HUNTINGTON'S DISEASE YOUTH ORGANIZATION

Talking About JHD with Children and Young People

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

www.hdyo.org

Talking to a child about a medical condition, especially a genetic one is difficult. It is even more difficult when that condition affects them. This section will explore ways to talk to children about Juvenile HD (JHD). It will include the challenges they might face, how to talk about JHD, and, how to explain what is happening to them or their sibling.

Things to think about when talking about JHD with your children

We at HDYO encourage families to talk openly about HD from a young age. We know research shows talking openly to children of all ages helps them to cope better. We suggest a gradual education about HD and to add more information as they get older or when the child asks more questions about HD. With JHD there are extra concerns making it more difficult to know how to discuss it. We still believe it is beneficial to explain JHD to some extent to your child(ren). There are however some really important factors to think about when you do talk to children about JHD. The first factor to take into consideration is how old the child is. Another factor is to think about whether the child has the ability to understand what you would like to tell them about the condition.

Age and Ability to Understand

Similar to talking to children about HD, age should impact the level of explanation you give to a child about JHD. A young child would only need a short and simple explanation of JHD. A teen or young adult might be able to understand more detailed information about JHD. The major difference between talking to children about HD and JHD is that for a child with JHD, they might already have symptoms impacting their ability to understand all the information you discuss with them. In terms of their cognitive ability (ability to understand, concentrate, and remember), the affected child might be regressing (“going backwards” with their ability-think of a child who had no problems doing puzzles and now can’t figure out how a puzzle works). Children with JHD might show problems with their cognitive ability and often need information at a younger level.

These children will require simple explanations and need to be assured that they will be taken care of. Other children might not yet be showing too many symptoms and might be able to understand more detailed information. Either way it is important to make sure the child knows they have support and will be involved in their own care.

Should I tell my child about JHD?

Talking to children about HD and especially JHD is a personal choice. As children and young adults who have grown up in a home affected by HD, we at HDYO feel that that being open and honest is the best way to deal with the situation. As a family member we understand the first instinct is to protect children from news that might upset them. We also know however that HD and JHD don't just go away. A child will recognize when something is different even if you or they don't talk about it. Having a reason for why things are different provides answers to questions children may have. In addition, families who are open about HD and JHD don't need to worry if extended family members or other discuss HD around them. The topic becomes "matter of fact" and not something that is hidden away. Trust can be built up in families where HD and JHD is discussed and children feel empowered to know they are part of the discussion. It becomes something that children don't learn to fear, but rather to deal with.

We recommend starting off slowly to determine the child's level of understanding. The child might ask questions or the child might be content with just a small amount of information. Talking about JHD should be an ongoing conversation rather than a one-time event. It is important to come back to the discussion from time to time. Always stress to the child that they can ask you (or another knowledgeable adult in the family) questions about JHD anytime they would like to. Talking to children about HD and JHD is not an easy topic as we've highlighted already. But know that kids are strong and it is really surprising how well they can hear news we feel is difficult to talk about. Check out our conversation starters below for examples of how to talk about JHD with your child(ren).

Telling children their sibling has JHD

If your child with JHD has siblings, then the impact is going to be significant on their lives too. JHD impacts heavily on siblings and they need to be well supported to overcome the challenges that lay ahead for them. A good first step to overcoming these challenges is having knowledge about JHD. When a child has an understanding of what is happening right now and what to expect in the future they are able to form a strong base to ask questions and begin to cope in a healthy manner.

We suggest educating siblings about JHD from an early age. Their ages will play a part in how much or how little an explanation you give to them. The one thing to think carefully about is if the siblings are at-risk for HD. If the child is at-risk then it might be helpful to begin to discuss symptoms of HD/JHD first. If the child who is at-risk starts to ask questions such as "Will I get HD/JHD?" then a good rule of thumb is not to lie. You can

tell the child that is does not appear that they have the same symptoms as their affected sibling and they can never "catch" HD. HD and JHD is not like a cold. It is something that people are born with and it can be difficult to tell who will begin to show signs of HD when they are older. If the child is asking for more details about their sibling you can begin to discuss some of the symptoms the sibling is having. It is VERY important to make a distinction between the symptoms the affected sibling has and the other children. For example, if the affected child has seizures and falls make sure the other siblings are aware that if and when they fall that doesn't mean THEY have JHD. Tell them all children fall once in a while but the types of falls and other symptoms their sibling has is JHD.

Conversation starters for telling a child about JHD

Here are some starters to help you think about having the discussion about HD and JHD with your child. We recommend using your own familiar words, but these might help to start the discussion.

"We have some news for you. We know why you've been finding it hard to pay attention at school, why your body feels different, and/or why you feel angry sometimes. The doctor has told us you have something called Huntington's Disease. They call it HD or JHD for short when it happens to kids. HD is a condition that affects how you think, move, and feel. All the doctors and other medical people are going to do their best to help us understand and treat some of the symptoms. Do you have any questions so far about this?"

You can continue by saying "You might have a lot of questions about JHD so if you ever have questions or need information about JHD, you can always ask us. We are also going to talk to the school to make sure they give you extra help when you need it. What questions do you have so far?" If the child doesn't have questions right away you can say, "It's okay that you don't have questions right now. You might have questions later. We will keep checking in with you about this and make sure we give you all the information you need".

Conversation starters for telling a child their sibling has JHD

For siblings, depending on their age, you want to also start out with basic discussion so that everyone in the family has been told the same information. You can say, “I want to talk to you about your brother/sister. You know that they have been having some problems. Well the doctor has diagnosed them with something called Huntington’s Disease. It is called HD or JHD when kids have this condition. JHD affects your brother/sister’s brain. It can make them have trouble thinking and remembering, it can make them move in different ways, and it can make them feel moody at times. We will let you know as much as possible about JHD but we also need your help. When he/she is having trouble thinking, is slow/clumsy, or angry, we really need you to be patient and supportive. It isn’t your brother/sister’s fault that they are acting this way. It is this disease. This will be different for all of us. Sometimes we will have good days and sometimes we won’t have such good days. But we are all in this together. So far do you have any questions?” Similar to the affected child, the sibling might not have any questions right away. They might also have a lot of questions and it is okay to say to both the affected child and the sibling, “I’m not sure about the answer to that. Let me check with some of the experts and I will get back to you”.

Support options

Please remember you are not alone in this journey. While your journey will be unique, there are other families coping with HD and JHD. We have found one of the most helpful ways to cope is to reach out to HD and JHD specific organizations and to other families dealing with JHD. Also please reach out to connect with us at HDYO. While we don’t offer medical advice, we can provide education and support. If we do not have a specific answer to your question, we will do our best to guide you to the experts who have the answers. So don’t hesitate to call, email, or browse our website.