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Talking with Kids about HD

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Disclosures & Gratitude

No disclosures to report

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Topics for today

- Reasons to talk to kids
- First conversation
- Differences by age
- Ideas for answering tough questions
- Additional recommendations
- Questions and Discussion

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Reasons to discuss HD with kids

- Kids are receptive and understand difficult topics faster than we know
- Access to online information either at home, school or friends' houses
- Develop sense of trust
- Create safe space to ask questions, express feelings
- Enhance feeling of security

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Remember….

- Don't put pressure on yourself to have **THE ONE BIG TALK**
  - Make it your goal to simply start the conversation and listen as much as possible
- Make yourself as informed as possible about HD
  - Through your local chapter, www.hdsa.org, support groups, etc.
- Write down and practice what you will say
- It's OK to not have an answer to everything: let your child know that you are there and will find the answer if you don't know it

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Remember….

- Don't cover everything at once
  - Leave time for them to process small bits of information
- Use your own words and pay attention to the child's age and maturity level
- Remember this is unchartered territory for you: the best you can do is do your best!

"A person who never made a mistake never tried anything new"
~ Albert Einstein

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Logistics for the First Conversation

- Choose a time and place with the least amount of interruptions or distractions
- Tell your child you want to talk to them about something important
- Turn off cell phones, iPads, iPods and any other electronic distraction
- Have something fun or calming planned for afterwards as this is bound to be emotional for both of you
- If your children are different ages, different maturity levels or react in different ways from one another- it may be beneficial to have one-on-one talks with each child by themselves (use your discretion or problem solve/discuss this with your local HDSA social worker)

What do we say?

- **Be honest**
  - Let them know there is a history of HD in the family
  - Tell them what is going on currently with their affected family member and how HD may explain certain events
  - Discuss their current care from doctors
  - Stick to the here and now and only discuss longer term issues if asked during first conversation

What do we say?

- **Prepare to <u>Listen</u>**
  - Helps you understand their feelings and what they need *<u>right now</u>*
  - Encourage your child to talk and use active/responsive listening (avoid distraction; use body language and gestures to convey attention; reflect and provide feedback by paraphrasing)

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What do we say?

- **Be patient**
  - Allow time for them to process the words you are saying
- **Be open to questions**
  - Let them know that you genuinely want to know their concerns, questions, thoughts, fears (positive or negative)
  - If you don't know the answer, state that you will try to find it
  - Let them know that this is just the start to an ongoing conversation and no question is off limits

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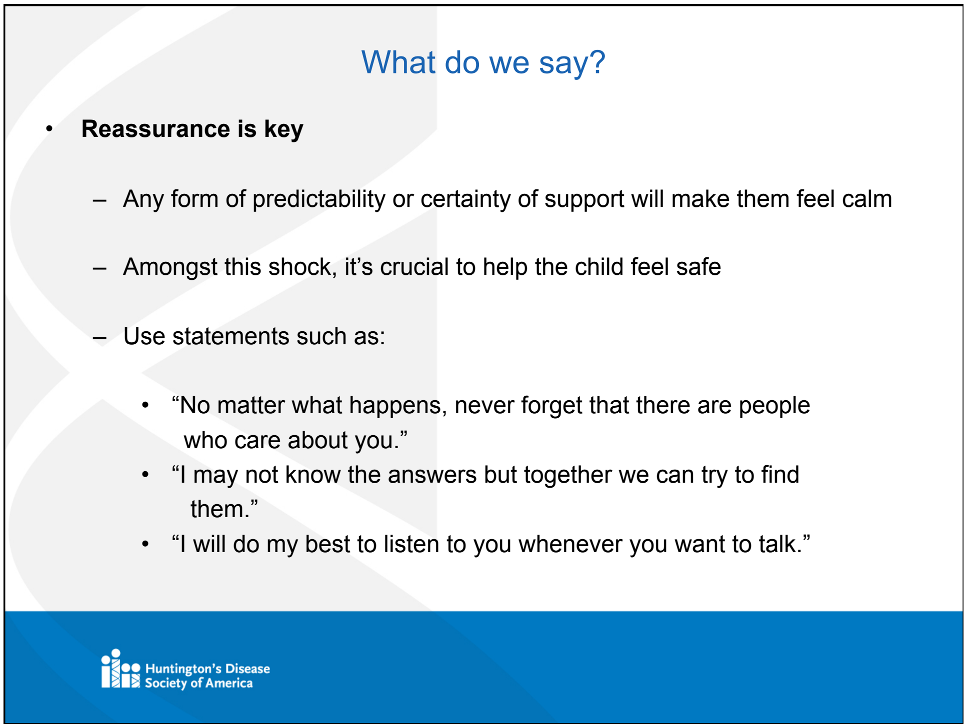
What do we say?

