

Talking With Kids



Huntington's Disease

Family Guide Series



Huntington's Disease
Society of America

Talking With Kids

Family Guide Series

Written by:

Karen Tarapata

HDSA Talking with Kids Workgroup:

Karen Baker, LICSW

Emily De Los Reyes, MD

Martha Driessnack, PhD, PNP-BC

Nelson Inz

Shana Martin

Brad Murdock

Cheryl Sullivan Staveley, RN

Janet Williams, PhD, RN, FAAN

Lindsey Zan, MS

Jane Kogan, LMSW

Published with funding from a generous educational grant
from The Bess Spiva Timmons Foundation, Inc.

Disclaimer

Statements and opinions in this guide are not necessarily those of the Huntington's Disease Society of America, nor does HDSA promote, endorse, or recommend any treatment or therapy mentioned herein. The reader should consult a physician or other appropriate healthcare professional concerning any advice, treatment or therapy set forth in this book.

© 2012 Huntington's Disease Society of America
All Rights Reserved

Printed in the United States

No portion of this publication may be reproduced in any way
without the expressed written permission of HDSA.

Contents

Why Talk About HD?	4-5
Prepare for the First Conversation	6-9
• Setting the time and setting the tone	7
• What to say – where to begin	7
Conversation Starters	10-14
• Young children	10
• Older children	11
• Teens	12
• General points to include in the first conversation	13
Short Answers to the Tough Questions	15-17
Keeping the Conversation Going	18-19
• Conversation stoppers	18
• Conversation calmers	18
Building a Team of Support	20-23
• Resources for the team of support	20
• Mental health professionals	23
Talking About Genetic Testing	24-25
Conclusion	26

Why Talk About Huntington's Disease (HD)?

When children are not given a reason for what they see happening in their family, or an avenue to discuss it, they will create explanations on their own or seek out information elsewhere.

They may think that the changes they see in the family are their fault or blame the affected person for behaviors caused by the disease. They may go online and become exposed to information that is neither factual nor applicable for their situation. **Giving your child information about HD – the right amount at the right age – will give him or her tools to deal with the changes in the family while helping him or her to feel secure and live positively.**

Although you may not feel that you know enough about HD to talk about it, you have the child's trust and that is what qualifies you to be the one to start the conversation. Know that you are not alone in your effort. There are many people ready to offer you support, including the physicians and professionals at HDSA Centers of Excellence, the social worker available through your local HDSA Chapter,

members of an HDSA Support Group, or HD knowledgeable mental health professionals.

Talking with children about HD should be thought of as a series of conversations over the course of many years. These conversations will develop as the child matures and the affected family member's symptoms progress. This guide will help you find the right words to start the conversation about HD early and keep the lines of communication open.

The conversation will be ongoing. Your child's needs will evolve over time and so will his or her thoughts, questions, and fears about HD. It is up to you to keep the conversation going as your child matures. The following section will help you develop a plan for your first conversation.

A Note on HD Families

Where we use the word "family" in this guide, we mean the relationships of trust between a child and the important adult figures in his or her life. These people may be related to the child by blood or not. Families are created by love, trust and a commitment to each other. We refer to people with HD as 'he' or 'she' and examples in this book are used for illustrative purposes only.

Prepare for the First Conversation

Talking about HD in the family can be difficult and emotional at the beginning. It may be hard to talk to children when your own feelings are not clear. Before you have the initial conversation, there are some things to consider:

- Give up the idea of a “big talk.” Your goal is to start a conversation and do a lot of listening.
- Learn as much as you can about HD before you have the talk. The better informed you are, the better you will be able to manage the conversation.
- Practice the words you plan to say to start the conversation. This is bound to be an emotional talk, so write out your opening statement and practice it. Also, write down the major points you would like to cover.
- Let your child know that you are there to answer any questions, even if your answer is “I don’t know” or “let me try and find that out for you.”

- Do not try to cover too much ground at one time. In each conversation there will be a point when you have given your child enough to think about for now. You can add more information next time.

