



Conversations about HD

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Conversations about HD

- Focus on adults (parents) talking with their own children who may be school age, teens, or young adults
 - Why
 - Who
 - How
 - Where
 - When
 - What



How do I know about this

- Pediatric nurse
- Genetic counseling with people at the time of diagnosis
- Research with HD families and teens
- Coeditor of “Talking with Kids about HD”
HDSA 2012 and 2013



WHY have the conversations

- Facts, although hard
 - may be better than imagination
- Under your control
 - not information of uncertain accuracy
 - uncertain impact from other sources
- Assure child/teen/young adult
 - wellbeing
- Brings child/teen/young adult into the process
 - coping with HD

Conversations

It's not the "BIG TALK", but the start of many conversations.

- Tackle what your C,T, YA wants to talk about now.
 - Some topics may not come up, they will be important at another time.
- Work together to find out what you don't know.
 - Finding credible resources.
- It's ok to acknowledge your emotions. You may need to take a break and talk again later.
 - It's not a marathon, just opening the topic.

WHO

- Children, teens, young adults
- Both parents, one parent, trusted adult
 - *[child]My best friend's mom is a nurse, she explained it to me.*
 - *[parent]A counselor was priceless. The children could talk with her in a different way than with me.*
 - *I decided to tell my son before he got married.*



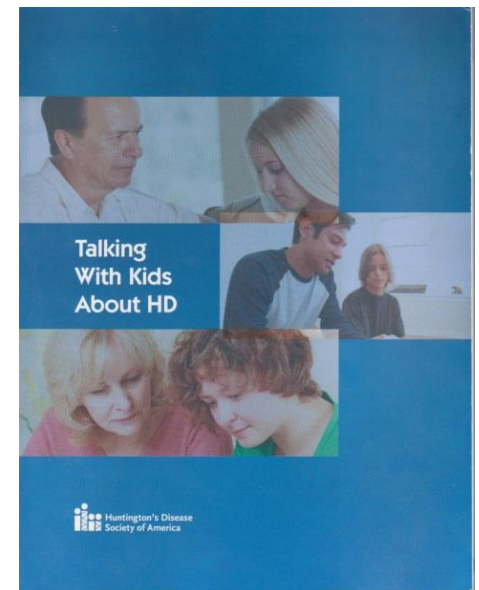
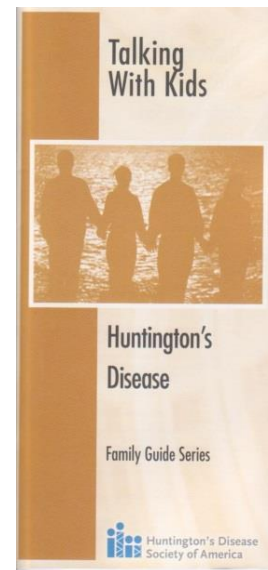
HOW

- How to bring it up
 - *This is hard for me, because this makes me feel sad, but there are some things we need to talk about regarding Mom/Dad*

HOW

Resources to help you

- HDSA 888-HDSA-506
- HD Centers of Excellence staff
- Talking with Kids: Huntington's disease
 - getting started,
 - different age groups
- Talking with Kids about HD
 - more topics



HOW

- Some ideas for starters
- These were actually written for Kids to coach them on how to talk with their parents, but this can work for parents too
 - Kids (or parents) may bring up the topic before parents (or kids) are ready
 - Kids (or parents) may have in mind what they want to tell you (the children)

HOW

- Keep to the ground rules - both get to talk. Stay calm. Be honest. Show respect. Listen.

You can say you understand where I'm coming from... but you don't have the risk of getting HD... you really don't understand.

- How to respond?

You are right... I want to hear what you're thinking... I care about you... How can I help...

