

Key Priorities for Canada's Parkinson's Community

Living successfully with Parkinson's is more than a health issue. It also requires thoughtful policy to address the social and economic implications of living with a chronic progressive neurodegenerative disease. People with Parkinson's know all too well that when one's brain doesn't work properly, every aspect of life is compromised.

The Canadian Parkinson's community is asking the Government of Canada to work together with Parkinson Society Canada in three key policy areas:

1. Support for Caregivers

We ask the Government of Canada to continue to recognize the valuable role caregivers play in helping people with Parkinson's maintain their health and well-being. Appropriate support programs and policies need to be in place to support this ever-expanding role. The Parkinson's community is asking the federal government to support caregivers by:

- Providing workplace protection for caregivers through EI benefits to balance caregiving and work responsibilities (i.e. Ontario Bill 21 - Leaves to Help Families)
- Providing improved access to information and education for caregivers
- Investing in research on family caregiving as a foundation for evidence-informed decision making

Significance for the Parkinson's Community:

In 2013, Parkinson Society Canada conducted a national survey in which more than 600 members of the Parkinson's community participated. The findings from the survey showed:

- 67% of respondents indicated caring for a loved one with Parkinson's disease has impacted their quality of life either significantly or very significantly
- The amount of time allocated to care giving per day grew with the progression of the condition. Spouses and adult children supporting those with more progressed Parkinson's reported that this role had become a full-time job and they were on call 24/7
- Caregivers reported the most challenging symptom of Parkinson's disease was their loved one's mobility impairment, including dyskinesia, tremors, freezing, lack of energy and strength, and speech impairment. Additionally, caregivers noted that hallucinations, anxiety, and depression were extremely challenging

From Parkinson's Caregivers:

"My daily routine is all about caring for my husband -18 yrs. with PD. Pill time...food time...there is no time off."

"It has affected me greatly. I am his sole caregiver and work full time. Due to my spouse's advanced Parkinson's I have less time for myself. Need to get everything ready (pills, lunch, etc.) before I leave for work. Social activities have changed a lot. Can't enjoy a night out with friends/family without having to get home early unless I make arrangements to have a "baby sitter". Can't do overnight stays or weekend getaway. Sleep deprivation, financial stress, etc."

2. Genetic Fairness Legislation

The Parkinson's community asks the Government of Canada to enact legislation to protect Canadians against genetic discrimination. Did you know Canada is the only G8 country that does not protect the genetic information of its citizens?

It is a well-established principle that individuals shall not be discriminated based on their disability. However, outdated laws still enable insurance companies to discriminate based on perceived disability or the prospect of future disability. Insurance companies can use our genetic information to unfairly determine eligibility, set premiums and manage their risks. This may mean being rejected for employment or loss of access to insurance coverage based on the notion that the individual may be disabled in the future.

Current legislation permits insurers to ask applicants to divulge personal health information, including genetic data and family history, and to consent to having this information verified. This unfairly puts consumers under duress because they are denied the needed coverage if they fail to do so.

- In Canada, we cannot discriminate against race, gender or disability, but we can against DNA
- Canada's lack of genetic fairness legislation prevents citizens from participating in health research, including personalized medicine initiatives through Genome Canada
- Genetic information should be used to better understand the prevention, treatment, and management of diseases to allow Canadians to live longer, healthier lives and make informed decisions

Significance for the Parkinson's Community:

- There is a genetic form of Parkinson's disease that impacts approximately 5-10% of the Parkinson's population, and people with a family history of Parkinson's are being denied insurance based on a future perceived disability
- Genetics is a vital area of Parkinson's research with the hope for finding a cure and better treatments, but many are reluctant to participate in genetic research because they fear discrimination from both employers and the insurance industry

3. Establish a Comprehensive Health-Care Plan to Address the Complex Needs of Seniors

The Parkinson's community asks the Government of Canada to lead a dialogue with provincial and territorial governments to ensure the chronic and acute healthcare needs of seniors are addressed at the point of care.

- Seniors currently account for 14% of the population, which will grow to 23% by 2036
- Thousands of seniors are being warehoused in acute care hospital beds at \$842 a day when they should be in long-term care at \$126 a day or assisted home care at \$67 a day. We are spending \$1 to \$2 billion a year unnecessarily.
- Less than 1/3 of Canadians have access to palliative care

Significance for the Parkinson's Community:

- Parkinson's disease is not a normal part of aging but the incidence increases with age
- 85% of those diagnosed with Parkinson's are over the age of 65
- Access to chronic care support is a significant issue for the Canadian Parkinson's community. There are over 700 neurologists treating more than 100,000 people living with Parkinson's – these specialists are also treating more than 1 million Canadians living with other neurological conditions. The wait time to see a specialist to get a definitive Parkinson's diagnosis is currently between 9 months to 2 years

Contact:

Vanessa Foran
Vice President, Public Affairs & National Programs
Parkinson Society Canada
4211 Yonge Street - Suite 316
Toronto - ONTARIO - M2P 2A9
t: 416.227.9700 ext. 3396 | e: vanessa.foran@parkinson.ca