

2014 Pre-Budget Submission to the Standing Committee on Finance

Executive Summary

Parkinson Society Canada is the national voice of more than 100,000 Canadians living with Parkinson's disease. Parkinson's is often associated with visible motor symptoms such as slowness of movement, rigidity, tremors and balance problems. But people living with Parkinson's often report that non-motor symptoms such as depression, anxiety, sleep issues, cognitive disorders and dementia, have a greater impact on their quality of life. 85% of those diagnosed with Parkinson's are over the age of 65. This age group is predicted to rise over the next 30 years from 11.6-23.6% of the population, increasing the expected incidence of Parkinson's disease significantly.¹

For the 2014 pre-budget consultation, Parkinson Society Canada is making two recommendations to the Standing Committee on Finance. The first is to expand the accessibility of the federal Compassionate Care Benefit to include caregivers who support Canadians living with a serious chronic or episodic medical condition, and to increase the flexibility of this benefit to accurately reflect the needs of Canadian caregivers. This expansion will provide the Parkinson's community with much needed access to this benefit, which due to the current restrictive criteria, is largely unavailable to Parkinson's caregivers.

The second recommendation is a request to introduce legislative and policy measures to end genetic discrimination. There is a 5-10% genetic/familial link for people living with Parkinson's disease (i.e. brother/sister; parent/child), and people with a family history of Parkinson's are being denied insurance based on a future perceived disability. Parkinson Society Canada is recommending the Government of Canada continue to support genetic fairness by enacting legislation and policy measures to protect Canadians and end genetic discrimination in this country.

Request #1: Increased Support for Caregivers

Parkinson Society Canada applauds the Government of Canada in its support of caregivers including the Family Caregiver Tax Credit introduced in 2011 and the recently announced Canadian Employers for Caregivers Plan. However, we believe additional measures are needed to support the essential role caregivers play in Canada's health care system. Estimates provided for unpaid caregiving replacement costs in Canada range between \$25 to \$26 billion.²

Support for caregivers is a key priority for the Parkinson's community. Last year, 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 that caring for a loved one with Parkinson's disease has impacted

¹ Parkinson's Disease: Social and Economic Impact, Health Canada and Parkinson Society Canada, 2003

² Hollander, M, Liu, G. and Chappell, N. "Who Cares and How Much? The Imputed Economic Contribution to the Canadian Healthcare System of Middle-Aged and Older Unpaid Caregivers Providing Care to the Elderly. Healthcare Quarterly. 12(2) April 2009: 42-49

their quality of life either significantly or very significantly

- Time spent on caregiving was reported as being directly related to the stage of Parkinson’s disease of the patient, with some caregivers reporting only a few hours a week of caregiving, while other caregivers, typically spouses or adult children, reported that with advanced Parkinson’s patients, caregiving was a 24/7 task
- 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.

For Parkinson’s caregivers in the workforce, there is little income support or job protection due to the restrictive eligibility criteria for the Compassionate Care Benefit. It is currently only available to caregivers of family members who are gravely ill and have a significant risk of death. Due to the neurodegenerative nature of Parkinson’s, identifying when a person will require palliative care is not predictable, yet the burden to the working caregiver of a person living with Parkinson’s is palpable:

“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.”

Recommendation:

As an active member of Health Charities Coalition of Canada (HCCC), Parkinson Society Canada fully supports HCCC’s recommendation for the Government of Canada to expand the Employment Insurance Compassionate Care Benefit by:

- **Extending eligibility to caregivers who are providing support to those who require care due to a serious chronic or episodic medical condition**
- **Increasing the benefit period from 6 to 26 weeks within a 52 week period**
- **Broadening eligibility criteria to allow for partial weeks over a longer period**
- **Eliminating the mandatory two week waiting period to receive benefits**

These measures will help alleviate financial stress and enable caregivers to provide vital support to Canadians living with health conditions.

Expected Cost:

HCCC has estimated that from 2005 to 2011, \$190 million of the Federal Budget was annually allotted for the Compassionate Care Benefit program based on an estimated 270,000 eligible applicants. In 2012/2013, there were a total of 6,102 claims totaling \$11.6 million. Of these claimants, 73% used all of their 6 week entitlement. Projections for claimants based on the recommendations listed above are estimated at 23,500. Using the average weekly benefit of \$389 over a period of 26 weeks, it is estimated that the maximum annual cost for the expanded program will be \$237,679,000. However, it should be

noted that not all claimants will access the full entitlement.³

Impact:

The recommended expansion of the Employment Insurance Compassionate Care Benefit will result in the following outcomes:

For the family:

