Living in a family with HD

HDYO has more information about HD available for young people, parents and professionals on our site:
www.hdyo.org

The people most affected by Huntington’s disease are those that have the condition (obviously). What is not quite as obvious is how the disease impacts hugely on those around the person with Huntington’s disease. This section focuses on some of the issues which young people may experience when living or growing up in a family with Huntington’s disease. It doesn’t cover issues regarding Being At Risk (which can seem quite similar).

First finding out about Huntington’s disease

Huntington’s disease comes into people’s lives at many different ages. Some people may find out about Huntington’s disease at a very early age, while others may be coming to terms with the emergence of Huntington’s disease in their family later in life (perhaps as a young adult). No matter what age this illness comes into your life, it can be difficult because when someone you love has Huntington’s disease there tends to be lots of changes to cope with in your family.

Early stages and sudden changes

Many young people find out about Huntington’s disease when a family member is diagnosed with the condition, usually when that person is in the early stages of the disease. This tends to bring with it various symptoms, some of which are more obvious than others. For instance, you might notice your family member dropping things more often, tripping up and generally being clumsy. These are as a result of the involuntary movements (the chorea) caused by Huntington’s disease and it may mean your family member’s balance could begin to become an issue.

There may be sudden behavioural changes with the person who has the disease, with people being affected by things such as depression, tiredness or temperamental outbursts. For a young person in the family, these sudden changes in their family member can be incredibly confusing. Sometimes it is hard to understand or remember that it is the disease affecting that person, and not the person themselves.

‘My dad used to lock himself away in his room and ignore me. It was crazy and I had no idea why he was suddenly behaving this way, he never used to do that. At the time I was so confused, but now I look back and understand that it was the disease causing my dad to behave that way and it makes more sense now.’ Diane

The person with Huntington’s disease may also stop working or driving, and may struggle to look after themselves. The effect of that person suddenly not working or driving can have a huge impact on the rest of the family. Financially and socially it begins to restrict the family and make things difficult. You may find that you are unable to do the things you used to do with your affected family member and that the dynamics of the family begin to change.

‘When my dad got diagnosed it made things difficult because there are four kids in the family and we all had our own activities at the weekends and stuff. But now that my dad wasn’t working and unable to drive, my mom had to do everything for us and it was impossible for her. In the end we had to give up some of our activities among other things, which was sad but we understood that it was necessary.’ Kirsten

Feeling embarrassed

Having an illness in the family can, at times, make you feel embarrassed or ashamed. With Huntington’s disease in particular, the involuntary movements caused by the disease tend to be very noticeable. People with Huntington’s disease can become very clumsy and this has a way of drawing attention from the general public, as they don’t understand why that person is acting the way they are.

As a young person, you may find yourself in a situation where you feel embarrassed or even ashamed to be seen out with your family member in public. This can make you feel very upset (sometimes with yourself because you feel you shouldn’t be embarrassed), but feeling this way is very common - many young people
experience the same emotions:

“When I was a young teenager my father was at a stage where he was still able to walk, but his movements were all over the place because of his symptoms. He used to generate plenty of attention, everybody used to look at us when we went out - it made me feel so embarrassed.’ Paul

People staring

One of the main reasons people get embarrassed when out in public with someone with Huntington’s disease is because people tend stare at them. Having people staring is not uncommon either, almost everybody who has lived with a family member who has Huntington’s disease will know what it feels like when members of the public stare.

‘Sometimes when we used to go out with Mum I would catch someone staring, laughing or pointing. I used to get very angry and want to cause them some physical pain. I was never brave or stupid enough to do this. So I developed something I named The Look of Doom. Whenever I noticed someone staring, I would shoot a look in their direction, staring back at them in such a manic way that they would immediately know it was not OK to continue what they were doing.’ Ben

People staring can cause a lot of anger, but it’s important not to let that anger get the better of you. This can often be more difficult than it sounds. One option to consider is bringing more people - family or friends - along with you when you go out in public with the person who has Huntington’s disease. They may be able to help you feel more relaxed and comfortable, and able to handle any issues that arise. If all else fails then using ‘The Look of Doom’ tactic is a useful way to let people know when they are being a little rude. Also, if you feel the person with Huntington’s disease is getting upset because of people staring, you may decide that talking to the people who are staring and explaining the condition to them might help. However, if you don’t feel talking to them would help then simply ignore them. Many people with Huntington’s disease seem to develop this wonderful attitude of not caring who is staring at them, so they don’t notice anything (it is usually the people accompanying them that notice and take offense).

Being misunderstood

The involuntary movements people with Huntington’s disease have not only draw people’s attention, but make them wonder what is wrong. Unfortunately, because the awareness of Huntington’s disease isn’t great, one of the first thoughts that these involuntary movements provoke is that the person may be drunk.