- **Future talks**
  - Do not push your child to react; if they need time and are not yet ready to respond or share their feelings, give them time and try again another time
  - Remember that every person is unique and has their own way of coping, even within the same sibship
  - Create an atmosphere of openness and transparency so they will feel comfortable opening up in the future

What do we say?

- **Avoid too much information**
  - Keep the focus on the present and near future
  - Avoid discussion at first conversation, if possible, of at-risk status/gene inheritance, disability and death (unless they ask questions about this directly)



What do we say?

- **Reassurance is key**
  - Any form of predictability or certainty of support will make them feel calm
  - Amongst this shock, it's crucial to help the child feel safe
  - Use statements such as:
    - "No matter what happens, never forget that there are people who care about you."
    - "I may not know the answers but together we can try to find them."
    - "I will do my best to listen to you whenever you want to talk."

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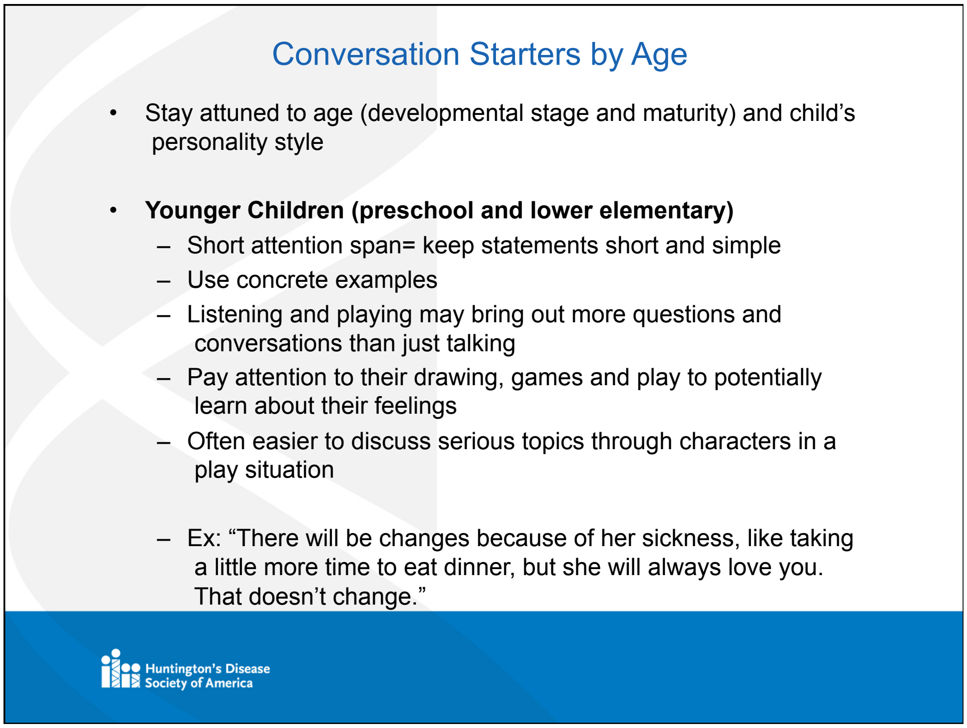

Conversation Starters by Age

- Stay attuned to age (developmental stage and maturity) and child's personality style
- **Younger Children (preschool and lower elementary)**
  - Short attention span= keep statements short and simple
  - Use concrete examples
  - Listening and playing may bring out more questions and conversations than just talking
  - Pay attention to their drawing, games and play to potentially learn about their feelings
  - Often easier to discuss serious topics through characters in a play situation
  - Ex: "There will be changes because of her sickness, like taking a little more time to eat dinner, but she will always love you. That doesn't change."

