

Advocating for Caregiver Support

"I was becoming fully dependent on my spouse as my caregiver." Kathryn S.



Services and supports provided by families and friends are an important component of care for people with brain conditions. Almost 40% of Canadians living with brain conditions across Canada receive care from family and friends.¹

"I have seen the sad and slow erosion of a person's mobility, ability to speak, and social interaction, the increase in anxiety and depression, and the great

demands placed on family members and finances." Joan G.

"I know how heavily the current health system relies on family caregivers and plans to provide support. However, there are many of us who have no caregiver other than ourselves. In fact, I was caregiver for several members of my family while coping with Parkinson's." Sandra L.

The impact of brain conditions reaches beyond the individuals diagnosed with the conditions, also affecting the quality of life of families and caregivers, and often changing the relationship between family members.

Caregivers provide assistance with activities, transportation, meal preparation and delivery, and much needed emotional support. Caregivers also incur costs, such as time away from work, or an inability to work due to their caregiving demands, and out-of-pocket expenses. The National Population Health Study of Neurological Conditions found that more than a quarter of family and friends caring for persons with brain conditions experienced some form of distress, more than twice as many as those caring for individuals without a brain condition (28% versus 13%).¹



Debra M, son Ryan and family.

"I am caregiver to my son who was hit by car in 1988 and have lived through some very hard times, always fighting for help along a long journey. To this day, I have been his rock and biggest supporter along his long journey. Now I am getting old and always trying to figure out how he will survive when I am gone." Debra M.

¹ Public Health Agency of Canada. Mapping Connections: An understanding of neurological conditions in Canada. Ottawa (ON): Public Health Agency of Canada; 2014. 98 p. Report No.: ISBN 978-1-100-24442-6. Report of the National Population Health Study of Neurological Conditions, conducted in partnership with Neurological Health Charities Canada.



Caregivers are critical members of the care team. They need support to carry out their important role. This support may come in the form of information, a short break from caregiving demands, financial support, and/or support from employers to allow them the flexibility to balance their work and caregiving roles. Health charities are working together, with governments, and other partners, to advance policy and program changes to benefit people living with brain conditions, as well as their families and caregivers.