Common Impacts and Needs

“Our human compassion binds us the one to the other - not in pity or patronizingly, but as human beings who have learnt how to turn our common suffering into hope for the future.” Nelson Mandela.

According to Mapping Connections: an understanding of neurological conditions in Canada, the report of the National Population Health Study of Neurological Conditions, individuals living with a brain condition share many of the same functional impacts and needs, regardless of diagnosis. Brain conditions can affect mobility, dexterity, skin and joint sensation, behaviour, bladder and bowel function, communication, consciousness and emotion.

“My father lived with Parkinson’s disease for more than fifteen years and each year the disease progressed and took more and more away from him. Routine tasks became ever more difficult and he required more and more care. The disease ravaged his body and his mind.” Mike Z.

“Daily medication is required to remain functional at both work and in the day-to-day (i.e. gardening, grocery shopping and the small joys of life). Simple tasks are becoming increasingly difficult as my energy level fluctuates.” Sue M.

Brain conditions can also create pain and discomfort, and lead to feelings of stigmatization and isolation.

“Both our husband’s, as RCMP members, were considered veterans. My husband, diagnosed with the devastating neurological disease Multiple System Atrophy (MSA), received no benefits or assistance, and I do not receive a veteran’s allowance. My friend’s husband, diagnosed with ALS, received numerous benefits, and she receives a veteran’s pension allowance. In view of the fact that these diseases are so similar (the person progressively loses the ability to walk, move their arms, talk and even breathe, while their minds remain sharp); our denial of veteran benefits was very unfair.” Jane M.

Mapping Connections brought to the forefront the impact of stigmatization on those with brain conditions, irrespective of condition. Up to one third of Canadians age 15 years
and older with a brain condition felt others were uncomfortable around them or avoided them. They also felt left out of activities and were embarrassed by their condition. This is a substantial burden shared by those living with brain conditions.

“Aboriginal people are affected doubly by stigmatization. People mix stereotypes about neurological conditions and social conditions.” Physician

Through promotion of Mapping Connections and the knowledge learned from the National Population Health Study of Neurological Conditions, we hope to create awareness of the burden these impacts have on people living with brain conditions, their families and caregivers. It is our hope that raising awareness will help to alleviate feelings of isolation and stigmatization among those affected, and will create a more tolerant and welcoming society.