



Talking With Kids About HD

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A young boy with a thoughtful expression, resting his head on his hand, sitting at a table. The image is overlaid with a blue tint. The text is centered over the boy's face and chest.

CHAPTER 1

**TALKING
WITH KIDS
ABOUT HD**

This handbook is intended to help you communicate openly about Huntington's disease with the children, teens and young adults in your family, so that you can help them lead positive and satisfying lives, whatever their gene status. It can also help you talk about HD with other important people in your child's life, such as teachers, coaches and other trusted adults. Sample conversation starters are included throughout the book and are intended as suggestions to help you find your own voice when talking about HD. There is also information about where you can turn for help.

The book covers many topics, not all of which will apply to your family. Where we use the word "family" in this book, 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 positive communication and a commitment to each other. We refer to people with HD as 'he' or 'she' interchangeably and examples in this book are used for illustrative purposes only.

The last chapter of this handbook covers the issues surrounding Juvenile Onset Huntington's disease (JHD).

WHY TALK ABOUT HUNTINGTON'S DISEASE (HD)?

When there is HD in the family, everyone is affected by the disease. This includes the children. Talking about HD with your children may not be something that you want to do at this time. You may want to protect your children from knowing about the disease, but children are very perceptive. The chances are good that they already know that something is different about their family.

Easy access to information on the Internet is a major reason to talk with your kids about HD. Anyone with access to a computer (or a smartphone!) can do a search for Huntington's disease on the web. They may find information that is not appropriate for their age, or true for the family's situation. Children need to learn about HD from an adult they trust.

You may feel that you do not know enough about HD to explain it to a child. You may not be a medical expert, but you do know your child and you have his or her trust. That trust is what qualifies you to be the one to start the conversation. By talking with your kids about HD—in an age-appropriate way—you will be giving them the factual information to understand what is happening, and the emotional support to remain engaged with family, school and friends. This handbook will help you find the right words to start the conversation about HD early, cover important subjects as they come up, and keep the lines of communication open.

A series of conversations

Talking with children about HD can be thought of as a series of conversations over the course of many years. These conversations will change as the child matures and the affected family member's symptoms progress. This conversation should be ongoing. Your child's needs will continue to change over time and so will his or her thoughts, questions, and fears about HD. It is up to you to start the conversation and to make a concerted effort to maintain an open and ongoing dialogue as your child matures. The following section will help you develop a plan for your first conversation.

HDSA is here to help

Talking with children about HD takes courage. Know that you are not alone as you face this challenge. There are people who understand the unique concerns of an HD family and who can offer you guidance and support. These include the physicians and social workers at the HDSA Centers of Excellence, the social worker at your HDSA Chapter, members of an HDSA Support Group, or HD-knowledgeable mental health professionals. You can call the HDSA Helpline at **888-HDSA-506** for more information or a referral to these resources.

GETTING STARTED—THE INITIAL CONVERSATIONS

Even thinking about talking about HD in the family can be difficult and emotional. Before you start talking with your children about HD, try to be aware of your own feelings about the disease. Talking to a social worker or counselor may be helpful. Here are some things to consider as you prepare to talk with your children about HD:

- Give up the idea of a “big talk.” Your goal is to start a conversation and to do a lot of listening.
- Learn as much as you can about HD before you have the talk. The better you are informed, 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.
- Prepare to 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 out about that for you.”
- There is no need to try to cover too much ground at one time. In each conversation there will be a point when you have given them enough to think about for now. You can add more information next time.

Plan for the right environment

Where and when you have this first conversation about HD is important. Try to choose a time and place where you can limit interruptions and distractions. Make sure you can turn off or mute your phone. Allow enough time for questions and try not to have something planned immediately afterward. You and your child may need some time for reflection.

What to say—where to begin

Be honest

You can be gentle with the child and still be truthful. Tell the child you want to talk with him or her about something important. Let the child know that there is a history of HD in the family. Talk to the child what is going on right now if a family member is already affected by HD. Tell him or her how HD may explain 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 they ask.

Consider the child's 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.

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,” and force yourself to wait 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 learned.

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.

- *"I know that I've given you enough information. Do you have any questions?"*
- *"I may not know the answers, but together we can try to find them."*

**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 will do my best to listen to you whenever you want to talk."*
- *"We can handle this if we can just keep talking with each other."*
- *"There will be changes because of the sickness, but we will always care about each other. That will never change."*



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.

- *“Do you have any questions for me right now? If I don’t know the answer, I will try to find out.”*
- *“I would like to hear what you think, whenever you feel like talking. I am here for you.”*

AVOIDING “TOO MUCH INFORMATION”

Sometimes “the big picture” turns into lots of details about the disease and it 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 24). The first step is to tell them that you/a parent/sibling/relative is sick or will become sick because they have or will develop HD. You can increase your child’s knowledge of the disease over time as you continue your conversations.

CONVERSATION STARTERS

Below are some possible ways you can start talking to your kids about HD. Some examples may not be relevant to your family and your situation. They are offered only to help you find your own voice. They are separated by age, but you may find the right words for your child in an example for a different group.

Young children (preschool & lower elementary school)

Young children have a shorter attention span, so try to keep your explanation short and simple. Use examples that are concrete and familiar.

Ways to start the conversation with young children

- *“I want to talk to you about something important. The doctor told me that Grandma is sick. She has Huntington’s disease. It is a disease 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 a sickness called Huntington’s disease. It is a kind of muscle problem he was born with. I will need you to be patient when that happens, ok?”*
- *“I am sorry that Mom got so mad the other day. We found out she has a sickness called Huntington’s and sometimes it can make her grumpy. She was not mad at you. She gets mad about the sickness.”*
- *“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 coordination. I want you to know what’s happening, and the reason for my problems.*
- *“The doctor has told me that someday I will develop a sickness called Huntington’s disease. I wanted to tell you about it now, before I get sick, so that I can help you better understand the changes that are going to happen to me.”*

Reactions

Young children may express their feelings and ask their questions by drawing a picture or acting out a scene with their toys. You may want to spend some time with the young child just listening and playing rather than talking. By keeping an eye on their drawings and games in the days and weeks that follow your first conversations, you may learn a lot about their feelings.

Older children (upper elementary to junior high/middle school)

Children seem to be growing up faster and they are more connected to the larger world at an earlier age. Media and the Internet have put a great deal of information in children's hands. Science education has been accelerated in recent years and topics that used to be covered in high school biology are now taught in middle school science classes.

If the trusted adults in their lives do not provide factual, age appropriate information for what they see happening around them, young people are likely to come up with their own explanations, which may be wildly inaccurate. Without a clear understanding of why things are changing and the role that HD is playing in these changes, older children may develop the mistaken belief that the problems in the family are their fault, your fault, or the fault of the person with HD.

Conversation starters with older children

- *“I want to talk with you about something important. I found out that Granddad is sick. 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 his brain. I wanted to tell you, because you are a smart kid who notices things.”*

- *“Because of this disease, 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 disease, and this means I won’t be able to do the work I’ve been doing. This will mean that your Mom will be going to work and I will be staying home. Your Mom and I are working out how we can adapt to these changes.”*
- *“Now that Dad is sick, he can’t do as many things around the house. I am going to need you to help me sometimes. Can I count on you?”*
- *“I know some of 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 or when you are ready.”*

Reactions

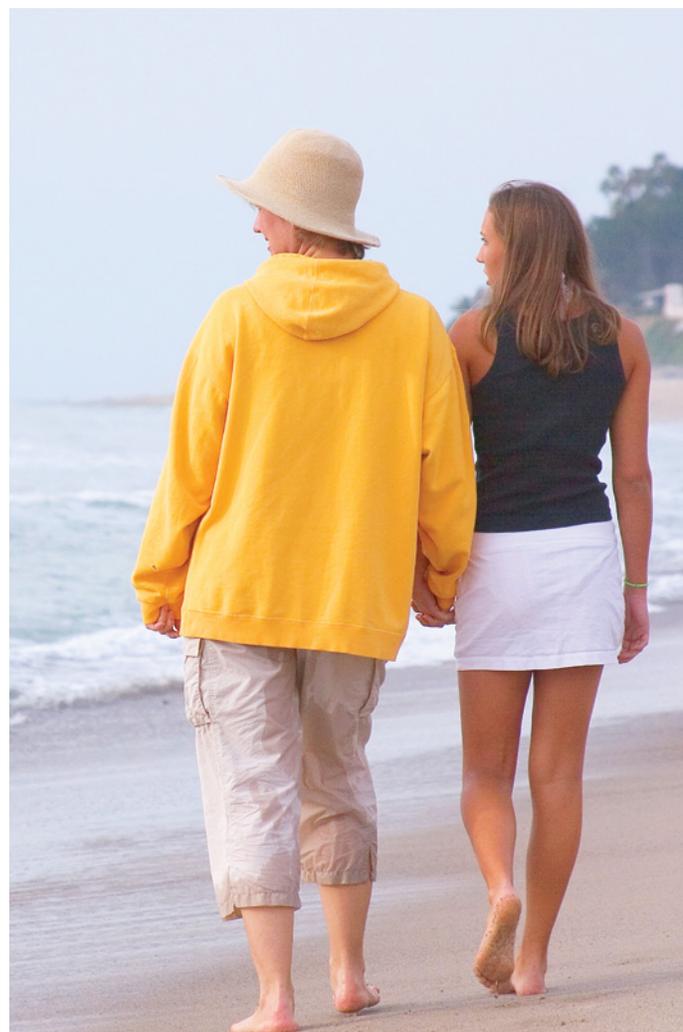
Older children vary in personality and maturity and each child will react differently to the news. Some children will brood and others will be very accepting and matter of fact. Changes in your child’s behavior may indicate that they are struggling with the news. Create opportunities for them to talk about their feelings and concerns, either with you or with another trusted adult, such as a counselor, social worker, nurse, teacher, or therapist.

Teens

The teen years are a time of growth, both physically and emotionally. The reaction of your teen to the presence of HD in the family can be hard to predict. They may be very mature or they may react like an angry toddler. Be prepared to start and stop and start again, depending on the reaction of the teen.

Conversation starters with teens

- *“I want to talk with 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. Because of this disease, she may have a hard time with some 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 disease he was born with. 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 center and they confirmed what we had suspected. I have a condition called Huntington’s disease. It is probably what your Grandmother had, but we didn’t know that when she 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.”*



Reactions

It is difficult to predict the response of a teenager to life changing news like this. They may take it all in quietly or get very upset. They may actually be relieved to have an explanation for behavior they have witnessed. Let your teen know you care and give them time to process this new information.

Continue to enforce rules and routines. It can be reassuring that certain parts of life are not going to change and that an adult is still in charge.

Be alert to changes in behavior in the days and weeks to come. The teen may become withdrawn or start acting out. He or she may need someone outside the family to talk to, such as a counselor, social worker, nurse, therapist, teacher, or coach.

SPECIAL TOPIC—EXPLAINING INHERITANCE OF THE GENE

Older children will be learning the basics about genetic inheritance in school, as part of their science curriculum. Over time, they may want to discuss what they have learned in the conversations with you about HD. Some children will be more curious about the workings of HD than others. It is wise to let the child take the lead in these discussions.

If you want to go over the science of inheritance with your older child, there are reputable websites that cover the topic in age-appropriate ways. One is the National Institutes of Health website www.history.nih.gov/exhibits/genetics/index.htm. Another is the Huntington's Disease Youth Organization (HDYO), www.hdyo.org.

At some point your child will go through a transition from thinking of HD as “Daddy’s illness” to understanding that there is a 50% chance that they have inherited the gene that causes HD. This can be quite a burden. If your child is struggling with this knowledge, counseling may be helpful. The social worker at your HDSA Chapter or HDSA Center of Excellence can help you find a counselor who is familiar with HD issues. He or she can also help you with strategies for educating other healthcare professionals, such as a local child or adolescent therapist, about HD.

THE FIRST CONVERSATION CHECKLIST

- Simply explain that there is a family history of HD
- Describe how the symptoms of the person with HD may affect the child's life right now
- Reassure that the child is valued and supported
- Identify something they can do to help
- Offer to listen to their questions or concerns, now and in the future
- Ask for discretion. Children and teens might post private family information on the social networking sites they use without giving it a thought
- Let the child know that there will be many future conversations. Note—there is no rule of thumb about when to follow up about the initial conversation. Consider your child's age, needs and abilities, and take cues from them.

KEEPING THE CONVERSATION GOING

Talking with your child about HD is as much about listening as talking. Your child may need reassurance or they may need to vent their anger. The important goal is to keep communication open and ongoing.

Encouraging questions

- *“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 with 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 take in. Do you want to think about this for now and we'll talk again tomorrow? I can answer your questions then.”*

Conversations stoppers

Just as there are ways to talk to your child that will help get a conversation started, there are things that will shut a conversation down quickly. 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:

- *“You’re too young to understand. I’ll tell you when you’re older.”*
- *“What a stupid question.”*
- *“Don’t bring that up anymore. We’re not going to talk about HD.”*
- *“That’s ridiculous! You know you don’t feel like that.”*
- *“How can you worry about yourself? Mom is sick.”*

Communication strategies

Below are communication strategies to consider as you work to create an environment where you and your child can communicate openly. Some of these ideas are inspired by the book *“How to Talk So Your Kids Will Listen,”* by Adele Faber & Elaine Mazlish (2002).

