HUNTINGTON'S DISEASE YOUTH ORGANIZATION

Conversation Starters

November 22, 2021

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

www.hdyo.org

Talking about HD with Young People

Talking with children about Huntington's disease (HD) can be difficult. What do you say? Where to start? How to approach the topic? How much information to provide? There are plenty of questions to think about before you go ahead and discuss this information with children. Other sections on this website provide great advice on talking with children. However, this section focuses on some examples of conversation starters with children of different ages, as well as some questions children may ask in response to this discussion about HD. You may find some of these examples helpful in planning out your own approach to talking with the children about HD. Take note, these are just examples, it is important you find your own words that you are comfortable with when talking with the children. But hopefully they will spark some ideas for you.

Young Children (preschool age) Conversation Starters

Young children tend to have a shorter attention span, so it may help to keep explanations of HD short and simple.

- "I want to talk to you about something important. The doctor told me that Grandma is ill. She has Huntington's disease. It is a condition that makes it harder for her muscles and brain to do their work. The doctor is doing his best to help her and we can do our best to help her too."
- "Do you remember last night, when Dad took a long time eating dinner? That happened because of an illness called Huntington's disease. It is a kind of muscle problem. I will need you to be patient when Dad is taking a long time to do things like he was with his dinner last night, ok?"
- "I am sorry that Mom got so mad the other day. We found out she has an illness called Huntington's and sometimes it can make her grumpy. She was not mad at you. She gets mad about Huntington's."
- "Sometimes I bump into things when I don't want to. That happens because I have

Huntington's disease. I just found out why I am having these problems with my balance. I want you to know what's happening, and the reason for my problems."

- "The doctor has told me that someday I will develop an illness called Huntington's disease. I wanted to tell you about it now, before I get poorly, so that I can help you better understand the changes that are going to happen to me."

Older Children (preteens) Conversation Starters

Children of this age are usually capable of understand the basics of a genetic condition and have access to far more information online than previous generations had. You may be able to give your child more detail about what HD is. It is best coming from the parents/guardians.

- "I want to talk with you about something important. I found out that Granddad is ill. He has Huntington's disease. It's not something you can catch, like a cold. It is a genetic condition that he was born with. Huntington's affects his muscles and brain. I wanted to tell you because you are a smart child who notices things."
- "Because of this condition, some things are going to be harder for her. You may notice that she is walking differently and her balance is off. She may seem grouchy for no reason you can see. Have you noticed anything like that?"
- "I think you've noticed that I can't keep up at work like I want to. I have a condition called Huntington's and this means I won't be able to do the work I've been doing. This will mean that I will be staying at home now. Your Mom and I are working on how we can adapt to these changes."
- "Now that Dad is ill, he can't do as many things around the house. I am going to need you to help me sometimes. Is that alright?"
- "I know some of this is hard to understand. What do you think about what I just said? If there is anything you want to know about HD I will try my best to find the information for you. Let's talk some more when you are ready."

Teen Conversation Starters

Teenagers are able to take in a lot more information and generally have an

understanding of what a genetic condition is, depending on where you are in the world. Teens may want to know plenty about the condition and the hereditary nature of it (if appropriate).

- “I want to talk with you about something important. I found out that your Mom has Huntington’s disease. She was born with the gene that causes it and this is now beginning to make her ill. It has affected her muscles and brain. Because of this condition, she may have a hard time doing certain things. She may forget to do things she promised to do. Her hands may shake sometimes. She may become very angry and you won’t know why. Have you noticed any of these things?”
- “I have some news to share with you. We found out what is going on with your Dad. He has Huntington’s disease. It is a genetic disorder he was born with that is now beginning to make him ill. I think this may explain a lot of what has been happening recently. I have some information here that explains the disease better than I can. I would like to go over it with you. Can we do that?”
- “I went to the medical hospital and they confirmed what we had suspected. I have a condition called Huntington’s disease. It is probably what Granddad had, but we didn’t know that when he died. I am learning about this condition and I have some information that the clinic gave me. I’d like to go over it with you.”

Encouraging children to share their thoughts and feelings

It is important that any discussion about HD is a two-way conversation. Therefore asking the child or children questions which encourage feedback is useful to learn what the child is thinking about or whether they have any questions about what you have just told them. You could ask:

- “What are you thinking about right now? It is okay to be scared, angry, or anything else. I feel sad and a little scared myself. We can get through this if we can just keep talking to each other.”
- “I am sure you have questions. Is there anything you want to ask me right now? If I don’t know the answer we can try and find someone who does.”
- “I know this is a lot to take in. Do you want to think about this for now and we’ll talk again another day? You can ask me questions anytime you want. I am always here to listen to you and help you through this time.”

Answers for questions children may ask regarding HD

With the discussion about HD children may be keen to ask questions, often asking many at once. It can sometimes be difficult to respond to these questions straight away if you are trying to be careful about how much information you give. At HDYO, we would encourage you to be honest with your answers and decide for yourself how much information the child or children can cope with. Here are some examples.

Q. Is Mom/Dad going to die from HD?

A. People with HD can live for many years, even decades. We don’t know for sure when any of us will die. Instead we focus on making the years we have count and creating some good times together.

Q. How did Mom/Dad get HD? Why did this happen to our family?

A. When Mom/Dad was born, she inherited the expanded gene that causes HD from her parent.

Q. What did I do to make Dad behave this way?

A. The behaviour is caused by HD – it makes people do things they don’t mean to do sometimes - it was not your fault. Your Dad loves you and HD does not change that.

Q. Am I going to get HD?

A. Every child of a person with HD has a 50/50 chance of inheriting HD. But it is usually a condition which affects people later in life and researchers are making great progress with treatments at the moment.

Q. Are my brothers/sisters/cousins going to get HD too?

A. Anyone who has a parent with HD has the same 50/50 chance of inheriting HD from that parent. It is like tossing a coin for each person. Each time the coin is tossed there is a 50% chance it will be either heads or tails. The coin does not remember what it landed on the previous time for the previous family member. Each toss of the coin is individual in this sense.

Q. How do you know if you have HD or not?

A. Some people start experiencing symptoms and go to a doctor to check on what they could be. Other times people take a genetic test to find out if they will get HD in the future. But you have to be 18 to take that test and most people don't because it is a very big decision to make which takes a lot of thought.

Q. What kind of a life am I going to have if I have HD?

You can live a very normal life and achieve the goals you want to achieve. The risk of HD should not stop you from going after your dreams in life and enjoying the journey along the way.

Q. Why isn't there a cure?

A. It is a very difficult challenge to find treatments to cure conditions like HD. Researchers are working incredibly hard to try and make that happen, but it takes time. There has been a lot of progress in research for HD and some exciting possible treatments are being worked on right now. There is hope that more treatments will be available in the future, that will help people with HD live a better life. But right now, that

is just realistic hope, not certainty.

Q. How am I supposed to handle this?

A. Know that you are not alone, we are here to support you, and there are plenty of young people going through similar situations. HDYO.org is a good place to start when looking for information and support.

Q. What will happen when Mom gets sicker?

As time goes on, there are going to be changes and decisions to be made. We will always keep you involved and up-to-date in those, so we can plan for the future together as a family.

Q. Why didn't you get the test before you had me?

A. The option to test was not available when I was younger.

A. We didn't know there was HD in the family.

A. We wanted to have children and enjoy life, no matter what.

If you, as a parent or guardian, have any additional conversation starters or questions and answers, you can send them in to HDYO on the Ask a question page.
