

Parkinson's Disease

Understanding and Moving Forward



Parkinson Society British Columbia
Société Parkinson Colombie-Britannique

Thank you to all who contributed to the development of this booklet for individuals living with Parkinson's and their families. I commend Parkinson Society British Columbia for their leadership in this project.

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Mission

Parkinson Society British Columbia is a not-for-profit charitable organization that exists to address the personal and social consequences of Parkinson's disease through education, community outreach, funding of scientific research, advocacy and public awareness.

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At the time of printing all information in this book was deemed accurate.

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Understanding and Moving Forward

This booklet is intended to give you – the men, women and children who are affected by Parkinson's – an introductory understanding of the disease and some tools for living well with it. **This booklet is for information purposes only and does not replace regular consultations with your team of healthcare professionals.**

Before you begin reading, please remember:

While there are similarities, no two people will have exactly the same symptoms or require exactly the same medication.

and

Parkinson's is most often a slowly progressing disorder.

Some people are overwhelmed when they read too much at one time. If this happens to you, read one or two chapters at a time. Also, keep a notepad handy so you can jot down any questions that come to mind and then take those questions to your next doctor's visit. It's also helpful to jot down your doctor's answers for your records.

As you read, you will see many references to additional information posted on the Parkinson Society British Columbia website (www.parkinson.bc.ca). If you do not have access to the internet and would like to receive a copy of the information mentioned, please contact our office and we will send it by mail.

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Chapter 1

What is Parkinson's?

The basics

Parkinson's was first identified and documented in 1817 by British physician Dr. James Parkinson who recorded his findings in his essay entitled "*An Essay on the Shaking Palsy.*"

Parkinson's is the second most common neurodegenerative disorder after Alzheimer's disease. It is a chronic, progressive neurological disorder that affects a person's motor functions (voluntary movements), such as walking, buttoning shirts and handwriting. It also affects non-motor functions (involuntary movements), such as mood, bowel function and sleep.

In general, the motor functions are symptoms that are visible on the outside while the non-motor symptoms are less visible, affecting processes within the body. It is common for non-motor symptoms such as pain, sleep disturbance, altered sense of smell or mood changes to precede the onset of motor symptoms and a diagnosis of Parkinson's. People with Parkinson's often report that the non-motor symptoms present a greater challenge to their quality of life and are harder to deal with compared with the impact of motor symptoms.

What Causes Parkinson's Disease?

While no single cause of Parkinson's has been identified, both genetic and environmental factors may be involved. Approximately 10% of Parkinson's cases can be traced to a genetic link. It is possible, however, that genetics and the environment may work together to cause Parkinson's.

How is Parkinson's Diagnosed?

There are no specific brain scans or laboratory tests to confirm the diagnosis of Parkinson's. Neurologists diagnose it with a thorough study of a person's medical history and a careful physical examination. A person is asked to perform various tasks to assess possible rigidity of his or her arms and legs, muscle tone, gait, and balance. Parkinson's can be difficult to diagnose in the early stages because certain symptoms mimic those of other conditions. Tests may be done to rule out conditions that resemble Parkinson's.

“People are defined by core values, not by diseases.”

Dr. Michael Okun, Parkinson's Treatment. 10 Secrets to a Happier Life.

A person's response to taking Parkinson's medications may also be used as a diagnostic tool. Discovering whether or not the medication results in a significant improvement in symptoms can be an important part of the diagnosis.

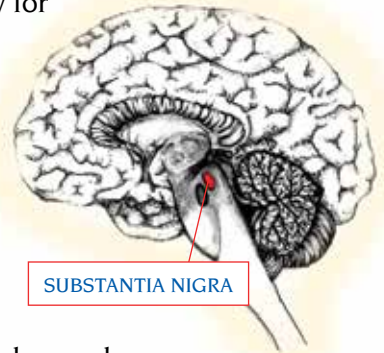
The Role of Dopamine

Dopamine is a neurotransmitter that enables nerve impulses to travel smoothly from one nerve cell to another. This allows for the transmission of messages to the muscles, a process necessary for initiating movement. Dopamine is produced by specialized cells in an area of the brain called the substantia nigra. Symptoms of Parkinson's appear when these cells begin to die and cease producing dopamine.

At least 50% of the dopamine cells are lost by the time the symptoms of Parkinson's appear.

As dopamine decreases, muscle movements become slower and more rigid, tremors can develop and reflexes become more impaired, contributing to a loss of balance. As the level of dopamine decreases, symptoms gradually worsen over time.

Discovering why dopamine-producing cells die is a major focus of Parkinson's research.



Is There a Cure?

While there is extensive research being conducted around the world, there is no known cure for Parkinson's at the present time. There are medications that help manage the symptoms but at present none appear to stop or slow the progression of Parkinson's. There is, however, early evidence that certain new medications may slow the progression and these medications are in clinical trials.

With good medical care, people with Parkinson's can enjoy good quality of life for many years and live virtually a normal lifespan.

Who Gets Parkinson's?

Parkinson's affects 1% of the population over 65 years of age. In Canada, there are approximately 100,000 people with Parkinson's, 11,000 of whom are in British Columbia. The average age of diagnosis is 60 but up to 20% of people with Parkinson's are diagnosed under the age of 50. Parkinson's disease does not discriminate with respect to race, gender or region of the

world, although slightly more men than women have Parkinson's. As the population of Canada ages, the incidence of Parkinson's will increase.

What Happens as Parkinson's Progresses?

Each person is unique and the type and severity of symptoms and the rate of progression differs from one person to another. Parkinson's is a life altering, but not life threatening, disease although changes in mobility and cognition can impact one's quality of life. According to the Canadian Guidelines on Parkinson's Disease, people with tremor-dominant Parkinson's (where tremor is an early presenting symptom) may experience slower symptom progression and longer benefit from levodopa. In general, an older age of onset, together with rigidity as a predominant symptom, may lead to earlier cognitive challenges.

As you read on, you will see that there are a variety of approaches to treating Parkinson's and to living well with it. You have many options. Remember, Parkinson's is one of the most slowly progressing neurological disorders. Changes happen over time, allowing you to learn and adapt as you go.

“Become an expert in PD. This helps you to partner with your healthcare team to get the most out of your consultations. Knowledge is power!”

Dr. Silke Cresswell, Pacific Parkinson's Research Centre

Chapter 2

Adjusting to Your Diagnosis

How do I do this?

It Takes Time

Just as everyone's experience with Parkinson's is different, everyone adapts to the diagnosis in different ways. There is much information to absorb and many questions to ask. Many people know little about Parkinson's at the time of diagnosis and the task of learning how to live with it can feel overwhelming.

Some common reactions to the diagnosis include shock, anxiety, anger, sadness and denial. Many people ask, "Why me?" or "How did this happen?" Some people seek a second neurologist's opinion while others feel like giving up or avoid talking about it. Some people feel relieved to finally have a diagnosis.

Whatever your response, your feelings are a legitimate and natural reaction to being diagnosed with a progressive neurological disorder.

Most people have many questions upon their diagnosis. Some of these questions or concerns may sound familiar to you.

- What will happen to me?
- What do I do when I can't work?
- Who will look after me when I need it?
- Will I need help at home?
- What symptoms will I develop?
- Will I have to take medication right away?
- How long will I live?

Questions are a healthy response to your diagnosis. While there are some common denominators for every person with Parkinson's, the answers depend on how the disease progresses, your age at the time of diagnosis, your treatment plan and other factors. A good place to start when adjusting to this diagnosis is to focus on what you need to know right now. Make it your goal to live life today. Tomorrow isn't here yet.

“*I was very anxious in the beginning but I felt better when I started learning what I needed to know right now, today.*”

Support Group Member

Find Accurate Information from Credible Sources

The internet provides a seemingly unlimited source of information about Parkinson's but you must be discriminating about the sources. Some online information is factually incorrect, some sites promote radical (and often dangerous or expensive) treatments while others claim miracle cures. As with all information, especially medical information, caution is important. Here are some credible resources for information gathering:

- Our website (www.parkinson.bc.ca)
- Parkinson Society Canada (www.parkinson.ca)
- National Parkinson Foundation (www.parkinson.org)
- Parkinson's UK (www.parkinsons.org.uk)
- Northwest Parkinson's Foundation (www.nwpcf.org)
- National Young Onset Center (www.youngparkinsons.org)

See the Bibliography and Resources sections for more information.

Talking about Parkinson's

The desire and willingness to talk about Parkinson's varies from person to person. Some tell the people close to them right away while others refrain from talking to anyone. For reasons relating to employment or to protect those close to them, some people choose to keep their diagnosis confidential.

We believe it is important to talk about your diagnosis but when and to whom you disclose the diagnosis is a personal decision. Many people begin by telling immediate family or a trusted friend. Remember, sharing the news of your diagnosis may help you feel less alone and you may receive some helpful and meaningful support. Talking to others can lighten your load.

To help them adjust to living with Parkinson's, some people attend a Parkinson's support group. For more information on support groups, go to Chapter 12.

“A sense of hope, held in a realistic way, is something that all Parkinson's patients can develop and share.”

Janet Reno, former Attorney General of the United States and a person living with Parkinson's, from "Surviving Adversity. Living with Parkinson's Disease" by Gord Carley

Talking to Children about Parkinson's

Parkinson's disease is a family affair. Everyone in your family is affected and each person is affected in a different way. Children of all ages are perceptive. They feel when something is not right and they often imagine that things are much worse than they really are. Whatever the age of your children, consider:

- Sharing your PD diagnosis.
- Providing age-appropriate information on the disease.
- Sharing your best understanding of what might happen to you.
- Discussing the possible impact on your family.