Avoid yes or no questions

Your child might answer the question with one word, which will satisfy the question but will not provide you with enough information to know how your child really feels about something. Don’t give your child the opportunity to say no right away when you are trying to find out what he or she is thinking. Sometimes yes or no questions can also sound like accusations, a good way to shut down a conversation. Instead of asking *“Do you want to talk about your Dad’s HD?”* try stating *“You seem to be bothered about the changes in Dad since hearing about his HD. Tell me more about that.”*

Don't make accusations

If you are concerned your child has done something you don't like or feels a way you don't approve of, state your observation instead of making an accusation. For example, instead of saying *"You don't like to help me with your sister!"* try, *"You didn't want to help with your sister today. What's going on?"*

Avoid blaming

Even if your child clearly did something wrong, blaming your child will put him or her on the defensive and you will lose the opportunity to find out what your child is feeling. Make sure feelings come first, not blame. Instead of saying *"It was your fault you were late for school today,"* try getting them to cooperate by stating, *"Mornings get pretty hectic around here. Let's think of ways we can make sure you get to school on time."*

No name calling

Name calling can damage trust and this will limit what your child will share with you. Remember to focus on the behavior and the feelings behind the behavior instead of labeling your child with a name when you are upset. It is sometimes tempting to tell a child who is bothering you, *"You are such a pest!"* A better way is to tell your child how you feel: *"I don't like it when you keep asking me the same question over and over again."*

Don't generalize your child's behavior

Focus on the topic at hand instead of making statements about what your child "always" does. Instead of saying, *"You are always so moody,"* let your child know you want to help: *"Something seems to be bothering you today. Tell me about it."*

Don't deny your child's feelings

When your child tells you how he or she feels, try not to react by saying *"You don't really feel that way."* For example, if your child says, *"I hate my brother,"* don't respond with *"No you don't."* An example of a better response is, *"Tell me why you are so upset with your brother today."*

Avoid giving advice

Unless your child specifically asks you for advice, don't give it! Instead, listen actively and your child is more likely to come up with his or her own solution. You can also offer to help him or her brainstorm ideas and talk about the possible consequences of each choice. This fosters independence and can't backfire. For example, if they follow your advice and it doesn't work out, they will be less likely to trust you in the future. Also, if they don't take your advice and you turn out to be right, they might feel resentful and as though they are not capable of making their own decisions. They will learn to be independent if they come up with their own solutions and learn the consequences of their own choices.

Conversation calmers

No matter how carefully you prepare, your children may say things you didn't expect or ask questions for which you have no ready answer. They may say something deeply upsetting or ask a difficult question at a time when you cannot answer, such as when there are a lot of people around or when you have to focus on driving or another important task. You may need more information or simply time to get your emotions under control. In these circumstances, it can be wise to pause the conversation and set another time to talk about it privately and calmly. Remember that your child will take their cues from you.

If you feel that you are losing control over a conversation with your 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."*

GRIEF IN CHILDREN AND TEENS

Loss is part of being in an HD family and grief is a natural response to the changes caused by HD. Each person, each child, copes with loss in his or her own way. Grief can take many forms, including:

- Anger
- Anxiety
- Apathy
- Detachment
- Embarrassment
- Fear
- Exhaustion
- Guilt
- Helplessness
- Loneliness
- Loss of hope
- Relief
- Resentment
- Worry

Avoidance is also a symptom of grief. Children may shut out feelings of loss by withdrawing, by pretending that everything is ok or by putting all their focus into sports, video games or hobbies. Teens, or younger children, may become the “life of the party” or indulge in dangerous, illegal or antisocial behavior. It may seem that the teen is not helpful and does not care about what is happening at home. The truth may be that they care too much. Counseling may be helpful to a child who is struggling with grief.

Q&A: SHORT ANSWERS TO TOUGH QUESTIONS

There are many questions about HD that no parent looks forward to answering. Here are some possible answers to 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? Why did this happen to our family?

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

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

A. *The behavior is caused by HD, **not by anything you did**. He 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 the disease, but there are a lot of dedicated scientists looking for a cure.*

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

A. *Anyone who has a parent with HD has 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 start to have symptoms, even if you do test positive for Huntington's disease. People have developed HD as late as their 80s. 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, whether they have Huntington's disease or not. Being at risk for HD should make you live every minute to the fullest—just as you would if getting HD wasn't a possibility. You should go after your dreams with all your heart.*

Q. Who will take care of me if something happens to you?

A. *If anything happens to me, [Relative/Godparent, etc.] will take care of you.*

Q. Why isn't there a cure?

A. *There are many dedicated scientists who are working as hard as they can to find one. Would you like to see some of the research? There are even research projects in which members of an HD family can participate in that may help to find a cure. Should we look into that?*



Q. How am I supposed to handle this?

A. *Know that you are not alone, and there are a lot of people who care about you, as well as professionals who can help. There may be a support group for at risk kids through our HDSA Chapter. You can also talk to a social worker at the HDSA Center of Excellence, or call the HDSA helpline. HDSA has a National Youth Alliance that is made up of kids like you, from all across the country (you can find them at www.hdsa.org/nya) and there is a worldwide internet based youth community you can access through www.HDYO.org. Plus, you know I am always here for you.*

Q. What will happen to Mom when she gets sicker? Who is going to decide what to do?

A. *As time goes on, there are going to be difficult decisions to make. You and I can work with the HDSA social worker so we know what to expect and we can plan for the future.*

Q. How can I explain HD to other kids?

A. *It depends on why the other kids are asking. If they want to know why your Dad is walking or talking differently, you can tell them that it is a muscle problem. If they are asking because of something that your father has said or done, you can say that he is not well and that the sickness can make him upset. If they ask if you Dad is sick, you can say yes, but it is nothing you can catch.*

Q. Why are we keeping this a secret?

A. *Because, right now, it is private family business. There is nothing shameful about having HD, but we think that your mom should be the one to decide who to tell. There are some out there who discriminate against people with HD. They can make it difficult for people in HD families to get some kinds of insurance or certain jobs. That may not be fair, and there are many dedicated people who are trying to change these attitudes, but right now we think there are a lot of people who don't need to know.*

Note: HDSA promotes neither secrecy nor transparency about HD, but respects the decisions of individuals and families as to with whom they share their private medical information.

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

- A. *There weren't the same options that are available now.*
- A. *I wanted to have children and I hoped you would be ok.*
- A. *We didn't know there was HD in our family when we were expecting you.*
- A. *No one else in the family wanted to be tested, so I didn't do it.*

Q. If your brother got tested for HD, why aren't you getting tested?

- A. *Deciding to test is a very personal decision and I am not ready to make that decision now.*
- A. *I know I'm at risk, but I know there is also a chance that I did not inherit the bad form of the gene. I've made my choices considering that my life could go either way. When you are 18, you can make your own decision.*
- A. *Because of my job, right now it is better for me not to know if I am going to get HD.*



SPECIAL TOPIC—CHECKING IN WITH YOURSELF

After you have started the conversations with your children and answered some of the hard questions, check in with yourself. Dealing with the changes to the family caused by HD can be overwhelming. It is important that you take care of yourself, so that you can take care of the people who depend on you. Ignoring your own well being is not a practical long term strategy.

Be aware of the signs of caregiving exhaustion and “burnout”:

- Being constantly tired, sad or depressed
- Feeling helpless and alone
- Eating more or less than usual
- Difficulty sleeping
- Feeling distracted or “spacey”
- Not taking time for favorite activities/turning down invitations
- Drinking alcohol or using drugs to relax or deal with pressure
- Thinking about death

HDSA wants you to know that you are not alone. There are people who understand what you are experiencing. These include the physicians and social workers at the HDSA Centers of Excellence, the social worker at your HDSA Chapter, members of an HDSA Support Group, or HD-knowledgeable mental health professionals. You can call the HDSA Helpline at **888-HDSA-506** for more information or a referral to these resources. Your primary care physician or nurse practitioner may also be familiar with the mental health resources in your community, such as mental health community centers or programs which are very affordable.

COUNSELING: ONE PARENT'S STORY

Counseling is a vital part of my life. I know that I am much better able to cope with my daily life and the HD in my family because of this counseling. I also know how fortunate I am to have had a great therapeutic relationship with this same psychologist for over 30 years. This continuity of care has been priceless. I understand that not everyone may have this opportunity. There have been months or years that I have not needed to have appointments with him, and then there have been extended periods ... years ... that I have seen him weekly or bi-weekly.

I would highly suggest personal counseling in dealing with this disease. I have been depressed, angry and sometimes thought that I could not do this anymore. But the counseling has helped me achieve a level of “normalcy and a peace of mind” that I doubt I would have otherwise have had. Useful tools have been given to me, which I can apply to many situations, not just dealing with HD in my family.

My health insurance early on had very limited mental health benefits for any of us. As time went on, the benefits increased and that certainly helped me to afford financially all of the counseling sessions. However, both the psychologist and the social worker were amenable in sliding scales and fees and helped work out payment plans so that we could continue to come as needed.

A photograph of a man and a young boy sitting at a desk in a library, looking at a book together. The man is wearing a red polo shirt and has a mustache. The boy is wearing a blue and white striped polo shirt. The background shows bookshelves filled with books. The entire image has a blue tint.

CHAPTER 2

SCHOOL AND SOCIAL LIFE

School is often a child's primary source of social interaction. Most of a child's day is spent at school or doing school-based activities, including school work, intramural sports, and after-school activities. A diagnosis of HD in the family will affect the child's school experience, as much as one might wish it were not so. There are ways that you can help your child navigate the ups and downs of living with HD in the family, and still be fully engaged in school work, and able to sustain relationships with friends and other kids at school.

Open communication between you and the child will make it easier when it is time to talk to people at school about the disease. By having conversations with your children about HD, you are helping them learn how to share appropriate information about HD at school and with their friends. If HD has been explained in a simple and basic manner, the child will be able to keep their explanations straightforward as well.

INFORMING THE SCHOOL

The school is the center of your child's day and the people who work there care about your child. Informing a few people at the school about the diagnosis of HD in the family will help to create a supportive and understanding atmosphere for your child. This section will guide you through the process of deciding who to tell, when to tell, and how much to tell.

You are the only one who can decide how much to share and when. Some parents believe that if there are presently no issues, then no one at the school need know. Other parents start by sharing the information with one or two individuals at the school. Some people you may consider talking to first are the principal, the child's teacher, school nurse, coach or school counselor. You can choose to meet with these important people individually or as a group.

Talking to any of these trusted adults will 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.

Keeping the child informed

It is generally wise to let the child know that you are going to share information with someone at the school. Sit down with the child during a quiet time and tell them in a loving, low key way that you are going to inform someone at school and who you are going to tell. Let the child know that you are doing this in case the child ever needs someone in the school to talk to—someone who understands what is going on and can be supportive.

If possible, the affected parent should give the child permission to tell whomever they need to at school.

Conversation starters about talking with the school

Young children (preschool and lower elementary grades)

- *“I want you to know that I am going to talk to the school nurse about HD. She probably does not know much about it. I think it is important that she learn about HD so that she understands what is happening in our family.”*

Older children (upper elementary and middle school)

- *“I want you to know that your Dad and I are going to talk to your teacher and guidance counselor about my HD. Most people don’t know anything about it. If they understand, they can help you if anything comes up, without making a big deal out of it. Do you want to see the booklet I am going to give them?”*



Teens (high school)

- *“I am bringing some information about HD to the school nurse and your guidance counselor. Most people don’t know anything about HD and it would be good for them to learn about it. I want what is best for you and these people are there to help you get the most out of school. Do you want to be there when I talk to them or is it ok if I go alone?”*

Conversation starters for talking with school personnel

- *“Thank you for talking with me about my daughter. Most of the time, she is handling her Dad’s HD really well, but I would appreciate it if you would let me know if you see that she is struggling with her feelings. I also count on you to keep this information private. Right now, we are only sharing this with you and a few other people. Let’s talk next week and you can ask me any questions that come up after you have read this booklet.”*
- *“My husband has HD and this means that my son may need to be at home to help in his care, or may have difficulties completing school work due to the demands that this condition places on the family. I would like to share some literature about HD with you, so that you can understand what is going on. I hope we can find ways to help my son, so that he can keep up.”*

TALKING TO THE SCHOOL: ONE FAMILY'S STORY

Within a month of my husband's diagnosis, I went in to talk to the school nurse. I wanted to make sure that someone at my daughter's school knew and understood what was going on at home, just in case her behavior or work ethic changed at school. I asked the nurse to just keep an eye on my daughter and to subtly check in with her teacher to make sure that she was not having any difficulty. The nurse was great and respected our privacy, while ensuring my daughter's mental and physical well being.

After a couple of months, I felt more comfortable to go in and explain the situation to both the teacher and guidance counselor. They too were very supportive and respected our privacy. I did tell my daughter both times that I went to the school to speak to the people involved. At age 8, she had no problem with that.

As she grew older, in later elementary and middle school, I would explain the situation to the school nurses and guidance counselors early in the school year, generally during the first parent/teacher conference. Luckily, she never seemed to have any problem in school, academically or socially, but it made me feel better knowing that key people knew what was going on. Also, by the time my daughter was in 5th grade, she understood that she was 50 percent at risk for developing the disease. I really wanted certain people at school to understand that she was walking around every day with this knowledge in her head. How many other 5th through 8th graders had that intense knowledge weighing on them? None that I knew of. I think that she probably would have been fine had I not told anyone, but, for me, it was reassuring.



When she was in high school, I let her decide whom she wanted to tell. When she was a sophomore, I went in and talked to a couple of her teachers, as well as the principal. She knew that I was doing this, and although she was not thrilled, she did not forbid me from going. She just did not want to be treated differently than any other student.

