

Helping Children Cope

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.

Here are a few ways that 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!



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.

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, respite, etc. 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.

Guidelines to Making Sure the Proper Steps are Taken to Help Your Children Cope

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 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.

Be Sure They Have Free Time

Set aside time for your child to be with friends. Living with HD day in and day out can create stress. If it's possible, arrange a break for your children. This could be a holiday without the affected parents or a 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. It provides emotional support, counselling, information and referrals. Local communities also 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.

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 which is an excellent source for youth-oriented information.