Children, teens in particular, may not want to talk to you about your PD. It is important, however, that they have someone to talk to. It could be a friend, parent of a friend, teacher, school counsellor, coach, relative or spiritual leader.

Children need time to adjust to and grieve the changes and losses in their life such as new and different roles in the family, changing schedules and activities, and the changes they see in their parent with Parkinson's. They need time and space to understand and to begin to cope with the new situation.

Remember: you are the expert on your children. If you sense that something is different or wrong in how they are coping, you are probably right.

Toolkit

For more information on this topic, go to our website www.parkinson.bc.ca and look for the following help sheets by Elaine Book, MSW, RSW, Pacific Parkinson's Research Centre:

- *"A Family Affair. Talking to your children and teens about Parkinson's"*
- *"What is Parkinson's Disease? Information for teens with a parent who has Parkinson's disease"*

Keep Your Social Life Alive

It is fairly common for newly diagnosed people to not want to be with other people. Some do not want to be "the person with Parkinson's" at social events. Others are self-conscious about their symptoms. It is, however, important to remain socially connected, even if it is by phone or email.

Isolating yourself for extended periods of time can slow the process of accepting your diagnosis and may contribute to feelings of depression and anxiety. Even when you may not feel like doing so, reach out to others in a way that works for you. In a nutshell, it's vital for you to get out of the house!

“I was worried that my diagnosis might be a downer for other people but I realized it wasn't. It was just me worrying.”

Support Group Member

Support Groups

Connecting with people you trust and who will support you on this journey is critical and many people find that connection in a support group. Groups provide a safe, supportive and confidential place to talk with others who are in a similar situation. Participants often share information about local resources, practical suggestions, ideas, tools and personal experiences which may be useful to others. Mostly, support groups help people know that there are others who understand Parkinson's because they face similar challenges. For more information on our support groups, see Chapter 12.

“The support group helped me understand the various stages of Parkinson's and how to cope with them. I shared my experience but I learned much more in return.”

Support Group Member

Medical Appointments – Making them Count

Medical appointments can be stressful. First, you may have waited a long time to see a neurologist. Second, you will talk about something you would rather not have to talk about. And third, medical language can be confusing. To help you manage the stress of an appointment and to ensure you get the best possible outcome, you may want to do the following:

- Bring someone with you. Two minds are better than one!
- Bring a list of all of your symptoms and what you think may or may not be a symptom.
- Bring a list of all of your questions – about symptoms, medication, etc.
- Ask about your next appointment, how long you will need to wait, and what to do if you experience a significant change prior to the appointment.
- Ask about getting a second opinion if you think it would be useful.
- Take notes so you remember the information your doctor shares with you.

Toolkit

Help sheet: “*Preparing for a Medical Appointment*” at www.parkinson.bc.ca

Planning for the Future

It is easy to procrastinate when it comes to planning for the future. We know it is important but we tend to put it off. There are many situations and life events, however, that necessitate planning and decision-making, particularly when you have been diagnosed with a chronic illness. Areas where planning is important include reviewing your financial circumstances, estate planning, advanced health care planning and more. If important decisions have been pending for a while, this may be a good time to attend to them.

You may want to explore what types of tax deductions and other benefits are available to you. You may also want to meet with your family, complete a representation agreement, meet with your financial advisor or consult a lawyer or notary public. For information on benefits available to people with disabilities, go to www.cra-arc.gc.ca/disability.

After the important conversations, the fact-finding and any relevant documents have been completed, many people experience a sense of relief.

Toolkit

For more information on planning for the future, see the Legal Series help sheets at www.parkinson.bc.ca

“*Accepting the diagnosis as one part of your life – and as one part only – allows you to enjoy the many other parts your life is made of.*”

Dr. Silke Cresswell, Pacific Parkinson's Research Centre

Chapter 3

Symptoms of Parkinson's

What are the most common symptoms?

Keep in mind that while some symptoms are common to most people with Parkinson's, other symptoms vary. With precise medication management and other forms of treatment and support, symptoms can be managed effectively.

Motor Symptoms

- **Resting tremor** – These are repetitive shaking movements that often occur in the hands, arms or legs while at rest. Tremor is the first symptom to appear in about 70% of people while approximately 30% never develop a tremor.
- **Rigidity** – Increased stiffness in muscles and joints, making it difficult to move. Rigidity usually responds well to treatment.
- **Slowness of movement or “bradykinesia”** – This involves all voluntary movements such as walking and writing. It also applies to internal processes such as the movement of food through the gut, a common cause of constipation. Bradykinesia generally responds well to medication.
- **Balance and postural impairment** – This means difficulty maintaining balance, difficulty standing up straight and walking. To learn how to manage these symptoms, consult a physiotherapist.

Note: Resting tremor, rigidity and bradykinesia are often exacerbated by stress. Reducing stress often reduces symptoms.

Non-Motor Symptoms

- **Hypomimia** – Reduced facial expression which makes a person appear uninterested or sad when they are not. It's often referred to as the PD mask.
- **Hypophonia** – A person's voice may become soft. Deterioration in the rhythm and quality of the voice is common.
- **Micrographia** – Small, cramped handwriting or writing that begins normally but progresses to smaller and smaller writing.
- **Depression and changes in thinking** – Both are common for people living with Parkinson's and may be present prior to the appearance of motor symptoms.

- **Sleep disturbances** – This can include insomnia, vivid dreams, nightmares, REM sleep behaviour disorder and daytime sleepiness. See Chapter 10 for more information.
- **Constipation** – 50% of people with Parkinson's experience cramps and/or constipation. This can almost always be remedied with a high fibre diet, lots of water and regular exercise.
- **Fatigue** – This is something that affects nearly every person with Parkinson's. Fatigue can affect movement and walking and it can also affect thinking and memory. It is strongly influenced by the presence of anxiety and depression. Fatigue may also be a side effect of certain PD medications.
- **Orthostatic hypotension** – This means a drop in blood pressure when standing. The common symptoms include light-headedness or dizziness. It can be caused by Parkinson's and it is sometimes worsened by certain medications. See help sheet “Non-Medical Management of Low Blood Pressure” at www.parkinson.bc.ca.
- **Swallowing** – People with Parkinson's sometimes have difficulty swallowing.
- **Other symptoms can include:**
 - Pain
 - Changes in taste and smell
 - Weight loss
 - Bladder dysfunction
 - Excess saliva

Symptoms of Gait Disturbance and Fluctuations in Mobility

- **Gait disturbance** – As Parkinson's progresses, it is common to notice a change in walking patterns. A toe-first step, known as festination, can develop, causing one to propel forward with accelerating, rapid, short steps. Any form of gait disturbance can increase your risk of falling.
- **Freezing** – This refers to the sudden inability to take a step. It can occur when turning corners, moving through a narrow space, rising from a chair or being distracted. Freezing is associated with “wearing off” of medication and “on/off” episodes. See page 15 for more information.

Your physiotherapist can help you manage gait disturbances and freezing.

Toolkit

For information on fall prevention, see “*Stay on your feet! Understanding and reducing the risk of falling for people with Parkinson's*” at www.parkinson.bc.ca

Emotional, Cognitive and Memory Changes

Although Parkinson's is classified as a movement disorder, the non-motor symptoms, including changes in mood, thinking and memory, have been acknowledged in recent years as components of the disease. This is an important development because it recognizes symptoms like depression and cognitive changes.

These symptoms fall into two categories relating to their primary cause. Anxiety, apathy, depression and cognitive changes may be symptoms of Parkinson's. Impulsiveness, psychosis and confusion are usually caused by the medications used to treat Parkinson's.

Even with greater awareness of this aspect of Parkinson's, many of these symptoms go undiagnosed. Why?

- Because there is a lack of understanding by family and others. Many people do not realize that these symptoms can be part of Parkinson's.
- Because social stigmas can make it difficult for some people to acknowledge that they are experiencing changes in their mental health.
- Because healthcare professionals may have an inadequate understanding. Some family doctors and other professionals may not know that these changes relate to Parkinson's.

The good news is that, with precise medication management and other forms of support, these symptoms are treatable. Some of the more common symptoms affecting mood, thinking and memory include:

- **Anxiety** – Anxiety is a fairly common symptom of Parkinson's. It can appear prior to the onset of physical symptoms and it is treatable. Anxiety may return later as a medication-related side effect of “wearing off” episodes. See page 15 for information on wearing off.
- **Depression** – At least 40-60% of people with Parkinson's experience depression and it is treatable. Like anxiety, it may appear prior to the onset of physical symptoms.

Anxiety and depression may be caused by two factors:

- Changes in brain chemistry caused by Parkinson's.
- The stress and uncertainty associated with being diagnosed with Parkinson's.

- **Apathy** – Apathy occurs in as many as 50% of people with Parkinson's disease yet it remains one of the more misunderstood symptoms. Apathy is likely caused by physiological changes in brain chemistry. Apathy in a loved one may increase the stress that carepartners experience.
- **Cognitive impairment** – As Parkinson's progresses, many people with Parkinson's develop some form of cognitive impairment. Symptoms may include having difficulty following more than one thought and difficulty carrying on conversations. If these symptoms begin to interfere with activities of daily living, some people are diagnosed with dementia.

