HUNTINGTON'S DISEASE YOUTH ORGANIZATION

Living in a Family with JHD

November 24, 2021

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

www.hdyo.org

This section is specifically for young people living in a family with Juvenile Huntington's Disease (JHD), who **don't** have JHD themselves. As we take a look at some of the concerns young people growing up around JHD may have.

An early introduction to Huntington's...

Often, in a family with JHD, the introduction to the disease for young people happens at a very young age. Children essentially 'grow up' with the disease as a part of their life. Usually young people have to watch their sibling(s) progress with JHD, which can be very difficult to cope with. However, as a result of having the condition in their life from a very young age, young people sometimes develop a good level of acceptance and understanding for the disease - which can really help young people cope in the long run, and be a good trait to have generally in life.

Understanding

To young people in a family with JHD, the disease may be seen as normal - a part of everyday life. But within the general public there tends to be very little understanding of what JHD or even Huntington's disease is. This can lead to misunderstandings sometimes.

> **'My daughter and I were shopping one evening when, by accident, my daughter lost her balance and bumped into an elderly couple. They were shocked and began to lecture me on how to keep a better eye on my daughter. I had to explain to them that my daughter couldn't help it and she has JHD.'** Sarah

These misunderstandings can be stressful encounters for families. But we must try to remember that people don't realise the young person has Juvenile Huntington's disease and that these misunderstandings do happen. However, that is not to say that these situations are not still emotionally upsetting for young people.

Feeling embarrassed

As a young person, you may find yourself in a situation where you feel embarrassed or even ashamed to be seen with your family member who has JHD 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 actually very common - many young people experience the same emotions:

> **'My brother would always misbehave when out in public, he was embarrassing at times but I got used to it after time. He would poke strangers or pull funny faces. Sometimes people would pull funny faces back but that just made him do it even more!'** Halle

Although it can be difficult to do so, it is important to try and remember that it is not the fault of the young person with JHD. It is the disease that can cause such situations to arise and leave you feeling embarrassed. Plus, just as it is not the young person's fault they have JHD, it is not your fault that you may feel embarrassed at times. It is a perfectly natural feeling to have and many young people in similar situations feel the same way. You may find HDYO's Feeling embarrassed is normal section useful. You will also find some good information about how to overcome embarrassment in that section too.

Stressful household

Having Huntington's disease in the family 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.

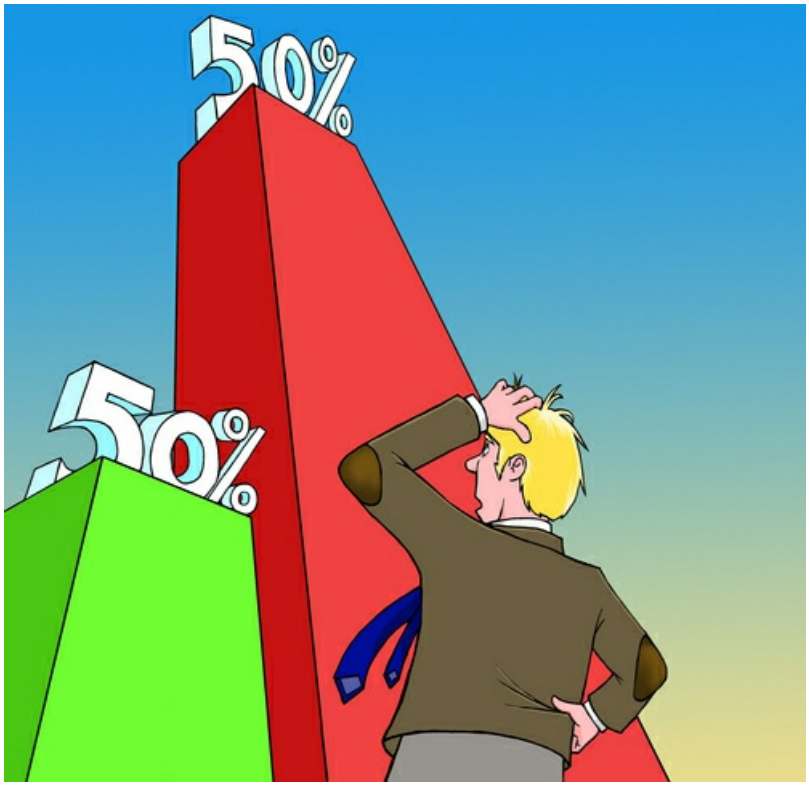
When the home becomes a place that stresses you out, then life can become difficult. You can feel like you have nowhere to turn to, nowhere to relax and get away from things. It can feel like the disease is constantly in your face and on your mind. As a result you may feel like wanting to get away from 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).

Education

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.

> **'My sisters had JHD and my dad has HD. It has been really tough growing up watching them suffer with this. I have suffered at school because of it, I don't go anymore. I find it too much.'** Daniel

Being at risk



Perhaps one of the biggest concerns for young people is the risk of inheriting the condition. This is a concern for all young people, whether they are surrounded by Huntington's disease or JHD. For more about being at risk and some really good explanations about how people are at risk, visit the being at risk section on HDYO.

Getting time with your parent(s)

When your sibling(s) have JHD they can understandably need a lot of care and attention to make sure their needs are met. This may result in young people feeling that they are not getting as much attention as others in the family. But, it can be very difficult for your parent(s) to provide everyone all the attention they want/need, especially when there is an ill child in the family.

> **'I try to give as much time and attention to all my children, but Julie's needs take over at times and I have to attend to them. It is so challenging trying to juggle everything at once, especially with my husband having Huntington's disease too. I am doing this effectively as a single parent.'** Michelle

It is not that parents don't want to give all their children attention, it is just that sometimes it can be almost impossible to do so - parents need support too. But talking with your parent(s) is a good way to let them know you need some time spent on you too. However, most importantly, try to be understanding of the situation.

Being a young carer

Many young people may find themselves helping to care for their sibling(s) with JHD. Sometimes young people in families with Huntington's disease become carers 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

If you feel you are a young carer, then be sure to read the being a young carer section on HDYO for more information and support.

Making time for yourself

Caring for a loved one can impact heavily on a young person's social life too. Often young carers find themselves not being able to go out with friends much (if at all), as they are required at home to look after their family member.

Try not to deny yourself opportunities to have a break and spend some time away from your family member. It is important that you don't try and do too much and overload yourself. You can't help anybody if you are not in a fit state to do so - look after yourself and seek support if you need it. Time away is not always an option for everybody, for example, you may be the only caregiver available to look after the family member. But if possible make sure that when you feel like things are becoming too much, that you listen to your feelings and have some time to yourself to relax.

It might be useful to organise a regular time slot for yourself where you can relax. Perhaps you could ask a relative or friend to look after your family member for a night every week/month, or maybe you alternate care shifts with a sibling etc. There may be the option of having a paid carer come in for a few hours a day/week to give you some time off to relax and enjoy yourself. Time away can be very beneficial to both yourself and your family to have that time.

Spending time together

Just as having time apart is important, so is spending good quality time together as a family. Having fun together can be such a great way to cope with JHD, and you get to create some nice memories of time together while you are at it.

> **'I like to go see my brother and spend time with him. We play games and watch DVDs together, we always end up in fits of laughter!'** Gabby

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-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.

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.

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. Some provide youth camps, JHD weekends or a youth worker to talk to.

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.

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.