In her last two years of high school, I just let it be and again, left it up to her. She knew that people would see that there was something different about her Dad, so she readily talked to her closest friends and their families about it. We were very lucky because her friends and their families were very accepting and supportive of our situation and we never felt ashamed or like we had to hide anything.

CREATING A NETWORK OF SUPPORT

While your child will continue to turn to you for information and support, there are other people who are also important in his or her life. They may include a favorite teacher, sports coach, counselor or other trusted adult, as well as friends from school, church, clubs and teams. Together, these people form a network of support for your child and this network will be much more effective if the people in it have a good understanding of HD.

Trusted adults

Teachers, coaches, spiritual leaders, and others can be an important part of your child's network of support. These trusted adults may offer a steadying influence and help the child to know that many areas of their life will remain the same. If your child needs to talk with someone outside the family circle about their feelings and experiences, he or she may feel more comfortable talking with someone they already know.

If possible, meet with the person before the child does and offer them some information on Huntington's disease. The discussion can be very simple and short. Most people are still unfamiliar with HD and many of those who think they are familiar with the disease may be aware only 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.

Conversation starters with trusted adults

"I know that my daughter trusts you, so I want to share something. Her mother is sick with Huntington's disease, which is a genetic disorder that affects both the brain and muscles. Right now there is no cure for it. I would like to give you this booklet, Fast Facts About HD, so that you can understand something about the disease."

Your child's friends

A child's friends can be a big part of his or her team of support. The simple, age-appropriate information that you provide your child will help them to explain HD to their friends in their own words. Friends are very important to children and youth. Much of the same information that you share with school personnel may be appropriate to share with parents of your child's close friends. In some families, children who are not close to your child may say hurtful things about the affected parent, and the parents of your child's friends may witness or hear of these statements. These parents can be of help to you in preventing or dealing with hurtful situations, if or when they happen. Parents of your child's close friends may also be sources of support for your child, such as pitching in to provide transportation to a school event when you can't be away from home.

Educating your child's friends will be ongoing. Your child will probably make new friends in middle or high school. You may not know these teens and may find yourself having to reach out to this new group of friends (and perhaps their parents), to let them know about HD in the family.

YOUR CHILD'S FRIENDS: ONE FAMILY'S STORY

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.

PRIVACY AND DISCRETION

It is important that kids feel comfortable sharing with others. However, sharing on social networking sites or on the Internet can result in a loss of control of 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.

COUNSELING

Sometimes your child may not feel comfortable talking about their feelings or concerns within the family circle or even with a teacher or coach. Your child may wish (or need) to speak with someone trained in counseling. Mental health professionals like counselors and psychologists can be very helpful for children who are learning about HD and need ongoing support. Ask your school, pediatrician or HDSA Social Worker to make suggestions. If you find a counselor who is not familiar with HD, ask if he/she would be willing to use HDSA resources (website, books, phone call with Social Worker) to educate themselves.

It is often better for a child to meet with a counselor and form a relationship before a crisis occurs. As parents, you probably take your children to the dentist for routine check-ups, in the hopes of preventing a cavity. Think of seeing a therapist as the same type of preventative care. If possible, meet with the counselor before the initial appointment with your child. Provide the counselor with some background on the family and the child. This will give you a chance to use your judgment and decide if this particular therapist is potentially a good fit for your child. Ultimately, the child will be the one who needs to feel comfortable and confident with the counselor.

Kids can be skeptical of new experiences, so before you take the child to counseling for the first time, try to get him or her to agree to go two times before making a decision about continuing to go.

Conversation starters about seeing a counselor

- *“I have found a person who knows about Dad and HD and who has been helpful to me and to Dad. I would like you to meet her. It’s okay for you to talk to this person about anything, like feelings or questions, that you may not want to bring up with me. What you talk about is completely private.”*
- *“Sometimes we are nervous when we try something new. Remember when you were a little nervous the first time you went to [kindergarten/ soccer/camp] but then you liked it? I would like you to try meeting with the counselor twice, then we will talk about how comfortable you feel with them. I have already met with him, and I think you will like him. The counselor is like our dentist and doctor, someone who helps take care of you to keep you as healthy as possible.”*



INDIVIDUAL AND FAMILY COUNSELING FOR CHILDREN: ONE FAMILY'S STORY

When my husband was first diagnosed with HD, we decided as a couple to go and see a psychologist to help us deal with this unexpected and shocking news. We had several sessions together, as well as several individual sessions. Not that the psychologist could change this news or the outcome, but he helped us cope and get adjusted to the life altering news that had been thrust upon us.

About three years after my husband's diagnosis, we decided as a couple that it might be helpful if we had family counseling with our two daughters, then ages 5 and 11. They both were fully aware by that time of their father's HD and knew much about the disease that was age appropriate. My husband and I had been very open and honest about their father's HD and we talked freely about it when our daughters asked questions or had concerns.

The psychologist recommended a licensed social worker who had an office in our town. My husband and I met with her initially, for a few appointments, without our daughters. We wanted to establish a relationship with her and to see if we felt comfortable with her. We also wanted to ensure that it was a good fit because we knew that if our daughters did not feel comfortable with her or like her, there was going to be no point in the family counseling.

After about three or four visits with the social worker, we felt comfortable with her. We were pretty secure that our daughters would like her as well.

When we first approached our daughters about going to see the social worker, we just told the girls that we would like it if they would join us in meeting a person with whom we could all go and talk. We explained that we had met her and that she was very nice. We told them that we might sometimes talk about “Daddy’s HD” and how they felt about Daddy’s HD. We told them that we would talk about other family things or anything that they wanted to talk about as well. We made it seem like a family outing, meeting a new person. The girls were amenable to going and did not present any objections. I realize that we were fortunate in this regard.

The first few meetings with the social worker were a little awkward, in that we all had to adjust to this new situation. As time went by, the sessions were much more comfortable as we came to know what to expect and got to know the social worker better. Sometimes the conversations were geared toward HD and other times just simple topics like school or my daughters’ activities. Initially we went bi-weekly and that seemed an appropriate amount. We went as a family for several months, and then, as the girls grew more comfortable, they would go on their own.

For about a year, I took my daughters to see her twice a week. After that they each saw her on a weekly basis. They chose not to go very often during their summer vacations. One daughter would go in for about a half hour and then the other one would get her half hour. Because there was a 6-year age difference between my daughters, the social worker’s approach to each of them was quite different.

My older daughter was about 12 at that time and being pre-teen in junior high, she enjoyed just sitting in the office and talking. My younger daughter, who was 6, loved the fact that they would often go outside, take a walk, go to a nearby pond and feed the ducks. I am sure that sometimes she talked about her father's HD, but whatever else was on her mind as a first grader was just as important.

As they girls grew older, they each wanted to have their "own hour." The social worker was creative and thoughtful as to how she handled their sessions. Sometimes she would bring a snack and sometimes brought her puppy, to the delight of both my daughters. Playing games and drawing was another aspect that my younger daughter enjoyed about this process.

A couple of times a year we would meet together as a family. As my husband's HD progressed and he needed full time care, it was just me with my daughters or individually with each daughter, if there was an issue that was important for me to discuss.

I know how lucky we are to have found this wonderful counselor as both of my daughters continued to see her even in their college years. (For my older daughter, she only saw the social worker a couple of times a year while she was in college.) My younger daughter was a sophomore in college when she was diagnosed with Juvenile Onset HD, and the social worker was with us in the neurologist's office as the diagnosis was confirmed.



My younger daughter continued to see this same social worker almost on a weekly basis up until the time that she needed to go to a nursing facility. Her emotions over the years totally ran the gamut and the social worker was able to address and resolve many of the issues. Obviously, with my daughter having JHD, there were some things that a social worker could never resolve, but just having that therapeutic relationship with my daughter for all of those years helped her immensely. The social worker has now transitioned to the role of friend and visits my daughter at the nursing facility about once a month.

Counseling may not be for everyone, but for my family, it helped tremendously. It has allowed us to cope with, as much as possible, in a positive manner, the ever-changing aspects of HD. This does not mean that we, as a family, did not weather some pretty stormy times or traveled rocky roads. There were hundreds of arguments and issues over the years. We are by no means “The Perfect Family.” We continue to weather new storms and travel unfamiliar territory. But with the help of this psychologist and social worker, we are more prepared to deal with the upcoming storms and find our way on the less traveled roads.



CHAPTER 3

TEENS

This chapter outlines some of the challenges that you and your teen may face as part of an HD family. Not all of the topics will be relevant to your family or not relevant at this time, but if you are aware of the issues that other HD teens have raised, you may be in a better position to help your teen address these concerns and remain positive about life.

LIVING AT RISK

Being at risk for HD can affect your teen's ability to focus on school, choose a college major or career, and even enjoy relationships with others their age. By keeping the conversation going with your teen, you can help them manage the worries that are part of being at risk and live a positive life.

You can provide compassionate support through open communication about HD and by letting your teen share their concerns without judgment. Support groups, online forums and in-person counseling can also provide safe havens for your teen to express their worries and frustration, and offset any sense of isolation. Talking about problems with someone who understands the challenges of HD can be a big relief to a young person. Encourage your teen to call the HDSA Helpline at **888-HDSA-506** to receive information about specific resources.

Some at risk teens find it hard to make decisions about a college major or career track, worrying that there isn't enough time to do what they want because they may get sick some day. No one can say when symptoms of HD will arise (or in the case of an at risk teen, if they will ever have the disease). Encourage your teen to choose a field of study and pursue it to their best ability. The school guidance counselor can be a valuable ally in helping with this process.

Some of the issues that worry at risk teens are the same as teens who are not from HD families, and some are different. Being aware of the range of concerns that have been expressed by other at risk teens may help you in starting conversations with your child.

SOME ISSUES OF CONCERN TO AT RISK TEENS

- The health of the parent with HD
- The parent's ability to care for the teen
- Whether they will be able to take part in "normal" teen activities
- Their ability to leave home for college/career
- What it would be like to know their gene status
- How they will handle their responsibilities to the family
- Being embarrassed in public
- Dealing with outbursts and harsh statements from the person with HD
- The welfare and future of their siblings
- Who else has the gene mutation in the family
- Seeing possible symptoms of HD everywhere
- The loss of social life, both the family's and their own
- Worries that no one will love them
- Not feeling at ease bringing friends home
- Family finances

All in addition to the ordinary ups and downs of being a teenager.

LIVING POSITIVELY WHILE AT RISK FOR HD

Hope is essential to a positive life. Help your teen stay hopeful for the future and see the potential in every day. Remind him or her that people in the HD community can (and have) accomplished great things in their lives. Keep informed about the research being done to find treatments and a cure for HD.

Ways for at risk teens to stay positive:

- Staying proactive and making plans for college/career
- Being involved in school and community activities
- Spending time with friends
- Staying physically active
- Contributing to household tasks for the family
- Asking for and accepting help when things get difficult
- Participating in HDSA's National Youth Alliance (NYA)
- Joining a local chapter of HDSA
- Attending a regular support group or counseling session
- Volunteering with fundraising
- Advocating for the rights of people with HD through HDSA
- Participating in Clinical Research or Observational Studies

GETTING YOUR TEEN TO TALK

Talking with any adolescent can be challenging. They feel things deeply and their reactions can be strong and emotional. Teens can shut down in silence or explode with harsh words. They may also try to mask their true feelings and pretend they are untouched and unconcerned by the changes around them. They may refuse to talk about HD with you at all.

While you cannot force your teen to talk about their feelings, you can try to keep the lines of communication open. Let your teen know that you are willing to listen to what they have to say, without judgment, whenever they are ready to talk.

It may also be helpful for the teen to talk to someone outside the immediate family. A support group, therapist, spiritual leader or trusted adult may provide your teen with an opportunity to speak openly about their experiences and concerns, without worrying that they will hurt your feelings.



PLANNING FOR THE FUTURE

The challenges of living in an HD family can sometime push planning for the future into the background. Encouraging your teen to make plans for college, or a career, can help him or her take a positive attitude about the future.

As the parent, you may have a good idea what your teen hopes for the future, but the two of you may not have talked openly about the teen's concerns or any hurdles that need to be overcome. Here are some possible conversation starters to help you begin talking about these sensitive subjects.

Conversation starters about planning for the future

- *“I know we have all been very focused on Mom recently, but I do not want you to change your plans about going to college. Let’s talk about how we can free you up to go to college in the Fall. I am sure we can find a solution together.”*
- *“You may be worried that we can’t pay for college or more training. Mom and I had talked about this. I have some ideas about what we can afford.”*
- *“Maybe you sometimes think about what might happen if your brothers or sisters get HD and you don’t. I think we can work something out, so that you don’t feel trapped. Let’s talk about it.”*
- *“You work pretty hard taking care of Dad. Are you worried about who will take care of you if you get HD?”*

GENETIC TESTING

Making a decision about being tested for the gene that causes HD is a serious decision and a highly personal one. Knowing one's gene status "changes everything and changes nothing." Gene status is a fact, but life is still there to be lived. While the current guidelines for the predictive test for HD specify 18 years as the minimum age for testing, many at risk teens have said they want opportunities to talk about the test even though they would not be able to make a final decision for years.

As a parent who has the gene mutation for HD, or a parent who does not, starting the conversation with your teen will help you discover what they think about the test. You may have strong feelings one way or the other about predictive testing for HD, but ultimately, the decision will be the young person's to make. Talking it out may help you accept whatever decision your child makes when they come of age.