“Symptoms” Resulting from Medications (Side Effects)

A few symptoms experienced by people with Parkinson's are actually side effects of medication rather than actual symptoms of Parkinson's. These symptoms can be a side effect of Parkinson's medications or other medications.

A number of medications must not be taken by a person with Parkinson's and they are referred to as being “contraindicated” for Parkinson's. For important information on contraindicated medications, go to page 23.

The following side effects can be alleviated through adjustments in your medication. If you experience any of these, talk to your doctor as soon as possible. Do not attempt to adjust your medication without your doctor's assistance; changing the dosage or timing incorrectly can result in serious complications.

- **Impulsivity** – Some people with Parkinson's may develop impulsive or compulsive behaviours such as uncontrolled gambling, shopping, hyper-sexuality or other behaviours. These serious and distressing behaviours can be a side effect of Parkinson's medications such as pramipexole (commonly known as Mirapex, a dopamine agonist). It is very important that you speak to your doctor immediately if you develop any of these troubling behaviours. A change in medication or dosage is needed. More information on impulsivity is in Chapter 10.
- **Psychosis** – Approximately 50% of people with Parkinson's may, at times, experience visual or auditory hallucinations. Some hallucinations are minor and may not require treatment. If they become disturbing for you or others, speak to your doctor immediately. Psychosis can be either a side effect of Parkinson's medications or other medications such as certain tranquilizers, anti-nausea drugs, anaesthesia or certain pain medication.

- **Dyskinesia** – Over time, certain receptors in the brain become less able to maintain a consistent level of dopamine. When Parkinson's medication is taken, these receptors may initially be flooded with dopamine but they are unable to maintain an optimal level in the brain. As a result of the unregulated, excess level of dopamine, a person with Parkinson's may develop involuntary movements called dyskinesia. These movements are often similar to dance-like arm waving and upper body swaying or rolling. Treatment may involve a change in the dosage or timing of your medication or the addition of another medication to treat the dyskinesia.

Chapter 4

How is Parkinson's Treated?

What you can do for your health and wellness

Medication

Medication is the primary way in which the symptoms of Parkinson's are treated. Although there are a number of non-pharmacological treatments that can have a significant impact on improving your quality of life, such as physiotherapy, speech therapy and surgical procedures, the best symptom control ultimately depends on the right medications used in an optimal manner. An overview of the medications used to treat Parkinson's follows this section.

When Should I Start Taking Medication?

The most important factor in deciding when to begin medication is whether or not Parkinson's symptoms are affecting your quality of life or your work performance. Most experts agree that there is no benefit in delaying medication therapy if bothersome symptoms appear. In fact, for people who are at risk of falling, delaying treatment may pose a risk. If you are concerned about when to begin taking medication, talk to your doctor about your symptoms, lifestyle, other health concerns, balance problems and changes in cognitive abilities.

Do the Drugs Slow the Progression of Parkinson's?

As Parkinson's disease progresses, increased medication and adjustment of doses are usually needed. While the current medications can minimize or alleviate symptoms, they do not appear to slow the progression of Parkinson's. New medications that show signs of being able to slow the progression are currently being studied in clinical trials.

What about Side Effects?

Like most medications, Parkinson's medications have side effects. A brief note about drug side effects is included in the following pages. To understand each medication and its side effects, ask your pharmacist or doctor for more information.

Most Parkinson's medications take time to be effective and it is during this time that side effects may be experienced. Some people feel discouraged when this happens. Many people report, however, that as the Parkinson's medication begins to take effect, side effects begin to diminish. As you learn more about how your body reacts to the medication, you can work with your doctor to make more appropriate medication decisions. Be sure to keep your doctor informed about your Parkinson's symptoms and any side effects you think are being caused by the medication.

What are “On/Off” Fluctuations?

On/off fluctuation refers to sudden and unpredictable changes in the effectiveness of levodopa therapy. A person may fluctuate from mobility (being on) to sudden immobility (being off). This phenomenon typically occurs much later in the course of Parkinson's.

What does “Wearing Off” Mean?

Wearing off occurs when your symptoms, such as resting tremor or rigidity, return before the next dose of levodopa is due. This is due to the current dose wearing off or being used up before your next dose. If this occurs on a regular basis, tell your doctor so together you can adjust your dosage or timing for maximum benefit. Do not adjust your medication without consulting your doctor.

What does “Dose Failure” Mean?

Dose failure is different from wearing off. Dose failure means that your medication failed to kick in, failed to provide any benefit and you didn't experience any relief of symptoms. Dose failure is a complication of long-term drug treatment and may relate to gastrointestinal complications associated with taking medication with food. In addition, stress and anxiety can play a major role in preventing medications from working. If you experience dose failure on a regular basis, be sure to tell your doctor. It is common to occasionally have a day when your medication just doesn't work. This is normal and it may be because your body is fighting an infection, the flu or the common cold.

Medication Safety and Effectiveness “Musts”

- Follow your prescribed medication schedule exactly. Timing is everything!
- Never stop taking your Parkinson's medication abruptly or change the dosage or prescribed times without consulting your doctor.
- Never chew, crush or split a pill unless your doctor or neurologist instructs you to do so.

“The goal of treating Parkinson's with medications is to ensure that you can be as active as possible. If symptoms interfere with your exercise, hobbies, daily tasks or social life, we need to adjust the medication.”

Dr. Silke Cresswell, Pacific Parkinson's Research Centre

Non-Medical Treatments

Medication may be the primary tool for treating Parkinson's, but it is not the only tool. Recently, treatment has expanded to include other healthcare professionals and other treatments. It is recommended that you learn how the following healthcare professionals can assist with the day-to-day management of your symptoms:

- Physiotherapist, particularly one specializing in neurological disorders.
- Speech-language pathologist, particularly one specializing in Lee Silverman Voice Training.
- Occupational therapist for activities of daily living.

More information about these professionals and how to contact them can be found in Chapter 6.

Things You Can Do Today

Exercise

According to the Canadian Guidelines on Parkinson's Disease, consistent exercise can result in an improvement in activities of daily living (such as dressing), gait, walking speed, decreased falls and reduced bradykinesia. Chapter 5 has more information on exercise and Parkinson's.

Manage Changes in Your Energy Level

One of the most common symptoms of Parkinson's is fatigue. Your ability to maintain your pre-Parkinson's pace will change over time. In addition, certain medications and sleep disturbances can contribute to low energy levels.

Recommendations for managing your energy level include:

- Having a nap during the day.
- Planning activities for your best times of the day.
- Speaking to your doctor if you feel your medication is causing significant fatigue.
- Allowing extra time to do tasks.
- Learning how to say "no."

Manage Your Stress

Stress can make certain Parkinson's symptoms worse, particularly tremor, rigidity and slowness of movement. Stress can prevent your Parkinson's medications from kicking in or it can contribute to heightened dyskinesia. Stress management is easy to talk about, but often hard to do, so identify simple activities that work for you. Here are some ideas:

- Deep breathing
- Yoga
- Tai Chi
- Brief walks throughout the day, particularly outdoors in the fresh air.
- Managing your activity levels and napping when you need to.
- Saying "no" to requests that would create stress, not reduce it.
- Meditation
- Keeping a journal.
- Doing what you like to do such as a creative outlet like painting or woodworking.
- Talking and walking with other people, or walking the dog.

Massage Therapy

Many people report finding temporary relief of their symptoms through massage. You may want to find a registered massage therapist in your community and speak to him or her about their treatment approach as it relates to neurological disorders.

Careful Medication Management

One of the best things you can do for yourself is to be meticulous with your medication management. Following your doctor's advice regarding the dosage and timing of your medication is essential to good long-term management of your symptoms.

Nutrition Matters

There is no specific diet for people with Parkinson's but it is highly recommended that you eat as healthfully as possible. Choosing from all four food groups (grains, fruit and vegetables, milk products and protein) is important. See Chapter 9 for more information.

Over-the-Counter Medications

All medications, whether prescription or over the counter, have side effects and interactions. It is essential that you speak to your doctor before starting any new medication, vitamin or supplement. See page 23 for information on drugs that must not be taken if you have Parkinson's.

Alternative Therapies

It is common for people to inquire about alternative treatments for Parkinson's. At present, there is no scientific evidence to support alternative treatments such as mega dose vitamins, CoQ10 and other supplements. Consult your doctor before trying alternative therapies.



What Medications are Used for Treating Parkinson's?

The more you know about your Parkinson's medications and the side effects you experience, the more tools you and your doctor have to find the right balance of controlling disease symptoms and managing side effects.

If you are concerned about the development or severity of any medication side effects, contact your neurologist. If you and your doctor decide to reduce or stop a medication, ask your doctor for a detailed plan that outlines dosage reductions and length of time for each reduction. Although there are no standard reduction guidelines, any PD medication must be reduced slowly and gradually to avoid serious complications.

Levodopa (or L-dopa)

What is it?

- Levodopa is the gold standard medication for Parkinson's with the broadest antiparkinsonian effects of any treatment. It remains the most effective medication for the treatment of motor symptoms such as rigidity and muscle movement and it is often the first to be prescribed.
- Levodopa works by replacing dopamine in the brain. The medication is converted into dopamine in the brain and is stored in nerve cells to replace depleted dopamine.
- It is available in many different pill sizes, colours and dose strengths and is provided in immediate release and controlled release formulations.
- Prescribing instructions must be followed exactly.

Examples:

- Levodopa plus carbidopa, referred to as levocarb or levodopa/carbidopa (Sinemet and Sinemet CR)
- Levodopa plus benserazide (Prolopa)
- Levodopa/carbidopa/entacapone (Stalevo)

What are some possible side effects?

