CARING FOR CAREGIVERS AND FAMILIES WITH HD

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. 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.

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 life:

- Connect with your HSC Family Services team member.
- Gather information and educate yourself — understand HD and its progression. HSC has fact sheets, booklets and related HD resources for both carers and people with HD (see links on page 4).
- Seek counselling and community services (such as home care) to assist with your caregiving duties.
- Join a support group and seek mutual support opportunities within the HD community.
- Connect with spiritual or religious advisor if this would be beneficial to you.
- Develop a support team including medical personnel (nurse, family doctor and HD clinic team) as well as community resources (HSC Family Services team, homecare, counselling, and financial supports).

Self-Care Strategies

Self-care is about taking care of yourself and identifying opportunities that “recharge your batteries” or “fill your cup”. They will help you to stay both mentally and physically fit. These can be simple activities, such as some of the suggestions in the following list.

- Stay true to your sense of self and preserve your own identity.
- Take time for yourself - stay active, keep up with regular activities, stay engaged socially. You could try yoga, relaxation techniques, going to the gym, reading, listening to music, having a bath, sitting in the sun, meditating - whatever activities you enjoy doing.
- Self-care is a mindset and doesn’t always need to be an activity. It can be as simple as taking a breath and being aware of and present in the moment.
- 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.

Self-Care Strategies (cont'd)

- Caregiver burnout 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.

Understanding Helps You to Plan for the Future

- Involve the person with HD and 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 with your support team.
- Let friends and family know what you need from them. Have a list of ideas ready to share.
- Work with a family doctor who is willing to listen, understand and take action, as this is essential for overall health.
- Planning for the future will help you cope with the changes of HD as it progresses. This plan may include finances, housing/living arrangements, and other aspects of life that are important to your family.
- Learn how to communicate differently with your loved one if thinking and language abilities decline.
- Consult a speech language pathologist (SLP) and the *Improving Communication in HD Fact Sheet* on the HSC website for communication strategies that will help avoid frustration for everyone.

Take Care of Yourself - Physically and Emotionally

- Eat well, rest when you can, and get plenty of exercise.
- Accept respite support and take a break when needed - learn to “let go”.
- Acknowledge the emotional challenge you face and remember it is 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.
- Take one day at a time and periodically assess what you need as a carer.
- Recognize that the new responsibilities that you are taking on add additional stress, but remember that you are not alone and help is available.
- Remember to access your support teams throughout this journey

Recognize Loss, Grief and Denial

Carers and families with HD experience many significant changes and losses. Some of the changes and losses have already happened, and some may occur 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 evolve 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 - stay connected and remember you are not alone.
- Denial is sometimes used to cope with a difficult situation, especially as you may feel overwhelmed. Denial may provide the time needed for a little space or distance from the situation but if ignored, it can become destructive. Please reach out to your supports to share how you are feeling as you do not need to carry this alone.
- Every person reacts differently. It is important to acknowledge the feelings you are having.

“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

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

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at www.huntingtonsociety.ca/family-services-team-list/

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

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at www.huntingtonsociety.ca/hd-booklets-and-publications/, on:

- A Physician’s Guide to the Management of Huntington Disease
- Understanding Behaviour in Huntington Disease: A Guide for Professionals.
- A Carer’s Guide for Huntington Disease

Young Caregivers Association | www.youngcaregivers.ca

Alzheimer Society of Canada | www.alzheimer.ca

Canadian Virtual Hospice has resources on providing care and grief | www.virtualhospice.ca