During your conversations, your teen may change his or her mind many times. Let your teen know that there is no need to make the same choice as other family members. It is common for some members of a family to choose testing while others decide not to test. Currently, less than 15% of people at risk ultimately choose to be tested.

If your teen seems interested in learning more about the process, you can offer to schedule a meeting with a genetic counselor or HD social worker who can talk to them about the test. The genetic counselor is a neutral party, outside the family circle, who can help the teen begin to think about what they might do when they reach the age when a test can be performed.

Conversation starters about genetic testing

- *“I know there a lot of important decisions ahead for you. One of them is whether to have the HD test when you turn 18. What do you think about that? Is this something that affects your thoughts about getting married, or other plans you want to make for your own life?”*
- *“I know that Dad’s HD puts a lot of stress on our family. And I know that you wonder about your own gene status. I want you to know that I can’t fully understand what that must be like, but I care about you very much. Is there anything I can do to understand how you are feeling? If you don’t want to talk about it, that’s OK, too, but I’m always willing to listen.”*
- *“There are people at the center where I get my HD checkups who can talk with you about this.”*

DATING AND SEXUALITY

When a teen begins to date, it can be an emotional time for the parents. Their child is growing up and forming attachments outside the family. It can also bring up issues around telling people about HD in the family. Your teen may need support from you to be feel comfortable not saying anything about HD with casual friends and also feeling confident, when the time is right, to tell their HD story to someone they feel more serious about. You may not be able to reassure your teen that the love interest will accept the family, but you can lend a sympathetic ear and listen carefully and respectfully to what they say.

Teen dating may also bring up the topic of pre-marital sex. Probably one of the thorniest issues faced by parents of at risk teens is talking about sexuality. Teen dating and sex is a hot topic in any family, but it has added weight when HD is present, because unless there has been a diagnosis of JHD, your teen probably does not know his or her gene status. If the teen were to parent a child the baby would also be at risk for HD.

The teenage years can be a time of risk taking and your child may not be thinking seriously about the consequences of their behavior. Even teens with a strong religious background can make poor choices when it comes to sexual behavior. While it can be difficult to accept that your child may be involved in a sexual relationship, it is important to let them know about the possible consequences for a person at risk for HD. Open communication and factual information can help your teen make good choices.

Conversation starters about sex and dating

- *“What do you think about becoming a parent someday? Do you think you are ready now? Having a child should be a serious decision. I want to know if you and your partner are using birth control. With HD in the family, avoiding an unplanned pregnancy is important.”*
- *“At some point you will want to tell your partner about your risk of developing HD. What do you think you will say? Are you comfortable keeping it to yourself right now?”*
- *“Some at risk people choose to be tested for the HD gene before having a baby, or even before getting into a serious relationship. What do you think about that?”*



TALKING WITH TEENS ABOUT HD AND DATING: ONE FAMILY'S STORY

When my daughters became of dating age, which in our house was 16, they both felt it was important to tell their serious dates about their father's HD, as well as their own personal at risk status. My daughters were 8 and 2 when my husband was diagnosed and we were very up front about HD. As they grew, we gave them age appropriate answers to their questions or comments about HD. Just like they would tell their friends about their father's HD after they felt comfortable and secure in their friendship, so they did with the few serious boyfriends they each dated. It was just a natural progression of their dating relationships.

Because they were not self-conscious, afraid or even ultimately embarrassed by their father's HD, it was a natural and normal topic. They wanted their boyfriend(s) to understand why their father might look, speak or act a particular way. Their mission in explaining HD was not only to inform, but also educate their boyfriend and his family and friends about HD.

My daughters felt that it was important for their boyfriends to understand their at risk status. A large part of wanting to share this knowledge was purely for HD education, and not to evoke sympathy, pity, or fear. It was pretty general knowledge in my daughters' social circles about their father's HD and that they were at risk, so the boyfriends may have also known this ahead of time.

It was not something that they dwelled on. They let the fact be known and they educated their boyfriend(s) about HD. However, once the information was imparted, they had a very normal teenage boyfriend/girlfriend relationship. The two most serious boyfriends that each daughter had, over the course of their high school and college years, were very accepting of their father's HD in general, and their at risk status in particular. It was not detrimental to the relationship at all.



When each daughter ended their first serious relationship it had nothing at all to do with HD and everything with the normal decision of wanting to “move on.” My older daughter’s second serious relationship was with her college boyfriend, whom she married after dating for 6 years. She told him about her father’s HD very early on as well as her at risk status, and what that could mean for the future. This knowledge of HD clearly did not hinder that relationship and they have been happily married for 7 years.

My younger daughter, who has JHD, met her most serious boyfriend when she was 23 and already symptomatic. She clearly had to tell him about everything on their first date, and he continues to be a devoted boyfriend almost

3 years later. My daughter has been in a nursing facility for a year and a half and he still visits her often and takes her out once a week.

In regards to dating and unwanted pregnancy, that was also a conversation that my daughters and I had often. My daughters and I had a good relationship when it came to the topic of sexual activity and birth control. My daughters knew that they could ask questions and talk about this freely with me or other important adults in their lives. After many conversations over time, as they were old enough to be talking about this subject, they understood that it was important for them NOT to get pregnant while they were still in high school or college.

I was always very emphatic that it was even more important in their cases not to have an unwanted pregnancy, as they did not know their gene status. We had many open conversations about what would happen if they got pregnant while they were still young and did not know themselves if they would ever become symptomatic with HD. They understood the serious ramifications of having a child that potentially could have HD. They also both understood that they could be symptomatic themselves earlier on and then to have a child who could also have HD would be very serious. We discussed as a family what a difficult situation that would be and how one person, (myself as the mother), would then potentially have to take care of 4 people besides their father that had HD.

The thought of bringing a child into the world that could have HD was worrisome and disconcerting to my daughters. They understood that it would be difficult enough to try to care for themselves and continue their education, while caring for a baby ... one that could develop HD. They both knew this was a situation that they did not want nor could handle, and knew that it was wise to either abstain from sexual activity or to make sure that they had taken the proper precautions by using birth control. This was another reason that I feel that they felt comfortable in telling any serious boyfriend about their father's HD and their at risk status. They wanted to make sure that their boyfriend would fully comprehend the circumstances if an unwanted pregnancy happened.

I cannot say how other teenagers would handle talking about HD and dating. I do believe that if the family has been open and honest about HD, and can have meaningful discussions, that the teenagers will follow suit. I believe that the teenagers will know which perspective dates they will want to tell about HD on their own. As a parent, I believe that you have to trust your child and give them the opportunity to discuss this with their dating partner. As their parent you can be open, supportive and encouraging, but still give them the final say as to whom they tell and when.

SPECIAL TOPIC—TEEN CAREGIVING

Many teens in HD families help with caregiving. Their assistance may make it possible for the person with HD to keep living at home and for the healthy parent to keep working. Caregiving teens can find themselves making day to day decisions about the care of the person with HD and taking on an adult caregiving role, often without supervision or support. Caregiving for a person with HD can be very stressful and teens who provide caregiving need support and understanding. Some of the responsibilities that teens take on include:

- Helping the person with HD with activities of daily life, such as eating, dressing and bathing.
- Acting as a peacemaker, to minimize outbursts and undesirable behavior in the person with HD.
- Finding their own solutions to behavioral problems and psychiatric symptoms in the person with HD.

Teens report both positive and negative feelings about being caregivers. Positive aspects of caregiving included strengthened relationships with the healthy parent and siblings, less tolerance for peers' insensitive behaviors and increased empathy for older adults, as well as feeling closer to the sick person. Some said they found caregiving hard but gratifying. Others derived self worth when their contributions to stability in the family are recognized and supported.

That said, there are many ways that caregiving affects teens negatively. Caregiving youth may have feelings of sadness, alienation, fear, anger, resentment and frustration. Caregiving can affect learning and reduce time for study. They may get into trouble with teachers, be unable to do homework, miss school or be chronically late for school. Teens can feel isolated from their peers and overwhelmed.

The difficult and emotional aspects of looking after a person with HD are well known to adult caregivers. But teens are not adults. They may have a powerful sense of responsibility, but they have no administrative or legal authority over the care of the person with HD. They may coordinate the daily care, but be left out of family decisions about that care.

Other members of the family may take the contributions of the teen for granted. If there is not a well parent on the scene, the teen may be left to coordinate care alone, without training as to how to ask for help from healthcare providers or social services. Lack of authority, high responsibility and high personal uncertainty make teen caregiving a very demanding responsibility.

In some households, there is more than one person with HD. Teens in an HD family may have a parent or adult relative with HD and a sibling with JHD. They may do a lot of caregiving for the sibling at home and act as a protector at school. However, the responsibilities of providing care for a parent with HD are heavier than caring for a sibling because the teen is taking over the parental role.

In addition, these teens are at risk for HD, which means that they know they may develop the disease in the future. This can color all aspects of their lives, influencing their decisions about their future, as well as their activities in the present. Although some teens may be eager to escape the family and the responsibilities, others are reluctant to leave once they have finished high school because of concerns regarding who would be in charge.

You may rely heavily on your teen for help with caregiving. By talking about the teen's contributions to the care of the person with HD and by asking for his or her observations and opinions about care, you will show respect for the teen's efforts. You may also hear some valuable insights about the person with HD.

To learn if your teen is feeling a great deal of stress and not expressing it, gently ask them about it. It could take several casual conversations to get them to share their feelings, as they may not want add to your burden.

As your teen matures and begins to prepare for his or her own life as an adult, it will be necessary for the family to find other hands to help care for the person with HD. The social worker at your HDSA Chapter or Center of Excellence can help you begin the process of locating resources for caregiving and in making a plan to help your teen become an independent young adult with a positive future.

Conversation starters about teen caregiving

- *“I know you missed going to the game because you had to stay home and watch your Dad and I want to thank you for that. Do you need some time off? I could ask (friend or relative) to take over tomorrow so that you can see your friends. What do you think?”*
- *“I’ve been asking a lot of you lately. How are you feeling? Are you able to keep up with your schoolwork? Is there anything I can do to share some of the burden with you?”*
- *“I’m sorry that (Person with HD) was so hard on you today. It must be frustrating to do so much for someone who doesn’t seem to appreciate it. Do you want to talk about it?”*
- *“I know that people in our family don’t all agree on how to take care of your Dad. You have good ideas and I agree with you when you tell dad he can’t have another cigarette (or beer). You are very patient with him and I really appreciate that, and I know he would agree with me. When you are upset by family arguments, please let me know, and I’ll deal with his relatives.”*
- *“I don’t want you to feel that you have to do all these caregiving chores yourself. Let’s talk about who else we can include to help with all that needs to be done for the family.”*



MAKING TIME TO “JUST BE A TEEN”

Teens can be very effective caregivers, performing physical and decision making tasks at the level of an adult. But they aren’t adults and they need time to “just be a teen.”

Teens are at a developmental stage where they are learning to make decisions about their own behavior; for example, choosing who to spend time with, who to date, and what course of study or training they want to pursue. The time that teens spend with their friends or on sports teams or in after-school activities is not wasted time. Teens may look like they are “goofing off,” but they are actually learning important social and decision-making skills and are developing a sense of themselves as individuals. They need time for these activities.

SPECIAL TOPIC—ALCOHOL & DRUGS

All teens are at some risk for substance abuse. Teens can be impulsive and fail to recognize the consequences of their behavior. Substance abuse can also be a teen’s response to stress. Living in an HD family is often stressful. Teens may react to the changes at home with lower self-esteem, aggression or depression, any of which can increase the risk for substance abuse. Most adolescents will be exposed to risky situations at some point, but there are factors that may help them make good choices.

According to the Partnership at drugfree.org, young people who learn about the risk of substance abuse from their parents are much less likely to abuse drugs and alcohol. Working to keep communication with your teen open and honest will help protect your teen from substance abuse.

According to the National Institute on Drug Abuse, other protective factors include: individual self-control, parental monitoring, academic involvement, anti-drug use policies at school, and strong social attachments.

Conversation starters about drugs & alcohol

- *“What would you do if you were with someone who was using alcohol or drugs? I want you to know you can call me anytime and I will come pick you up. I won’t be mad. I’ll be proud of you for calling.”*
- *“I really care about your future and that you grow up to be happy and independent. Drugs and alcohol can really make it hard for people to accomplish these things. Tell me what kind of thoughts you have had about drugs and alcohol.”*
- *“Now that you are driving, I want to talk to you about drinking and driving. This is a very serious thing. What do you think about it?”*

Conversation stoppers about drugs & alcohol

- *“I need to know where you are and who you are with all times. I don’t trust you.”*
- *“You are never going to take drugs or drink, so we don’t need to talk about it. Ever.”*
- *“You can’t go to the [event]. Kids just go there to drink and take drugs.”*
- *“If I ever find out you have been drinking or taking drugs, I will never speak to you again.”*
- *“If any of your friends is drinking or taking drugs, I expect you to tell me so I can call their parents and you will never see them again.”*

WHAT PARENTS CAN DO

There are protective factors that you can foster to help your teen avoid substance abuse and dangerous behavior. You can help your teen by:

- Working toward open and honest communication
- Letting your teen know that you know that you care where they are and who they are with
- Showing an interest in their school work and activities
- Engaging your teen in caregiving and making family decisions
- Encouraging your teen to be part of something bigger than themselves, by volunteering through school, church or an organization such as HDSA
- Sharing the healthy ways that you to cope with stress, such as taking a walk, exercising
- Watching funny movies or playing games
- Helping your teen find a trusted adult to talk to
- Getting help if you need it, through a support group or counseling.

