



Huntington's
Disease
Association



**Huntington's disease:
Behaviour and
communication guide**

Contents



Behaviour 3



Insight 5



Drive, apathy and initiation 7



Doing two or more tasks at once 10



Daily tasks 12



Hygiene and self-care 14



Dishinibition 16



Perseveration and obsessive behaviour 18



Sympathy and empathy 20



Depression 22



Irritability and aggression 24



Relationship changes 34



Communication 36



Support from the Huntington's Disease Association 40



Resource library 41



Notes 43



Why does behaviour change?

Behavioural changes in Huntington's disease are common. These changes can be caused by physical changes within the brain, however, they can also be due to the pressures of dealing with the disease. Factors such as reduced independence, strained social life, poor mobility, lack of understanding from others and the effect that the disease could have on employment can naturally be cause for stress.

It is not surprising that many people with Huntington's feel frustrated and sometimes angry and this could have a harmful effect on how they react in certain situations.

An example would be if a person with Huntington's, falsely accused of being drunk, reacted by assaulting the person who was accusing them. It is understandable that the false accusation would cause anger. Combined with the lack of emotional control, courtesy of the Huntington's itself, there would be a higher chance of a negative reaction.

Whilst certain behavioural changes may be common, all experiences of Huntington's disease are different and unique. Discovering what triggers specific behaviours may help when developing strategies to manage them.

Someone with Huntington's may be having behavioural changes caused by neurological changes. In these cases, the people may find it best to modify their own behaviour, rather than expecting the person with Huntington's to control their own.

Medication can be helpful in reducing changes in behaviour. If behaviour is becoming a problem, it may be worth contacting a GP or specialist.

For friends and family, watching a loved one change with Huntington's disease can be tough, but it is important to remember that this is something they have no control over.

Behaviour and disease progression

Behavioural changes become more pronounced as the disease progresses. For example, someone will typically show less and less initiative over the course of the disease, as well as less concern over their own appearance and less awareness of the feelings of others.

In some cases, however, some behaviours may become more manageable as the disease becomes more advanced, for example irritability and aggression may gradually give way to apathy and a lack of concern.

Similarly, disinhibited behaviour may be most pronounced early in the disease when the person is more active, whereas this behaviour may become less of a problem later, as the person loses drive and initiative. Mood disturbances, such as depression, tend to occur sporadically and are unrelated to the duration, severity or progression of the disease.

How behaviour can change and how to help

The following sections in this guide will provide further information about the different ways behaviour can change and offer advice and guidance on how to help.



Insight

People with Huntington's may not recognise that they have the disease. To an observer, it may be clear that they have signs of the disease, but the person themselves may not be aware of any symptoms.

This lack of awareness is usually caused by changes to the brain and means that it may be difficult to explain to someone with Huntington's what is happening to them. Seeing someone with Huntington's refuse help may be difficult for family members, but it is understandable that they would refuse help when they don't see that anything is wrong.



Tips on how to help

- Some people find it difficult to accept help, especially if they don't believe they have Huntington's. Encouraging them to accept small assistances for particular challenges may be best. For example, if a person is struggling to cook, offering to buy them microwave meals may be a starting point. If someone has always enjoyed sport but are now finding it difficult, they might be willing to see a physiotherapist.
- Encouraging someone to accept help early on could make it easier for them when the condition has progressed and they require more help. In the beginning, someone may need help with things like opening letters and paying bills. Often a family member or friends can assist with tasks like this, but paid support is also available.

- As someone with Huntington's may find it harder to process information, it is important that any decisions they need to make are explained slowly and clearly and that they are given time to consider their options. Sometimes a person with Huntington's will need a little time before they accept help.
- Keeping to a set and clear routine may also help people with Huntington's to accept help.

"My wife was absolutely adamant that she didn't need any help, but my local Specialist Huntington's Disease Adviser pointed out to her that it was putting too much strain on me. I was amazed that she agreed with this and said she was concerned about my poor health. She agreed to a cleaner and Social Services understood our dilemma and organised a carer to do this role. Over time my wife got to know the cleaner and they would go to the local shop together for groceries. My wife slowly accepted more and more help."



Drive, apathy and initiation

A person with Huntington's may be reluctant to engage in activities. They may show loss of drive, initiative and become apathetic. If left alone, they may stay in bed or spend the whole day watching television.