‘I can remember one time I was taking my mom to the toilet at a restaurant where my brothers were playing in their band...I held my mom as she stumbled her way through the crowd to get to the toilets. After juggling the toilet trip I was washing my mom’s hands and a young women said to me “give her a drink of water, she will sober up just fine” I felt really humiliated and angry…and completely misunderstood. I remember thinking “If only it was that easy” ’ Susan

This is a case of people assuming incorrectly, and let’s be fair - how are they meant to know that the person has Huntington’s disease? But that is not to say that when people make these comments to a young person, about their family member, that the young person is not hurt by those words - they are emotionally upsetting. Again, just like the staring issue, explaining the condition to people may help and don’t lose your calm in these situations. Experiences like the ones above are why raising awareness of the disease is very important, so that people will understand the condition better.
Stressful household

Having Huntington’s disease in the family (as you have seen) can cause great amounts of stress, and many young people speak of their homes turning into a very stressful environment. This usually is as a result of symptoms getting worse for the person in the family with Huntington’s disease and the demands on the rest of the family becoming greater.

When the home becomes a place that stresses you out, then life can become difficult. You can feel like you have nowhere to turn to, nowhere to relax and get away from things. It can feel like the disease is constantly in your face and on your mind. As a result you may feel like wanting to get away from it all. You should not feel guilty about “wanting space” during this time. When there is so much stress in your life you naturally need an outlet to get your emotions out and relax. It is important that you seek support, and you should contact either us (HDYO) or your national Huntington’s disease organisation and ask what support is available to you (some organisations may have youth camps, conferences or events for young people that you could attend). It is also important that you look after yourself in these situations, and no matter what age you are, take steps to get rid of the stress in your life. Whether that means as a teenager you spend more time with friends or getting involved in after school or evening activities. If you are a young adult, you may want to take a holiday or go travelling - there are options if you feel you need a break.

Arguments

If you’ve read our ‘What is Huntington’s disease?’ section then you might have seen that behavioural symptoms can cause people with Huntington’s disease to do or say things that they don’t mean to. The person with Huntington’s disease may get angry and lose their temper over things that seem unimportant to those that don’t have the condition. This can cause lots of arguments in the family home which doesn’t lead to a nice atmosphere for anyone. It also doesn’t help that often people with Huntington’s disease will not recognise a problem and refuse to discuss the issue. The best thing to do in these situations is not to argue back and perhaps go for a walk while everybody calms down. And keep reminding yourself that it is the Huntington’s disease causing the person to act this way, and not the person themselves. However, if something is causing you a lot of frustration then talking can help, either with family, friends, or your local HDA or HDYO. Getting your frustration out and discussing things can be such a great relief mechanism - don’t be afraid to bring up your concerns, there are plenty of people willing to listen and offer support.

Abuse

In some cases, people with the Huntington’s disease can become abusive to family members, either emotionally or physically. This is as a result of people with Huntington’s disease experiencing the behavioural symptoms of the condition. In these situations you should always seek support from your national Huntington’s disease organisation or the local authorities. It is always important to remember that it is Huntington’s disease causing the person to act this way, and not the person themselves. But this in no way means that you should put up with abuse, whether the person has Huntington’s disease or not it doesn’t matter. Seek support; HDYO can put you in contact with those that can help.

Educational/career impact
The impact of the disease is not only felt in the home environment. Many young people, as a result of being in a family with Huntington’s disease, find it harder at school. Their results might fall, or they may start acting out in class and getting into trouble. Sometimes young people leave school altogether as they just can’t cope with all the stress and changes in their lives. If you feel your education is being affected by Huntington’s disease being in your family it is important you speak to your family and the school about this issue. Also, HDYO is here to help you so please contact us if you want to talk about this issue.

For young adults, careers can also be affected. A job and the increasing demands on you at home can become too much to handle at once. Having to perform caring tasks for your family member can end up becoming tiring work on top of your full-time job - one that can cause great stress too. It is important that you don’t try to do too much and overload yourself. You can’t help anyone if you don’t take care of yourself first. Look after yourself and seek support when you need it. Your national Huntington’s disease organisation should be able to offer you advice and support. Again, HDYO is here to help you so please contact us if you want to.

Having Huntington’s disease in the family can also influence the decisions, especially young people make in their lives. Some young people may be caught in two minds: whether to go to or continue at university, for example, or take a new job in a different area. They have a family member at home with Huntington’s disease and they feel torn between living their own life and looking after their family member. Having to make such decisions can be extremely difficult:

‘I was working full-time and my mum was looking after my dad who was in the late stages of Huntington’s disease. But as time went on my mum struggled to cope on her own and I knew I had to either stop working and become a carer or we’d have to let my dad go into a care home. I felt like those were my two choices and it was so emotionally difficult to make a decision like that at the age of 18.’ Marcus

Looking after a person with Huntington’s disease

Many young people help care for their family member in some manner at some stage in their lives. Some may provide care for their family member without even realising it:

‘My mum was my dad’s carer, but I used to help out with things around the house and if my mum wanted to go out I would look after dad by myself - I was only about 14 at the time. I didn’t see it
as caring; I just saw it as staying at home with my dad.’ Tony

Other young people take on the responsibility of the caring role on a more permanent basis and provide regular care for their family member - doing all the duties that (perhaps) the family member used to do and making sure that they are looked after. This may also include looking after other family members, such as brothers or sisters and making sure they are cared for.