Setting the time and setting the tone

Decide where and when to have the first conversation. Try to choose a time and place where you can limit interruptions and distractions. Tell the child you want to talk with him or her about something important, not that you “have to talk to him or her,” because the child may immediately think that you are angry about something. Plan to turn off your phone (and ask the child to do the same, if applicable).

This will be an emotional conversation, so try not to have something planned immediately afterward. You both may need some time for reflection.

What to say – where to begin

Preparing for that first conversation is daunting, but going into the conversation with a plan will help you to make the most out of this first discussion. Here are some things to think about.

Be honest – You can be gentle with the child and still tell the truth. Let the child know that there is a history of HD in the family. Tell the child what is going on right now with the affected family member(s). Tell him or her how HD explains certain events. Talk about the care the person is now getting. Keep your focus on the here and now. You do not need to go into long-term issues during your first conversation, unless asked.

Prepare to listen – Listening is the only way to find out what the child is feeling and what information he or she needs right now. Encourage the child to talk. Practice “responsive listening,” or waiting to respond, especially if your child becomes angry or emotional. Listening, instead of reacting to the child’s feelings, will help you remain in control of your own emotions during your talk. Responsive listening can also keep you from giving too many details about things the child is not interested in at this time.

Be patient – Remember, you came to this conversation prepared. You practiced what you wanted to say and how you would say it. The child was not prepared. He or she will need time to process what has been discussed.

Be open to questions – Communicate that you are interested in the child’s thoughts, opinions, and questions. Promise that if you do not know the answer to a question, you will do your best to find out. Tell the child that the conversation will be ongoing and that questions can be asked as they come up. Let the child know that there are no “bad” thoughts, feelings, or questions.

Keep the door open for further talks – By talking about HD, you have opened a door. You cannot push or pull the child through it. If the child is not ready to share feelings and questions, let the child be and try again later. Try not to judge what has been said, so that the child will feel safe sharing in the future.

Remember to offer reassurance – Children want to feel safe. Prepare to include reassuring thoughts like these in your initial conversation.

- “No matter what happens, never forget that there are people who care about you.”
- “I may not know the answers but together we can try to find them.”
- “I will do my best to listen to you whenever you want to talk.”
- “We can handle this if we can just keep talking to each other.”

Avoiding Too Much Information

Sometimes “the big picture” turns into lots of details about the disease and can be too much for the child to absorb. During your initial conversation, keep the focus on the present and near future. You may want to avoid introducing topics such as the inheritance of the gene, disability, or death, unless your child asks questions about these directly (see Short Answers to the Tough Questions, page 15). The first step is to tell them that a loved one is sick because they have HD. You can increase your child’s knowledge of the disease over time as you continue your conversations.

Conversation Starters

There is a lot to think about when preparing for your first conversation with a child, or children, about HD in the family. What you say to a particular child should be in your own words, and will depend on the child's age and maturity, and your personal communication style.

Personality

Every child has a different outlook on the world. Some kids love to talk, others don't. Some kids want lots of information and reading material, while others just want to hear that you are taking care of things. Some kids are worriers, while others face the future without fear. Any combination can be found in the same family.

Young Children

(Preschool & Lower Elementary School)

Young children have a shorter attention span, so be sure to keep your explanation short and simple. Use examples that are concrete and familiar. Young children may be better able to express their feelings and ask their questions by drawing or acting out a scene with their toys, so much of your part of the 'conversation'

will be listening and playing rather than talking. After your conversation, keep an eye on their drawings and games. You may learn a lot about their feelings.

Sample conversation starters for young children

“I want to talk to you about something important. The doctor told me that [name] is sick. She has Huntington’s disease. It is a disease that makes it harder for her muscles and brain to do their work.”

“Her sickness is going to make it harder for her to do some things. It may take her more time to eat her dinner and it may be harder for her to play with you.”

“There will be changes because of her sickness, but we will always care about each other. That hasn’t changed.”

