

Talking to your children about Huntington disease (HD) is difficult for parents. We all want to protect our kids, keep them safe and shelter them from bad news. Some parents believe that saying "Mom or Dad has a fatal illness," will hurt their children too much, so it's better to keep HD a secret. However, secrets can cause a child to feel betrayed or erode trust in their parents.

No matter how difficult it is to break the news, not telling them is worse. Most children will realize something is wrong, despite your efforts to hide it. If no one tells them about HD, children will try to make sense of things themselves. What they imagine can be far worse than the truth.

Children have a right to know. HD is a disease that will affect them in many ways now and in the future. Telling them about HD gives them the information they are going to need to make good decisions and feel safe and reassured.

Before you talk to your children, you need to feel ready and able. There are a variety of approaches to speak to children, but this fact sheet provides some guidelines for communication.

Here are just some suggestions:

## **Prepare Your Explanation Beforehand**

Rehearsing what you are going to say will help you to stay calm, so that you can put aside your own fears for the time being and focus on your children's fears.

## **Break it Into Manageable Bits**

Telling your children the truth doesn't mean telling them everything all at once. Provide a small amount of information at a time that is developmentally and age appropriate. Use words that are easy for them to understand. Include as little or as much detail as you feel your children can comprehend. Give them time to grasp the information. Ask if they have any questions. Encourage them to ask questions at any time.

## **Answer Questions as They Come Up**

Be open to being asked questions or having discussions. Asking questions is a sign that your children are ready for more information. Be ready to take advantage of these opportunities whenever possible. Think about questions your children might ask and prepare answers in your mind so that you are ready to respond. It's okay if you don't have all the answers. Tell them you don't know, but you will find out for them. Let them know that they can always come back and ask more questions.

## **Clarify Misunderstandings**

Make sure your children don't have any misconceptions about HD. For example, they may be afraid of getting sick if they hug Mommy.

## **Discuss Their Risk**

In addition to telling your children about the symptoms of HD, it is important to tell them about the hereditary nature of the disease. Children can begin to understand the idea of genetics and inheritance around 11 or 12 years old. Younger children may ask and teens need to know. Tell them scientists all over the world are working to find better and meaningful treatments.

## Take Age and Personality Into Account

How much you will say will depend on your children’s ages and personalities. You know them better than anyone else, so you’re the best judge of what your children can understand. Here are a few things to keep in mind:

### Ages 3 to 6

Tell your children that it’s not their fault that mommy or daddy has HD and it is not a result of something that they did. Explain that HD is not contagious. You can’t catch it by hugging or touching or sharing a snack. Reassure your children that they will continue to be taken care of. Explain who will do the mommy and daddy things.

### Ages 7 to 12

At this stage, children are ready for more detail, so give them your best understanding of what may happen. Expect many questions from them about what is wrong and what the doctors are going to do about it.

### Teens

Give your teenagers as much information as possible. Many teens want to be treated like adults. Answer every question fully and honestly. Don’t expect empathy or support. While it’s tempting to turn to your teenagers when you feel overwhelmed, remember that they are dealing with enough already. Be flexible with chores. Respect their need for privacy. Once you’ve given the information, give them time and space to process it. Don’t feel offended if they prefer to talk about their feelings with someone else such as a friend, mentor, teacher, coach, etc. Check in with your child periodically; ask if they have any new questions or concerns.

## Sources for Support and Information

Be sure your children know where they can get help:

- The Kids Help Phone (1-800-668-6868) is a toll-free, bilingual telephone counselling service for children and youth. It provides emotional support, counselling, information and referrals. Local communities have crisis support lines.
- Your local Huntington Society of Canada (HSC) HD Resource Centre or Family Service Worker can provide information and support to all members of the family. Become involved in a local HSC Chapter so your children can meet other families affected by HD.
- The HSC Family Service’s Youth Mentorship Program is designed to support young people across Canada facing the everyday challenges of growing up in a family affected by Huntington disease.
- YPAHD ([www.ypahd.ca](http://www.ypahd.ca)) is a virtual youth chapter of HSC made up of young people faced with challenges associated with HD.
- HDYO ([www.hdyo.org](http://www.hdyo.org)) is an international youth organization that an excellent source for youth-oriented information.