Someone with Huntington's may be withdrawn and appear to be depressed. It is important to be aware that their facial expression may not always reflect how they are feeling.

This behaviour can be highly frustrating for family members, who may mistake it for laziness. The family members may find it difficult to accept this behaviour when they are having to take on extra responsibilities.

It is important to recognise that the person's behaviour is due to changes in the parts of the brain which are crucial for drive and initiative. The parts of the brain that are affected are the ones that allow us to think ahead, to make plans, to generate the actions appropriate to those plans, and to persevere at tasks until goals are achieved. When those parts of the brain are damaged, the drive or foresight to self-initiate activity is severely compromised, even though the skill to carry out the activity is still retained.

The person with Huntington's may be capable of carrying out a task, yet is unable to generate the motivation or initiative to proceed with it.



Tips on how to help

- It may help if the person with Huntington's is encouraged to take part in activities that they would enjoy. They may just need a little support or prompting to get them started.
- Someone may be more likely to take part if they do not have too long to think about it. So presenting an activity as a last minute idea may be better than asking the day before.
- Encouraging joint participation in chores, like the washing up, may be helpful, and is generally more successful than expecting the person with Huntington's to do things on their own. This is because the other person doing the activity acts as an external motivator. The person with Huntington's does not have to rely on their own drive and initiative.
- A structured routine can help reassure someone who is struggling by providing a framework of predictability. A person may be more comfortable if they know what to expect on a day-to-day basis.
- If the person with Huntington's receives professional care, they are likely to prefer to be cared for by a regular group of people and staff who know them well. Care homes and care agencies should strive to ensure consistency in which carers work with which person. When a new carer becomes involved it may take time for the person with Huntington's to accept them. Your local Huntington's Disease Adviser can provide training and advice to new staff.
- It can be useful to have prompts and reminders easily accessible to the person with Huntington's, for example a calendar, notice board or white board for leaving notes. If they regularly use a mobile phone it could help to set reminders. An occupational therapist may also be able to provide advice and recommend useful equipment.

"I'm ashamed to say that I used to get really angry with my husband. He had to give up work and I was taking on a lot more so we could pay the bills. I asked him to do the housework while I was out, I'd get back and he had done nothing. I now realise that this was part of the disease. Now, at the weekend we do chores together and I'll ask him to do small tasks alongside me. I've also set a reminder on his phone for bin night and this prompts him to go and put them out. I am still doing a lot but I do feel that we are more of a team again."



Doing two or more tasks at once

Many everyday situations involve multitasking. For instance, a person may be ironing, whilst also speaking to their children or watching television.

Doing two things at once requires the mental flexibility to switch attention rapidly between tasks; no matter how engrossed in a television programme someone may be, it is essential to keep switching attention back to the ironing to avoid burning the clothes.

Huntington's can impair the speed at which someone can divert their attention, making it difficult for the person with Huntington's to carry out two tasks at once effectively. In many cases they will fail at one of the tasks. In contrast, when focusing on a single task, many people with Huntington's are very good at sustaining attention, provided they are not distracted.

A physical activity, like walking or eating a meal, requires much more conscious attention for the person with Huntington's than for somebody without Huntington's. Someone with Huntington's may find it difficult to carry on a conversation at the same time as walking or eating and may sometimes stop their activity before answering a question. This is because both activities require conscious attention.



Tips on how to help

- 'One thing at a time' is a good general rule. Overloading the person with Huntington's with too many tasks may be a source of irritability and could lead to disruptive behaviour.

"Dad lives in a residential home. He was struggling at meal times and getting quite frustrated. We met with the home and looked at some guidance around behaviour. We realised that he was overwhelmed; he was trying to eat, but the room was so noisy that he couldn't concentrate. We spoke to dad about it and he decided that he would prefer to eat in his room. It seemed a bit anti-social at first but it has really helped. He then goes into the dining room afterwards so he doesn't miss out on that social time."



Daily tasks

Someone with Huntington's disease may carry out everyday tasks less efficiently than they did before. For example, they may miss out words when writing a letter, or may not clean the plates very well when doing the dishes. This is the reason that many people with Huntington's give up paid work.

This could become a source of irritation to the person's family, and they may mistakenly perceive the person as simply not caring.

This is, of course, not the case; many people with Huntington's put an enormous amount of effort into their tasks and activities.