“The doctor is doing his best to help [name] and we can do our best to help her, too.”

“Do you have any questions for me right now? If I don’t know the answer, I will try to find out.”

Older Children

(Upper Elementary to Middle School)

As children get older, they become more and more capable of participating in conversations, and are able to understand much more about Huntington's disease. Consider giving your child written material from HDSA and encourage him or her to write down questions.

Sample conversation starters for older children

"I want to talk to you about something important. I found out that [name] is sick. He has Huntington's disease. It's not a disease you can catch, like a cold. It is a genetic disease that he was born with. Huntington's affects his muscles and his brain. I wanted to tell you this right away, because you are a smart kid who notices things."

"Because of this disease, some things are going to be harder for him. You may notice he is walking differently and his balance is off. He may seem grouchy for no reason you can see. Have you noticed anything like that?"

"Now that [name] is sick, I am going to need more help around the house. Will you step up and help me?"

"I know all this is hard to understand. What do you think about what I have just said? If there is anything you want to know about HD I will try my best to find the information. Let's talk some more after school on Friday."

Teens

Teens are full of contradictions. Many are capable of adult-like conversation, though they may often speak in one-word sentences. They can act like angry toddlers or jump in to assume adult-level responsibilities. Their emotions and responses may rollercoaster from day-to-day.

Sample conversation starters for teens

“I want to talk to you about something important. I found out that your mom has Huntington’s disease. It is a genetic disorder she was born with. It has affected her muscles and her brain. I wanted to tell you this right away.”

“Because of this disease, she may have a hard time with some things. She may forget to do things she promised to do. You may notice that her hands shake sometimes. She may become very angry and you won’t know why.”

“I am going to need you to be extra helpful and not get mad at your mom when things don’t go right, because it is not easy being sick. The most important thing is that we look out for each other. Your mom being sick with Huntington’s disease doesn’t change that.”

“What are you thinking right now? It’s 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, I will try my best to find out. I know this is a lot to understand, so let’s take some time to let it sink in and we can talk some more in a day or so.”

General points to include in the first conversation

- A simple explanation that there is a family history of HD.
- How the affected person's HD symptoms may affect the child's life right now.
- Reassurance that the child is valued and supported.
- "It is OK if you want to tell me how you feel, or if you don't."
- A description of something they can do to help.
- An offer to listen to their questions or concerns.
- The expectation that there will be future conversations. *Note - there is no rule of thumb about when to follow up after the initial conversation. Consider your child's age, needs and abilities, and take cues from them.*

Expect the unexpected

No matter how carefully you prepare, your children will ask questions for which you are not prepared, or will ask them at a time when you cannot answer. For example, when there are a lot of people around, or you have to focus on driving or another important task, you may find you need more information, or you may need time to get your emotions under control. Remember that your child will take their cues from you. So, be prepared to pause the conversation if you aren't able to fully participate or if you find yourself getting overwhelmed by your emotions. Be sure to set up a time to come back to the topic.

Q&A: Short Answers to the Tough Questions

There are some questions about HD that no parent looks forward to. Here are some possible answers to the really tough questions. Use these to formulate your own responses.

Q. Is mom/dad going to die from HD?

A. *People can live for many years, even decades, with Huntington's disease. We don't know for sure when any of us will die. Instead, we focus on living our best life now.*

Q. How did mom get HD?

A. *When mom was born, she inherited the mutated gene that causes HD from her parent.*

Q. What did I do to make [family member] behave this way?

A. *The behavior is caused by HD, not by anything you did. [Affected family member] 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 developing the disease, but there are a lot of very smart scientists looking for treatments and a cure.*

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

A. *They have the same 50/50 chance you do.*

Q. Why can't I just get the test now?

A. *Getting a test for the HD gene doesn't tell you when you might get symptoms. Some people develop HD late in life. If you want to talk about the test with a genetic counselor, we can make an appointment at an HDSA Center of Excellence or call our HDSA Social Worker. However, if you decide that you want to get tested, you won't be able to do so until you are 18.*