WHERE



- Where you least expect it
 - In the car, when you are busy, when there is a crisis
 - You can acknowledge the need to talk, ask to talk more when there are less distractions
- Private space without distractions would be ideal



WHEN

- Ordinary conversation
 - *Your mom has a disease that affects her muscles and her brain, that's why she has trouble walking and remembering.*
- Changes in person with HD
 - *Daddy is having trouble controlling his emotions and making decisions at work, that is why we are going to see the doctor. We will let you know what we find out.*



WHEN

- HD is mentioned in family or parent medical care before you've talked with your child
 - *I saw a letter from a HD clinic so I asked my dad what that was.*
- HD in school curriculum
 - *I first heard of HD in my biology class and then I looked it up on the internet.*



WHAT

- Depends on age of child/teen/young adult
- Facts about HD
 - What is HD
 - What will happen to Mom or Dad
- Facts about your child
 - What will happen to me when Mom or Dad gets sick(er)?
 - Will I get it?
 - Did I cause it?

What is HD and what does it have to do with me

- Brief facts
 - *Daddy has a muscle problem and he has to eat slower*
 - *HD affects muscles, memory, and thinking skills*
- What is it like in your family
 - *In our family it tends to start like this....*
 - *In our family, we... (how do people in your family react to...take care of... the person with HD?)*



What is HD

- What do you think HD is?
 - *What have you observed?*
 - *She really gets stuck on an idea and you just have to go with it.*
 - *What do you wonder about?*
 - *I thought Dad was always mad at me.*

What is HD

- *It is caused by a mutation in a gene....*
 - *You didn't cause Mom/Dad to do the things that upset you.*
- *You could, or you could not have the mutation in the gene....*
 - *When you are 18 or older you can find out if that is what you decide to do.*
 - *If I can't answer your questions, we can find someone who can.*



What is our plan-for HD parent

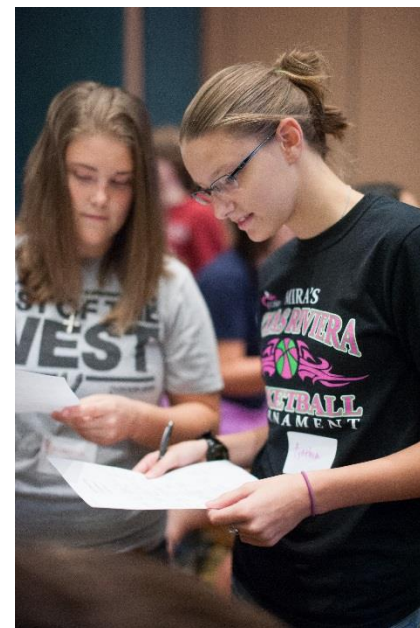
- Some teens/youth want to help
 - *I know she shouldn't have cigarettes so I try to explain that to the rest of the family. They just don't get it.*
- Some quietly help
 - *When my dad eats, it's a mess, I clean up the kitchen when he's done.*
 - *When my mom washes dishes, she doesn't do a very good job. When she's done I just wash them again.*



What T YA told us they use often and this helps them

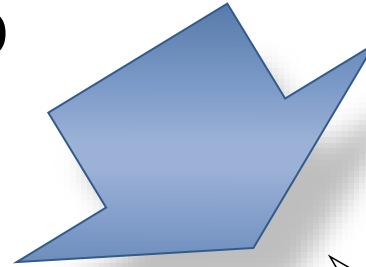
- National survey 23 teens and 21 young adults
- Main things that helped them
 - Information they find on their own
 - own reports
 - own research

“I did a project on HD for biology class.”



What helps

Main things that helped
them value the parent
with HD



- time
- talk
- relationship

What helps- value the parent with HD

- Parent
 - *Want to enjoy being with my mom before something really bad happens.*



What helps-

- Main things that helped them
 - How they cope
 - keep busy away from home
 - do things that are fun
 - spend time with friends



What helps- how T YA cope

- Priority is being a teen or young adult who wants to be with friends; wants to succeed in school, sports, etc.; wants to be valued in the family
 - *I'd like to go to the mall without having to plan it.*
 - *I'd just like to be myself, and I can't.*
 - *My mom doesn't have much time for me, she's always taking care of ...*
 - *I stay away from home as much as I can.*



What T YA do often that doesn't help

- One main thing that didn't help
 - Hold my emotions in
- What are the alternatives
 - Teens and Young Adults didn't know who they could talk to
 - Some did find a trusted adult, school counselor, close family friend, counselor
 - HD social media sites and programs for teens and youth