GETTING HELP FOR YOUR TEEN

Teens may have a difficult time managing stress because they feel there is no one to talk to who understands what they are experiencing. They may not want to burden you or other family members with their feelings. Their friends may not have the emotional maturity and life experience to help them. Finding a trusted adult outside of the family to whom teens can go with their difficult or embarrassing questions is important. This person might be a social worker, coach, guidance counselor, nurse, spiritual leader, grief counselor or other mental health professional. There may also be a support group they can join.

HDSA has a Helpline that can put you in touch with people who can help. HDSA Chapters have social workers with information about local resources and support groups for your teen. HDSA Centers of Excellence have genetic counselors who can discuss the testing process. Call the HDSA Helpline at **888-HDSA-506** to access these resources.



Conversation starters about asking for help/counseling

- *“I know that you are very worried these days and you and I are butting heads. Would it help you to sit down and talk to (trusted adult) without me around? It could be an entirely private conversation. What do you think?”*
- *“You seem very sad. Would you like to spend some time talking to (social worker) next time we go to the HDSA Center of Excellence for Dad’s check up? She might have insights that I don’t have.”*
- *“I can tell you are pretty angry. A lot of what’s been going on isn’t fair to you, or to your Mom or our family. Sometimes talking about that can help. It doesn’t have to be me, but I’m willing to listen if you want to talk.”*



CHAPTER 4

**YOUNG
ADULTS**

Young adults in HD families can be faced with very “adult” decisions, including genetic testing, career, love, and marriage. At the same time, they may be managing the affairs of their affected parent or providing direct caregiving. The adults that they trusted to talk to them about HD when they were small can also help them navigate their new responsibilities as young adults. Some of the topics that may be important to young adults, and ways to begin to talk about these important, and often stressful, topics, are included in this section.

A TIME OF TRANSITION

Young adults are different than teens. They are legally adults. They may not be living at home. Thinking about HD may be the last thing on his or her mind. This may bring relief to the young person, but also feelings of guilt. It can be revealing to talk to your young adult and learn how he or she is doing.

Conversation starters for checking in with young adults

- *“It seems like a lot of good things are happening in your life. You now are on your own, you don’t have to check in with your parents. I just want to know how you are doing.”*
- *“It makes me very happy to see you making decisions for yourself—where you live, doing well in your job, how you spend your free time. How are things?”*
- *“You know I care a lot about you and your family. I want to remind you that you are not responsible for them. Now that you are an adult, you now can find ways to be a part of our family while making your own decisions about what your life should be like.”* [For a trusted adult who is not a parent]
- *“I was thinking about all the discussions we had about HD while you were a teenager. Now the responsibility and opportunities are your own and you can decide what’s best for you. I am here and will do all I can to help you with these decisions.”*
- *“Now that you are on your own, you now can begin to plan for your life and choose the ways in which you will balance your HD family with your own life.”*

GENETIC TESTING—A TIME OF DECISION

When a young person reaches the age of 18, he or she can choose to have the genetic test for HD performed. By that time, most teens in HD families are aware that the test is available and many have given it considerable thought.

HDSA's *Genetic Testing for Huntington's Disease: A Guide for Families* is available for download at www.hdsa.org. This pamphlet contains background on the testing process, Q&A's about the decision to test, guidance for choosing a testing center, as well as other important information.

If your adult child is considering being tested, encourage them to call the HDSA Helpline or speak to an HDSA social worker to learn about the HDSA-recommended protocol for genetic testing, which was developed by a consortium of healthcare professionals. That way you are assured that he or she will meet with a genetic counselor before any decision to test is made and, if the test is performed, that your adult child will be counseled when the results are returned. You can call the HDSA helpline at **888-HDSA-506**. You can find a list of testing centers that follow the HDSA-recommended genetic testing protocol at www.hdsa.org, in the *Living with HD* section.

Conversation starters about genetic testing

While ultimately the decision to test or not to test is up to the at risk individual, you can be a supportive listener and help him or her to make this major life decision. Below are some conversation starters of different topics that may affect a person's decision to test or not to test.

- *“A while back, we talked about the gene test for HD. What do you think about the test?”*
- *“Because I am not at risk for HD, I will never completely understand how you feel, but I was wondering what your thoughts are about the gene test for the disease.”*
- *“You have brought up the gene test for HD several times recently. Are you thinking of having the test done? Do you want to talk to me about it? Would you like to talk to a genetic counselor? I know there is one at the HDSA Center of Excellence.”*
- *“Quite a number of people at risk for HD ultimately choose not to be tested for the gene. What do you think about that?”*
- *“I know you are thinking about have the gene test for HD. What does your husband/wife/boyfriend/girlfriend think about it? Have you two talked it over?”*

DEALING WITH YOUR OWN FEELINGS

Genetic testing can bring up strong emotions in a parent, including grief and guilt. You may dread learning your child's gene status. This is completely normal, however painful. Consider talking to a counselor if you are struggling with your grown child's decision to have the gene test performed.

Choosing not to test—one person's story

I frequently talk to people in my community about HD. Usually, these conversations lead me to confide that I have a 50/50 chance of inheriting the defective gene and I have chosen not to know. A typical response I receive is “Well, if it were me, I would want to know.” But the decision is not that simple.

There is no cure or proactive treatment. If I were to test positive, what is there to do with that knowledge? From my perspective, nothing but worry and symptom search. Though research on HD has come far, and the results are very promising, currently there are no treatments that I could take to prevent the onset of the disease.

I am not at a point in my life where I am planning on having children. If I were, I would definitely get tested.



I want to live my life the way I would if HD wasn't an issue. Sure, if I tested negative I would be free of having to constantly think about my fears of getting HD, but if I were to test positive, how would I react? I feel that knowing I was gene positive would lead me toward making different life choices than if I didn't have to worry about HD. Knowing myself, I would also focus on that part of my life and constantly think about the future rather than appreciating and living in the "here and now". There are no guarantees in life—regardless of my gene status I could get cancer, have a car accident, eat a poisoned apple, etc. and die. I want to live my life without thinking about my demise and make decisions based on what makes me happy in this moment. If I were to test and find out that I was gene positive, I'm not sure I could do that.

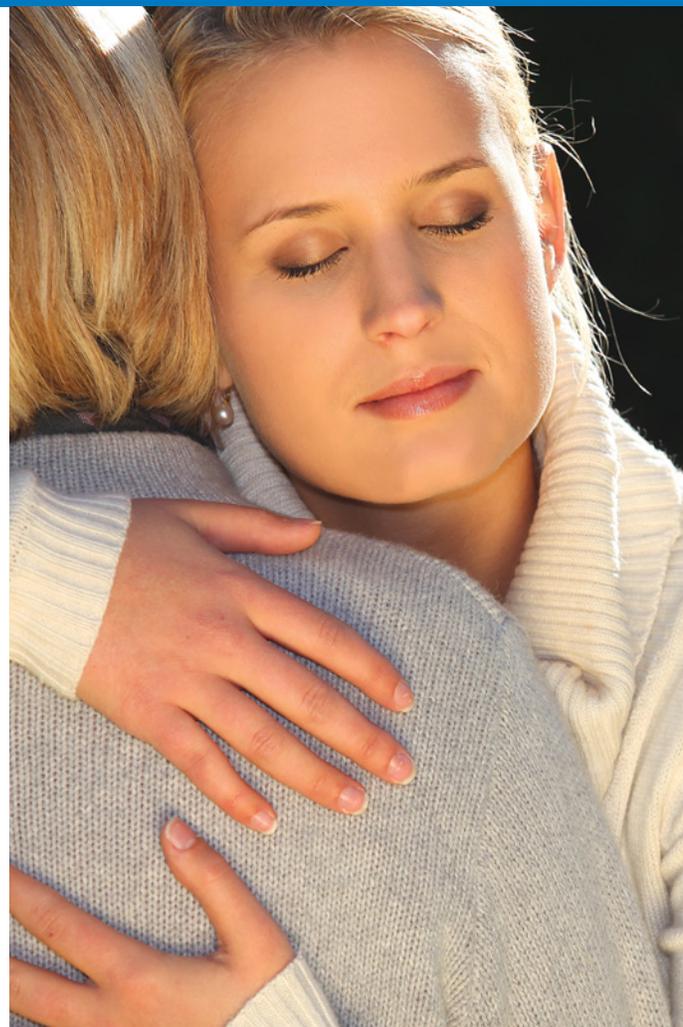
There is no right or wrong here. This decision, what I consider for me as The Decision, is so very personal. What's right for one person might not be right for another. Each person's ability to handle the known, or unknown, is so different. What I do know is what is right for me at this moment in time. I am constantly re-evaluating my decision to make sure it's right for me, and that's the advice I would give to others having to make the decision.

Choosing to test and testing positive—one person's story

After seeing my mother suffer day after day from the devastating effects of Huntington's disease, it seemed like I had no other choice then to take the genetic test that would tell my fate. I felt I could not plan my future without this knowledge.

I was 24 years old when I made this decision. I went to get my test results and learned that one day I would have to battle this disease as well. For many, this would have been the worst day of their life, but not for me. I decided it was time to live. I put a smile on my face, and I spent every day living life to the fullest and feel I have not stopped. I bought my first house, opened my own business (over 13 years now) and have made the decision to not have children. This is not a bad thing; I enjoy all the children that have come my way and try to be the best aunt I could be. I am blessed to have so many nieces and nephews (not all blood related).

I have had the privilege to take over the job of co-facilitator (trained by my father) to the local HD support group and I try to help all those that have lost their smile. I will work day after day to try and help those that fight this disease whether they are the person with HD, a caregiver or just a friend. I hope to make a difference. I feel blessed to have been given the chance to make these choices based on my results. My life may have been different without this knowledge, but I can't complain. I guess it's true what they say; you CAN make lemonade out of lemons!



Choosing to test and testing negative—one person's story

I had always planned to get tested when I turned 18, but when the time actually came, I decided the chance of testing positive was just too scary for me to gamble. I made the decision to test in 2005 because of the crossroads I was at in my life. I was about to graduate from college with my bachelor's degree and was engaged to get married.

When deciding to finally get tested, I knew that if I tested positive I would still get married, but no longer plan to have kids; I also was trying to decide whether I wanted to go on to grad school or if I wanted to stop with my bachelor's degree and choose a job that I enjoyed but also enabled me to do things in my life. I had been struggling with whether I was showing symptoms during the previous year and I could not handle not knowing anymore.

I wanted to make sure that if I tested positive I started taking proper precautions and preparations, even making healthier decisions; things really anyone should do anyway, but I felt was more important in prolonging my life, if positive. Without discussing it with anyone else, I called and set up the testing process so I didn't have more time to change my mind.

When looking back, I think I would have still tested for the reasons I did, but I wish I would have taken the time to talk to a genetic counselor about it. I wasn't prepared for a positive result; I had worked out what I would do but not actually talked it out in my head and had the proper support system set up. Someone who could walk through the pros and cons without being directly involved might have helped me be more confident walking into that room that day.

I took the gamble and got lucky; I now look at it as if I were chosen to be one of the ones who fights for those who can longer fight for themselves.

SIBLINGS AND GENETIC TESTING

Results of genetic testing can sometimes strain the relations between siblings. Those who test positive for the gene may express resentment toward brothers and sisters who do not. Siblings who test negative may feel guilt as well as relief (although they had no control over which gene they inherited). Siblings who are still too young to be tested may have a strong reaction to the results of an older siblings test results. Counseling may be helpful during this difficult time.

DATING—WHEN TO TALK ABOUT HD

Young adults at risk for HD carry that knowledge with them everywhere, including their social life. When they are attracted to someone and when they date, there is always an anxiety that they will be rejected because of their gene status.

If they are dating, they are faced with several dilemmas. When is the right time to talk about the disease? How do they begin the conversation and what is the right thing to say?

There are many different opinions and approaches about what to tell and when to tell it. Some young adults feel that, even in casual or initial dating, it is dishonest not to reveal the presence of HD in the family. Others want to postpone the discussion indefinitely. As a trusted adult, you can ask your adult child about their feelings and support them in their decision making process. You may be able to introduce ideas he or she may not have considered.

Considerations may include:

- The risk of bringing up such a serious discussion too soon in a relationship.
- Is the person trustworthy and discreet?
- Is there an intimate relationship developing where pregnancy is a possibility?
- Are they afraid of being hurt or rejected?

Your young adult is not alone in facing this difficult decision. Others in the HD community have insights to share. If possible, he or she should talk to other young people who have been through the process. He or she may want to talk about this experience, perhaps in an HD support group. The decision can also be discussed in a supportive setting with a counselor, spiritual leader or other trusted person. Caution should be exercised before talking about gene status on social networking sites or anywhere on the Internet, as it is easy to lose control over private, personal information.

Conversation starters about dating

- *“You and (girlfriend/boyfriend) seem to be getting serious. Have you talked to (her/him) about HD? Is this something where you’d like some help?”*
- *“I heard that your friend is getting married. I hope you don’t think you can’t get married because you’re at risk for HD. What do you think about getting married?”*

MEETING THE FAMILY

A time may come when your grown child will want to introduce their boyfriend/girlfriend to the extended family. He or she may be concerned that a relative with HD may behave inappropriately or that the physical symptoms of HD will be shocking to a person not familiar with the disease.

If possible, talk with your adult child about their hopes and fears around the event. Find materials and information for their loved one to read before the family gathering. *Fast Facts About HD* is a brief overview of HD that is available in English and Spanish and can be downloaded from the HDSA website, www.hdsa.org.