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

A. *No one knows how long they will live. Being at-risk for inheriting HD should make you live your life to the fullest. You should go after your dreams with all your heart.*

Q. What will happen to me if something happens to you?

A. *If anything happens to me, [name of guardian] will take care of you.*

Q. Why isn't there a cure?

A. *Scientists are working as hard as they can to find one. There are research studies that members of an HD family can participate in that may help to find treatments and a cure. Should we look into that?*

Q. How am I supposed to handle this?

A. *Know that you are not alone, and that there are a lot of people who care about you, as well as professionals who can help. You can talk with an HDSA Social Worker, or we can find a counselor.*

HDSA has a National Youth Alliance that is made up of kids like you, from all across the country, that you can connect with online. Plus, you know I am always here for you.

Q. What will I need to know as [name's] illness progresses?

A. *As time goes on, there are going to be difficult decisions to make. We can work together with the HDSA Social Worker so that we know what to expect and can plan for the future.*

Keeping the Conversation Going

Conversation stoppers

Responses that are dismissive or dishonest can cause children to retreat from the conversation. These Conversation stoppers usually arise when parents are too upset or scared to answer a question. Here are some examples:

- “That’s ridiculous! You know that’s not true.”
- “How can you feel like that?”

Conversation calmers

If you ever feel that you are losing control over your emotions during a conversation with a child, consider using one of these responses:

- “I am not sure how to answer that right now. Let me think about it and we’ll talk before bedtime.”
- “That’s a good question. I don’t know the answer, but I will find out when I talk to the doctor.”
- “This sounds important to you. I think we need more time than we have right now to talk about it. Can we talk after soccer practice?”

- “There’s too much going on right now for me to answer. Can we talk after everyone goes home?”
- “We are both pretty upset. Let’s take a break and talk about this in a couple of days.”

Building a Team of Support

As a trusted adult, you will remain the child's main source of information and emotional support, but because the presence of HD in the family will elicit many strong and complicated feelings, you may find that the child needs to talk with someone outside the family circle. Here are some ideas and guidelines to help you develop a support network for your child.

Resources for the team of support

Your extended family

The extended family of the affected individual can be a very important source of support as they are likely to understand family dynamics surrounding HD and may have a personal understanding of what the child is experiencing. You may find that some family members are uncomfortable speaking openly about HD in the family. Some may feel that HD is something to hide. This often arises from that person's fear about the future, as well as fear of potential discrimination. Generally, the more straightforward and honest you are with the children about family dynamics surrounding HD, the more they will feel they can trust you and come to you with their concerns.

Your child's friends

A child's friends can be a big part of his or her team of support. At the start, many children want to tell only their closest friends about HD in the family. What they tell their friends will depend a great deal on what you have told them and what is being discussed in the home.

If communication at home is open and positive, then it will be easier for the child to share information about HD in their family with friends and other kids. If HD has been explained in a simple and basic manner, the child will be able to keep it straightforward as well.

Family member perspective:

When my younger daughter was five, she had her kindergarten friend over for supper. My husband, who was in the early stage of HD, made noises when he ate, and had mild chorea. My daughter's friend was watching him during the meal. My daughter noticed this and just said, "Oh, my Dad does that because of his HD!" She told her friend that HD was "kind of like a muscle problem."

My daughter was not apologetic, just matter-of-fact. Her friend acknowledged my daughter's statement and then went on eating without paying any further attention as to how my husband ate. Nor did my daughter's friend have any questions... she just accepted as fact what my daughter had told her.

Teachers, coaches, spiritual leaders, and adult friends

Your child may feel more comfortable talking to someone they already know. A favorite teacher, sports coach, or other trusted adult may offer a steadying influence and help the child to know that many areas of their life will remain the same. The school counselor may also be a willing listener when the child needs to talk.

A child may also want to talk privately to the family's spiritual advisor. Many children (and adults) find spiritual counseling to be very helpful and supportive.