The quality of a person's performance may also suffer due to other reasons, such as anxiety, depression or loss of confidence.

When a person with Huntington's disease struggles with a task it is generally not because they have forgotten how to do it. It actually relates to their impaired ability to self-motivate and to check the results of their own performance. Because of this, the person with Huntington's will often not be aware that they have made any errors or mistakes.



Tips on how to help

- Whilst encouraging a person with Huntington's to persevere with a task may be best, it is important to be accommodating and to be aware of the person's limitations.

- If the person is lacking initiative then others around them may have to be responsible for encouraging them to be productive.
- Similarly, if the person is carrying out tasks inefficiently then those around them may have to assist with those tasks.

“Work were excellent with me. I was struggling with some of my day-to-day tasks, so I spoke to Occupational Health, and they worked alongside a Specialist Huntington’s disease Adviser to find solutions. I was particularly struggling with multi-tasking, so it was decided that when I was focusing on a piece of work I would leave my desk, so as not to be distracted by my phone or emails. I was also struggling with tiredness, so HR arranged for me to get taxis to work and to work shorter hours. All these things have helped me produce better quality work.”



Hygiene and self-care

Someone with Huntington's may show less interest in their personal appearance and their standards of hygiene may decline. Loss of drive and initiative contribute to this change. Huntington's disease can also impair personal and social awareness and cause blunt emotions, which could also contribute to a decline in how much someone looks after themself.

The person is likely to be unaware of the way in which they've changed and often won't notice the effect that their appearance has on others. Moreover, they may not experience the feelings of shame or embarrassment that, for many, act as a strong motivator to practice self-care.



Tips on how to help

- In many cases, gently prompting the person with Huntington's to bathe or change their clothes may help. However, some people with Huntington's still adamantly refuse to do these things. Establishing bathing and changing clothes as part of a routine may also be helpful.
- The best way to encourage cooperation can be dependent on the specific person. Some people may react badly to being told what to do - yet respond positively when encouraged to participate in making decisions. For instance, they may refuse to put on the clean clothes that have been given to them, but may be willing to put on clothes that they have selected themselves.

“My brother has got very particular about his clothes. He likes to wear a black tracksuit all the time as it is what he is comfortable in. He doesn't seem to think about washing anymore, but he comes to us on a Wednesday for his tea and seems happy to have a shower afterwards. He leaves his clothes in the bedroom and I swap them for an identical clean set when he is in the bath. It feels like a funny set-up that we have got into and I'm not even sure if he knows he is putting a clean set on, but it works for us.”



Disinhibition

Some people with Huntington's may act in a disinhibited way that others could find embarrassing.

Disinhibited behaviour can appear in a variety of forms. Someone may act impulsively or rashly without thought, such as making a sudden purchase of a car that they cannot afford. They may make socially inappropriate remarks, for instance making personal comments about a person who is within earshot. They may behave in a sexually disinhibited way, such as making sexual advances to a partner in front of their children.

This behaviour is due to a breakdown in the person's social awareness and ability to consider the social consequences of their actions. They may not be aware of the repercussions of their actions and may also no longer experience the feelings of embarrassment, guilt and shame that, under normal circumstances, place constraints on social behaviour.

A person with Huntington's cannot simply be made to see the consequences of their actions if the capacity to do so has been damaged by the disease. Nor can they be made to feel guilt, shame or embarrassment if those emotions have been taken from them by the disease. A person displaying disinhibited behaviour may have to face restrictions to their freedom, for instance a partner or family member may have to take control of their finances.



Tips on how to help

- Some disinhibited behaviour, such as socially inappropriate sexual advances, can best be managed by clarifying to the person what is acceptable and what is not.

“I was so embarrassed when we got a call from the nursing home saying that dad was taking his clothes off in the public spaces. We had a good chat about it with the home and involved our local Specialist Huntington’s Disease Adviser.

When we thought a bit more about it, it made more sense – the home is so hot and he was simply making himself comfortable - but it was upsetting some of the other residents. We worked on making his room a more comfortable temperature and also agreed that his room is his own space and he can wear what he wants there. I got him some really comfy shorts and t-shirts and he is now happy to wear these in the communal areas.”



