

## Parkinson's Disease and Aging - A Case for Support

### Parkinson's disease in Canada

- It is estimated that more than 100,000 Canadians have Parkinson's disease today.<sup>1,2,3,4</sup>
- We expect this number is under-estimated as there is no national population-based data on PD in Canada. Canada's first-ever National Population Health Study of Neurological Conditions is currently underway and will deliver results in 2013. This study includes Parkinson's in 17 of the 18 research projects which will provide a much better understanding of Parkinson's in Canada.
- Parkinson's disease is not a normal part of aging<sup>3</sup>; but the incidence does increase with age.<sup>1</sup>
- 85% of those diagnosed with Parkinson's are over the age of 65 and that age group is predicted to rise over the next 30 years from 11.6% to 23.6% of the population, increasing the expected incidence of Parkinson's disease significantly.<sup>1</sup>
- 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.<sup>5</sup>
- The PHAC estimates that in 2000-2001, Parkinson's Disease was associated with almost 53,000 Disability-Adjusted Life Years (DALYs are a summary measure of years of life lost because of premature mortality and years of healthy life lost as a result of disability). The years of healthy life lost due to disability for those with Parkinson's disease represented a larger component (72.2%) of the DALYs for PD than the years lost due to premature mortality.<sup>6</sup>

### Key priorities for those living with Parkinson's disease

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.

Living with Parkinson's means that one must navigate complex health and community service systems, negotiate with employers and government agencies to meet financial needs, and sort through changing dynamics in relationships as self-sufficiency slips away and the role of supportive care partners expands.

Members of the Canadian Parkinson's community identified four priorities to improve the quality of life of those living with PD:

- **Establish neurological conditions within Canada's chronic disease framework** - Parkinson's is one of a thousand brain disorders that affect approximately 5.5 million Canadians today and that number is expected to increase as our population ages. Parkinson Society Canada believes that Government of Canada must commit to a comprehensive and coordinated approach to meet the needs of the increasing number of Canadians living with a neurological condition like Parkinson's, by including chronic neurological conditions within the Public Health Agency of Canada's chronic disease framework.
- **Systems navigators** - It is important for those living with PD and their care partners to easily navigate the health care and community service systems to access the most appropriate therapies, interventions and support services at the right time. Parkinson Society Canada advocates that those living with PD have access to systems navigators to help them find the most appropriate care to suit their individual needs. Systems Navigators will improve the quality of life and productivity of those living with Parkinson's and

their caregivers.

- **Support for caregivers** - The Canadian Government must recognize the valuable role that care partners play in helping people with Parkinson's maintain their health and well-being, and ensure that appropriate support programs and policies are in place to support care partners in this ever-expanding role.
- **Education to decrease the stigmatization of Parkinson's disease and other neurological conditions** – Everyday, those living with neurological conditions such as Parkinson's are mistaken for people living with substance abuse issues, mental illness, and/or developmental disabilities. Parkinson Society Canada believes that the Government of Canada should provide a comprehensive public awareness campaign to educate Canadians about the misconceptions associated with Parkinson's disease and other neurological conditions.

### **About Parkinson's disease**

- Parkinson's is a disorder of the brain. When cells in the brain that normally produce a chemical called "dopamine" die, symptoms of Parkinson's appear.<sup>7</sup>
- Most common symptoms of PD are: tremor (shaking), slowness in movements, muscle stiffness and problems with balance.
- Other symptoms may also occur for some people, such as fatigue, difficulties with speech and writing, sleep disorders, depression and cognitive changes.
- Currently there is no cure for Parkinson's disease.
- Most people manage their symptoms through medication; a small percentage of people with Parkinson's may benefit from surgery; other interventions such as exercise programs and speech therapy can also help.
- Parkinson's will worsen over time; each person with Parkinson's is unique and may experience different symptoms.<sup>5</sup>
- Finding the right treatment as symptoms change over time is important and requires the expertise of specialized health-care professionals.
- A single cause for Parkinson's has not been identified. Researchers are studying many theories such as the role of genetics and environmental exposure.

### **References**

<sup>1</sup>*Parkinson's Disease: Social and Economic Impact*, Health Canada and Parkinson Society Canada, 2003

<sup>2</sup>*Parkinson's: The Facts*, Parkinson Society Canada brochure 2003

<sup>3</sup>*A Manual for People Living with Parkinson's disease*, Parkinson Society Canada, 2003

<sup>4</sup>Parkinson Society Canada donor brochure.

<sup>5</sup>Canadian Institute for Health Information. *The Burden of Neurological Diseases. Disorders and Injuries in Canada*, Ottawa: CIHI 2007, pg. 84

<sup>6</sup> Ibid

<sup>7</sup> *Progression of Parkinson's Disease* Information Sheet, 2009

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