

HELPING CHILDREN COPE WITH HUNTINGTON DISEASE (HD)

When a parent or loved one has Huntington disease (HD), children often notice changes long before adults realize they do. They may have questions, worries, or feelings they don't know how to express. Every child copes differently and needs reassurance, honest information, and ongoing support. This information is designed to help parents, caregivers, and other trusted adults support children and youth as they grow up in a family affected by HD.

Reassure Children

- Children need to know they are loved, safe, and important. Tell them often.
- Make time for fun, friends, and family activities.
- Reassure them that they will always be cared for.
- Help them understand that their needs are just as important as those of the family member with HD.

Talk About HD

- Children often cope better when they receive honest, age-appropriate information.
- Explain HD in words they can understand.
- Encourage questions at any time.
- Listen carefully to their worries and fears.
- Let them know who they can turn to during a crisis.
- Give information a little at a time as they grow and mature.
- Resources such as HSC's Child and Youth Practitioner can help families talk about HD in age-appropriate ways.

Encourage Healthy Expression

Children need safe ways to express difficult feelings. **Encourage them to:**

- Talk with a trusted adult.
- Share feelings with a friend, teacher, or relative.
- Draw, paint, journal, or write stories.
- Talk to a pet or stuffed animal if that feels comfortable.
- Join activities where they can meet other children from families affected by HD.

Remind children that all feelings are normal and that they are not alone.

Keep Expectations Age Appropriate

- Children need structure, but they should not be expected to become caregivers.
- Avoid giving children adult responsibilities.
- Ask for help from family, friends, or community services when needed.
- Set clear rules and routines.
- Provide consistency and healthy boundaries.

Structure helps children feel safe.

Create Positive Memories

Although HD brings challenges, families can still enjoy meaningful time together.

Ideas include:

- Reading together
- Looking at family photos
- Playing games
- Going for walks
- Watching a favourite movie
- Sharing hobbies

Simple moments often become lasting memories.

Encourage Other Positive Relationships

Trusted adults can provide additional support and stability. Children may benefit from spending time with:

- Grandparents
- Aunts and uncles
- Family friends
- Coaches
- Teachers
- Older cousins

These relationships help children feel connected and supported.

Make Time for Childhood

Children still need opportunities to simply be children. **Encourage them to:**

- Spend time with friends.
- Participate in sports, clubs, music, or other hobbies.
- Attend camps or community activities.
- Take breaks from the stresses of HD whenever possible.

Maintaining friendships, interests, and opportunities to have fun can help support resilience and healthy development.

Factsheet developed by the HSC Family Services team. Reviewed by Tanya Greaser, BA, BSW, Registered Social Worker and Family Services Educator, and Winnie Diverlus, CYC-P, MACTE ME (0-6), Child and Youth Practitioner.

RESOURCES & WHERE TO FIND SUPPORT

Many organizations offer support for children, youth, and families affected by HD. Your HSC Family Services team can help connect you with programs and services in your community.

- YPAHD (Young People Affected by Huntington Disease) | www.huntingtonsociety.ca/youth/
- HSC Youth Mentorship Program | www.huntingtonsociety.ca/youth-support/
- Local HSC Chapters and family support groups

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at hdsupport.ca

If you are ready to receive individual or group support from the Huntington Society of Canada, you can self-refer here: <http://contactme.cloud/form/huntingtonsociety>

Informational factsheets for family and friends impacted by HD are available to view, print and download at hdfactsheets.ca

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at hdresources.ca

Kids Help Phone | <https://kidshelpphone.ca/> | 1-800-668-6868

HDYO (Huntington Disease Youth Organization) | www.hdyo.org