- Nausea
- Light-headedness
- Sleepiness
- Hallucinations (in some cases only)
- Dyskinesia (involuntary movement)

Two Myths about Levodopa

Is Levodopa toxic?

- According to the Canadian Guidelines on Parkinson's Disease, there is no current evidence to suggest that levodopa is toxic.

Will Levodopa cease working over time?

- According to Dr. Eric Ahlskog of the Mayo Clinic in Rochester, Minnesota, levodopa does not stop working as Parkinson's progresses except in very advanced cases. Over 10 to 20 years, the responses may not be as dramatic compared with initial use. Notwithstanding these changes, levodopa remains beneficial. Any decline in the levodopa benefit is primarily related to the duration of Parkinson's, not how long you have been treated.

Dopamine Agonists**What are they?**

- Dopamine agonists are the second most potent class of medication (after levodopa) for control of motor symptoms.
- May be useful as an initial treatment or with levodopa in more advanced stages.
- Dopamine agonists stimulate the parts of the brain that are influenced by dopamine. They mimic the effect of dopamine and trick the brain into responding as it would when receiving the dopamine it needs.

Examples:

- Bromocriptine (Parlodel)
- Pramipexole (Mirapex)
- Ropinirole (Requip)
- Rotigotine (Neupro transdermal patch)

What are the possible side effects?

- Sleepiness, including sudden onset of sleep
- Hallucinations
- Leg swelling
- Weight gain
- Dyskinesia
- Impulsive, uncontrolled behaviours such as binge eating, hypersexuality, and compulsive gambling. See Chapter 10 for more information on compulsive behaviours.

Catechol-O-Methyltransferase (COMT) Inhibitors**What are they?**

- COMT inhibitors block a key enzyme in the blood responsible for breaking down levodopa before it reaches the brain.
- May improve the duration and response to levodopa.

Examples:

- Entacapone (Comtan)
- Tolcapone (Tasmar) (limited availability)

What are the possible side effects?

- Nausea
- Light-headedness (orthostatic hypotension)
- Hallucinations
- Increased dyskinesia
- Diminished impulse control

Levodopa/carbidopa/entacapone (Stalevo)

What is it?

- This is a combination of immediate release levodopa/carbidopa plus entacapone in one pill.
- May be used to extend the benefits of levodopa and reduce “wearing off” reactions.

What are the possible side effects?

- Nausea
- Light-headedness
- Sleepiness
- Hallucinations (in some cases only)
- Dyskinesia

Monoamine-Oxidase-B Inhibitors

What are they?

- MOA-B Inhibitors may be used for symptom control in early Parkinson's.
- May enhance the effect of dopamine by preventing its breakdown in the brain.
- Particularly beneficial for fatigue and gait problems.

Examples:

- Selegiline (Eldepryl)
- Rasagiline (Azilect)

What are the possible side effects?

- Headache
- Weight loss
- Nausea
- Hallucinations
- Increased dyskinesia

Levodopa/carbidopa Intestinal Gel (Duodopa)

What is it?

- This is a levodopa/carbidopa gel administered throughout the day with a pump via a tube inserted into the small intestine.
- May be used in advanced Parkinson's disease when response to oral medications is limited.
- This drug delivery system is approved by the Health Canada “Special Access Programme” in certain instances only. It has limited availability, involves medical specialists and is very expensive.

Amantadine (Symmetrel)

What is it?

- Amantadine promotes the release of dopamine from nerve terminals, blocks its re-uptake and blocks the neurotransmitter glutamate.
- Amantadine can reduce dyskinesias and improve “wearing off.”

What are the possible side effects?

- Dry mouth
- Nausea
- Dizziness
- Insomnia
- Swelling of the legs and purplish discolouration of the skin

Anticholinergic Drugs

What are they?

- Anticholinergic drugs are used to help relieve the early symptoms of Parkinson's by correcting an imbalance between dopamine and acetylcholine in the brain.
- May help reduce tremors, slowness of movement and rigidity.

Examples:

- Trihexyphenidyl (Artane)
- Benztropine (Cogentin)

What are the possible side effects?

- Dry mouth
- Constipation
- Blurred vision
- Retention of urine
- Confusion/psychosis

Medication Contraindications

Certain non-Parkinson's medications must be avoided because they can block or decrease the amount of dopamine in the brain and worsen Parkinson's symptoms.

When you are prescribed a new medication by your family doctor, dentist or neurologist, be sure to ask about drug interactions with your Parkinson's medication. Before you purchase over-the-counter medication such as cold medication, pain relievers or cough syrup, read the label and follow the instructions carefully. Make sure it does not interfere with your Parkinson's medication.

| People with Parkinson's Must Not Take: | |
|--|------------------------------|
| CATEGORY | ONE EXAMPLE* |
| Prescription medications: | |
| Certain antipsychotic medications | Haloperidol |
| Certain antidepressants | Amoxapine |
| Certain nausea medications | Metroclopramide |
| Certain blood pressure medications | Reserpine |
| Pain medication caution | Demerol – use with caution |
| Over-the-counter medications: | |
| Certain cough medications | Dextromethorphan (Benlyn DM) |
| Certain cold medications | Pseudoephedrine (Sudafed) |

*Please note this is just one example of each category. There are other medications in each category that must be avoided. Ask your doctor or pharmacist for more information.

Toolkit

If you have any questions about drug interactions, speak to your doctor and/or your pharmacist. In BC you can phone BC HealthLink (dial 811) and speak to a nurse or, after 5:00 pm, you can speak to a HealthLink pharmacist.

Timing is Everything!

If you are taking medications to treat Parkinson's, timing your doses of medications is extremely important. If you are recently diagnosed, you may not notice any difference in your mobility or your symptoms when you forget to take a dose. As the disease progresses, however, timing your medication becomes critical. This is primarily due to the nature of the medication and how your brain uses it.

Why is Timing so Important?

- Medications must be taken on time to maximize normal functioning and symptom control. Delaying your medication can decrease its effectiveness and interrupt your symptom control. A delay may also increase anxiety.
- A regular schedule may help delay the development of motor fluctuations down the road.
- When a medication routine is interrupted, it may take hours or days to return to optimal functioning.

Some people with Parkinson's experience heightened anxiety when they are "off," that is, when their medications are not working. For maximum physical and emotional comfort, take your pills on time.

Toolkit

For more information on medication management in the hospital click on "PD Medication, Timing is Everything" at www.parkinson.bc.ca/information-resources

Surgical Treatment of Parkinson's

What is Deep Brain Stimulation?

Deep Brain Stimulation (DBS) has been used to treat Parkinson's since the late 1980s. Performed by a specialized neurosurgeon, the procedure involves inserting electrodes into one or more target areas of the brain. The DBS electrodes are connected to a device, similar to a heart pacemaker, which supplies electrical impulses to the selected areas of the brain. The intent is not to stimulate the function of the area but to decrease the function or stop it. Unlike other neurosurgical procedures used to treat Parkinson's, such as thalamotomy and pallidotomy, DBS does not lesion or destroy brain tissue and, if necessary, the electrodes can be removed.

Is DBS a Cure?

While DBS can be an effective treatment for the symptoms of Parkinson's, it is not a cure. DBS will work for many years but only for those symptoms that have responded favourably to dopaminergic (dopamine enhancing) medications. One goal of DBS is to extend a person's best "on" time that they have with Parkinson's medications. It is important to remember that DBS does not slow or stop the progression of Parkinson's.

Who is a Good Candidate for DBS?

DBS is not for every person with Parkinson's. A candidate for DBS will be assessed by a movement disorder specialist or neurologist prior to referral to a neurosurgeon. Some of the most common selection criteria are, but not limited to, the following. Candidates must:

- Be in relatively good health apart from Parkinson's.
- Have no mood or cognitive impairments.
- Continue to be responsive to levodopa to the extent that they can walk unassisted for at least a few hours a day.
- Have no major difficulties with swallowing, balance or speech.
- Have adequate social and family support to rely upon during recovery .
- Demonstrate a clear understanding of the procedure and what the possible outcomes, both positive and negative, might be.
- NOT be affected by severe heart, lung, kidney or liver disease or incurable cancer.

What are the Risks?

As with all surgeries, there are risks associated with DBS. Some of these include:

- Infection (5%)
- Confusion or behavioural changes (4%)
- Difficulties with speech, swallowing and memory
- Potential for bleeding during surgery
- Potential for stroke (1%)

Follow-up Appointments

Numerous follow-up appointments for equipment programming and medication changes are required after surgery. The person with Parkinson's and family members must be willing and able to travel to the surgeon's office approximately 6 times in the first 6 months following surgery and periodically after that for adjustments. In addition, the battery in the implanted pulse generator requires replacement every 3 years.

Referral from Your Neurologist to a Neurosurgeon

The referral to a neurosurgeon begins with your neurologist. Your neurologist prepares a report on the status of your Parkinson's, your response to medication and other important selection criteria. There is a lengthy wait list for seeing a neurosurgeon and a second wait list for the actual procedure. In British Columbia, there is currently only one surgeon who performs DBS surgery.

