

Huntington disease (HD) creates many significant losses, not just for the person who has the disease but for everyone in the family.

Although different children respond differently to the fact that Mom, Dad or another family member has HD, all children go through a grieving process over the changes that HD brings into their life. Grief is a normal emotional reaction to a significant loss. Having HD results in many significant losses both for the person who has the disease and for other members of the family.

Grieving the losses brought about because of HD is not a one-time thing. Children may have lost their involvement with a physically active parent. They may have lost the opportunity to have a carefree childhood, free from the worries that having an ill parent brings. They may have lost free time because of having to take on more responsibilities.

The grieving process for children can include the following emotions:

## **Shock and Denial**

Some children may be shocked to learn that Mom or Dad has HD, especially if the parent with HD doesn't look sick. Shock is then often followed by denial.

Children may pretend that nothing has really happened. Some children do not ask questions simply because they want to forget about HD. They think that if they ignore HD and don't talk about it, the disease will go away. Denial may allow them some time to absorb the news and get over the initial shock without having to deal with painful emotions.

## **Anger and Frustration**

Anger and resentment are very common in families affected by a chronic illness. These are natural feelings that come when we are confused, hurt, scared or frustrated. On top of that, children may feel angry because of the changes caused by HD.

Keep in mind that your children's anger is a reaction to the disease and the changes it has caused in their lives. It may be a sign that their needs are not being met. Anger may be the most difficult feeling to deal with, but it is a very natural feeling. Children may express their anger in inappropriate ways. Let your children know that it's okay to feel angry, but there are positive and negative ways to express it.

## **Embarrassment**

Children face a lot of pressure to fit in; having a parent who looks or acts different can leave them feeling confused. They may avoid bringing friends home, and they may not want their parent going to their school or to activities. This can lead to feelings of guilt, resentment, anger and sadness.

## **Fear and Anxiety**

Most children are afraid of losing their parent with HD. On top of this, they may worry about what will happen to their family and themselves. Some worry about their parents' feelings. As parents, we need to talk to our children about feelings.

Journalling can help to express concerns. Teens sometimes worry that they will have to stay home to look after Mom or Dad when the disease gets worse. They may experience doubts about their own future because of their genetic risk.

## Sadness and Guilt

After expressing anger, children may feel sad and guilty. They would like to see the disease go away and have their parent back as they were before.

They may feel guilty about getting angry, or they may imagine that they are responsible for the disease or certain symptoms. Sometimes the sadness feels overwhelming, as though it will never end. Although sadness usually does diminish, in some cases it may turn into depression. Watch for signs of withdrawal and isolation in your children, such as spending less time with friends or not doing activities they used to enjoy. If depression occurs, you may need to turn to outside help (e.g. school counsellor, another family member, family doctor, HSC Family Services Team Member).

## Grieving is a Unique and Ongoing Process

The feelings and reactions that are part of the grieving process may escalate or recur as the disease progresses and there is one more thing the person with HD can no longer do. Tell your children this, so they are not surprised by their feelings or think they should be "over" something which is part of the grieving process.

Remember that every child is unique. Brothers and sisters may react very differently depending on their age and personality. Try to be attentive to the personal needs of each child. Being aware of your child's emotional response and understanding are the first steps to helping your child cope.

## Sources for Support and Information

- Kids Help Phone (1-800-668-6868) is a toll-free, bilingual telephone counselling service for children and youth. There is also a live chat (<https://kidshelpphone.ca/live-chat/>) and a text option (text "CONNECT" to 686868).

Kids Help Phone provides emotional support, counselling, information and referrals. Local communities also have crisis support lines.

- Ongoing support, education and information is available from the Huntington Society of Canada (HSC). You can find a listing of our Family Services team members at [www.huntingtonsociety.ca/family-services-team](http://www.huntingtonsociety.ca/family-services-team).
- Join a local Chapter with HSC so your family can meet other families who are affected by HD.
- HSC's Youth Mentorship Program is designed to support young people across Canada (ages 12 and up) facing the daily challenges of growing up in a family affected by HD. The program pairs a mentee with a trained mentor who also comes from a family with HD and has had similar experiences. Learn more at 1-855-253-0215 or email [mentorship@huntingtonsociety.ca](mailto:mentorship@huntingtonsociety.ca)
- 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 has excellent articles, webinars and videos that are relevant to children, youth and young adults.
- Fact sheets: Helping Children Cope, Talking to Children About HD, Caring for Carers and Families with HD at [www.hdfactsheets.ca](http://www.hdfactsheets.ca)
- Talking With Kids About HD: <https://hdsa.org/living-with-hd/caregivers-corner-webinars/talking-with-kids-about-hd/>