Conversation starters

- *“I am glad you want to bring your boyfriend over to meet Dad. Let me know what day so I can tell him in advance. Let’s also think about the best time of day for you two to come over.”*
- *“We are all looking forward to meeting your girlfriend. I am sure you’re wondering what her reaction will be. Can I tell you about the night I met your father’s family?”*
- *“You seem concerned about bringing your boyfriend to Thanksgiving dinner. Do you want to bring it up in the support group and get their advice?”*



FAMILY PLANNING

Some young people cannot wait to have children. Some are more focused on career or other activities. For those young adults who want children and are at risk or positive for HD, this desire for children is offset by the knowledge that each child of a person with HD has a 50% chance of inheriting the gene mutation that causes HD.

Wanting to start a family is often the reason an at risk person decides to have the genetic test performed. If the test result is negative for the gene mutation, the young adult and their partner will know that HD is probably not in their future and that their children will most likely not be affected (there is a small possibility if the test result was in the indeterminate range).

If the test is positive, there are family planning options for a person at risk or gene positive for HD. Each of these might be right for some couples, or may not be something they would choose. A genetic counselor at an HDSA Center of Excellence, or in the community, can talk to the young adult and their partner about the range of family planning options for a person at risk or gene positive for HD. The HDSA National Youth Alliance (NYA) has information for young adults about having children and the options that are available on the HDSA website, www.hdsa.org/nya.

HDSA's *Genetic Testing for Huntington's Disease: A Guide for Families* is available in English and Spanish, also covers this topic in more depth. It can be downloaded from the HDSA website.

Conversation starters about family planning

- *“I see how much you like babies and little children. What do you think about having children? Do you want to know more about how other people at risk handle that decision?”*

CAREER PLANNING

A major task for all young adults is choosing a career path. This may bring extra challenges for those at risk for HD, or concerned about caregiving responsibilities. Ideally, young adults in HD families will not feel limited in their career choices. Many people who are gene positive have successful careers and young adults in HD families may benefit by talking with them. For other young adults, HD is still something way off in the future and they do not find it difficult to focus on going to school or finding a job. Some discover that after college is over, they begin to think about HD and their future more as they are faced with big life decisions, such as marriage, career, deciding where to live, or buying a house. Parents can be supportive by encouraging their young adults not to limit their career choices, and by ensuring them that their parent with HD will be well cared for.

TAKING CHARGE

Young adults in HD families may find themselves having to take charge of a parent or sibling with HD. They may find themselves dealing with legal problems, living situations, behavioral issues and other concerns, even as they wrestle with their own genetic status. Instead of focusing on building their own lives, these young adults are cast in a decision-making role, very much as if they are acting as their family member's parent. They may find this overwhelming.

As a trusted adult in the life of this young person, you can have a positive influence by encouraging the young adult to share their feelings with you, a social worker, a nurse, therapist, spiritual counselor or support group. You may also want to direct them to a lawyer or other legal professional who can help them manage the affairs of the person with HD. Mostly, however, just the knowledge that they are not alone in their struggle may help these young adults cope with their responsibilities.

Conversation starters

- *“You have taken over a lot of your Mom’s affairs recently. How do you feel about that? Could you use some help?”*
- *“I see that you’ve stepped in to help your brother now that his symptoms are acting up. How is that going?”*
- *“I heard that you dropped out of college to help your Dad. Have you talked to the social worker about getting him a home aide so you can go back to school?”*
- *“You have taken on a lot. Does your brother/sister know how many hours you are spending with your Mom? Have you talked to them about splitting the work?”*

YOUNG ADULTS AND THE BURDEN OF CAREGIVING

Young adults in HD families may find themselves in the role of caregiver and primary decision maker for a parent or other relative with HD. Even in families where there are several children or an unaffected parent, one grown child may take on the majority of the caregiving for the parent with HD.

The young person who has taken on the primary responsibility may feel isolated and emotionally exhausted. He or she may feel taken advantage of or resentful of siblings and other family members who may seem to have more freedom from caregiving concerns.

The high level of care that a person with HD requires, as well as the difficult decisions that must be made, can lead to feelings of resentment and cause disagreements between the primary caregiver and the other family members. These feelings can be complicated by family members who also worry about their own gene status.

FINDING HELP AND SUPPORT

To avoid emotional burnout and family strife, it is important for the young adult primary caregiver to talk to someone about these feelings and concerns. You can support the young adult caregivers by letting them know that they are not alone. The HDSA Helpline can put a young adult caregiver in touch with people who can help them navigate the difficult emotions of caring for a person with HD. Call the HDSA Helpline at **888-HDSA-506** to access these resources.



COPING STRATEGIES FOR THE YOUNG ADULT CAREGIVER

It can be difficult to know what advice to give to a young adult caregiver who is experiencing conflict with other family members. The Family Caregiver Alliance (www.caregiver.org) has compiled the following list of strategies, some of which may be applicable for the young adult caregiver in your life. You can use these suggestions in your conversations with the young caregiver or share the entire list.

Possible ways for a primary caregiver to manage relationships

- Express your feelings honestly and directly. Let your siblings and other family members know their help is both wanted and needed.
- Keep family members informed regarding a parent's condition.
- Be realistic in your expectations. Allow siblings to help in ways they are able and divide tasks according to individual abilities, current life pressures and personal freedoms. Assistance with errands, finances, legal work or other indirect care may be the best option for some family members.
- Express appreciation to your family for help they are able to provide.
- Accept siblings for who they are and expect differences of opinion.
- Try to respect others' perceptions and find opportunities to compromise.
- If communication is particularly contentious, arrange a family meeting that includes an outside facilitator, such as a social worker, counselor, religious leader or friend. A trusted outside party can ensure that everyone's voice is heard.
- If siblings or other family members are unable to help with care, seek other assistance to provide a respite for yourself. Call your local Caregiver Resource Center, Area Agency on Aging, Senior Center or other community resource to locate help.
- Try to forgive family members who continue to refuse to get involved in a loved one's care. The only thing we have control over in a situation is our reaction. Attempt to work through your negative emotions to take care of yourself and move forward.

CHECK IN WITH YOURSELF

Caregiving in HD can seem overwhelming. It is important that you take care of yourself, so that you can take care of the people who depend on you. Signs of caregiving exhaustion and “burnout” may include:

- Being constantly tired, sad or depressed
- Feeling helpless and alone
- Eating more or less than usual
- Difficulty sleeping
- Feeling distracted or “spacey”
- Not taking time for favorite activities/turning down invitations
- Drinking alcohol to relax or deal with pressure
- Thinking about death

Check in with yourself and see if you need to talk to someone. The HDSA Helpline can also help you identify sources of support. You can access the Helpline at 888-HDSA-506.

Counseling: One parent's story

Counseling is a vital part of my life. I know that I am better able to cope with my daily life and the HD in my family because of this counseling. I also know how fortunate I am to have had a great therapeutic relationship with this same psychologist for over 30 years. This continuity of care has been priceless. I understand that not everyone may be able to have this opportunity. There have been months or years that I have not needed to have appointments with him, and then there have been extended periods ... years ... that I have seen him weekly or bi-weekly.

I would highly suggest personal counseling in dealing with this disease. I have been depressed, angry and sometimes thought that I could not do this anymore. But the counseling has helped me achieve a level of “normalcy and a peace of mind” that I doubt I would have otherwise had. Useful tools have been given to me, which I can apply to many situations, not just dealing with HD in my family.

My health insurance early on had very limited mental health benefits for any of us. As time went on, the benefits increased and that certainly helped me to afford financially all of the counseling sessions. However, both the psychologist and the social worker were amenable in sliding scales and fees and helped work out payment plans so that we could continue to come as needed.

If you are interested in counseling, but don't know where to turn, I would suggest first speaking to the social worker at your HDSA Chapter or Center of Excellence, your primary care physician or the nurse practitioner. He or she should be familiar with the mental health resources in your community. Mental health community centers or programs may also exist near you, and the costs are very affordable if one has limited resources or insurance ... or none at all.

A photograph of a man and a child sitting together, looking at a baseball. The man is on the left, wearing a grey and blue long-sleeved shirt, and is holding the baseball in his hands. The child is on the right, wearing a dark blue t-shirt, and is looking at the baseball. The background is a simple indoor setting with a window. The entire image has a blue tint.

CHAPTER 5

**THE PARENT
WITH HD—
WHAT KIDS
WANT TO KNOW**

Over time, HD takes away so much. The ability to move. The ability to communicate. Children who were very young when their parent was diagnosed may not have a strong memory of what that person was like when he or she was healthy.

Children are often curious about their parents' lives, asking questions like, "*What were you like when you were a kid?*" and "*Where did you meet Dad?*" These kinds of stories can be lost as HD makes communication increasingly difficult.

CREATING A MEMORY BANK FOR THE CHILDREN

Many teens and young adults have expressed a wish to know more about their parent's life before HD. What did they like to do? What were their special talents? Who were their friends? Were they good in school? Knowing something about the personality, preferences, wishes and dreams of the parent with HD can be very comforting in the long run.



A memory bank could include written or recorded reminiscences, videos, photos of the person when they were young, memorabilia and other heirlooms, such as a football from school, a jewelry box or any object that has special meaning. It can also include statements from the affected parent about his or her life, values, and aspirations, such as:

- What are his or her hopes for the child?
- What is the parent’s definition of “success”?
- Does the HD parent have regrets or things they wish they had done differently?
- Is there a love story to share?
- What is his or her religious philosophy?
- What was his or her career like? How did he or she choose a college or a career?
- Are there things that the HD parent would want to say to the child at life’s milestones: graduation, marriage, baby, when they turned 18, 21, 30, 40, etc.?
- What are his or her opinions about getting tested? What does he or she see as the pluses and minuses of knowing or not knowing?
- “Coming out of the closet” about HD with employers—what was his or her experience?
- What does he or she think about having children and the current options for people at risk for HD?

Even if the HD parent cannot directly participate in the creation of the memory bank, anyone in the family can collect reminiscences that cover these topics and provide the children with evidence of what kind of person the parent was when he or she was healthy.

Archiving other important information

There is additional information that may be helpful to family members, children who are still in their teens, or young adults, who want or need to know more about their parent's experiences with HD. These 'facts' may help the person who is facing important decisions for themselves, or who are trying to fill in the gaps in their parent's HD medical and life history.

- Information about the disability. In addition to memories and mementos, grown children can benefit from very practical information about the parent's experience of HD, including when did the parent really first start showing symptoms and what were they?
- Information about when and where the parent got tested, and whether it was predictive or confirmatory.
- A timeline of symptoms and notable events and how the disease affected his or her job and other abilities.
- What were the advantages and disadvantages of disclosing HD family history to their physician?
- What was the experience like applying for benefits, insurance, etc. What challenges were there and how can the child avoid them in the future?
- How did the parent handle long-term care, disability, and life insurance issues? What were the challenges?

DOCUMENTING PREFERENCES AND PREPARING ADVANCE DIRECTIVES

Young people in HD families sometimes find themselves having to make difficult decisions for a family member with HD, with little or no idea what that person would have wanted, or alternately, knowing what the person with HD wanted but being unable to convince siblings or other members of the family to agree to a course of action.

If at all possible, the person with HD should share their preferences about end of life care in an Advance Directive, Living Will or Medical Power of Attorney. These legal documents outline what type of care a person wants (or doesn't want) in regards to topics such as nursing home placement, feeding tubes, do not resuscitate orders, etc.

If you are the parent with HD, try to make these decisions and complete the documents sooner rather than later, then share them with your doctor and your family. Your social worker, nurse, religious advisor, family physician or lawyer can help you in the preparation of your Advance Directives.

If you are the parent without the HD gene, encourage the person with HD to let their wishes be known and to complete their Advance Directives as early as possible. If you are uncomfortable starting the conversation, ask your social worker, nurse, religious advisor, family physician or lawyer for help.

Open communication sometimes means talking about very difficult and emotional subjects. By talking about end of life decisions with your children, and documenting these wishes, you are actually giving them the gift of certainty.

