

*Edited by Wayne Martin, Oksana Suchowersky,
Katharina Kovacs Burns, and Egon Jonsson*

Parkinson Disease

A Health Policy Perspective



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Edited by
Wayne Martin,
Oksana Suchowersky,
Katharina Kovacs Burns,
and Egon Jonsson

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Preface

Two years ago, the Institute of Health Economics (IHE) initiated a discussion about different aspects of Parkinson Disease. The aim was to identify potential gaps between findings from research and health policy and practice. Initially, the IHE invited a small group of researchers to these discussions; however, the pilot scheme quickly grew into a larger project and eventually involved 18 people representing clinical and health services research, patient associations, and persons with Parkinson Disease.

In order to make a difference for people with Parkinson Disease, this group felt that they should focus on the policy aspects of the disease, namely the organization and management of services for people with this condition.

This book is written for a broad audience—not only for health policy makers but also for anyone interested in this condition, such as people with the disease, family members and other caregivers, healthcare professionals, and community health and social services providers. It includes recommendations of what might be done at the policy level to improve the situation for people with this ailment.

Parkinson disease is a complex, chronic condition that presents challenges not only to those living with it but also to their caregivers, to their healthcare providers, to Parkinson societies, and to health policy makers. As one of many chronic diseases, it is important to not lose sight of Parkinson Disease and the associated impact and burden, particularly in view of aging populations and the projected increases in the numbers of people that will be affected by this condition.

We would like to acknowledge the contributions of all those individuals who shared their personal stories and experiences of Parkinson Disease, who contributed to the chapters and their editing, and to the IHE staff that provided administrative support, namely Wendy McIndoo, Kris Schindel, and Melissa Waltner.

Institute of Health Economics

*Egon Jonsson, Paula Corabian,
and Liz Dennett*

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Summary and Policy Considerations

Wayne Martin, Oksana Suchowersky, Katharina Kovacs Burns and Egon Jonsson

It is estimated that six million people worldwide have Parkinson disease (PD), with about one million cases in the US [1] and 100 000 in Canada [2] (although prevalence estimates vary widely from study to study [3–8]). In the Province of Alberta, there are about 7000–8000 people with the disease (see Chapter 11). Moreover, as the population continues to age this number will increase substantially.

Parkinson disease is a both chronic and progressive condition, which causes significant disability, handicap, and suffering and impairs the quality of life for the affected person and his or her family. The management of the condition may be improved in many different aspects. A major theme of this book is the need to coordinate services to more effectively utilize existing scarce expertise in the field, and to provide more coherent services from interdisciplinary and multidisciplinary teams composed of expertise in different aspects of health, social and community care for the person with PD.

There is, therefore, a need to develop a comprehensive strategy for early and accurate diagnoses and effective treatment, support and care for patients with PD. Such a strategy would require a more detailed investigation than has been presented in this book. However, it is suggested that responsible authorities establish a special committee to review the findings presented here, along with other data and facts about the situation for people with PD and other neurological diseases, and subsequently develop a proposal of how to improve the services for these patients. It is also recommended that actual or virtual centers for PD are established (where needed) that would consolidate the research, expertise and other resources in the best possible manner.

The following is a condensed overview of the common themes presented in this book.

A Structured Surveillance System for PD

Some countries and states have established registries of different diseases that are used in the planning, monitoring, and assessment of the provided services. Currently, there is no structured surveillance system or registry for PD in Canada

or in its individual provinces (see Chapter 11). Moreover, a lack of information on the prevalence and incidence of the condition, particularly as the population ages and more people are diagnosed with PD, may hamper health planning, including the appropriate allocation of resources. A PD Registry and structured surveillance system are needed to more accurately and consistently track relevant data about PD, including population-based trends. This would also address the gap in epidemiological data that currently exists.

Accuracy of Diagnosis

Even with advances in clinical assessment and developments in medical technology, the accurate diagnosis of PD remains a major challenge (see Chapter 2). At present, there is no reliable technology or test that clearly distinguishes PD from other similar conditions. Currently, the diagnosis is based primarily on the patient's history and clinical examination, with examinations often carried out in a primary healthcare setting, without necessarily having access to a specialist in brain disorders. Therefore, in order to avoid underdiagnoses or misdiagnoses, it is important to coordinate the available capacity to increase timely and easy access to specialist evaluation and treatment.