What is our plan-who do I tell

- What do I say to others (friends, boyfriend/girlfriend)
 - Some children can be bullied, planning for what to do
 - AAP's Patient Education Online, *Bullying: It's Not OK*

patiented.aap.org/content.aspx?aid=6263

- What don't I need to say
 - Consider what is private information and what is shared

What is our plan-who do I tell

- The school principal or counselor
 - *Please let me know if she is struggling with her feelings... we ask you to keep this information private...*
- Casual friends
 - *She knew which friends were supportive of the problems her dad was having*

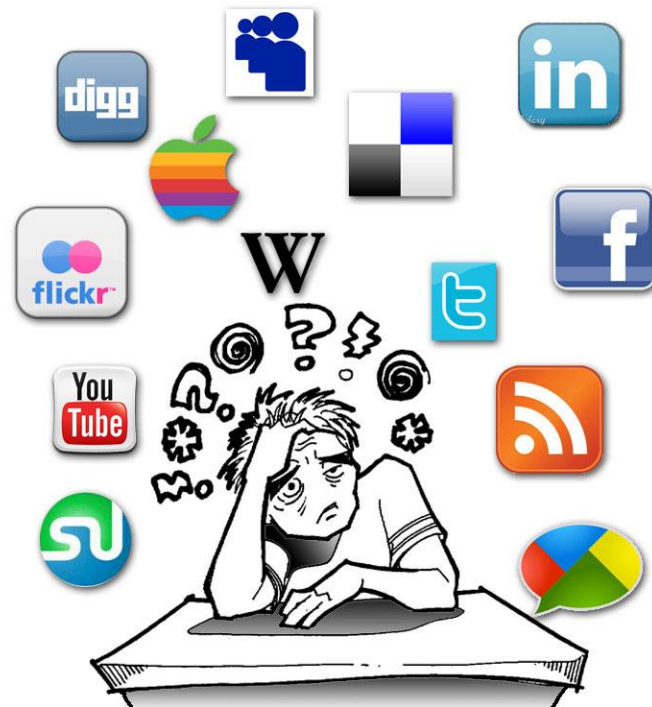
What is our plan-who do I tell

- Serious dating- there is a risk that the boyfriend/girlfriend will not remain, but that isn't always the case
 - *Serious boyfriends already knew about her dad, they were very accepting.*
 - *I'm glad you want to bring your girlfriend over to the house, let's think about the time of day that's best for your Dad.*



What is our plan-who do I tell

- Social media
 - Can't control subsequent sharing of information you post
 - Caution about accuracy of information seen on social media or internet



What is our plan-for decisions

- Some decisions are hard
 - *I run her errands for her now, but if I go away to college, who will do that?*
- Some decisions can wait, or may be changed as children move into young adult years
 - *I thought I wanted the HD test, but sometimes I'm not sure*
 - *I'm pretty sure I won't have children. I would consider testing if I really thought I might have children.*

Things to consider for your C T YA future

- What plans do they want to make for themselves after the leave home
- Can they be relieved of some caregiving responsibilities
 - *How do you feel about going on to school? Mom and I planned for how much financial help we can give you.*
 - *We know how much you've helped with Daddy, and I am figuring out how to manage when you get your own place.*

What about the person with HD's long term decisions

- It can be tough to talk about end of life issues for anyone.
 - HDSA Center of Excellence, HDSA Social Worker, Primary Care provider can help
- Young adults may be asked to carry out their parent's wishes.
- People with HD may have beliefs or requests that are important to know.
 - *Daddy is healthy now, but he wants us to know what he wants us to do when he is unable to speak for himself.*

What is our plan- for the adult- in the conversation

- Support groups
 - HD Centers of Excellence
- Trusted friend
 - Similar situation... Long term friendship... Sounding board
- Health Care Provider
 - Taking care of yourself

Resources

- *Talking with Kids: Huntington's Disease*. (2012) Family Guide Series. HDSA, NY. 26 pages
- *Talking with Kids about HD* (2013). HDSA, NY. 111 pages
- Sparbel, K.J.H. et al (2008). Experiences of teens living in the shadow of Huntington disease. *Journal of Genetic Counseling* 17, 327-335.
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Let's Talk

888-HDSA-506