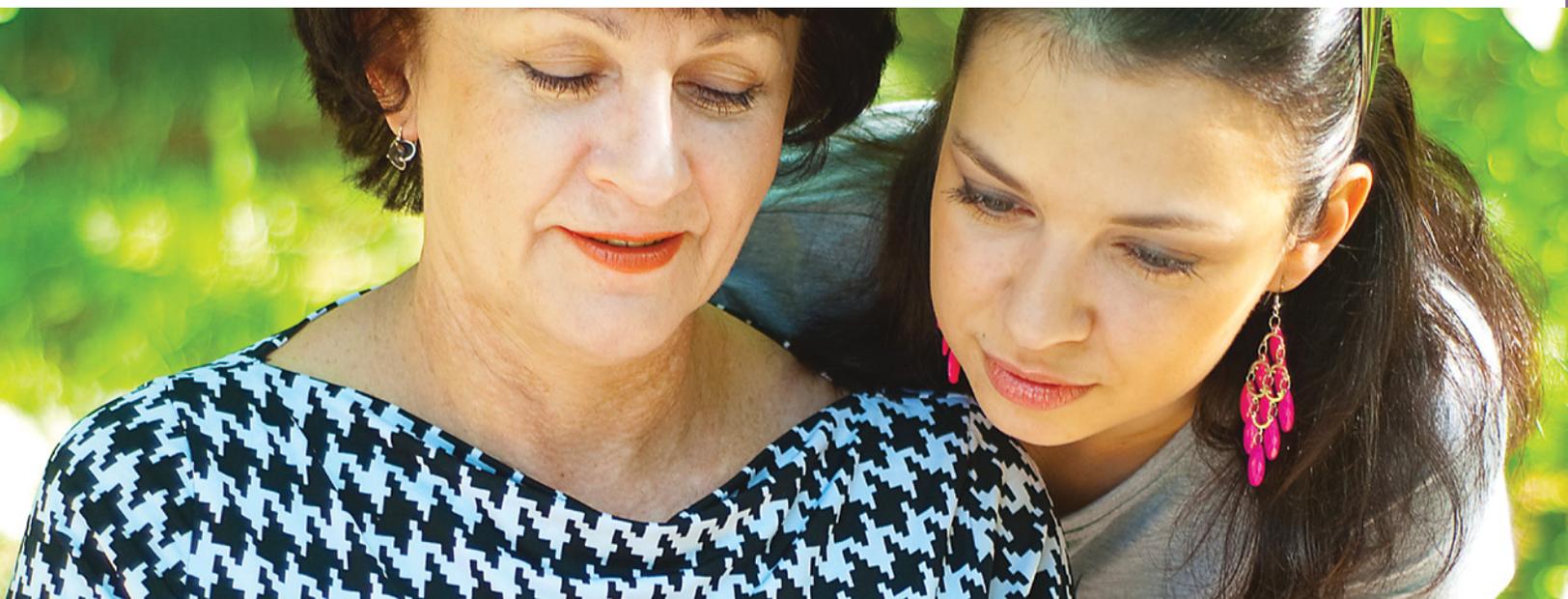
Conversation starters about advance directives

- *“It might become important for you to know your Mom’s preferences about how she wants her treatment to go when she gets sicker. Would you like to help me talk to her about this so that you can also be aware of her wishes?”*
- *“As your Dad becomes sicker, you might have to help make decisions about his healthcare and what medical treatment to give him. Let’s talk to him about what he wants. We can write these down and we can talk to someone who can help us make these official. That way, when the time comes, it will be less difficult for you to help make decisions about his care because you’ll know what he wanted.”*
- *“I know I am healthy now, but I want to talk to you about my wishes for care when I have more symptoms of HD.”*



Assistance with Advance Directives

There is help available to support you in the process of documenting preferences and completing Advance Directives for yourself or the person with HD. The *Advance Directives for Huntington's Disease: A Guide for Families* also covers this topic in depth. It can be downloaded from the HDSA website. The social worker at your HDSA Chapter or Center of Excellence can help you identify the information you need and the correct documents to use. Your family lawyer or financial advisor may also be able to assist you. You can be connected to HDSA resources by calling the HDSA Helpline at 888-HDSA-506.



CONCLUSION

In this book, many difficult topics have been brought up. You may be overwhelmed by the amount of information that has been presented. That is normal. This handbook was written to cover the broadest number of possible conversations a parent might have with a young person about HD, or with the important people in that young person's life. No single family will ever have all the conversations that are presented. The goal of this handbook is to provide strategies and conversation starters to help you find your own voice when navigating your family's journey with HD. The single most important idea to take away is the importance of maintaining open, ongoing communication about HD in the family.

Open communication also means finding safe outlets for your feelings. Know that there are many people ready to offer you guidance and support. These include the healthcare team at the HDSA Centers of Excellence, the social worker at your HDSA Chapter, members of an HDSA Support Group, or HD-knowledgeable mental health professionals. You can call the HDSA Helpline at **888-HDSA-506** for more information or a referral to these resources.



CHAPTER 6

JUVENILE ONSET HUNTINGTON'S DISEASE

When Huntington's disease develops before age 20, it is known as Juvenile Onset Huntington's disease (JHD). Talking to a young person about his or her own medical condition is very different than talking about the disease in another family member. This chapter takes a look at the unique challenges of JHD, both in terms of talking with the child about their symptoms, and in working with the school system to ensure that the child continues to succeed in school as long as possible.

TALKING ABOUT JHD WITH YOUR CHILD

Talking to your child about Juvenile Onset Huntington's disease is challenging. Ordinary issues of childhood and adolescence are intertwined with the progressive multiple disabilities caused by JHD. As symptoms change and progress, different approaches will be needed to maintain quality of life. In the following sections, examples of conversation starters are provided for some of the symptoms and challenges you may encounter. The goal is to start talking about the issue in a way that is non-threatening and encouraging to the child.

ANOSOGNOSIA

Some children with JHD have a symptom called anosognosia. This means that they literally are unaware of their symptoms. This is not to be confused with denial—anosognosia is a lack of insight. Be gentle, steady and consistent in your efforts to help and educate.

SYMPTOMS OF JHD

JHD often presents different symptoms and challenges than adult onset HD. While there is no symptom or group of symptoms that are absolutely required for the diagnosis of JHD, most affected children have several symptoms of the disorder by the time that the diagnosis is made.

- Positive family history of HD, usually in the father
- Stiffness of the legs
- Clumsiness of arms and legs
- Decline in cognitive function
- Changes in behavior
- Seizures
- Changes in oral motor function
- Chorea in an adolescent
- Behavioral disturbances

Juvenile Onset Huntington's disease symptoms may show up in ways that are similar to symptoms of Autism Spectrum Disorder (ASD). Children with JHD may, like those with ASD, experience challenges conveying information to other people and processing the information that they receive from others. Additionally, individuals with JHD & ASD share like challenges with social skills. They may not read facial expressions and non-verbal cues. Furthermore, the facial expression and non-verbal communication of the individual with JHD may not match what they are truly feeling. Because of the comparable symptoms between JHD and ASD, some of the strategies this handbook refers to were initially developed for individuals with ASD. Parents of children with JHD may find other valuable information in resources developed for ASD.

Conversation starters to explain JHD

Talking about motor problems

“Remember when Grandfather started using a walker? It really helped him. I’ve noticed that you are a little unsteady when you are walking. Make sure you use the railing on the stairs. Maybe we can try a walker for you and see if that helps. What do you think?”

Talking about cognitive decline

“It’s normal for school to be more difficult for kids with Juvenile Onset HD. It’s not your fault. I am so proud of your effort. We are going to keep making helpful changes so you can do well. How can I help you with your homework?”

Talking about depression

“Sometime I feel really sad and like I don’t want to do anything. Do you ever feel that way? It’s normal to feel that way and sometimes kids with JHD feel that way even more. That’s really hard for you. Please tell me if that’s happening. I want to help you and there’s ways we can make that better. You deserve to feel happy.”

Talking about behavior

“Do you know what impulse control is? It’s the ability to stop and think before you do something. I remember a time when I didn’t think before I acted [Relay anecdote]. Sometimes it’s harder for kids with JHD to control their impulses.”

Talking about hygiene

“I know sometimes it’s hard for you to remember things. That’s a part of having JHD. It’s really important for you to remember to brush your teeth and stay clean. Look—I have listed the steps for brushing your teeth. Let’s put this up by the bathroom sink. I think it could help the whole family! Maybe tomorrow, we can sit down together and write the steps for taking a shower.”

Talking about speech challenges/dysphagia

“Sometimes when I am excited, my words don’t come out how I want them to sound. That can be even more challenging for kids with JHD. At school, you are going to work with an expert called a speech therapist who can help you get your words out. She might give you some word and picture boards that will help you communicate by pointing. It’s a great tool to use when you need it. I’m excited to see and hear how your speech therapist helps you!”

JUVENILE ONSET HD AND THE SCHOOL ENVIRONMENT

Children with Juvenile Onset Huntington’s disease can, with proper accommodations, continue to succeed in school for quite some time. Students with Juvenile HD are entitled to accommodations in their school environment. As soon as possible, after your child’s diagnosis, make the school aware of the student’s disability.

Once the school is aware of the JHD, an Individualized Education Plan (IEP) team will most likely be assembled. The team may consist of the school staff members who will provide services to the student with JHD, such as a speech-language therapist, occupational therapist, physical therapist, school psychologist, social worker, parents, and teacher(s). The team writes a document, the IEP, that includes the accommodations or modifications for this student. The accommodations may be for academic, physical, communication, behavioral, and personal needs.

EDUCATING THE SCHOOL ABOUT JHD

Parents should be prepared to help educate the staff about JHD. Juvenile Onset Huntington's disease will most likely be new to the people at your child's school and it is important that they understand the breadth and complexity of the disorder. You may want to have a discussion with your child prior to talking to the school. If your child is interested, you involve them in the conversations when it's appropriate to do so.

HDSA has prepared materials to help parents of kids with JHD to find appropriate resources and provide education to relevant professionals. These resources include a *JHD Handbook*, a *JHD Resource Directory*, as well as the *JHD and the School Experience* publication, which includes questions and answers for school staff, administrators, teachers, students, and parents, as well as a CD with additional resources for parents, teachers and administrators. For more information, or to order these publications, please call HDSA at 800-345-4372.



Conversation starters with the school about accommodations

Academic activities

- *“My daughter is going to be in your class this year and, as you may know, she has been diagnosed with Juvenile Onset Huntington’s disease. Because JHD is different than other movement disorders you may have worked with, I am making appointments with each of her teachers to talk about the disease and the accommodations she may need in class. When is a good time for us to meet?”*
- *“I want to talk to you about my son. He has Juvenile Onset Huntington’s disease, which affects his movements, his speech and the way he learns. He is going to need some accommodations in class to help him participate fully. JHD is pretty rare, so I would like to sit down with you and talk a bit about what the disease means as far as his schooling. I also have some literature to share with you about the disease.”*
- *“I want to talk to you about my daughter’s disability. You may know that she has Juvenile Onset Huntington’s disease, but you may not know all the ways that it affects her. I know she doesn’t look “sick,” but JHD affects the way she learns and even the way she behaves. With your help, I would like to set up a meeting with all her teachers, if possible, and share some information about JHD written specifically for educators.”*
- *“I want to talk to you about my son. The symptoms of his JHD are making it really hard for him to complete his assignments and keep up with the work. I would like to set up a meeting to talk about his Individualized Education Plan (IEP) because things are changing for him, and I’d like to talk with you about what changes may need to be made in his IEP.”*

- *“I need to talk with you about the upcoming tests. My daughter has JHD, and while she doesn’t look “sick,” she needs extra time to figure out the problems and write down the answers. I will be happy to share her recent assessment by the Huntington’s disease clinic with you, and to see what kind of testing accommodations could work for her.”*

Physical activities

- *“I would like to talk to you about my son’s participation in physical education class. He has a movement disorder, Juvenile Onset Huntington’s disease. He loves gym, but he is going to need some adaptations in order to participate. Is there a time we can sit down and talk about a plan for him? Here is some background on JHD so you can know what he is up against before our next meeting.”*
- *“I am sure you have seen my daughter struggling to keep up in physical education class. She has a disease that affects her coordination and she keeps losing her balance and falling. Do you have any ideas for keeping her active without getting hurt? I have heard about adaptive physical education programs. Can we talk about that?”*

Music, arts, and other creative activities

- *“Thank you for taking time to talk with me. I am meeting with all of my daughter’s teachers. I want you to know that she has a disorder called Juvenile Onset Huntington’s disease and it is going to affect what she will do in your music/art class. The disease affects her coordination and her ability to initiate activities, so she may need accommodations in class. She loves to make music/art, but she may need a little help getting started and more time to finish projects.”*

Talking with the teacher about hygiene

- *“I want to ask for your help with something. You know my daughter has JHD and can be forgetful. Can you ask one of the other students or the teaching assistant, to go with her when she uses the bathroom and remind her to wash her hands before she comes back to class?”*

Talking with the school nurse about personal hygiene

- *“I have something I need your help with. As you know, my daughter has JHD and now that she has reached puberty, I am concerned about hygiene during her periods. Can I tell her to come to you if she forgets what to do about her period? And, if I know when it’s about time for her period, could I let you know so that you can check with her?”*

Talking with the physical education teacher about personal hygiene

- *“Coach, I want to ask you to feel free to remind my son to wash after gym class. He gets distracted because of his JHD and will go back to class smelling very strong. Can I give you a stick of deodorant to keep for him? Can you help him stay on track?”*

Talking with the principal about personal hygiene

- *“I need to talk to you about my son’s hygiene at school. Because of the JHD, he is having difficulty using the toilet without making a mess of himself. I think it may be time to talk about having a personal attendant to help him use the bathroom successfully and keeping his underwear and pants clean.”*



Talking with the principal/assistant principal about behavior

- *“I would like to talk with you about making a plan to help my son manage his behavior at school. His JHD is interfering with his impulse control and, as you know, there have been a few incidents where he forgot how to behave. May I have his neurologist call the school psychiatrist to coordinate a solution?”*
- *“I would like to bring a situation to your attention. You know how sweet and easy going my son is, even with his JHD. I have recently noticed that he is very confused when he gets off the bus. I asked him about it and it seems that certain students are pulling pranks on him during the ride. I know the school has a strong policy about bullying. What can we do to stop this?”*

Talking with teachers about behavior

- *“I know we both want what is right for my son and what is acceptable to the rest of the class. There seem to be certain situations that are triggers for him when he can't control his response. Can we sit down and make a short list of them and see if we can't figure out ways to prevent the outbursts? I think that if we work together we can find solutions.”*

Talking with school administrators/staff about safety–falling

- *“Thank you for taking time to talk to me about my daughter. I am concerned about the falls she has taken recently. The JHD is affecting her coordination, so she is going to need some accommodations to get around safely. I am particularly worried about the stairs. Can she be given permission to use the elevator between classes? Or can we have an aide walk with her so she doesn't get jostled and lose her balance?”*