A mnemonic from University of Florida for people with Parkinson's considering DBS

D-B-S-I-N-P-D

| | |
|----------|--|
| D | D oes not cure. |
| B | B ilateral DBS is often required to improve gait, although sometimes unilateral DBS has a marked effect on walking. |
| S | S mooths out on/off fluctuations. |
| I | I mproves tremor, bradykinesia, stiffness and dyskinesia in most cases, but may not completely eliminate them. |
| N | N ever improves symptoms that are unresponsive to your best "on." For example, if gait or balance do not improve with your best medication response, it is unlikely to improve with surgery. |
| P | P rogramming visits are likely to occur many times during the first six months with follow-up visits as frequently as every six months. There are multiple adjustments in the stimulator and in your medications. |
| D | D ecreases medications in many, but not all, patients. |

What about Stem Cell Treatment?

Extensive research is being undertaken throughout the world and advances have been made but much more work is needed to ensure the safety and effectiveness of stem cell treatment. The following are some of the problems that remain unresolved:

- Once a stem cell is implanted and made to divide, the challenge then becomes how to control the growth of the cells. Uncontrolled growth of the new cells has the potential to form tumors.
- Stem cell transplants can lead to the development of uncontrollable dyskinesia, known as “runaway dyskinesia” because of the extra movements in both the “off” and “on” medication state.
- Stem cell research fails to address the complexity of Parkinson's and the multiple motor and non-motor areas of the brain.
- Research is needed to ensure that implanted cells do not get “sick” and cease producing dopamine.

Caution

There are organizations outside of North America that advertise “stem cell miracle cures.” These procedures cost thousands of dollars. When evaluating these claims, look for scientific evidence including journal articles and other evidence of a scientific peer-review process. Most of these internet sites contain patient testimonials only. **Talk to your doctor!**

A Final Note about Your Treatment Plan

As you can see, there are many treatment options for someone with Parkinson's disease. Work closely with your doctor to determine the right medical treatments and explore the treatments and strategies that you can do on your own. By managing both, you can learn to live well with this disease.

Chapter 5

Exercise and Parkinson's

Have you had your daily dose of exercise?

Caution

If you experience chest pain, dizziness, severe shortness of breath or acute pain while you are exercising, stop and seek immediate medical attention.

Why is Exercise Important?

Exercise is important for everyone but there are significant and unique benefits for people with Parkinson's. According to Dr. Nina Browner of the University of Carolina, there is growing evidence showing that exercise promotes neuroplasticity and the ability of the brain to repair itself. Neuroplasticity brings about changes in neural pathways and synapses, allowing healthy brain cells to take over the work of damaged cells. Conversely, there is evidence that inactivity may contribute to disease progression.

There is also significant clinical evidence showing that exercise can be a key factor in the long-term management of Parkinson's symptoms. Along with the standard health benefits, exercise can enhance your quality of life by improving your fitness level, strength, flexibility and balance. Exercise also helps to alleviate depression and anxiety and it reduces stress. To maintain your long-term physical and mental health, exercise is a must!

Getting Started Safely

If you are not exercising, get started! Before you begin, however, consult your family doctor if you have any concerns. Factors to consider include your blood pressure and other health problems such as diabetes or arthritis. Your doctor can advise you on the safest ways to exercise.

Exercise will have a positive impact on your symptoms, which will give you an improved sense of well-being and a more positive outlook on life. By exercising regularly, you are making a significant contribution to your health. Make it your goal to work into an exercise routine that is safe and that causes you to break a sweat.

Make it Fun!

You will stick with an exercise program when you enjoy what you are doing. Plus, by choosing exercises and activities that you enjoy, the sense of reward you experience increases the natural dopamine levels in your brain.

Keep it Going!

Motivating yourself to exercise consistently can be difficult. Some ways of maintaining your motivation include:

- Starting small, noting positive changes, and working up to a more challenging routine.
- Having an exercise buddy for both encouragement and accountability.
- Keeping an exercise log and/or using a pedometer.
- Committing to an exercise or walking group.
- Changing your routine to keep it interesting.
- Rewarding yourself for meeting the challenge of exercising regularly.
- Exercising with a group for the added enjoyment of socializing with others.
- Reminding yourself that with a safe and effective exercise program you are making a positive contribution to your overall health and wellness.

Timing is everything! Take into consideration your medication cycle, sleep patterns and when you feel you are functioning at your best. That's the time to exercise.

Elements of an Exercise Program

Aerobic Fitness

- Aerobic activity helps to build your heart and lung capacity. Activities like walking briskly (with or without Nordic poles), jogging and swimming are some examples of aerobic activity.

Strength

- Using free weights, resistance bands or your body weight helps to build muscle and enhance your bone strength. For more information on bone health and Parkinson's, see Chapter 9.

Flexibility

- Flexibility or stretching exercises help to reduce stiffness and to maintain a good range of movement in your limbs and trunk.

Balance

- Balance exercises tune up your response to changes in your balance, enhancing your safety and decreasing your risk of falling or fear of falling. Yoga and Tai Chi are excellent for improving one's balance.

Posture

- Be aware of your posture. Most people with Parkinson's tend to slouch, straining their neck forward. Stand tall, keep looking forward with your chin in and keep your head aligned above your shoulders. Not sure about your posture? Look at yourself in a mirror.

Suggested Activities

There are many wonderful exercise options including:

- Brisk walking
- Golf
- Racquet sports such as pickleball or doubles tennis
- Gardening
- Dancing
- Swimming or aquafit classes
- Cycling or a stationary bike
- Yoga or chair yoga
- Tai Chi
- Pilates
- Wii exercises
- Lawn bowling
- Fitness classes at your local community centre or gym

Some support groups organize their own exercise or dance classes. Consider starting one in your area. Contact us for ideas and assistance.

When you exercise make your movements **BIG!**

Safety Considerations

It is important to note that as you age or when you are further along in the disease process, you will need to be more aware of your safety when being active. You may have to alter the way you are active such as switching to a recumbent stationary bicycle, an arm or leg ergometer (an apparatus for measuring the work performed by exercising) or to a chair-based exercise routine.

Interested in learning more? Consult a physiotherapist or certified fitness instructor with expertise in Parkinson's disease. They can tailor an exercise program for your specific needs.

Our bodies are designed to move, so keep moving. Use it and improve it!



Toolkit

- Exercise booklets can be obtained from these resources:
www.parkinson.bc.ca
www.thera-bandacademy.com
www.parkinsons.ubc.ca
www.parkinson.ca
www.apdaparkinson.org
www.parkinson.org
www.parkinson.org/helpline or 1 800 473 4636
- Exercise DVDs available online or by calling Parkinson Society British Columbia:
 - “*Smart Moves*” Exercise, Yoga and Tai Chi
 - “*Delay the Disease.*” Exercise and Parkinson’s Disease DVD and manual by David Zid.
- Exercise book available at Parkinson Society British Columbia library:
 - “*Yoga for Movement Disorders*” by Renée Le Verrier.
- www.physicalactivityline.com 1 877 725 1149 or 604 241 2266
Help for setting up exercise programs and for exercise research references.

“*Make your feet your friend.*”

J.M. Barrie, Scottish author and dramatist

Chapter 6

Your Healthcare Team

Who they are and how they can help you

“Parkinson’s disease is best managed in a multidisciplinary environment. In addition to your neurologist, nurse specialists, physiotherapists, social workers, occupational therapists, speech language pathologists and dietitians can each contribute to various aspects of your well-being.”

Dr. Martin McKeown, Pacific Parkinson’s Research Centre

Introduction

There are a number of healthcare professionals who can be involved in the care of people living with Parkinson’s. Whether you have recently been diagnosed or have been living with Parkinson’s for some time, it’s helpful to know who you can call upon for information and direction.

Family Physician

For many people, the process of diagnosis begins with a family physician. Some family physicians choose to manage the initial stages of Parkinson’s, particularly in locations where there are no neurologists. We highly recommend, however, that your family doctor refer you to a general neurologist or to a movement disorders clinic for ongoing care and treatment. This is especially important if you have young-onset Parkinson’s, if your symptoms are not consistent with those of Parkinson’s, if your medication is ineffective, or if your symptoms change rapidly.

“Ideally, patients suspected of having PD or a related movement disorder should be referred to a specialized movement disorders clinic or centre for evaluation.”

Canadian Guidelines on Parkinson’s Disease

Neurologist

The neurologist will conduct an assessment based on your symptoms and your medical history. During the assessment you may undergo several tests such as walking a short distance, moving your hands and arms in certain ways, as well as doing other neurological tests and activities. There are no

brain scans or medical tests to diagnose Parkinson's but a neurologist may request certain scans and tests to rule out the presence of other conditions. Once there is a diagnosis, a neurologist will discuss your treatment options.

Pacific Parkinson's Research Centre

In British Columbia, the centre for excellence in Parkinson's disease is the Pacific Parkinson's Research Centre (PPRC) at the University of British Columbia in Vancouver. Under the direction of Dr. A. Jon Stoessl, the team at PPRC is comprised of neurologists specializing in the treatment of Parkinson's and other movement disorders, together with Parkinson's nurse specialists, a social worker and a physiotherapist. Regardless of their location in BC, many people travel to PPRC for treatment. A referral by your family physician or your current neurologist is required. PPRC often hosts post-doctoral fellows from around the world who are undertaking the advanced education and training necessary to specialize in the treatment of Parkinson's.

Parkinson's Disease Nurses

PD nurse specialists at PPRC help to coordinate care for people with Parkinson's and their care partners. The PD nurse provides educational support and advice regarding diagnosis and medications to help patients maintain independence and maximize their abilities. The PD nurse also refers patients to fellow PPRC team members when appropriate.

