

Talking to Kids About HD

Dr. Bonnie L. Hennig-Trestman

HD Reach Raleigh, NC

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Talking to Kids About HD

Yesterday is history.
Tomorrow is a mystery.
But today is a gift...that's
why they call it the present.
Author Unknown

Topics of Discussion

- Understand the reasons for talking to kids about HD.
- Know the who, when, how and what of talking to kids about HD.
- Learn about kid's emotions.
- Learn approaches of sharing information.

Reasons for Talking to Kids About HD

- A child has a right to know about anything that effects the family. By not talking about HD, children learn not to trust.
- Children know something is wrong. By not saying anything, they may have fears worse than the real situation (they may for instance, imagine they did something to cause a family member to become ill). In turn they may develop anxiety and guilt.
- Not talking about HD gives the message that it is a subject too terrible to be discussed.

More Reasons

- Children may find out the truth from someone else.
- Children who are informed can be a comfort to you. You will not feel that you must spend more energy into remembering what you actually told them.
- Children have an amazing ability and capacity to deal with difficult situations (fears are learned).
- If the person with HD shows behaviors which now have an explanation, children will learn this is “normal” and continue to show affection and respect towards that person.

Who Should Tell the Kids?

- If you can, you should tell the kids about HD.
- A close family member who has the correct facts about HD can tell them.
- Professional staff who works in the HD field could help you follow up.

When Should I Tell My Kids?

- At any and all ages.
- The younger the child is, the more basic the information should be.
- Adolescence may be a time for more specific questions.
- It is never too early. (It's also never too late).

How Should I Tell My Kids?

- Look at your own feelings about HD.
- Find a language that is comfortable to you.
- You may need to talk to different age children separately.
- Role play. Practice what you will say and anticipate the toughest questions.
- Find a comfortable/familiar place to talk to kids. (i.e., while doing the dishes, taking a walk or during a quiet drive).

What and How Much Should I Tell My Kids?

- Tell children information they can understand.
- Listen to them.
- Tell them how you feel.
- Be aware of the “Don’ts”.
- Some ways to talk to kids.

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Tell Children Information They Can Understand

- Gradually share bits of information.
- Leave them with a feeling of hope.
- Tell them they will always be loved and cared for.

Listen to Them

- Answer questions simply.
- Ask them “Tell me what you think HD is”.
- Correct things that aren’t true.
- Ask them if they are worried about you/the family member.
- Look for non-verbal cues to see if the child has “had enough”.
- Stop, but tell them you plan to continue this discussion another time.

Be Aware of the “Don’ts”

- Don’t lie.
- Don’t overburden them with a lot of medical detail. (Tip: “Did that answer your question?”)
- Don’t trouble them with financial concerns unless it impacts them directly (i.e., lifestyle changes).
- Don’t make promises you can’t keep.
- Don’t be afraid to say, “I don’t know”.
- Don’t push kids to talk. (Tip: “I gave you a lot of information today. I know your friends can be a support for you. But not a lot of people know about HD, so if you have questions, I can put you in touch with HD experts.”)

Ways to Say Things

- “Mommy/Daddy has an illness. It is called Huntington’s Disease.”
- “This illness makes Mommy/Daddy do some things that aren’t always normal at times.”
- Draw a family tree or talk to kids about the family member with HD. (Without discussing at-risk status right away, the child will be able to understand that there are other people in the family with HD.)

Coping with the Unknown and Uncertainties

- There are many unknowns and uncertainties in dealing with HD.
- There are some questions you will not be able to answer. Accept this and help children accept this fact also.
- Find out as much as you can to make the unknown more familiar.

Tips to Deal with Changes

- Let children know gradually that there will be changes in what the person with HD is able to do.
- Try to keep household routines as normal as possible without denying illness.
- Ask for help.
- Be flexible when necessary.
- Have an “emergency plan”.

Kids' Feelings and Reactions

- Kids can feel sorry for themselves, “why is this happening to me”.
- Kids may feel angry at the affected person for being sick.
- Kids may feel angry at the disease but then take it out on the well parent.
- Kids might try to become “super kid” and set unrealistically high goals for themselves.
- Kids might feel scared and be fearful that something will happen to the sick person when they are not there.

Kids' Feelings and Reactions

- Kids might withdraw in order to becoming independent in case something happens to their parent.
- Kids might resent the fact that they need to take care of the affected person.
- Kids might make a joke about everything to cover up their real feelings about HD.
- Some children will “act out” to get attention or might say they feel ill in order to stay with the affected person.

Discipline Ideas

- It is very important to continue to set firm limits with children.
- It is normal to see some acting out when there are changes in a family.
Communicate with children your love and acceptance of them but not their misbehavior.
- Reward good behavior and let them know how much you appreciate their help.
- Set limits with the Internet. One great site is HDYO.org

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Sharing

- Try to do things together as a family.
- Laugh together. “Laughter is the best medicine”.
- Make up an inspirational “slogan” together and post it around your home.
- Share stories and uplifting experiences.
- When you create positive memories, you teach children that it is okay to have fun, even in the midst of sadness.

Children Can Grow in Their Ability to Face Difficult Experiences

- Children may become more self confident and independent.
- Children may become more responsible.
- Children may become more sensitive to others needs.
- Children may grow in their ability to understand and love another person, even if that person is different.

Resources

- www.talkingtokidsabouthd.com

Digital copies of the book, “Talking to Kids About HD” can be ordered on Amazon Kindle

- HDYO.org

Wonderful website written for young people by young people!

- HDSA.org (HDSA-NYA)

Publication list

- huntingtonsociety.ca (HSC-YPAHD)

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Talking to Kids About HD

“The more we feel at home with our fears, the easier it is to accept the reality of what is or what will be”.

Marjorie Guthrie