

Strength & Knowledge

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Strength & Knowledge

Every other month, the Huntington Society of Canada publishes *Strength & Knowledge*, a practical guide for helpful information and assistance for those who are managing HD; highlighting the Family Services department recommended care, where to find help, who to connect with, and what advocacy efforts are currently underway.

News

May is Huntington Disease Awareness Month

Join us this May and help spread awareness about Huntington disease. Together we can make a difference! As part of our 2015 May Awareness Campaign, we are profiling members of our community from coast to coast, highlighting who they are and how they choose to raise awareness in their communities and beyond. Click [here](#) to read their stories.

Deciphering signals from Huntington disease brains in the search for treatments

May 10, 2015, *At Risk for Huntington's Disease Blog*

From coast to coast and around the world, scientists like Andrew F. Leuchter, M.D., and Michael Levine, Ph.D., are engaged in the quest for HD treatments. During May, Huntington Disease Awareness Month, I want to call attention to the critical work of Drs. Leuchter and Levine on the West Coast. They exemplify the partnership of scientists and physicians with the HD community, aiming to advance potential remedies into crucial clinical trials. Click [here](#) for the full article.

A Child's Response to HD

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 by 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 of having an ill parent. They may have lost free time because of having to take on more responsibilities.

Grieving

The feelings and reactions that are part of the grieving process may escalate or reoccur 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.

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Physician's Guide

HSC has published the 3rd edition of *A Physician's Guide to the Management of Huntington Disease*, with the assistance of HDSA. For a copy please contact us at info@huntingtonsociety.ca or 1-800-998-7398.



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The grieving process can include:

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 good and bad 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 parent, their family and themselves. Some worry about their parents' feelings. As parents we should try to talk to our children about their feelings.

Journaling 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 Resource Centre Director or Family Services Worker).

Getting 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. Also, become involved in a local HSC Chapter so your children can meet other families affected by HD.

HSC'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. Learn more at 1-855-253-0215 or email mentorship@huntingtonsociety.ca.

YPAH (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) is an international youth organization that is an excellent source for youth-oriented information.