Perseveration and obsessive behaviour

Sometimes people with Huntington's can get 'stuck' on certain ideas and find it difficult to move on. This is known as perseveration. This may also be apparent when someone with Huntington's becomes obsessed with a particular item and buys it in excess – for example, somebody may fill their house with bottles of water.

Someone with Huntington's may have compulsions that take the form of repetitive behaviours and actions that are associated with an obsessive thought. They may also have become obsessed with intrusive thoughts that cause them anxiety.

Arguing with the person with Huntington's is unlikely to be effective and they probably won't understand why you think they are being unreasonable.



Tips on how to help

- It may be better to help the person find a new, healthier pursuit to turn their attention to. Encouraging them to become passionate about an activity may be helpful.
- Compromising, by agreeing to dedicate some time to the idea that they are 'stuck' on, in exchange for them considering new ideas, could also be a helpful tactic.
- It may be that the person with Huntington's will accept the opinion of a professional, like a doctor, rather than that of family or friends who are expressing the same opinion.

- It can be difficult to encourage somebody with Huntington's to become unstuck, but sometimes they will eventually do it of their own accord.
- Medication can also help with these issues, but it is important to talk to a medical professional first.

“Mum had an obsession with Galaxy chocolate. We would have to buy at least 12 big bars at a time. If presented with an alternative, she would become extremely angry and refuse to accept them. There was no reasoning with her; we just had to accept this as her current obsession. In time it wore off and she moved on to something else.”



Sympathy and empathy

Someone with Huntington's disease could seem self-centred, uncaring and thoughtless. The person's apparent disregard for the emotional needs of a partner can be particularly hurtful and is especially poignant when it contrasts with a former loving and caring relationship.

It is important to remember that the person with Huntington's is not being deliberately awkward, wilful or unkind. Apparent self-centredness is a consequence of the loss of mental flexibility associated with Huntington's.

The person may no longer be able to practice empathy, see another's point of view, or weigh up all sides of an argument. They may fail to see how their remarks or actions affect others.

Huntington's can also impair the ability to experience the complex range of subtle emotions that contribute to interpersonal relationships, so that the person's emotions are shallower and less complex. The effect that Huntington's disease can have on a person's capacity for sympathy and empathy is a major reason that Huntington's can have such a devastating effect on families.



Tips on how to help

- It is not possible to replace emotions and feelings that have been lost to the disease. It is important to remember that the person is not being deliberately uncaring and the emotional changes are not under their control.

“My husband used to be really thoughtful, but now he doesn’t seem to think of me. I was so upset the first time I didn’t get a birthday card from him. I spoke to others at the support group and realised that many of them were in the same boat. This helped me realise that this was the disease and that made it easier. I love him dearly, but he is no longer my emotional support. I buy my own birthday presents now and give them to him to give to me. This suits us all.”



Depression

Depression is something that many people with Huntington's will face. However, there are ways to treat the depression fairly effectively and this can dramatically improve the well-being of the person with Huntington's.

Depression should not be confused with apathy or loss of drive and initiative, which are integral mental changes that occur as part of Huntington's and do not equal depression.

A specialist can differentiate depression from apathy. It is possible that apathy could appear as a symptom of depression, particularly if the lapse in the person's motivation and interest has occurred rapidly.



Tips on how to help

- GPs are well-equipped to advise in cases of depression and may recommend medication where necessary.

“I was feeling really low for quite some time and I was withdrawing from social situations. I felt sad and couldn’t see any happiness in my life. On a particularly low day, I decided that I could no longer do this to my wife and children, so I decided to get help. I went to see the GP and she gave me medication, which really has helped. She also gave me advice on my lifestyle. I started going to the gym and that really made me feel as if I was doing something positive.”

Irritability and aggression



It is not uncommon for someone with Huntington's to become emotionally volatile. They may become angry for no apparent reason, or become annoyed by trivial issues. A person with Huntington's may be aware that they are beginning to be agitated, but the sudden surge of anger often arrives without warning and is outside of their control.

If the person with Huntington's becomes suddenly angry it is best to avoid confrontation and to leave the room if possible. It is especially important to leave if there is the threat of physical aggression.

Advice for if you find yourself in a crisis

Occasionally, a relationship may change in a way that leaves the carer feeling physically, emotionally or mentally abused. This may make it incredibly difficult to cope with. There are no easy answers, but it is important that you think about your own safety, and that of the people who depend on you.