Trying to care for or help someone with Huntington’s disease can sometimes be hard, because people with the condition may not want or see a need for support - this may be due to denial that they even have Huntington’s disease or simply because they are proud and do not want to be looked after. For more on being a carer visit our young carers section.

Eventually though, everyone with Huntington’s disease gets to a stage where they need to be looked after. This can mean family members having to leave jobs to become full-time carers. The family home may need to be adapted to suit the needs of the person with the condition. Eventually, people with Huntington’s disease may need to be moved into a care home for specialist care support.

Care homes

Not all persons with Huntington’s disease go into a care home. Some people remain in the family home for the duration of the illness. It depends on each family’s situation. But if your family member does go into a care home then this, again, can be an emotionally difficult time for everybody involved. Visit the care home section for more on how care homes work and the impact on a young person’s life.

Keep communicating

Some may find that the person with Huntington’s disease gets to a stage where they find it either very difficult to communicate or can’t communicate at all. This can make it very hard to interact with the person who has the condition and young people may find it difficult.

It is important to remember that, just because the person with Huntington’s disease can’t talk, it does not mean they can’t hear you. If you speak to the person with the condition they will and do understand what you are saying to them. So keep on talking to your family member who has the disease and tell them all the latest stories from your life, so they can share in what you have been up to. Having a conversation where
you are the only one talking can feel very odd, knowing what to say can be difficult. Try talking about things that you both share an interest in, or news that you think they would want to hear about. There are many things you could talk about, sometimes thinking beforehand about what you could talk about can help you plan ahead, so that you don’t end up unable to think of anything to discuss.

Memories

It can be very difficult to watch a loved one gradually deteriorate with Huntington’s disease. The gradual decline can be so slow and happen over so many years that you may feel like you’ve forgotten how your loved one was before they had Huntington’s disease. You may have forgotten how family life was before Huntington’s disease affected it. Having pictures and videos can help you remember those fond memories from years gone by and it is good for you to reminisce. However, some people are so young when Huntington’s disease affects their family that they may not have many memories of life before Huntington’s disease:

‘My father got Huntington’s disease when I was just a young boy, I was too young to take much in back then and I genuinely struggle now (aged 20) to remember my father before he had Huntington’s disease. It is quite upsetting actually when I think about it.’ Joe

As Joe states, it can be upsetting not being able to remember your family member before they were affected by Huntington’s disease, but that doesn’t mean there aren’t good times and good memories to treasure. You may not have many pictures or videos of your family member before Huntington’s disease, but other family members may have lots of pictures, videos and good memories to share with you if you asked them.

Enjoying life

You can still have good memories of family members, even if they have Huntington’s disease. You may have lots of funny moments that you have witnessed or been a part of over the years that have had you smiling and laughing with your family member:

‘Mum has a tendency to unexpectedly jerk forwards or backwards and head-but innocent bystanders, not on purpose, but due to Huntington’s disease. So (one night) I was unexpectedly head-butto. As a reflex, my head shot back into my brother’s head. His head then flew back and hit the light switch. The lights went out. We stood in the darkness shocked at what had happened... Mum was first to break the silence. “Why did you turn the lights out, I was talking to you?” she said, mystified!’ Tom

Laughing at stories like the one above, and your own stories of living in a family with Huntington’s disease, is so important. They say laughter is a great medicine and taking the time to laugh can be a great way to relieve some of your worries and anxieties.

Support

Young people living in a family with Huntington’s disease have to go through a lot of changes in their family, at a time when they may be growing up themselves and having a lot of changes in their own lives. Support and understanding from family and friends is important at this stage, however, if you don’t feel like you can talk with your family or friends about a particular issue then HDYO is always here to discuss things with you, so please contact us if you wish. HDYO is run by young people who have experienced living in a family with Huntington’s disease; we know all too well how difficult it can be at times. You may also wish to contact your national Huntington’s disease organisation as they might be able to offer you support in your area or on a national level.

You might also wish to talk to other young people living in families affected by Huntington’s disease. If so, then you may find them on the Facebook Group, feel free to stop in and say hello.

Living positively
Living in a family with Huntington's disease provides a lot of difficulties and challenges. But it is not all bad and even in the midst of Huntington’s disease you can enjoy life and find things to laugh about. It is important for both young people and the family to learn about Huntington’s disease, so that everyone is aware of the condition. Knowing about the disease and how it affects families may help young people cope when these changes start to impact on their own lives.

Being positive and proactive is also very beneficial for young people and the whole family. Fundraising and generating awareness are two great ways of getting your family and friends involved in something positive with regards to Huntington’s disease. It is amazing how much of a positive impact both can have on not only family life but the support you receive from others. You don’t have to go as far as the Viau family have (in the video), but it highlights how big an impact being positive can have on a family, but more specifically the young people.

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