In addition, the PPRC PD nurses can help with the following:

- Completing forms for Canada Pension Plan, disability tax credits and insurance coverage.
- Monitoring and adjusting medication between clinic visits under the direction of the neurologist.
- Providing advice, guidance and information on dosing of new medications and potential side effects.
- Submitting applications for Special Access Medications to Pharmacare and accessing compassionate supplies from providers when possible.

Physiotherapists

Physiotherapists are healthcare professionals who help keep people moving and functioning when they are affected by injury, illness or long-term conditions, such as Parkinson's. Physiotherapists work in a variety of settings including hospitals, clinics, health authority home and community care departments and in private practice. Physiotherapists may specialize

in the treatment of certain conditions including neurological disorders. According to the *Canadian Guidelines on Parkinson's Disease*, physiotherapy should be available for people with Parkinson's.

Treatment Goals

A physiotherapist can help you understand and manage the physical challenges of Parkinson's and it is recommended that you consult a physiotherapist as soon as possible after your diagnosis. In the early stages, your treatment may be focused on maintaining your fitness levels in order to help you stay active and independent. In the later stages, your treatment may focus on improving your walking, posture, balance and how to manage activities of daily living, such as how to roll over in bed.

In addition, a physiotherapist can help you with:

- Improving or maintaining your muscle strength through exercise.
- Staying flexible and moving easily.
- Preventing falls.
- Improving gait and posture.
- Relieving or managing pain.
- Improving breathing and circulation.
- Managing stress.

A medical referral is not necessary to see a physiotherapist but you may want to ask your family doctor or your neurologist for a recommendation. The Physiotherapy Association of British Columbia website (www.bcphysio.org) provides information on physiotherapists specializing in neurological conditions in your community. (If you are unable to use the internet, call our office for help.)

Occupational Therapists

Occupational therapists are healthcare professionals who assess your ability to perform activities of daily living. An occupational therapist can recommend appropriate assistive devices in addition to developing strategies to help you improve your ability to manage activities such as dressing, eating, bathing, walking and sleeping. An occupational therapist can help you to maintain your work and leisure activities and your self-care for as long as possible. The *Canadian Guidelines on Parkinson's Disease* recommends that occupational therapy be available for people with Parkinson's.

Treatment Goals

In addition to managing activities of daily living, some of the activities that an occupational therapist can help you with include:

- Maintaining your ability to carry on with hobbies and interests.
- Dealing with changes in your abilities such as handwriting or using a computer.
- Carrying out tasks such as dressing yourself (e.g. managing shirt buttons) as well as eating and drinking.
- Identifying tasks that may become a problem and preventing them from developing.
- Improving walking, getting in and out of a bed or bath, using stairs and keeping your balance.
- Recommending assistive devices or adaptive equipment for your individual circumstances.

Toolkit

You may want to speak to your physician about a referral to an occupational therapist or you can contact your local health authority's home and community care department. BC health authorities are included in the Resources section of this booklet.

Speech-Language Pathologists

Speech-language pathologists, commonly known as speech therapists, specialize in communication and swallowing disorders. Speech problems occur in up to 40% of people with Parkinson's and can have a significant impact on quality of life.

The most common communication problem affecting people with Parkinson's is hypokinetic dysarthria, a speech disorder that causes rigidity and slowness of the systems of communication including breathing, voice and speech. Evaluation and treatment of hypokinetic dysarthria is performed by a speech-language pathologist. You may also need to meet with an ear, nose and throat physician. Ask your doctor or neurologist to refer you to a speech-language pathologist for an assessment.

Toolkit

The Lee Silverman Voice Treatment® for PD is a specialized treatment for voice disorders designed specifically for the communication problems experienced by people with PD. Information on LSVT® certified clinicians can be found at www.lsvtglobal.com or by contacting Parkinson Society British Columbia.

For more information on speech and swallowing, go to Chapter 8.

Social Workers

Social workers are concerned with helping individuals and families enhance their well-being by providing support and information on a broad range of issues and resources. Their work requires an understanding of the unique needs of an individual or family together with an understanding of the challenges presented by broader social issues such as limitations within the healthcare system.

Social workers often work within a hospital or clinic setting where they are important members of the treatment team. With an in-depth understanding of Parkinson's and its effect on the patient and on the family, the social worker provides information, counselling and referral options. The social worker helps the patient and family to understand the initial diagnosis, to adjust to changes as the disease progresses, and to manage the emotional, social and practical concerns that may arise as a result of Parkinson's. This work may include:

- Coordinating communication between the patient and/or their family and the medical team and community supports.
- Evaluating how well the individual and their family are coping and assisting them to adjust and adapt to living with Parkinson's.
- Counselling individuals and families.
- Providing information about the home and community care system, including home care options, assisted living and other residential care facilities.
- Providing information about financial, legal and general resources available for people living with a chronic condition and/or a disability.
- Liaising with hospital staff regarding discharge planning and the development of strategies for transitioning home.

Chapter 7

Preventing Falls

What you should know

Anyone can fall but symptoms of Parkinson's such as rigidity, bradykinesia (slowness in executing movement) and postural instability can increase your risk of falling. Falls are a serious health risk and, in the general population, they are the leading cause of injury-related hospitalizations and in some cases can lead to injury-related deaths. Falls can also be a factor in the decision to move into a residential care facility.

While not every fall can be prevented, being proactive reduces your risk of falling and enhances your confidence. Even small changes, such as removing loose rugs in your home, can make a difference. At the end of this section you will find information on healthcare professionals who can assist you in improving your balance, strength and walking and ensuring your home is as safe as possible.

What Causes People with Parkinson's to Fall?

Having Parkinson's can increase your risk of falling in the following ways:

- Certain Parkinson's medication can cause dizziness or light-headedness.
- Orthostatic hypotension (low blood pressure) experienced when sitting up or changing from sitting to standing.
- Changes in your posture.
- Changes in vision.
- Reduced strength and impaired balance reactions.
- Changes in walking patterns including difficulty turning, backing up, moving around obstacles and changing direction.
- Dyskinesia, the involuntary twisting or turning of the head, body, legs and/or arms, can affect your balance.
- The tendency to propel forward as your walking pace accelerates but degenerates into rapid, short steps. This is known as a festinating gait.
- Freezing, when your feet suddenly are unable to move so your feet stick to the ground and you are unable to take another step.
- Certain changes in thinking or memory can cause anxiety and lead to feeling unsteady.
- Bradykinesia, or slowness of movement, can hinder the response time you need to adjust your balance when you change direction or position.
- Fear of falling, particularly after an initial fall.

In addition to changes in your mobility and in your confidence to move easily, your risk of falling can also be increased for other reasons. Do any of these sound familiar?

- Managing Parkinson's along with another chronic or acute illness which involves additional medication and other complications.
- Taking unnecessary risks, pushing yourself too far or too hard and overdoing it.
- Having clutter in your living space, particularly on stairs or on the floor.
- Walking on uneven surfaces in and around your home or not watching for uneven surfaces such as at the grocery store or at a friend's home.
- Wearing poor footwear.

Where Do I Start in Reducing My Risk of Falling?

- **Learn about Parkinson's and the medications** you are taking and their possible side effects. Optimal medication management, including management of side effects, is one of the best ways to reduce your risk of falling.
- **Take your medications on time every time!**
- **Write down any medication side effects you experience** including when they happen, what happens, and how often. Make a special note of any episodes of dizziness or light-headedness (certain medications cause a drop in blood pressure), excessive sleepiness and dyskinesia.
- **Talk to your doctor.** If you have not already done so, speak to your family doctor about a referral to a neurologist and a physiotherapist.
- **Ask about a bone-density test.** Parkinson's may increase your risk for low bone density and osteoporosis in men and women. Talk to your doctor about being tested.



What Can I Do to Reduce My Risk at Home?

- Make repairs to unsafe areas of your home such as:
 - Install or repair handrails on both sides of stairs.
 - Repair worn or broken steps and walkways, inside and out.
 - Increase light bulb wattage.
 - Add night-lights to hallways and bathrooms.
 - Remove carpets or rugs that you may slip on.
 - Clear clutter of all kinds from stairs and walkways.
 - Consider using a cordless phone.
 - Use a non-skid bathtub or shower mat.
 - Consider a shower chair and hand-held shower.
- Store items on lower shelves.
- Keep regularly used items within arm's reach and take care reaching forward.
- Learn how to walk so your centre of gravity is not too far forward over your feet.
- If you have to lean forward, keep your feet wide apart, one foot in front of the other.
- Stand directly in front of what you are reaching for.
- Hold the counter to steady yourself.
- Sit down to dress and to do other chores.
- Take special care when turning or backing up.
- Look where you are going and try to not be distracted or to rush.
- Ask for help to carry or move heavy objects.
- Avoid sudden movements or quick changes in positions.
- Take time to plan your movements.
- Rest when you need to and practise saying “no” to less important activities.
- Consider subscribing to a personal alarm system which can call for help if you fall.

I Have Already Had a Fall. What Can I Do to Overcome My Fear of Falling?

Fear of falling can limit your activities and affect your lifestyle. Becoming less active or less social in order to avoid falling can lead to anxiety, a greater risk of falling and eventually reduced health and well-being.

decreased activity + **decreased strength** + **increased anxiety** = **increased risk of falling**

If you have had a fall and you worry about falling again, consider the following:

- Stay as active as possible.
- Ask a physiotherapist about safe ways to move.
- Take a daily walk.
- Exercise to improve your strength and balance.
- Try Tai Chi for flexibility, balance and relaxation.
- Try yoga to enhance relaxation and improve flexibility, breathing and posture.
- Continue to exercise, socialize and participate in normal activities.
- Learn how to get up from the floor after a fall (ask your physiotherapist).
- Use a cane or walker for stability and to maintain independence (ask an occupational therapist).
- Consider protective equipment such as hip protectors and knee and elbow protectors.