If you can, meet with the teacher, coach, etc. before the child does and offer them some information on Huntington's disease. Most people are still unfamiliar with HD and many of those who think they are familiar with the disease may only be aware of the motor disorders, such as chorea. *Fast Facts About HD*, available for download in English and Spanish on the HDSA website, gives solid background information about the disease. Talking to the adults in the child's support system will also allow you to enlist them as your "eyes and ears." They can alert you to changes in the child's behavior (poor performance, inattention, social isolation, aggression, etc.) that may be linked to the child's emotional state. Choose the people you tell for their sensitivity and discretion. Children of any age dislike being singled out.

Dating and HD

The decision to tell a significant other about HD in the family may be an emotional one. Teen dating may also bring up the topic of unplanned pregnancy. The at-risk teen that is sexually active should understand how HD is inherited. An

HDSA Social Worker or the HDSA Helpline can help provide more information on this topic.

Using discretion

It is important that kids feel comfortable sharing with others. However, sharing on social networking sites or on the Internet can cause the child to lose control over the family's private information. We suggest that you have a discussion with the child about appropriate sharing of information. It is also important to convey to the child that not everything written online is factual and that you are there to help them separate fact from fiction.

Mental health professionals

Mental health professionals like counselors and psychologists can be very helpful for children who are learning about HD and need ongoing support. You can talk to an HDSA Social Worker about identifying the appropriate professional for your child.

Family member perspective:

When I first went to a therapist, it was difficult because I was uncomfortable with sharing my story with a perfect stranger. After a few sessions, it became a relief to speak to somebody who was a complete "outsider." Although it was a very scary step in my life, I truly do not know where I would be without that professional intervention.

Build a team for yourself

Huntington's disease has affected your life as well as the lives of your children. You may be shouldering greater strains and responsibilities than ever before. You, too, need a team of support. Take care of yourself, physically and emotionally, so that you can be there for your children.

Talking About Genetic Testing

Your conversations about genetic testing will be different than the conversations about the affected person's disease. These conversations are about your child's future.

As your children learn about HD, they will become aware that each child of a person with HD has a 50% chance of inheriting the gene and that a child who does not inherit the gene cannot pass on the disease. They will also discover that there is a simple blood test that can determine the presence of the HD gene, although it does not reveal when symptoms will arise.

The decision to test for the HD gene is a very personal one and many people choose not to have the test. The HDSA publication, *Genetic Testing for Huntington's Disease: A Guide for Families*, available for free download in English and Spanish, has answers to many common questions you and your child may have about

genetic testing. When a child shows interest in learning about the topic, you can use this guide as a starting point for your conversations. There are genetic counselors at HDSA Centers of Excellence who are available to talk to you and your child at any point about genetic testing for the HD gene. You can find your closest Center of Excellence in the “Living with HD” section of the HDSA website.

Conclusion

The conversation about HD will be an ongoing process over many years. You may choose to talk to your children as needed or use the annual pediatrician “check-up” as a reminder to “check-in” on the subject. There will be many small conversations and a few major conversations: when your child is studying biology in school; when your child takes a major step towards independence such as beginning college or enlisting in the military; when your child begins dating or speaking of future plans for a family; or when the affected family member shows a decline or need for increased care. HDSA is here to help you begin and sustain your conversation. To connect to HDSA resources, please call HDSA at 800-345-HDSA(4372).

**HELP FOR TODAY.
HOPE FOR TOMORROW**

HDSA Mission

To improve the lives of people
with Huntington's disease and their families.

**Huntington's Disease Society of America
National Office**

505 Eighth Avenue, Suite 902

New York, NY 10018

Phone: 212-242-1968

800-345-HDSA (4372)

Fax: 212-239-3430

Email: hdsainfo@hdsa.org

Web: www.hdsa.org



**Huntington's Disease
Society of America**



Published with funding from a generous educational grant
from The Bess Spiva Timmons Foundation, Inc.