

Children from families affected by Huntington disease (HD) face challenges that most children their age do not. Children know and see what is happening and will see a parent or loved one change as the disease progresses. They need support and understanding as many people feel better knowing that they are not alone in having to face HD. Huntington disease does not have to take over a young person's life. There are ways you can help your child cope:

Reassure your children and ensure their needs are met

- Children need food, shelter, clothing and love, but make sure they also have a chance to enjoy friends, fun and attention.
- Reassure your children that their needs are just as important as the needs of their parent with HD.
- Frequently reassure them that they will always be cared for and that you love them.

Provide information about HD

- It is important for children to know what HD is and how it is going to affect their parent and themselves.
- Encourage your children to ask questions any time.
- Listen to your children's concerns, fears, and worries.
- Be sure your children know where they can get help during a crisis!
- Age-appropriate information is very important. There are resources that help parents determine the kind and amount of information that will be suitable for different age groups. This article discusses the who, what, when and how questions: <https://en.hdyo.org/par/articles/43#what>
- This webinar provides excellent information on talking to children about HD: <https://en.hdyo.org/kid/videos/582>
- HDYO Land (<https://en.hdyo.org/kid>) provides a game that children can explore to help them understand what HD is – in simple language.
- HDYO also has specific resources for teens including videos on a variety of topics.

Ensure they have an emotional outlet

- It is important that your children have people they can talk to about their feelings.
- Anyone who can listen is a support: a parent, friend, teacher... even talking to a pet, a stuffed animal or a doll can help.
- Painting a picture to express their feelings or writing about them can also help.
- Corresponding with an email or pen pal might be beneficial.
- Let children know that their feelings are normal, not crazy or bad.
- Encourage them to share problems and concerns as this is a good first step to overcoming them.
- Many people feel better knowing that they are not alone in having to face HD.
- Consider including children in HD community social activities where they could meet other young people from a family affected by HD.

Don't give them too much responsibility!

Children shouldn't have to take on adult tasks and worry. If you're finding that you need more help, seek out support services in your community, such as home care and respite. You can contact your local HSC Family Services team member for more information.

On the other hand, you may be tempted not to push your kids because they're dealing with enough as it is, but there needs to be firm, clear limits.

Boundaries and structure help create a sense of security for children.

Foster Positive Interaction and Encourage Other Relationships

Arrange enjoyable outings or activities together if possible. These activities will maintain a positive relationship and create happy memories.

Quiet times at home can also be positive. This could involve looking at family pictures, bedtime stories, or cuddling on the sofa while watching TV.

Encourage children to become involved with other trusted adults or older youth, such as a friend's parent, an aunt, uncle or older cousin. This will provide them with an additional role model. It will also give them the opportunity for more activities and fun. This is especially important if the parent with HD is in the advanced stages.

Children may also benefit from participating in social activities separate from the family. Communities may offer a wide range of activities including low cost and no cost options.

Ensure Children Have Free Time

Set aside time for your children to be with friends and/or pursue other hobbies and interests. Living with HD every day can create stress. If it's possible, arrange a break for your children. This could be a holiday away from home with your child's friend's family or other relatives, or it could be a period of time at summer camp.

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.
- 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
- YPAHD (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 has excellent articles, webinars and videos that are relevant to children, youth and young adults.
- Fact sheets: A Child's Response to HD, Talking to Children About HD, Caring for Carers and Families with HD www.hdfactsheets.ca
- Talking With Kids About HD: <https://hdsa.org/living-with-hd/caregivers-corner-webinars/talking-with-kids-about-hd/>