Toolkit

Go to www.parkinson.bc.ca/information-resources and click on Help Sheets. Two sections relate to fall prevention.

Mobility and Physical Health:

- Balancing and Falling
- Freezing
- Stiffness and Slowness
- Walking

Living with Parkinson's Disease:

- In-Home Safety Check
- The Bathroom
- The Bed
- Assistive Devices and Home Adaptations

Also see “*Stay on Your Feet! Understanding and reducing the risk of falling for people with Parkinson's.*”

Working with a Physiotherapist

For individualized treatment and advice on reducing your risk of falling, consult a physiotherapist. To find a physiotherapist in your community who has experience working with neurological conditions, ask your doctor for a recommendation or go to the Physiotherapy Association of British Columbia website (www.bcphysio.com) and follow the search criteria. In-home physiotherapy may be arranged through some private clinics and through your health authority home healthcare team. For health authority contact information, please see the Resources chapter.

In-Home Safety Assessment

For an in-home assessment of your mobility and your safety, contact the home healthcare team within your local health authority. Home safety assessments are usually conducted by an occupational therapist who can offer ideas, suggestions and recommendations for making your home safer and for adaptive equipment that can enhance your mobility and improve your safety. You do not need a medical referral. For health authority contact information, please see the Resources chapter.

*If I tell anyone I've fallen
I'll lose my independence.*



*Don't worry! I fell too, but
after my fall:*

- *I had a check up to make sure I was well*
- *Some of my medicines were changed*
- *I was given advice on how to make my home safer*
- *I was given information about suitable exercise classes.*

Chapter 8

Speech and Parkinson's

I don't have a speech problem. You have a hearing problem!

Speech and Voice Problems

Many people with Parkinson's will experience problems with their voice. Initially, the precision of speech (articulation) may deteriorate and you may notice a garbled quality. Second, the volume of your voice may decline and you may be told you are speaking too softly. Problems with communication can result in social isolation and difficulty expressing your needs to your healthcare providers and caregivers.

While you may feel that you are speaking loudly, or even shouting, listeners may have difficulty hearing you, asking you repeatedly to speak up. Many people with Parkinson's firmly believe they are speaking loud enough to be heard when they are not.

What Causes Speech Problems?

The most common communication problem affecting people with Parkinson's is hypokinetic dysarthria, a speech disorder that causes rigidity and slowness of the systems of communication including breathing, swallowing, voice and speech.

In the same way that PD can cause slowness, rigidity, tremor and difficulty with initiation of movement, it can also affect your breathing, your voice and your speech. You may experience one or more of the following symptoms:

- Reduced volume, even when you think you are speaking loudly.
- Hoarse voice quality.
- Monotone in conversation.
- Imprecise articulation.
- Vocal tremor.
- Change in rate of speech.

Evaluation

The best person to evaluate hypokinetic dysarthria is a speech-language pathologist. You may also benefit from a referral to an ear, nose and throat specialist. Don't hesitate to ask your doctor about both.

Treatment Options

Optimal and precise medication management can alleviate some speech problems.

In addition, treatment by a speech-language pathologist is highly recommended. The most effective speech therapy for people with Parkinson's is the Lee Silverman Voice Treatment® (LSVT®). This intensive and specialized speech therapy is specifically designed for treating the speech problems unique to Parkinson's. Information on LSVT® certified clinicians can be found at www.lsvtglobal.com or by contacting Parkinson Society British Columbia.

Note: Only a few speech-language pathologists are certified in LSVT® at present so there may not be one in your area. However, a referral to another speech-language pathologist may also be beneficial.

What Can I Do on My Own to Improve My Voice?

- Make sure you have your listener's attention before speaking.
 - Maintain eye contact with your listener.
 - Avoid speaking in the presence of distracting background noise.
 - You may need to speak more slowly and more intentionally. Make sure every word is clear.
 - Swallow before speaking to clear any pooled saliva.
 - Try to speak louder than you are used to speaking.
 - Begin speaking with a topic phrase, such as, "I would like to talk about..."
 - Try to plan important conversations during a time when you are feeling your best.
- 66 *"Practise your speech in front of a mirror, reciting or reading familiar text while raising your voice. Shout this out so that someone in the next room could easily hear you with the door closed. Do this to develop a habit of "thinking loud" whenever you speak. For this to be consistently effective, you must practise on a daily basis; otherwise you tend to fall back to your old speaking habits."*

J. Eric Ahlskog, MD, *The Parkinson's Disease Treatment Book*

Toolkit

See the following help sheets at www.parkinson.bc.ca

- *Voice and Parkinson's*
- *Management of Saliva and Drooling*
- *Swallowing*

Chapter 9

Nutrition and Parkinson's

Eating well helps you live well

At the present time there is no evidence to suggest that specific diets or supplements affect the progression of Parkinson's. Good nutrition is, however, essential to your health and well-being at all stages of the disease.

Achieving good nutrition and maintaining a healthy weight involves eating a variety of foods each day in adequate amounts. This is not always easy for people with Parkinson's. Outlined below are some nutrition challenges you may encounter plus some ideas for overcoming them.

Weight Loss

As many as 70% of people with Parkinson's will experience unplanned weight loss. Some of the reasons for this weight loss include:

- Involuntary movements associated with Parkinson's can burn more energy than you consume.
- Loss of sense of smell and taste makes food less interesting.
- Fatigue can affect the ability to shop for groceries and prepare meals.
- Chewing and swallowing problems can make meal times unpleasant and stressful.
- Symptoms of depression can include a lack of appetite.
- Nausea can be a side effect of certain Parkinson's medications.
- Constipation can cause discomfort and a lack of appetite.

Strategies for stimulating appetite and increasing food intake:

- Eat small, frequent meals.
- Check with your doctor about whether or not it's wise to eat high calorie foods such as ice cream, butter, mayonnaise, honey, juice and milkshakes, especially if you have high cholesterol or diabetes.
- Experiment with new spices to enhance the flavour of food.
- Eat foods that are easy to prepare and easy to eat.
- Prepare meals when you are feeling your best.

Swallowing Problems

Swallowing problems become more common as Parkinson's disease progresses. Warning signs include coughing or choking while eating/drinking, a gurgling voice after eating, excessive chewing or drooling, delayed or absent swallowing, and pocketing of food in the mouth. If you

experience any of these symptoms on a regular basis, ask your doctor for a referral to a speech-language pathologist who can conduct a thorough swallowing assessment.

Toolkit

See the help sheet entitled “Swallowing” at www.parkinson.bc.ca

Overweight

It is well known that being overweight can lead to a variety of health problems. For a person with Parkinson's, being overweight can lead to difficulty with symptom management. For example, extra weight has the potential for making exercise more difficult, leading to a loss of strength and decreased mobility. If you experience unexplained weight gain that concerns you, check with your doctor. Some medications like dopamine agonists and anti-depressants list weight gain as a side effect.

Talk to your doctor or a dietitian about achieving gradual weight loss and a healthy lifestyle.

Compulsive Overeating

Weight gain can be associated with uncontrolled or compulsive overeating. Compulsive behaviour, such as overeating or binge eating, may be a side effect of certain Parkinson's medications. If you are experiencing this, or any compulsive behaviour, speak to your doctor as soon as possible. Your medications can be adjusted in order to reduce or stop the troubling behaviour. Do not adjust your medications without your doctor's guidance. For more information on compulsive behaviour, see Chapter 10.

Constipation

Constipation is a serious and common symptom of Parkinson's that can appear prior to the onset of other Parkinson's symptoms. Factors contributing to the development of constipation include poor appetite, inadequate physical activity, medication side effects, and the impact of Parkinson's on the function of the gastrointestinal track. The good news is that constipation can almost always be treated with a daily routine of healthy eating. The benefits are tangible!

Change your eating habits as soon as possible and consider the following:

- Include 6 – 8 cups of fluid in your diet each day, including soup, juice, milk, and water.
- Increase your activity level. Whether it's a short walk around the block or a longer walk every afternoon, everything helps.
- Eat high fibre foods including oatmeal, bran, whole grains, fruit, vegetables, beans, peas and lentils.
- Talk to your doctor if the situation persists or worsens.

Toolkit

See the help sheet entitled “*Bowel Management Program*” at www.parkinson.bc.ca

Nutrition and Bone Health

Men and women with Parkinson's can be at increased risk of developing osteoporosis which, combined with balance problems associated with Parkinson's, can put you at risk for serious injury.

Osteoporosis in people with Parkinson's can be caused by:

- Decreased activity level and a sedentary lifestyle.
- Decreased vitamin D relating to limited sun exposure and to a lower intake of milk products and other calcium-rich foods.
- Aging

Osteoporosis can be prevented by:

- Increasing your intake of calcium and vitamin D.
- Eating foods high in calcium which include dairy products, fortified soy milk, fortified orange juice, canned fish with bones, baked beans, almonds and broccoli.
- Exercise

Ask your doctor about calcium, vitamin D, multivitamins and other supplements to ensure compatibility with Parkinson's medications and to establish the correct dosage.

