reading emotions
- Compulsive behaviours
- Anxiety
- Cognitive decline
- Changes with the body clock

Your questions answered

The following Q&A is taken from a session held in October 2020 with Prof Hugh Rickards, a consultant psychiatrist specialising in HD, working with the West Midlands Regional HD Service. Please note that the answers given are general and you should seek advice from your GP or a referral to a mental health specialist, HD Specialist Nurse and/or neurologist for specific advice.

Can depression in people with HD be treated or is it just the way it will be forever?

Depression is among the most treatable things in HD. First it's important to make sure the depression is properly diagnosed (other things such as apathy can mimic depression, and depression can be secondary to other conditions which have their own treatments, like vitamin deficiencies). The bad news about depression is that it's a rotten illness. The good news is that it gets better in almost every case.

Any suggestions for the psychological impact of chronic pain and fatigue?

There's no doubt that chronic pain and fatigue has a significant impact on the patient and the rest of the family. Some forms of both of these conditions are treatable but it needs appropriate investigation, like depression.

Do you have any help for sleep loss/insomnia?

Sleep loss/insomnia is relatively common in HD but there's not one specific treatment for it. It needs proper assessment. Sometimes the person with HD is fine with not sleeping, it's just that this leads to additional risks (like falling down the stairs at night, or insomnia in the spouse). Treatment is sometimes medical but also, if the patient is not distressed by insomnia, it's about risk management and adapting to their routine.

Any tips for helping prevent memory loss?

Memory function has different components, the most commonly affected in HD is "working memory" (that is the ability to hold stuff in mind while you think about what to do). I think that practice is probably good, although I can't prove it. There may be different ways of practicing. For instance, some people are studying if drumming can help, in general, exercising your brain is good but it's important to do something you like, otherwise you probably won't keep doing it.

Although there is no HD drug are there any specific drugs you could name which are known to help manage the various symptoms of HD?

Some symptoms of HD are more readily treatable than others. The ones that can often be treated include depression, anxiety, irritability, chorea and dystonia. Some of these can be treated by a combination of drugs, psychological treatment and changes to the environment (including physical, emotional and social adaptations). I don't think I can name specific drugs as there are too many of them. The most important thing is to target those things which are causing the most problems and to think carefully about whether the particular side-effects might be a problem for the individual, or whether the proposed drug would not mix with other drugs the patient is taking. At this stage, it's probably not a good thing to take medication just for "Huntington's" as such a thing doesn't exist right now. We hope in future that it will.

My partner has lost their 'get up and go' - is this depression?

Many people feel short of 'drive' or 'lose their 'spark' occasionally, but apathy is a persistent loss of motivation to do things, or a lack of interest in things. It is different from depression which is generally accompanied by sadness. Apathy is much more common among people with dementia than in older people without dementia. HD is a cause of dementia.

Apathy can start at any stage of dementia but often develops early on. Many studies suggest that apathy becomes more common as Huntington's progresses. Once present, apathy tends to persist rather than come and go.

What are the symptoms of apathy? A person with apathy will have less motivation, as well as some of the following changes:

- lack of effort or energy to do everyday tasks (such as personal hygiene)
- reliance on others to structure daily activities
- loss of interest or curiosity in new things (such as people or conversation)
- lack of concern about their own problems
- unemotional responses to news or personal events (seeming indifferent or detached).

Some of these symptoms (such as loss of interest in things and lack of energy) are also common in depression. It can be hard to know whether a person has depression or apathy – even for a doctor. The main difference is that a person with depression will have feelings of sadness, be tearful, feel hopeless or have low self-esteem. A person with apathy alone will not have these symptoms of low mood, more a feeling of being without energy or spark.

A person with apathy and HD is often not concerned by their symptoms. However, these symptoms can make the person's life less enjoyable and often put a strain on relationships and anyone helping them. Carers can feel frustrated because the person needs more support with daily tasks and because they seem so withdrawn and unresponsive.

One of the reasons that people with HD are thought to develop apathy is damage to the brain's frontal lobes. These control motivation, planning and sequencing of tasks. When someone withdraws, stops doing things and loses their confidence and abilities, their apathy can get worse and so they become even less motivated. It is important for anyone supporting the person to help them avoid this.

While depression in people with HD is very treatable there is less evidence about what treatments do or do not help someone with apathy. Non-drug approaches should generally be tried first. According to recent research, music therapy, group art therapy and cognitive stimulation (when delivered by a trained professional) can all help.

Tips for carers:

- Try tasks and activities that the person can do, enjoys and finds meaningful.
- A daily routine may help.
- Break tasks down into manageable chunks.
- Several smaller steps may be easier to take than one bigger step and help the person to feel like they are achieving things.
- You will often need to gently prompt or help the person, or start an activity (such as dressing).
- Offer lots of encouragement to keep them engaged, but don't fuss over them.
- Be positive and focus on what they have achieved.
- Don't blame the person for being 'lazy', unhelpful or not caring – it's not their choice.
- If you feel frustrated, try to remain calm. The person may pick up a negative mood.
- Look after yourself: take regular breaks and see if replacement (respite) care is an option.
- Talk to someone you trust or join a HD or carer support group, perhaps online as others may have helpful tips to share.

Drugs play only a small part in the treatment of apathy. Some people who are already taking a cholinesterase inhibitor (donepezil, rivastigmine or galantamine) for Alzheimer's disease or mixed Alzheimer's-vascular dementia will have an improvement in their motivation, as well as in memory and concentration. A person with apathy may also be offered an antidepressant drug, although there is very little evidence that common antidepressants bring any benefits for apathy in Alzheimer's disease, mixed or vascular dementia. There is some evidence that these drugs make apathy worse.

Online resources

There are some excellent, specialist HD resources available online which provide an explanation of how HD affects a person's mood and behaviour and provide tips to try including the following;

Neuropsychiatric aspects of Huntington's disease

https://www.researchgate.net/publication/277449673_Neuropsychiatric_aspects_of_Huntington's_disease

A fantastic resource for family members and professionals alike

<https://www.lulu.com/en/gb/shop/james-pollard/hurry-up-and-wait/paperback/product-197ngqq.html>

This UK Guide is a good resource for family members

<https://www.hda.org.uk/media/2517/behaviour-and-communication-guide.pdf>

To view our video training sessions please visit <https://youtu.be/CVC-EcwqRsc>