HUNTINGTON'S DISEASE YOUTH ORGANIZATION

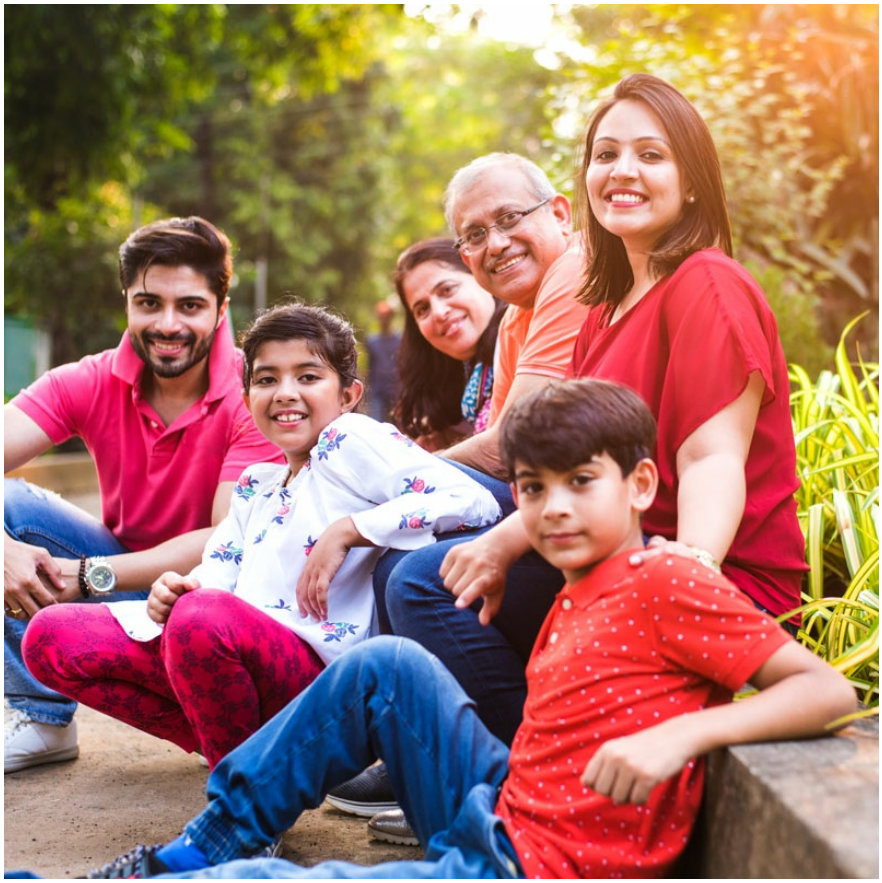
Living in a Family with HD

November 24, 2021

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

www.hdyo.org

Updated in 2025 by Education and Research Committees



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

People can learn about HD at any life stage. . Some people find out about HD at a very early age, whereas others don't learn about HD until later in life (perhaps as a young adult). At any life stage, HD can bring a lot of changes to your family which can be difficult to manage.