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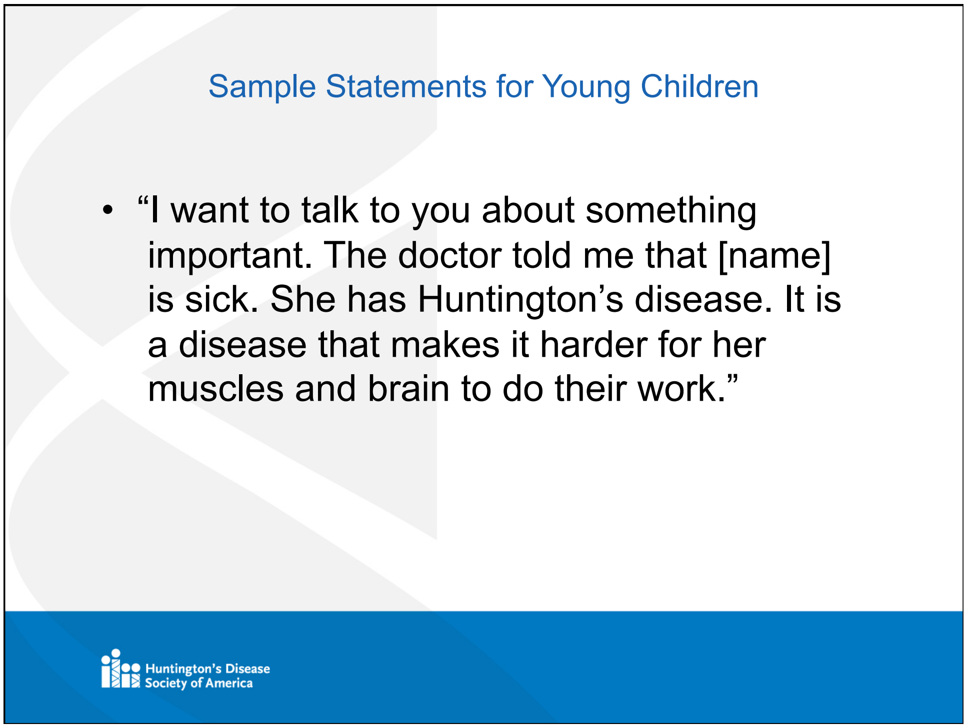

Sample Statements for Young Children

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

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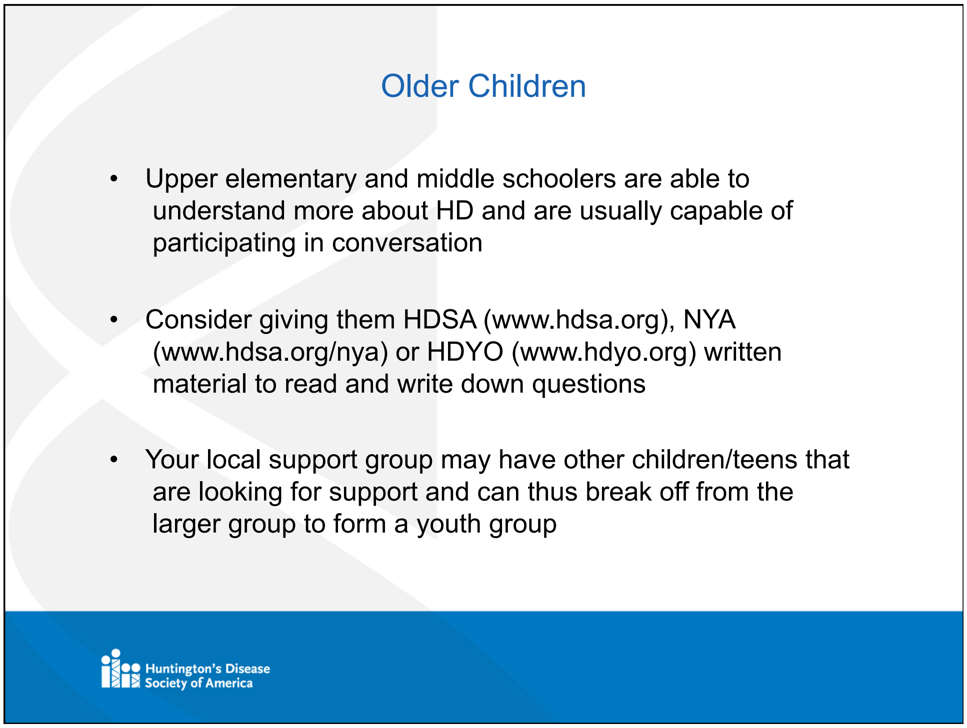

Older Children

- Upper elementary and middle schoolers are able to understand more about HD and are usually capable of participating in conversation
- Consider giving them HDSA (www.hdsa.org), NYA (www.hdsa.org/nya) or HDYO (www.hdyo.org) written material to read and write down questions
- Your local support group may have other children/teens that are looking for support and can thus break off from the larger group to form a youth group

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Sample conversation starters for older children

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

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Teenagers

- ☐ Assess readiness and maturity level as emotions and responses may go up and down from day to day….
- ☐ "I want to talk to you about something important. I found out that your mom has Huntington's disease. It is a genetic disorder she was born with. It has affected her muscles and her brain. I wanted to tell you right away."
- ☐ "Because of this disease, she may have a hard time with some things. She may forget to do things she promised to do. You may notice that her hands shake sometimes and she may become very angry and you won't know why."

