

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

is relaxed (rigidity); and (iv) poor balance (postural instability). The onset of these features is asymmetric, with one limb being affected first. The signs and symptoms then spread to the other limb on the same side, and later affect the limbs on the opposite side of the body.

Other common signs may include shuffling and freezing while walking, a stooped posture, difficulty with fine coordinated movements, difficulty in swallowing (dysphagia), small handwriting (micrographia), a soft voice (hypophonia), and a mask-like face with little expression (hypomimia).

In addition to experiencing any of these movement-related symptoms, suffering from PD impacts upon all aspects of the affected individual's life, including their emotional well-being and social functioning. For example, depression has been reported to occur in the majority of people with PD, which seems to be more frequent than in many other chronic diseases. Apathy also is experienced frequently by those living with the condition. PD-associated fatigue can be debilitating, and is an issue of growing research focus. In one study, almost half of the patients with PD claimed that fatigue was one of the three most disabling symptoms of the condition [3].

Weight loss also negatively impacts quality of life for people with PD, and can become especially marked during the advanced stages of the condition. A number of factors lead to such weight loss, including a reduced energy intake and an increased energy expenditure, a loss of appetite due to a disturbed smell and taste, a slowing of the gastrointestinal tract, as well as depression, nausea, and constipation.

Cognitive dysfunction and decline, dementia, hallucinations, and psychosis, can also occur during the advanced stages of PD. Other troubling symptoms include urinary incontinence, sleep-wake cycle dysregulation, and pain. All of these so-called "non-motor" symptoms can be particularly problematic, as there are few effective treatments.

1.3

Diagnosis of Parkinson Disease

A number of other conditions have a similar clinical presentation as PD, but at present there is no reliable technology or test that can distinguish between these ailments and PD. Rather, the diagnosis of PD is based primarily on the patient's history and a clinical examination.

1.4

Treatment for Parkinson Disease

Five classes of medications are available to treat the movement-related (motor) symptoms of PD, including: levodopa; dopaminergic agonists; anticholinergics; amantadine; and monoamine-oxidase B inhibitors.

Levodopa remains the most effective medicine, in particular for treating rigidity and slowness of movement. It is usually combined with another medication that works to prevent the rapid breakdown of levodopa in the digestive system. Most patients initially do well on levodopa. However, the treatment is associated with several side effects that people with PD may experience, such as nausea and appetite loss, involuntary movements, twisting motions and abnormal postures (dystonia), hallucinations and paranoia, and even impulse-control problems such as excessive gambling. Therefore, treatment must be adjusted individually for each patient so as to maximize the benefits and minimize the side effects.

Surgical interventions for PD were attempted as early as the 1930s, but were abandoned because of the high morbidity and mortality related to the procedures. However, in 1987, it was first shown that deep brain electric stimulation could improve tremor with PD patients. Since then, this technology has been developed for several motor symptoms in PD, although the procedure is still associated with serious side effects.

The first attempt to treat patients with PD with *cell transplantation* was made by a Swedish research group during the 1980s [4]. This involved transplanting cells from one area to another within the patient's brain, but it caused serious side effects. In recent years, attention has been focused on stem-cell research, which has shown promise but is currently still in the experimental phases.

Patients often turn to *complementary and alternative medicine* in search of therapies to help them cope. The most common reasons stated for accessing complementary therapies are to achieve better symptom relief, to augment the effects of prescription medications, and to boost strength. However, there is limited scientific data available on the effects of most alternative therapies. This topic is explored in greater detail in Chapter 6.

There is some evidence suggesting that, with regular exercise, PD patients may experience an improvement in their motor function, gait, and balance [5].

Ongoing research in PD strives to improve available treatments and to slow the progression of the disease. In the meantime, access to multidisciplinary services and support (e.g., specialized medical care, physiotherapy, occupational therapy, speech language therapy, and community support programs) is essential for good outcomes.

New theories have emerged about the onset of PD actually occurring many years before it is currently diagnosed. This may have substantial implications for the early detection and treatment of this chronic disease.

References

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