Having a plan in place, should the worst happen, is very important. This means that if a difficult situation arises in the future, it may be easier for you to handle.

Planning may include considering the best way to react in a variety of different situations, including a crisis.

It can help to have a record of certain phone numbers, put these into your mobile phone. Keeping a list of numbers of your friends, family and colleagues who can help could prove invaluable. Keeping a list of emergency numbers in your mobile phone, including the police, domestic violence agencies, a local GP, a

social worker, any children's schools, mental health crisis team and legal aid; such as a solicitor, could also be vital to your safety.

You should be aware of the National Domestic Violence helpline, which is free to call and operates 24-hours a day. You may also want to ensure that your children know how to call the emergency services in the event of an emergency, and are able to recite your address and telephone number.

It may also be worthwhile to ask your neighbours to stay vigilant and to call the emergency services should they suspect something is wrong. A neighbour may also be willing to keep hold of an emergency bag for you.

An emergency fund can come in handy should you need to buy any bus or train tickets. Any keys should be kept in a safe place that you can access easily if needed. Your mobile phone should be kept charged and close to hand.


Should you feel that you are at risk from a partner you should head away from any immediate danger, try to avoid the kitchen or garage where there may be implements and tools which could be used as weapons and avoid rooms with only one exit or where you could be shut in a cupboard or other small space. You may need to leave your home all together.

Friends and family can be a great means of support when making difficult decisions and talking the situation through with people who are trusted could help.

You must remember to prioritise your own safety and that of your children. Leaving an abusive partner can be a long and difficult process. Having a plan in place doesn't come with any obligation to leave, or to involve the authorities, but makes it a lot easier should you choose to do either of these things.

Other resources

The government website also has information on domestic abuse and how to report it:

 www.gov.uk/guidance/domestic-abuse-how-to-get-help

A person with Huntington's may become irritable if they don't get their own way or if someone disagrees with them. This may be because they struggle with empathy, so perceive the person who is opposing them as being unreasonable. They are unlikely to become convinced through argument and will likely only become more upset and angry.

As people with Huntington's struggle to do more than one thing at once, overloading them with information may further cause them to lose their temper.



Tips on how to help

- If the irritability or aggression is a symptom of depression then medication can help. There may, however, be no definitive way to stop emotional outbursts.
- There may be specific contributing factors that can be avoided. The sections below on 'Spotting and managing common behaviour triggers' and 'Anticipating and managing irritability' can help in identifying triggers.
- In addition, it may be helpful to keep a simple diary recording possible triggers in a person's day which may have caused them to have a temper outburst. Identifying common factors that can lead to outbursts will make them easier to avoid.

- A fixed and clear routine can make life a lot easier for someone with Huntington's, as the part of their brain that deals with change and choice is damaged. They know what to expect and when, which can be very re-assuring. Making decisions can be difficult for somebody with Huntington's, so it is easier if things are planned for them.
- Allowing the person with Huntington's to help in constructing an appropriate routine will ensure that it best suits them. When explaining the routine to the person it is best to keep information clear and concise. Once a person has agreed to a routine, they can be encouraged to keep to it with prompting and reminding. This can be done verbally or by making a physical schedule for the person.
- If deviating from the routine, the person with Huntington's may be reluctant as they do not like change. Clarifying exactly what it is that they are reluctant about may help in reassuring them that trying something in a different way is okay.

“Mum loved to smoke, but we were concerned about her burning herself and spending money she didn't have. She would chain smoke if we didn't intervene. We took advice and created a routine for her. We told her that she could have a cigarette every hour and she actually got used to this better than we thought she would. We feel her smoking is much more manageable now, even if she does spend a lot of time watching the clock for her next cigarette.”

Spotting and managing common triggers

There are some common triggers which can cause a person with Huntington's to be irritable. It may become apparent that the person is irritable by the way they are behaving or by an increase in their movements.

Someone with Huntington's may become annoyed by things that many people would find irritating, it is just that they may have a lower tolerance than somebody without Huntington's.



Hunger

Hunger can lead to irritability and may also cause an increase in movements and fatigue. A person with Huntington's usually requires significantly more calories than an average adult, so encouraging them to eat often is important. A dietitian can help.



