

Lasting Life Changes

“And here is the upbeat part: the pills kick in and I walk out....” William P.



Imagine requiring the pills to “kick in” to have an upbeat moment in your day. This situation is familiar to many Canadians living with Parkinson’s disease, a chronic condition that, like many other brain conditions, can compromise quality of life. William tells a story of going to a restaurant with his family, struggling through the crowd in his wheelchair, navigating his way up three steps and to the elevator (the

restaurant is on the third floor), finding an ‘out of order’ wheelchair accessible stall in the second floor bathroom, and finally, some reprieve...his pills kick in and he is able to walk out.

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.

“I had to take an early long term disability leave from my work in the teaching profession. Depression set in and requires medication and therapy to keep in control. Much of my social life was impacted. Even closer to home, a marriage of some 27 ½ years was fractured and resulted in a divorce.” Ryan T.



Ryan T. 4th World Parkinson Congress Ambassador

According to [Mapping Connections: an understanding of neurological conditions in Canada](#), the report of the National Population Health Study of Neurological Conditions, caregiver distress was more than twice as high for family and friends caring for individuals with a brain condition compared to those providing care to individuals without a brain condition.

“I handle all the household duties and look after my wife, who was diagnosed with early onset Parkinson’s disease in 2000 and no longer able to work; and my daughter, who has Down syndrome. Until 2009 when I took early retirement, I juggled caregiving with my full-time job.” Bruce I.

Quality of life can be diminished by the negative impacts brain conditions can have on mental health, general health and financial security. Brain conditions can result in

functional impairments related to cognition, mobility, hand-finger dexterity, speech, vision, hearing, emotion, and pain and discomfort. *Mapping Connections* also found that adults age 18-64 years with a brain condition were five times more likely to be permanently unable to work, compared with adults without brain conditions (8.1% vs. 1.7%). If individuals living with migraines were excluded from this analysis, individuals affected by brain conditions were 12 times more likely to be permanently unable to work (25.4%).

“Imagine only having a limited number of years (perhaps as little as 25, assuming you start working at age 20) before you are forced to retire from any sort of work due to the effects of this illness, thereby seriously reducing your savings and any chance for a reasonable pension to retire on.” James B.

“I had to quit my job six years after I was diagnosed as I was unable to carry out my duties. Who knows what the future will bring.” Jacqueline O.



Regardless of the specific diagnosis, *Mapping Connections* highlighted that brain diseases, disorders and injuries present similar challenges to individuals, families, health care systems and our economy. The stories described here are not unique to these individuals or families, but are reinforced by individuals and families affected by various conditions in communities across Canada.

“I was diagnosed in 1996 and since then my life has become diminished in many ways by things I have had to give up or can no longer participate in and the loss of people involved.” Sandra L.

While gaps in information still exist, and more research and information is needed, the National Population Health Study of Neurological Conditions provided evidence to support the future direction of activities related to brain conditions, and identified better ways to meet and manage the health needs of individuals living with these conditions and their families.

It is time for governments, health charities, health providers, researchers and all other stakeholders of the brain community to build on the momentum fostered by the National Population Health Study of Neurological Conditions, to partner and take collective action, and to improve the quality of life for all persons with chronic brain conditions, their families and caregivers.