

Living with Huntington disease (HD) is challenging for people who are affected by the disease as well as for carers and other people who provide support. As each person within a family affected by HD has a role to play, it is important for everyone to take care of themselves.

The term ‘carer’ means the same as caregiver or care partner. A carer is a person who provides a caring role for someone who needs support because of a physical, cognitive or psychiatric condition, an injury or a chronic life-limiting illness.

This fact sheet acknowledges the importance of the role of the main carers of a person with HD, but it also recognizes that the strategies outlined here are applicable to everyone – including people with HD. Sometimes, the main carer in a family with HD is a young person (youth or young adult) who may have special or different needs from other carers.

The following are suggestions to help carers in families with HD to live their best lives and take care of themselves and others around them.

Get Help Early - Know it is okay to reach out for support!

- Connect with your HSC Family Services team member: www.huntingtonsociety.ca/family-services-team.
- Gather information and educate yourself — understand HD and its progression.
- Seek counselling and investigate services (such as home care) to assist with your caregiving duties.
- Join a support group and seek mutual support opportunities within the HD community.
- Seek support from a spiritual or religious advisor if this would be beneficial to you.

Understanding helps you to plan for the future

- Involve family members from the beginning.
- Remember that each person experiences HD in a unique way. Even if you have cared for someone with HD in the past, the person with HD for whom you care now - may live with HD in a totally different way.
- Share your concerns during the different stages.
- Let friends and family know what you need from them.
- A family doctor who is willing to listen, understand and take action is essential for overall health.
- HD will impact day to day life as it progresses. Planning for the future will help you cope with these changes.
- Learn how to communicate differently with your loved one if cognitive and language abilities decline.
- Consult a speech language pathologist (SLP) and the HSC communication fact sheet for good communication strategies which will help avoid frustration for everyone.
- Create a plan for the future which may include finances, housing/living arrangements and other aspects of life that are important to your family.

Take care of yourself - physically and emotionally

- Eat well, get plenty of rest and exercise.
- Accept respite support and take a break when needed—learn to “let go”.
- Acknowledge the emotional challenge you face each day and remember it’s your right to have strong emotions; know that it’s okay to cry or laugh.
- Accept yourself for being human, even if you lose patience sometimes.
- Forgive yourself for not being perfect—no one is—caring for someone with a chronic illness means your world has been turned upside down, every day.
- Take one day at a time.
- Recognize that the new responsibilities that you are taking on add additional stress, but remember that you are not alone and help is available.

Recognize Loss, Grief & Denial

Many significant changes and losses are experienced by carers and families with HD. Some of the changes and losses have already happened, and some are expected in the future.

- As with other progressive diseases, losses appear at different times over the years. It is important to know that your grieving is a process that will also continue over time.
- There are different kinds of loss. Loss can be about the person with HD losing abilities and independence over time, or about the loss of shared dreams and plans for the future; it can also be about a person passing away.
- Grief is an internal feeling that impacts us in many ways. It may feel like anger, anxiety, stress, guilt, regret or even depression.
- Sometimes you may have conflicted feelings of being hopeful and experiencing grief at the same time.
- Seek out someone who understands your grief and can support you throughout this journey.
- Talk about it—don't isolate yourself or feel that you are on your own or alone.
- There may be times when you deny what is happening as a way to cope with difficult situations. Perhaps you believe things are fine or that you don't need support. Other times things seem overwhelming. Recognizing the denial will allow you to get the support you need.
- Every person reacts differently. It is important to acknowledge the feelings you are having.

Self-Care

- Stay true to your sense of self and preserve your own identity.
- Take time for yourself - stay active, keep up regular activities, stay engaged socially, try yoga, relaxation techniques, going to the gym, reading, enjoying music, having a bath, sitting in the sun, meditating, whatever activities you enjoy doing.
- Every situation is different. It is important to acknowledge your unique feelings and experience.
- Be kind to yourself—you are experiencing normal reactions to challenging circumstances.
- Caregiver burn-out is real; embrace support and seek it out as needed.
- Understand that different stages of HD may require new and different types of support for you and your loved one.
- Information is power—stay informed, empowered and strong.
- Take Action for YOU to stay healthy and well in order to be the best advocate and care provider that you can be for your loved one.

“ALONE WE CAN DO SO LITTLE, TOGETHER WE CAN DO SO MUCH” - Helen Keller

Resources

This resource has been adapted from “Action Plan for Caregivers”, Dorothy Orr, RSW

Ongoing support, education and information about HD is available from HSC. You can find a listing of our Family Services team members at www.huntingtonsociety.ca/family-services-team.

Fact sheets on Improving Communication and Benefits of Exercise: www.hdfactsheets.ca.

Talking to children about grief: www.hamiltonhealthsciences.ca/documents/Patient%20Education/ChildrenGriefHelp-PORTRAIT-lw.pdf

Alzheimer Society of Canada has resources on caring for someone, grieving and ambiguous loss: www.alzheimer.ca/en/Home/Living-with-dementia/Caring-for-someone OR www.alzheimer.ca/en/www/Living-with-dementia/Grieving OR www.alzheimer.ca/en/www/Living-with-dementia/Grieving/ambiguous-loss-family

Canadian VirtualHospice has resources on providing care and grief: www.virtualhospice.ca