Availability and Access to Needed Treatment and Services

An early diagnosis and appropriate treatment is of fundamental importance for all patients. In PD patients, this alleviates stress and anxiety regarding physical and psychological signs and symptoms (see Chapters 2 and 3). A tailor-made management approach using various therapies is critical for optimum care, while easy access to selected treatment choices may minimize any functional disability and maximize the patient's quality of life. This includes the prevention of adverse reactions to medications, and the coordination of different appropriate therapies (Chapters 3, 6, and 7). Interdisciplinary teams are critical to the success of managing PD.

As indicated in Chapters 12 and 13, it is also important to consider the needs of the caregivers, who are often spouses or family members. Indeed, PD will have a substantial impact on the health and social well-being of caregivers—an issue that has been well documented (see Chapter 13). Evidence from clinical practice makes it clear that an holistic approach to treatment and care is essential to ensure that individuals with PD are able to maintain their independent functioning capacity, and have an acceptable quality of life (Chapters 3, 12, and 13). Availability and access to different services are high priorities for people with PD. Highly sought-after services include access to specialists and movement-disorder clinics, as well as to various therapies (physiotherapy, physical, speech and occupational), counseling, support groups, home care, adult day care, respite for caregivers, and others. One serious barrier to accessing services for people with PD who live in

rural communities is the fact that many of them cannot drive or do not have transportation available (see Chapters 12 and 13).

Impact on Quality of Life and Personal Cost for Persons with PD

Parkinson disease has a clear and strong negative impact on both the physical and mental aspects of the health-related quality of life, and this has been well documented in the scientific literature (see Chapters 12–15). One personal burden for those with PD and their caregivers is simply to understand and cope with the physical and mental changes and deterioration that result from PD (see Chapters 12–15).

Many people with PD have to make substantial financial sacrifices in order to maintain their quality of life. PD is common among older individuals who are close to retirement or who have retired, and who are often living on a fixed and modest income or have had to stop working at an early age. They may lose their driving privileges and independence, and have to pay out-of-pocket for some medications, nonprescriptive supplements, home renovations, medical devices, and much-needed therapies. By the same token, the caregivers' health and well-being will also be affected; they may have to stop working in order to become a full-time caregiver, or perhaps start working to supplement the household's income (see Chapters 12 and 13). Whilst the contribution of the caregivers clearly reduces the burden on the healthcare system, the extent of this has not been well researched, and neither is it recognized in healthcare policy making (Chapters 8 and 13).

As PD progresses, the severity of the condition increases such that the patient requires more access to specialists and to specialized services, care, and assistive devices (Chapter 12). This not only places greater demands on the health system but also adds to the overall cost burden of PD (see Chapter 8). Moreover, as the population continues to age and the projected rates of PD increase, the burden of costs will rise accordingly unless strategies are put in place to address these various cost-escalating factors.

Existing Research Evidence and Future Research Needs

A review of the literature published between January 2006 and October 2008 revealed 18 relevant systematic reviews and 11 practice guidelines related to PD (see Chapter 9). These selected studies reflect and confirm the findings in some of the previous chapters, and also provide health policy makers with useful evidence for their decision making. However, as they are limited in their range of topics, there is a need for more systematic reviews concerning many other aspects of PD.

The gaps in PD research, including basic research, epidemiological studies and risk factors, as well as the impact of therapeutics and therapies in clinical studies,

and policy-related research, are highlighted in Chapter 10. Although both genetic and environmental influences related to the development of PD have been identified to some extent, the complex interaction between these factors remains largely unexplored. Close collaborative links between basic and clinical neuroscientists will enhance the likelihood of developing relevant new insights into the mechanisms underlying the etiology and inexorably progressive nature of PD. There is also an identified need for health services research related to PD, especially in view of the fairly good availability of research findings of the management and organization of services in other chronic disease areas (see Chapter 12). Other research gaps are noted in areas such as the burden and costs of disease and treatments (Chapter 8), and in comparing various interventions and their impact on quality of life (Chapters 3–7, 12, 13, and 15).

Specific policy considerations for Alberta are presented in Chapter 16.