- Reduced caregiver stress and impact on caregiver health
- Reduced hospital stays for individuals living with a condition, which the Public Health Agency of Canada has estimated as 42.2% of the direct costs associated with Parkinson’s disease⁴
- Increased length of time individuals living with a condition can stay in their home/delaying move to long-term care facilities

For the employer:

- Reduced employee stress/burden and absenteeism, increasing productivity in the workplace
- Retention of employees, reducing the cost of retraining new hires

Request #2: Genetic Fairness Legislation

It is a well-established principle that individuals shall not be discriminated based on disability. However, outdated laws still enable insurance companies to discriminate based on perceived disability or the prospect of future disability. Insurance companies can use 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 an individual’s perceived future disability. In Canada, we cannot discriminate against race, gender or disability – why is discrimination against DNA tolerated?

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 Canadians under duress because they are denied the needed coverage if they fail to do so.

For the Parkinson’s community, there is a 5-10% genetic/familial link for people living with Parkinson’s disease (i.e. brother/sister; parent/child), and people with a family history of Parkinson’s are being denied insurance based on a future perceived disability. In addition, genetics is a vital area of Parkinson’s research to find a cure and better treatments, but many are reluctant to participate in

³ ESDC, Compassionate Care Benefits (Ottawa: ESDC, Evaluation Directorate, 2013) retrieved on July 25, 2014 at <http://www.esdc.gc.ca/eng/jobs/ei/reports/mar2013/index.shtml>

⁴ The Public Health Agency of Canada (PHAC) estimates that the total costs associated with PD in 2000-2001 were \$446.8 million. Direct costs were \$201.9 million: \$89.2 million (44.2%) for hospital care, \$13.4 million (6.6%) for physician care and \$99.3 million (49.2%) for drugs. Indirect costs were \$244.9 million: \$93.8 million (38.3%) in mortality cost and \$151.14 million (61.7%) in morbidity cost.

Canadian Institute for Health Information. *The Burden of Neurological Diseases. Disorders and Injuries in Canada*, Ottawa: CIHI 2007, pg. 84

genetic research because they fear discrimination from both employers and the insurance industry:

“My father had PD and when I applied for critical illness insurance in 2006, I had all coverage related to PD excluded from my policy. The insurance company did not ask for genetic testing.”

“I have thought many times about participating in genetic testing. I have not acted on that because I fear my children will be at risk of discrimination should a possible link be found.”

“My father, aunt and 2nd cousin were all diagnosed with Parkinson’s disease and my sisters and I were interested in receiving genetic testing to see if we have the gene associated with PD. However, we found out that we would be treated unfairly and would have difficulty receiving insurance, etc. We therefore decided against any genetic testing based on the negative impacts it would have. I am strongly against this discrimination and would be highly in favour of having these policies changed.”

Genetic information is personal, complicated and often misunderstood. Evidence-based research suggests that, from an economic and actuarial perspective, the insurance industry would not be negatively impacted if they did not have access to genetic information. With the exception of Canada, all other G7 countries, including the US, have a strong insurance industry while protecting their citizens’ genetic information.

In addition, the Office of the Privacy Commissioner of Canada recently reviewed the use of genetic test results by life and health insurance companies. The commissioner concluded it was not clear that the collection and use of genetic test results by insurance companies are demonstrably necessary, effective, proportionate or the least intrusive means of achieving the industry’s objectives at this time.

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. It should not be used to make business decisions.

As an active member of the Canadian Coalition for Genetic Fairness (CCGF), Parkinson Society Canada applauds the Government of Canada for elevating genetic fairness in the 2013 Speech from the Throne and is grateful for the work of the Office of the Privacy Commissioner of Canada on this issue. We ask for your continued support by ending genetic discrimination in Canada.

Recommendation:

Parkinson Society Canada stresses the need for immediate action and recommends the Government of Canada enact legislation and policy measures to protect Canadians against genetic discrimination.

Expected Cost:

There are no budget requirements for this request.

Impact:

This legislative change would strengthen the confidence Canadians have in accessing their personal genetic information. Benefits gained by eliminating the barrier of using genetic information for the greater good of Canadians include:

- Encouraging Canadians to participate in clinical trials to better understand the prevention, treatment, and management of diseases without fear of discrimination
- Allowing Canadians to make more informed decisions about their health
- Setting Canada on equal-footing with our G7 partners who have already established protections against genetic discrimination

Conclusion:

Parkinson Society Canada looks forward to the Government of Canada's support and implementation of the recommendations outlined in this pre-budget submission. We would be pleased to participate in any consultations or opportunities to move these important issues forward, providing much needed support to the Parkinson's community.

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