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First Conversation - Points to Include:

- A simple explanation that there is a family history of HD
- How the affected person's HD symptoms may affect the child's life at this current moment
- Reassurance that the child is valued and supported
- A description of something they can do to help- something tangible
- An offer to listen to their questions or concerns
- The expectation that there will be future conversations

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Ideas for Answering Tough Questions

Often, questions may come forth that are difficult to answer. Here are some ideas of ways to respond….

It might also be helpful to chat with other parents to explore what was particularly useful or helpful for them when having these conversations…

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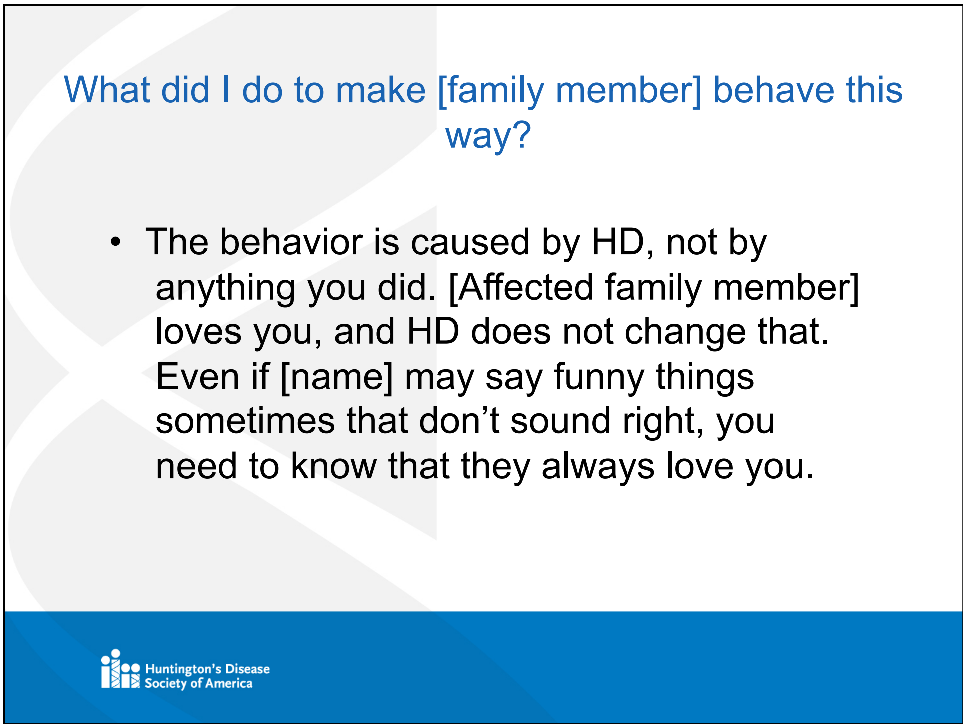
Is mom/dad going to die from HD?

- People can live for may years, even decades, with Huntington's disease. It's important that we continue to encourage [name] to go to their doctor appointments to get the best care possible. We don't know for sure when any of us will die. Instead, we focus on living our best life now.

How did mom/dad get HD?

- When mom/dad was born, she/he inherited the mutated gene that causes HD from her/his parent.



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

- The behavior is caused by HD, not by anything you did. [Affected family member] loves you, and HD does not change that. Even if [name] may say funny things sometimes that don't sound right, you need to know that they always love you.