References

- 1 Michael J. (2006) Fox Foundation for Parkinson's Research [Internet]. Parkinson 101. Available at: http://www.michaeljfox.org/living_aboutParkinsons_parkinsons101.cfm (accessed 8 May 2009).
- 2 Parkinson Society Canada, Health Canada (2003) *Parkinson's Disease: Social and Economic Impact*, Parkinson Society Canada, Toronto, ON. Available at: http://www.parkinson.ca/atf/cf/%7B9ebd08a9-7886-4b2d-a1c4-a131e7096bf8%7D/PARKINSONSDISEASE_EN.PDF (accessed 8 May 2009).
- 3 National Institute of Neurological Disorders and Stroke [Internet] (2004) Parkinson's disease backgrounder. Available at: http://www.ninds.nih.gov/disorders/parkinsons_disease/parkinsons_disease_backgrounder.htm (accessed 8 May 2009).
- 4 National Parkinson Foundation [Internet] About Parkinson's disease. Available at: <http://www.parkinson.org/Page.aspx?pid=225> (accessed 8 May 2009).
- 5 de Lau, L.M. and Breteler, M.B. (2006) Epidemiology of Parkinson's disease. *Lancet Neurology*, 5, 525–535.
- 6 Nussbaum, R.L. and Ellis, C.E. (2003) Alzheimer's disease and Parkinson's disease. *New England Journal of Medicine*, 348, 1356–1364.
- 7 Tanner, C.M. and Goldman, S.M. (1996) Epidemiology of Parkinson's disease. *Neurology Clinics*, 14, 317–335.
- 8 de Rijk, M.C., Launer, L.J., Berger, K., Breteler, M.M.B., Dartigues, J.F., Baldereschi, M., *et al.* (2000) Prevalence of Parkinson's disease in Europe: a collaborative study of population-based cohorts. *Neurology*, 54 (11) Suppl. 5, S21–S23.

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Part I

Parkinson Disease – Diagnosis and Treatment

A Spouse's Story

We Will Live for Today

Bill Austen

Parkinson's Disease was something I had heard of, but knew very little about. However, I was on a huge learning curve when my wife (Rose) was diagnosed with the disease in June of 2002. My initial reaction was very emotional—along with fear of the unknown and of the future. My fears proved to be unfounded after a session with Jan Hansen, the Support Services Director, of the Parkinson's Society of Southern Alberta. Rose has always had a positive attitude and looked after her physical well-being, which is important for those with Parkinson's.

At this point in time we have been very fortunate in that the disease has not had a great impact on our everyday life. Yes, some days there have to be some changes as each day is different, so we must be prepared for those changes to our schedules. Rose has days that we call "A Parkinson's Day" where she may need to rest a lot, or just need quiet time alone. There are also those days when she will drive herself to activities, while on other days she would rather not drive, so I am prepared for that change in my plans. Falling is a problem—we don't know when it will happen, where it will happen, or how serious the after-effects will be. Because of her poor balance, using the escalators in the shopping malls and department stores is a problem, so I am with her when she needs to shop. Her muscular strength has diminished somewhat, so there are physical things that she needs some help with. There are friends that we don't see as often, and that is fine as that is their way of dealing with the disease, and it has given us the opportunity to make new friends. At this point I don't consider myself a caregiver—more like the spouse who tries to support her.

I am however, familiar with the caregiver role, having been at her side while she recovered from a serious car accident. Following that accident our lives changed dramatically for several years, and I became the household engineer—cooking, cleaning, shopping, etc. It was an eye-opener into the work involved with running a household. I feel at this point that Rose and I are ready for whatever road Parkinson's takes us on. With Rose's attitude and through our support group, together with the Support Services team of the Parkinson's Society, we will live for today—but we will also be prepared for tomorrow and the future.

1

Parkinson Disease

Ray Williams

In 1817, James Parkinson, an English doctor, published *An Essay on the Shaking Palsy*, in which he characterized the symptoms he had observed in six people, some of whom were his patients, but the others he had just observed in his neighborhood. His writings described “... involuntary tremulous motion, with lessened muscular power, in parts not in action and even when supported; with a propensity to bend the trunk forwards, and to pass from a walking to a running pace; the senses and intellect being uninjured.” Four decades later, the “father of clinical neurology”, the French doctor Jean-Martin Charcot added symptoms to Parkinson’s clinical description and attached the name Parkinson Disease to the syndrome [1].

1.1

Patient Burden

Parkinson disease (PD) is a common ailment; one in every 1000 of the population will develop the condition, and for those aged between 60 and 80 years the risk is approximately one in 100 [2]. While symptoms generally appear around age of 60, they can present in much younger people, which makes it a condition that does not recognize the boundaries of age, gender, or race.

PD is a progressive, neurologic disorder caused by a degeneration of dopaminergic neurons. Once a significant number of these neurons has been lost, that part of the brain that promotes movement no longer works effectively. As a result, people with PD experience substantial impairments in motor control and movement.

1.2

Characteristics of Parkinson Disease

PD is clinically characterized by four main features: (i) shaking back and forth when the limb is relaxed (resting tremor); (ii) slow physical movement (bradykinesia); (iii) stiffness, or resistance of the limb to passive movement when the limb