Pain

Pain can lead to irritability and an increase in movements. A person with Huntington's may struggle with communication and may not tell anyone if they are experiencing pain, so it can be helpful to directly ask the person if they are showing signs of distress. Huntington's may also cause someone to not feel pain in a traditional way and this can be dangerous, as someone could not be aware that they have hurt themselves. If issues are arising it may be necessary to monitor someone's ability to sense pain and to modify their environment as a result.



Tiredness

Huntington's disease can be hugely tiring. Poor sleep is quite common and can cause a drop in mood and overall well-being. Naps throughout the day may be necessary. If a day has been extra tiring, extra rest may be required.



Body temperature

People with Huntington's sometimes have difficulty regulating their body temperature and this can affect their mood, motivation and overall wellbeing. Asking somebody if they are a comfortable temperature can help, as well as looking out for signs that they may be too hot or cold. Ensuring that they are wearing appropriate clothing and have access to items like blankets or ice packs is essential.



Medication levels

Too much or too little medication can affect a person's mood. Any changes in medication should be monitored. Medication levels should be reviewed on a regular basis.



Depression or low mood

Feeling sad or depressed can lead to irritability or aggression. Talking to a specialist may be necessary.



Communication issues

If someone can't make themselves understood, this can lead to frustration and irritability. Someone with Huntington's will communicate most effectively when they are not hungry, tired, in pain, or too hot or cold, and when their moods are stable. A speech and language therapist can help with communication strategies as the disease progresses.



Other health conditions

If a person is experiencing additional health conditions this can be incredibly hard to deal with. An acute issue such as an infection can lead to sudden changes in mood and behaviour. The best thing to do in a situation like this is to seek help from a health professional.



Lack of stimulation

A person with Huntington's is still deserving of a well-rounded life, so it is important that they still have the opportunity for things like recreational activities, social events and exercise. Having an element of balance in their life can help them to feel as if they are not missing out. It would be frustrating if they had to face Huntington's with no life outside of the disease.

“When my son started becoming aggressive, I was quite scared, more for his little sister than me. We spoke to the neurologist and they suggested that we keep a behaviour diary, and that if there was an incident we note down what led to it, who he was with, how it was resolved and any other comments. Keeping a log proved incredibly helpful; we were able to identify topics and people that were most likely to trigger an incident. I used to get annoyed that he wanted to play on his Xbox when family were visiting, but realised that it helped him to focus on one thing when there were multiple people around. It has been hard, but by keeping the diary we are able to significantly reduce the incidents that occur.”

Anticipating and managing irritability: The 5 A's

The neurological changes in Huntington's can often lead to irritability, and the 5 A's focus on anticipating difficult behaviour and then either allowing it, accommodating it or making adaptations and arrangements to prevent and avoid it.

Anticipate

Anticipating the needs of the person with Huntington's can ensure that problems don't arise in the first place. An awareness of what can be irritating or upsetting to the person can mean that these things can be avoided.

Allow

In some cases, allowing a little inconvenience may be the best option. If someone with Huntington's is being insistent on ordering food that they don't like, allowing them to have a meal that they don't enjoy may have less of a negative impact than arguing with them about what they should order.

Accommodate

Sometimes, irritability can be avoided by allowing some of the disputed behaviour to continue, under compromised circumstances. For instance, allowing the person to watch what they choose on television for a set amount of time, but then letting another family member choose.

Adapt

Adapting a situation to make things easier or safer can be helpful. For example, if a person insists on smoking, acquiring a flame retardant vest for them would be an appropriate adaptation.

Arrange

Consistency and scheduling can make things easier, so arranging something way in advance can help cut down on stress.

*The 5 A's have been adapted from the book *Hurry up and Wait* by Jimmy Pollard*

The books 'The Selfish Pig's Guide To Caring: How to cope with the emotional and practical aspects of caring for someone' by Hugh Marriott and 'Hurry up and Wait' by Jimmy Pollard are very helpful in understanding why people with Huntington's can behave in certain ways and offering useful solutions. Our Carer's guide may also provide helpful information. They are available from our website:

 www.hda.org.uk

Problem solving

Listed below are some guidelines to consider when a problem occurs.

Step 1

Try to identify the problem. Can you see what it is? Is it measurable?
Can others see it?

Step 2

With the problem in mind, ask yourself the following:

- When did it happen?
- Where did it happen?
- Did anything happen before the problem occurred?
- Who was involved?
- What follows the behaviour?
- What emotion was expressed? Fear? Anger? Frustration?

