

## Parkinson's Disease – An Ontario Perspective

### Parkinson's Disease in Ontario

- Parkinson's disease is one of the most common neurological conditions. We suspect that up to 40,000 Ontarians are living with Parkinson's today. It is chronic, progressive and there is no cure.
- 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>1</sup>; but the incidence does increase with age.<sup>2</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>3</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>4</sup>
- One in three Canadians will be affected by a neurological or psychiatric disease, disorder or injury at some point in their lives. In fact, if we consider death and disability, the current burden of brain conditions outweighs that of cancer and cardiovascular disease combined.
- To address this issue, a group of neurological disease charities came together in early 2008 to form the Neurological Health Charities Canada (NHCC) coalition. Parkinson Society Canada and Parkinson Societies in Ontario are both lead organizations in this coalition. The NHCC's aim is to position the brain as a health, social and economic priority for all levels of government in Canada.
- The Ontario Ministry of Health and Long-Term Care was very engaged in discussions with NHCC about improving the health, social and economic quality of life for Ontarians with neurological conditions and we in the Parkinson's community are most grateful for this shared work.

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

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 Parkinson's community would like the Ontario government to:

- **Create a healthcare system that provides integrated care and support to both individuals with chronic conditions as well as those with acute illness, to accurately reflect the needs of Ontario citizens.** A comprehensive healthcare system that includes case management, integrated mechanisms among primary care, institutional care and community providers, and evidence-driven plans or protocols modified to meet the needs of individual patients, will improve the quality of care for all Ontarians and save the province money.

- **Acknowledge our appreciation and continue your support of multi-disciplinary clinics – like the movement disorder clinic in Markham.** Multidisciplinary health care teams save the government money and improve the quality of care of Ontarians. With its multi-disciplinary team the Markham clinic was able to double its case load without doubling its cost. We ask that you continue to provide sustainable long-term funding for this kind of healthcare service delivery.
- **Acknowledge our appreciation and continue your support of the Ontario Brain Institute, which focuses its research specifically on neurological conditions but has the unique mandate of marrying scientific innovation and research with job creation.** We ask that this government continues to provide long-term sustainable funding for this organization.
- **Improve drug coverage in this province for neurological conditions – currently only 28% of all new drugs brought to the Canadian market for neurological conditions is covered on provincial formularies – compared to 85% coverage that new neurological therapies receive internationally.** An increased coverage will give those who live with Parkinson’s and other neurological conditions the necessary options to better manage their disease and will provide cost-savings for Ontario today by allowing those affected by these conditions to be more productive and participate more fully in society.

### **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>2</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**

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

*2 Parkinson’s: The Facts, Parkinson Society brochure 2003*

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

*4. Ibid*

*5 A Manual for People Living with Parkinson’s disease, Parkinson Society Canada, 2003*

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