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

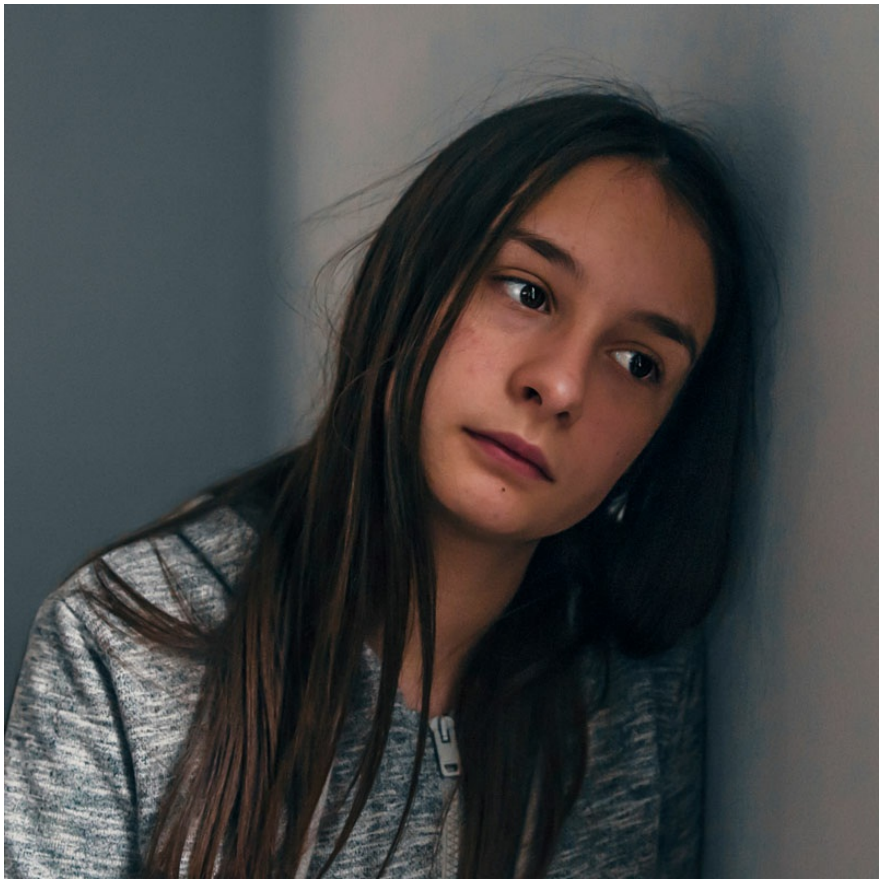
member can be incredibly confusing. Sometimes it is hard to understand or remember that it is the disease affecting that person, and not the person themselves.

> **'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 and misunderstood



When someone in your family is sick, you might feel like nobody understands what you're going through. With HD, the involuntary movements that come with the disease can be very noticeable, and it might look like the person is clumsy or drunk. This can make people stare or ask questions, which can be hard for everyone to handle.

> **'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

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 HD is because people tend to 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

Although many people with HD are not bothered by people staring, the people accompanying them may take offense. Although people staring can cause a lot of anger there are strategies to help you cope with strong emotions. For example, bring family or friends with you when out in public with the person who has HD. Family and friends may help you feel more relaxed and comfortable, and help you handle any issues that arise. If you feel the person with HD is getting upset because of people staring, you may decide to explain the condition to people who are looking.

Stressful household

Having HD in the family may cause your home life to become more stressful, as the demands on the family increase and symptoms in the person with HD progress.

When the home becomes a stressful place, life can become difficult. You may feel like you have nowhere to relax or get away. When there is so much stress in your life you naturally need an outlet to get your emotions out and relax. You should not feel guilty about "wanting space" during this time. It is important to take steps to protect your mental health.

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 HD can become abusive to family members, either emotionally or physically. In these situations you should always seek support from your national Huntington's disease organisation or the local authorities. It is important to remember that it is HD causing the person to act this way, and not the person themselves. However, this does not mean that you should tolerate abuse, whether the person has HD or not.

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 HD gets to a stage where they need full time care, and this may lead other family members to consider leaving jobs to become full-time carers. No one has to become a caregiver, and family members are not the only people who can provide the care. As an alternative, people can choose to move their loved one into a residential facility. Their loved ones may even ask for this, as they don't want family caring from them. However, this may not be an option depending on the country or culture you're from. In these cases, it is important to reach out to friends and family for support and help with care.

In some countries, in-home, medical caregivers may be available and the family home can be adapted to suit the needs of the person with the condition, as symptoms and caring need progress. However, even in these cases, the family member with HD may eventually need to be moved into a care home, for care support from specialists.

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.

Enjoying life

Living in a family with HD provides a lot of difficulties and challenges. However, it is not all bad and even in the midst of HD, you can enjoy life. It is important for both young people and the family to learn about HD, 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 their lives.

You can still make good memories with family members, even if they have HD. 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-butt innocent bystanders, not on purpose, but due to Huntington's disease. So (one night) I was unexpectedly head-butted. 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.

Living positively

Being positive and proactive is also very beneficial for young people and the whole family. Getting involved with the HD community, such as fundraising and generating awareness, is a great way to get your family and friends involved in something positive with regards to HD. It is amazing how much of a positive impact both can have, not only on 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.

Contact us

Living in a family impacted by HD can be challenging but you are not alone. We encourage you to reach out to HDYO anytime or take a look at our Ambassadors scheme.

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.