Step 3

Review possible causes of behaviours including changes in the brain, environmental causes and other health related considerations. Evaluate any communication or triggers that might have caused the behaviour.

Step 4

Develop a list of possible responses to the behaviour and prioritise them e.g. try changing the environment or changing your own behaviour.

Step 5

Be flexible and ready to try different strategies. Allow yourself several attempts and time for trial and error.

Step 6

After a stressful event, reassure everyone involved that you care and are trying to understand how to make things better. Ask for help, advice, assistance and support.



Relationship changes

Relationship issues caused by Huntington's disease

Sexuality plays an important part in peoples' lives and many fear that a disease like Huntington's will alter this. Many couples, however, manage to maintain a good sexual relationship, although this may change as the disease progresses. Some couples do report a gradual decline in sexual relationships, perhaps as a result of the apathy which affects some people who have Huntington's. Some couples may find that they are simply too tired.

Some men with Huntington's may experience erectile dysfunction. Advice regarding this can be sought from a GP, as it may be due to an underlying medical condition or as a side effect of medication. Choreic (involuntary) movements or contractions may require a couple to experiment with new positions.

Some people may become hyper-sexual due to neurological changes. They may lose their inhibition and display inappropriate behaviour.

An individual with Huntington's may feel that they are less attractive and desirable to their partner or may feel guilty that they do not feel the same way about their partner as they did prior to the Huntington's.

If sexual demands are causing problems it is important to seek help, medication may be appropriate but this can be a very sensitive issue to discuss at a clinic appointment, especially if the person with Huntington's is unaware that there is an issue. A discrete conversation with the clinician in advance can prompt them to bring up the issue gently in a consultation.

Intimacy is about more than just sex. Touching and cuddling are just as important as they ever were.

Information and advice on sexual issues can be found here:

 www.enhancetheuk.org

“My wife and I reluctantly agreed to sleep in separate bedrooms as her choreic movements meant we could not sleep together. She joins me in bed once or twice a week for a cup of tea and a cuddle.”

Communication



Changes in communication

It is important to remember that Huntington's disease brings on more than just physical changes. Cognitive and behavioural changes can also have an impact on the ability that someone with Huntington's has to communicate.

As a person with Huntington's can't control the muscles used for speech as well as they could before, their speech may become slurred, or they may struggle with volume control, exacerbated by difficulties in coordinating breathing and speech. They may appear to be shouting angrily, when in fact they are having problems with controlling the volume of their speech.

Cognitive changes in the brain can mean that someone with Huntington's struggles to articulate what they are trying to say. They may find it hard to start a conversation. They may become focused on one topic and not be able to move on from it (this is particularly common if there is a change to the normal daily routine, e.g. if there is a clinic appointment and they are worried about getting there). They may also repeat certain words that seem important to them.

A person's communication skills can also suffer if they are apathetic, anxious, or depressed. They may not have the drive to organise their thoughts into words, or they may find it hard to be in a group of people, which may mean they avoid social situations, start to withdraw and feel socially isolated. This can create a cycle of decreasing communication.



Tips on how to help

- It is easier for a person with Huntington's to follow a conversation if it centres around one topic and is kept simple. The use of short sentences and visual cues such as showing the item you are offering can ensure that they're not overloaded with information.
- It is also important to be patient as it takes longer for somebody with Huntington's to process information and form a response. They should be given plenty of time. If they are taking some time to form an answer, repeating the question can interrupt the thought process, so it is best just to wait.
- Be calm, gentle, matter-of-fact and relaxed.
- Avoid distractions and try to focus conversation. For example, it may be difficult for the person to walk and talk or to hold a conversation when the TV is on.
- Use good eye contact and try to be at eye level. Keep the rate, pitch and volume of speech steady and low. Lower pitch and conversational tone are easier to hear.
- It can take a lot of effort for someone with Huntington's to speak, so it is important to listen carefully to what they are saying. Don't do two things at once, make listening a priority. Ask the person with Huntington's to repeat what they have said if it was unclear. Repeat this back if helpful to clarify what is being said.
- It may help to drop it and try again later. Sometimes a change of subject can help.
- People often answer 'no' to begin with as an initial response to having to deal with change, give them time and they may well agree.