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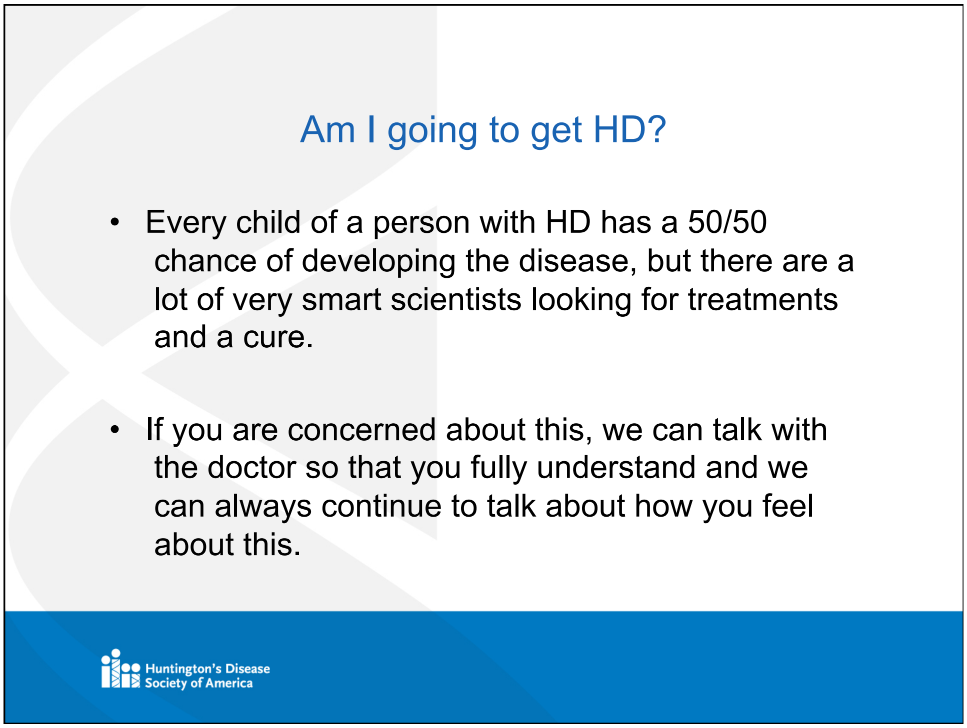

Am I going to get HD?

- Every child of a person with HD has a 50/50 chance of developing the disease, but there are a lot of very smart scientists looking for treatments and a cure.
- If you are concerned about this, we can talk with the doctor so that you fully understand and we can always continue to talk about how you feel about this.

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Are my brothers/sisters going to get it?

- They have the same 50/50 chance that you do.

Why can't I just get the test now?

- I know sometimes it is easier to just know right now- like ripping off a Band-Aid. However, getting a test for the HD gene doesn't tell you when you might get symptoms. Some people develop HD late in life.

- If you want to talk about the test with a genetic counselor, we can make an appointment at an HDSA Center of Excellence or call our HDSA Social Worker.

- However, if you decide that you want to get tested, you won't be able to do so until you are 18.

Why isn't there a cure?

- Scientists are working very hard to find one. There are research studies that members of an HD family can participate in that may help to find treatments and a cure. We can talk about whether that is something you want to do or not- it is up to you.

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I'm a kid. How am I supposed to handle this?

- You need to know that you are not alone. There are a lot of family and friends around that care about you and there are also other adults, like doctors and counselors that are there to help.
- The National Youth Alliance and HDYO are also there for kids like you from all across the country and the entire world. I am always here for you and will try to answer any questions you have.
- If you want, we can look up the HDYO and NYA websites now and see what they have available for you.

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What will happen to us as their illness gets worse?

- We will have to make some difficult decisions as a family together, but we will work as a team the entire time. We can also work with a HDSA social worker to know what to expect and can plan for the future together.

Watch your responses….Conversation stoppers

- Kids are resilient and perceptive!
- Responses that are dismissive or dishonest can cause children to isolate
- Ex: “That’s ridiculous! You know that is not true” or “How on earth can you feel like that?”
- Parents need to check their own anxieties and feelings before responding

Calming the conversation for you and your child

- When you are feeling overwhelmed with emotion, it is OK to show that, as it shows your child that it is OK to show your feelings and not know the answer.
- Ex: “That’s a good question. I don’t know the answer, but I will find out when I talk to the doctor- are there other questions you have that you want me to ask the doctor?”

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Counseling for Children and Teens

- Sometimes children may not feel completely comfortable and able to be open with family, coaches, or teachers
- Mental health professionals such as counselors, clinical social workers and psychologists can be very helpful for children and teens who are learning about HD and need ongoing support
- HDSA Social Workers are also available to provide referrals as well as education and consultation to local psychotherapists so that they become knowledgeable about HD and the role it plays on families and children
- Therapy is extremely beneficial, but may feel strange at first for someone. Always try going to at least two sessions before making a decision of “good fit”

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Closing Thoughts…

> *"While we try to teach our children all about life,*
> *Our children teach us what life is all about."*
> *~Angela Schwindt*

More information

- Contact HDSA for a copy of the brochure entitled *Family Guide Series: Talking to Kids about HD*
- You might also talk with your school or child's therapist to determine if they would benefit from reading more about HD or consulting with an HDSA social worker

Call HDSA with questions or for local referrals

HDSA Helpline: 888-HDSA-506

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Questions & Discussion

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