Talking with the school nurse/administrators/staff about eating/nutrition

- *“I think that a number of problems that my son is having are tied to lunchtime. Children with JHD need a lot of calories and I know he is not getting them. I am not sure he is even eating most days. When he goes back to class hungry and thirsty, all kinds of behavioral problems crop up. I wonder if he needs to have access to extra snacks. It might also be helpful to have an adult sit with him to make sure he eats enough, or be in a quiet place where he can take his time and not get distracted.”*

Talking with the school nurse/administrators/staff about choking

- *“There is a problem I need your help with. My daughter has had a couple of close calls with choking in recent months. You know that she has JHD and that makes it harder for her to swallow. You may have noticed that she has difficulty with her speech. Both are part of the same problem. My point is that she really can’t drink regular milk or juice without choking. Her doctor would like her to have a thicker drink at snack time and during lunch, perhaps something like Ensure or a yogurt drink. If I send the drinks with her, can you arrange for someone to be sure she gets them at mealtimes?”*

HELPING YOUR CHILD ACCEPT ACCOMMODATIONS IN THE SCHOOL ENVIRONMENT

- *“You know how some kids wear glasses so they can see better and other kids wear hearing aids to help them hear better? Your teacher and I have an idea that will help you in class with [specific issue]. Let me tell you how it works.”*
- *“Tomorrow you are going to have lunch with [aide] in the teacher’s lounge, so you can get more to eat and not be so hungry in the afternoon. I think you will like it.”*



- *“I want you to know we got you the seat right behind the bus driver, so the big kids can’t bother you.”*
- *“I know how upset you were about the problem in the bathroom yesterday. I think we have a solution that I would like to talk to you about.”*
- *“Your teacher said that you can wear your headphones during the test next week because they seem to help you focus on your work. I am glad you were willing to give them a try.”*

HDSA RESOURCES ABOUT JHD AND JHD IN THE SCHOOL ENVIRONMENT

HDSA has created several publications that can assist parents, healthcare professionals and school administrators to cope with the ever changing needs of the young person affected by JHD. Unless otherwise specified, publications are available for download, and one print copy is available free of charge.

Publications about Juvenile onset HD that are available from HDSA include:

- *Family Guide Series to Juvenile Onset HD*: this 20-page brochure provides an overview of the juvenile version of HD.
- *The Juvenile HD Handbook*: this 87-page guide for families and caregivers was revised in 2007 and can assist in the diagnosis and care of a child affected by JHD.
- *The Juvenile HD Resource Directory*: this 78-page state-specific guide also contains a CD loaded with additional resources for families.
- *Juvenile Huntington's Disease and the School Experience*: This 150-page handbook is designed to educate school administrators, teachers and classmates about JHD. A Resource CD is included at the back. Note: This publication is only available in print.

You can download or order HDSA resources at www.hdsa.org/publications. For more information, please call HDSA at 800-345-4372.

JHD AND BULLYING

Bullying is defined on www.stopbullying.gov as “unwanted, aggressive behavior among school-aged children that involves a real or perceived power imbalance. The behavior is repeated, or has the potential to be repeated, over time.” Both kids who are bullied and who bully others may have serious, lasting problems.

Children and teens with JHD are at high risk for bullying—both as victims and aggressors. Not only are they affected by a movement disorder, they are also experiencing cognitive and behavioral changes caused by the disease.

Teasing and bullying can worsen symptoms of JHD, such as distraction, impulse control and sensory overload. In older children and teens with JHD, there is an added risk that the affected child may be bullied into engaging in socially inappropriate, sexually inappropriate, aggressive or even dangerous behavior. The types of conversations you may have around the issue of bullying will depend on whether the child or teen is the person being bullied or the person doing the bullying.



Bullying does not only occur in person or at school. Much of today's bullying happens by text, online, or on the school bus. Bullying can be verbal, social or physical. While many schools are working on addressing the issues of bullying, parents must remain alert to thoughtless and cruel behavior on the part of other students and be prepared to ask the school to intervene. Parents may want their child to be resilient and know how to ignore bullies, but they must also be alert to signs that the bullying is affecting the child's well being and sense of self worth. Let your child know that they can talk to you openly and without judgment about problems at school, on the bus or online.

You can learn more about bullying, what signs to look for, and what can be done to stop it at www.stopbullying.gov.

JHD AND SEXUAL VICTIMIZATION

Children with JHD may be at higher risk for sexual victimization. This can be due to a variety of factors, including reduced impulse control associated with JHD. If you are concerned about your child's relationship with an adult or another child, it is best to talk to them. For guidance, you can talk to HDSA or the National Child Abuse Hotline at **800.4.A.CHILD (800.422.4453)**.

According to the American Psychological Association, children who have been abused may exhibit the following behaviors:

- An increase in nightmares and/or other sleeping difficulties
- Angry outbursts
- Anxiety
- Depression
- Difficulty walking or sitting
- Withdrawn behavior
- Pregnancy or contraction of a venereal disease, particularly if under age 14
- Tendency to run away
- Refusal to change for gym or to participate in physical activities
- Regressive behaviors depending on their age (e.g., return to thumb-sucking or bed-wetting)
- Reluctance to be left alone with a particular person or people
- Sexual knowledge, language, and/or behaviors that are unusual and inappropriate for their age

As many of these behaviors are similar to the symptoms of JHD, you should talk to your child about their relationships and be honest about your concerns.

Talking to your child about possible victimization

When talking to your child about sexual abuse, it is important to remain calm and non-judgmental. One concern is that if the child has been a victim of sexual abuse, they might become re-traumatized by feelings of shame about the event. If the child feels ashamed about their actions, they may not feel comfortable talking about future dangerous situations. The child may not be able to understand why these actions are wrong. A parent may be required to explain things two or three times.

It is best to make time for the conversation, instead of having it in-between other activities. The conversation should happen in a calm, comfortable environment. It's possible that your child will not have any questions or much to say. Allowing your child to absorb the information is the most important thing.

Conversation starters

Here are few ways to start a conversation about this difficult topic, both if you do or do not suspect that your child has been the victim of sexual abuse:

- *“What are some of the things you do with your friends?”*
- *“If your friends are doing anything that makes you uncomfortable, I want you to know you can call me and I will pick you up right away, no questions asked.”*
- *“Can you tell me what the difference is between an appropriate and inappropriate touch?”*
- *“I have noticed that you have been spending a lot of time with Mr. Green. What do the two of you enjoy doing together?”*

Conversation stoppers

You may be shocked and horrified to learn that your child has been victimized. It is essential to realize that the child with JHD is just that, a victim, both of the abuser and of the cognitive changes and reduced impulse control caused by JHD. Accusing, blaming and shaming the child will only cause the child to shut down the conversation.



Avoid saying:

- *“How did you let that happen?”*
- *“I am ashamed of you. I thought you knew better.”*
- *“What did you say to make him think you wanted to do that?”*

Talking with the principal/assistant principal about bullying and sexual harassment

When bullying or sexual victimization occurs at school or school events, the parent should get the assistance of the principal's office in making it stop. Schools have very strict policies about these behaviors. Below are some possible ways to talk about the subject with the school administration.

Conversation starters

- *"I need to talk to you about a concern I have. I have discovered that my child with JHD is being repeatedly touched inappropriately by a certain group of students. My child has a disability and I am asking for your help to keep him safe while he is in your care. I believe we need to talk about getting him a personal assistant during school to prevent this behavior. There may be other things that you can suggest to make it clear to all students that this behavior is never acceptable in any circumstances, and that includes the school."*
- *"I need your help with something. My daughter is being persuaded to engage in antisocial behavior on the school grounds by some kids in her class. You know that JHD is affecting her impulse control and she will agree to almost anything if someone asks her. Can we arrange a meeting with these kids and talk to them about this before something terrible happens? I am afraid for her safety."*
- *"I am concerned about my daughter and I need your help. There are a couple of boys that were trying to get her to engage in sexual behavior during sports events after school. With her disability, she is very easy to persuade. You know that she is too young to legally consent. What is the school's policy about this kind of behavior and what can we do to protect her? I think she will need a personal aide to sit with her during the games."*

Although some of the scenarios described above present difficult or uncomfortable circumstances, parents and caregivers need to know that there are constructive ways to work together with the school to ensure the safety, well being, and opportunity to learn for their child with JHD. Schools are more aware of the rights of the students with special needs and are better equipped than ever before to accommodate them. In the case of a rare disorder such as JHD, recognition of the many challenges presented by the disease may require some educating and advocating on the part of the parent.

SELECTED RESOURCES ON CHILDHOOD SEXUAL ABUSE

The National Child Traumatic Stress Network

www.nctsn.org/

Autism Speaks: Autism Safety Project

www.autismspeaks.org/family-services/autism-safety-project/abuse

American Psychological Association: Understanding Child Sex Abuse

www.apa.org/pubs/info/brochures/sex-abuse.aspx

Rape, Abuse, & Incest National Network

www.rainn.org

Child Help

www.childhelp.org

Stop It Now

www.stopitnow.org

SEX AND THE JHD TEEN

The transition to adolescence can be challenging for families with JHD. An open discussion about sexuality is important because of the impulsivity and impaired judgment that are frequent symptoms in JHD. Young people with JHD need to have reliable information about protecting themselves against sexually transmitted infections or pregnancy.

Technology has created new forms of inappropriate sexual behavior, including “sexting,” which is sending inappropriate messages or pictures over a cell phone. This has become a common problem because young people do not understand the potential consequences. Children with JHD may have an even more difficult time understanding the consequences of exposing themselves and may be more likely to “sex” someone who asks them. Start a conversation with your child about sexting and gently inform them that a cell phone message can reach thousands of people in a matter of minutes.

Conversation starters about sex and sexting for a teen with JHD

- *“I am concerned about the way some kids your age talk about sex. Tell me how you feel about kids your age having sex.”*
- *“A lot of kids think that everyone else in school is having sex, but I read that’s not true. Most kids your age are not sexually active. What do you think is true?”*
- *“Sex is a very private thing. It is not something you do over the phone or on the Internet, no matter what kids tell you. I just read about ‘sexting.’ Why do you think kids are doing it?”*

Curbing inappropriate sexual activity can be difficult for the teen with JHD. If the behavior becomes difficult to manage, your teen may need counseling or medical care. An HDSA social worker or the child’s doctor can help you understand treatment options.

SETTING LIMITS AND JHD

When your child is first diagnosed with JHD, you may have so many concerns that it is difficult to set limits for your child. However, it is important to set limits early so that behavioral issues such as aggression and impulsivity that often develop in JHD are easier to manage later. Furthermore, it is important to focus on helping your child have the most positive experiences at school and at home as possible. As the disease progresses, you may have less control over your child's behavior but your child will have more positive interactions with others if he or she has learned limits early.

Be sure you make your expectations about appropriate behavior clear. You need to be very direct and straight forward with a symptomatic teen. State, for example, "You need to bring your dirty dishes to the dishwasher after dinner." You may need to repeat your expectations often and make sure your child follows through. Offering limited choices is another way to encourage positive behavior. For example, ask your child "Would you like to do your homework before dinner or after dinner?" That way, the expectation is clear that your child must do homework, but gives the child a feeling of control by offering a limited choice. Giving choices is one way to reduce frustration in children with JHD.

Conversation starters on limits for a teen with JHD

- *"We expect everyone in the family to keep their rooms tidy. Do you want to clean your room before lunch or after lunch?"*
- *"It's not okay to yell at other kids in your class when you get angry. Let's think of some other things you can do when you feel mad. You go first."*

JHD AND MORTALITY—WHAT TO SAY

Juvenile Onset Huntington's disease is a terminal condition for which there is currently no cure. As a parent, coming to terms with this diagnosis is extremely difficult.

How can a parent respond when their child with JHD asks, "Am I going to die?" With as much honesty, reassurance and hope as possible. Surprisingly, children can sometimes be more matter of fact than adults.

Conversation starters

- *“A lot of research is being done to cure Huntington’s disease. There are many scientists who are researching JHD. We are hoping that they will discover a cure. There are things we can do to help make it easier for kids with JHD to stay healthy.”*
- *“You can trust me and I will always be honest with you. Right now, people with JHD do die from the disease. That’s not going to happen to you tomorrow, next week, or even this year. We have a lot of things that we can look forward to. Let’s do some reading together to help you understand how JHD progresses.”*
- *“I am sure you are scared. What are your questions? You can ask whatever you want. If I don’t know the answers, we can find out together.”*

ADVANCE DIRECTIVES AND JHD

Advanced planning can increase the ease of life down the line. Knowing that your child with Juvenile Onset HD will need the assistance of a caregiver when they become a legal adult, there are some proactive steps that you, as a parent and caregiver, can make. For example, it can be very important that you or another trusted adult, become the child’s legal guardian when they reach adulthood.

There is help available to support you in the process of documenting preferences and completing Advance Directives for the person with HD. The social worker at your HDSA Chapter or Center of Excellence can help you identify the information you need and the correct documents to use. Your family lawyer or financial advisor may also be able to assist you.

CONCLUSION

No matter where you are in your HD journey, living with HD is about living. HDSA is here to provide information and support, and to connect you to other HD families. The HDSA website, www.hdsa.org, is a portal to local chapters, support groups, affiliates, Centers of Excellence, information and publications, as well as other HD resources. You can also be connected to HDSA resources by calling the HDSA Helpline at 888-HDSA-506.

Talking With Kids About HD



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Child Welfare Foundation

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