- Someone's ability to communicate will vary depending on their level of fatigue, so prioritising communication at times of the day when they are most likely to have more energy can be effective.
- Limiting a person's choices can help them with decision making. Closed questions, that require a yes or no answer, are a lot easier to deal with than open questions. This may feel counterintuitive, as choice can be empowering, but for someone with Huntington's, making a choice can often feel difficult and stressful.
- Communication is hugely important, not only to fulfil needs, but also for social interaction. More opportunities for conversation can mean that the person feels more positive.
- If communication becomes difficult, try setting up a signalling system to allow the person with Huntington's to communicate non-verbally. Make flashcards of specific objects that they can hold up or point to.
- Create a message centre where routines, appointments and to do lists can be put in writing. Consider using a large calendar. Keep the information simple and easy to read.
- Respond to the emotional tone of the communication e.g. you may recognise the tone as angry or sad even if you can't make out the exact words.
- A speech and language therapist (SALT) can help with difficulties with communication, as well as eating, drinking or swallowing. They can also make recommendations about equipment that can help. This can include equipment, such as communication charts, books and apps. Some of the more technical communication aids may not be suitable for people who are having problems with manual dexterity or who may have issues learning how to use these aids. A communication aid is most effective when used regularly. A referral to a SALT can be made via a GP or a specialist Huntington's clinic.

“My wife relies increasingly on me to help with her communication. I try to give friends and family tips on how to engage her. Asking how her football team are doing is always a good conversation starter. Although she cannot speak much anymore, she knows exactly what is going on and wants to be included in conversation. I’ve also become more aware of her visual cues. She has a way of raising her right eyebrow when someone is annoying her!”



Support from the Huntington's Disease Association

Specialist Huntington's Disease Advisers (SHDAs)

Our Specialist Huntington's Disease Advisers have a background in health or social care and are knowledgeable about Huntington's disease. They operate throughout England and Wales and support the person with Huntington's, their carers and any professionals involved in their care. To get in touch with your local Huntington's Disease Adviser, contact us at:

- 📞 0151 331 5444
- ✉ info@hda.org.uk

Website

Our website offers practical advice and sources of help and support, including downloadable information guides. It also holds information about events and activities that you can attend and details of local branches and support groups. Additionally, the website hosts an online message board for people to access peer support, information and ideas.

- 🖱 www.hda.org.uk
- 🖱 hdmesssageboard.com

Membership



Huntington's Disease Association membership is free for people with Huntington's and their families and it is easy to join. If you become a member you'll receive a bi-annual newsletter with up-to-date information on events and research. To find out more about becoming a member, please contact us or take a look at our website.

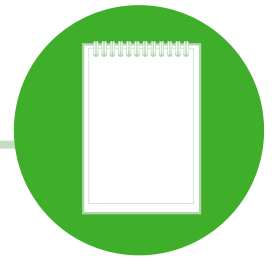


Resource library

The following charities, organisations, publications and websites may be able to provide further information and guidance on the topics covered in this guide:

Organisation	Contact details	Support
Huntington's Disease Association	0151 331 5444 info@hda.org.uk www.hda.org.uk	Advice Support resources Online forum
Carers UK	0808 808 7777 info@carersuk.org www.carersuk.org	Advice Support resources Online forum
Carers Trust	Local telephone list info@carers.org www.carers.org	Advice Support resources Online forum
Enhance the UK	www.enhancetheuk.org	Advice Support resources
A selfish pig's guide to caring	Book available at: www.hda.org.uk	Advice Personal perspective
Hurry up and wait	Book available at: www.hda.org.uk	Advice Information

NHS UK	Local telephone list www.nhs.uk	<ul style="list-style-type: none">  Advice  Medical services  Referrals
GOV UK	Local telephone list www.gov.uk	<ul style="list-style-type: none">  Advice  Local services  Financial support
Emergency services	999	<ul style="list-style-type: none">  Medical  Crime  Fire
NHS 111	111	<ul style="list-style-type: none">  Non emergency medical advice
National Domestic Violence line	0808 200 0247	<ul style="list-style-type: none">  Advice  Support  Local services



Notes

Get in touch

For advice and support
or to speak to a
Specialist Huntington's
Disease Adviser

email **info@hda.org.uk**

phone **0151 331 5444**

www.hda.org.uk

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We'll be there