A Word about Vitamins, Minerals and Supplements

Although there is no research or scientific literature that can be cited regarding the role of vitamins, minerals or nutritional supplements in supporting a person with Parkinson's, some people with Parkinson's do take them on a regular basis. Certain supplements can help boost your nutrition, particularly if you find it difficult to eat enough healthy food throughout the day. As noted previously, many liquid meal replacements contain significant amounts of protein and you should keep this in mind when taking your pills. Check with your doctor before adding supplements to your diet.

Alcohol and Parkinson's Medication

Alcohol in moderation will not affect your Parkinson's medication. In addition, there is no scientific evidence to suggest that alcohol use in any way contributes to the development of Parkinson's disease. However, the effects of alcohol combined with certain symptoms of Parkinson's and certain medications could be problematic.

Suggestions for Staying Safe

- Check with your doctor to ensure alcohol is compatible with any and all medications you take.
- If you experience dizziness or light-headedness due to low blood pressure, balance or gait problems, consuming alcohol may exacerbate the problem and put you at greater risk for falls.
- Alcohol can contribute to sleepiness so use caution if your medications also cause you to be sleepy.

Toolkit

- Outpatient nutrition counselling is available at many hospitals by physician referral.
- HealthLink BC for free nutrition information at 604 732 9191, 1 800 667 3438 or www.dialadietitian.org or www.healthlinkbc.ca/healthyeating
- Dietitians of Canada www.dietitians.ca
- Osteoporosis Canada www.osteoporosis.ca

Chapter 10

Special Topics

Impulsive behaviours, hospital stays and sleep problems

Impulse Control Disorder and Parkinson's

Approximately one in eight people taking certain Parkinson's medications may develop a side effect of impulsive and uncontrolled behaviours known as Impulse Control Disorder (ICD). For some people, these behaviours may be a minor nuisance but for others they have a serious, negative impact. Some of the more common behaviours include:

- Excessive gambling at casinos, through lotteries or on the internet.
- Hyper-sexuality – excessive, abnormal sexual urges.
- Binge eating.
- Compulsive shopping.
- Punding – repetitive performance of unnecessary tasks such as continuously wiping a spot on a wall or sitting at a computer for hours but accomplishing little.

Important: The majority of people who take dopamine agonists do not develop impulsive, uncontrolled behaviours.

What Causes Impulse Control Disorder?

Medications known as dopamine agonists, such as pramipexole (Mirapex) and ropinirole (Requip), can contribute to ICD. Because the medication takes time to work, the compulsive behaviour may appear weeks or months after beginning or increasing the medication. If you are the person with Parkinson's, you may not realize you have developed impulsive, uncontrolled behaviours. If you are a family member or carepartner, it may be your observations and experience that help to identify their impulsive behaviours. If you are developing these abnormal behaviours or if you notice them in your family member, inform your doctor as soon as possible. Some people who develop Impulse Control Disorder may be resistant to telling their doctor. If this is the case, it is recommended that caregivers talk to the doctor about the situation.

How is ICD Treated?

The most effective treatment is either lowering the dosage of the dopamine agonist (or other non-levodopa Parkinson's medication) or stopping the medication. Most often, the impulsive behaviours resolve in response to a dosage reduction. Please note that it often requires several months to reduce the dosage or stop the medication in a safe manner.

Do not decrease or stop your medication on your own. Ask your doctor for a schedule and plan for reducing the medication gradually and safely.

Many people who develop impulsive behaviours are embarrassed and may avoid talking about it with anyone, even their doctor. Many people are troubled by their behaviour but don't realize that it is a side effect of the medication. Some people may deny they have a problem, even when negative consequences, such as gambling-related financial stress, begin to affect them and their family.

ICD is not a character flaw. It is a side effect of medication and it can be treated.

Can People with Parkinson's Who do not Take Parkinson's Medication Develop ICD?

Research has found that people with untreated (un-medicated) Parkinson's were not likely to develop impulsive behaviours. The disease itself does not lead to ICD.

Hospitalization and Parkinson's

People with Parkinson's have unique care needs while in the hospital. Not all healthcare professionals are familiar with these needs and you and your family may have to educate the hospital's medical personnel about Parkinson's.

If you are hospitalized, it is likely for reasons other than Parkinson's and, particularly in the case of an emergency, medical personnel will be focused on diagnosing and treating the health concern that led to your hospitalization. If your PD symptoms are under control, medical staff may not recognize the ongoing importance of maintaining that control.

The best way to manage your needs in the hospital is to be prepared.

Getting your Medications on Time in the Hospital

A common and serious concern for people with Parkinson's in the hospital is the challenge of taking their medications on time. Parkinson's medications must stay on a precise schedule which usually does not fit with the timing of hospital rounds.

Taking your medication on time every time allows for smooth management of your Parkinson's symptoms. It can also have a positive impact on your recovery process. A change or delay in receiving medication may worsen your symptoms, causing you discomfort and anxiety, possibly leading to a delay in your release.

Make Your Needs Known

- Speak up when your medication is wearing off!
- Bring with you all of your medications in their original bottles plus a detailed list of pill times and dosages.
- Bring a friend or family member with you to help inform the staff of your needs.
- Try to arrange for self-administration or self-management of your medications. Be aware, however, that not all hospitals allow self-administration.



Contraindicated Medications

Certain medications must not be taken by people with Parkinson's and not all healthcare professionals know this. The contraindicated medications can block or decrease the amount of dopamine in the brain and worsen Parkinson's symptoms.

Contraindicated medications fall into a number of categories including certain antipsychotic medications, specific types of antidepressants, nausea medications, certain blood pressure medications, some analgesics and even cough and cold medications.

If a hospital doctor, or any doctor, prescribes a new medication for you, be sure to ask if it is compatible with your Parkinson's medications.

Toolkit

See page 23 for important information on contraindicated medications.

Managing Your Parkinson's Symptoms in the Hospital

For most people, being in the hospital is stressful. You are out of your comfort zone and you are worried about your health. People with Parkinson's who are in the hospital can experience additional challenges such as the following:

- **Anxiety** – Anxiety is a common problem among people with Parkinson's and it can worsen in the hospital. Keep the medical staff informed on how you are feeling. Practise de-stressing by listening to music, breathing deeply and acknowledging your anxiety to a friend or family member. Ask for help if your anxiety escalates.
- **Constipation** – Many people with Parkinson's have constipation. Different food, inadequate fluid and lack of mobility and exercise can worsen the problem. While you're in the hospital, drink lots of water. Ask a friend or family member to bring you bran muffins or prunes and eat them every day. Avoid constipating foods such as breads, rice and bananas. Walk as often as you are able.
- **Confusion** – Different medications (including anaesthesia), the activity around you, and the hospital lights and noise can lead to a feeling of confusion. Even certain infections can contribute to this problem. If you are not sure what is happening, ask. When possible, have a family member or friend with you during discussions with medical staff.

Informing medical staff about your needs as a person with Parkinson's is an important part of your hospital stay.

Toolkit

Resources to take with you to the hospital:

- **PD Medication – *Timing is Everything*** – a package of information for medical staff regarding the timing of your medication.
- **Hospitalization and Parkinson's** – a comprehensive outline of your unique care needs.
- **Medication Card** – provides information on contraindicated medications and allows you to record the dosage and timing of your medications.
- **Bowel Management help sheet** – a guide to managing constipation for people with Parkinson's.

These resources are available at

www.parkinson.bc.ca/information-resources

Sleep Problems and Parkinson's

Excessive Daytime Sleepiness

Excessive daytime sleepiness is an increase in the amount of sleeping in the daytime, to the extent that it interferes with everyday activities and quality of life. In mild cases of excessive daytime sleepiness, a person will tend to fall asleep when they're not active. In more advanced cases you may fall asleep while eating, walking or working.

What causes it?

Parkinson's can affect the parts of the brain that regulate the sleep/wake cycle. Many medications used to treat the motor symptoms of Parkinson's contribute to excessive daytime sleepiness.

How is it treated?

- Improving sleep hygiene – this includes having a bedtime routine, sticking to set bedtime and wake up times, making sure you have a comfortable environment to sleep in and not having stimulants like coffee in the hours before you go to bed.
- Getting exposure to adequate light during the day and darkness at night; indoor lighting may not be sufficient to promote a normal circadian rhythm.
- Talking to your doctor about modifying your Parkinson's drugs by using the lowest effective dose and reviewing your use of all medications.
- Discontinuing sedatives or stimulant drugs.
- Treating mental health issues such as depression.
- Avoiding sedentary activities during the day.
- Getting physical exercise appropriate to your level of functioning, but avoiding it too close to bed time.

If you have excessive daytime sleepiness, use caution while driving.

Insomnia

Insomnia is when you find it difficult to either fall asleep or stay asleep and it affects more than half of people who have Parkinson's. People with Parkinson's generally have more trouble staying asleep rather than falling asleep.

What causes it?

Similar to excessive daytime sleepiness, insomnia in Parkinson's is caused primarily by changes in the brain. Some Parkinson's medications may cause insomnia.

How is it treated?

The first and most important step in addressing insomnia is to practise good "sleep hygiene," as described on page 56. Sleeping pills may be necessary but they often have the side effect of increasing sleepiness throughout the day. Ask your doctor about this option.

Restless Leg Syndrome (now called Willis-Ekbom Disease)

Restless Leg Syndrome (RLS) can occur if you have Parkinson's and it can disrupt sleep. Symptoms include pins and needles, painful sensations or burning of the legs and the irresistible urge to move while resting or when trying to sleep. It may also cause one's limbs to jerk while sleeping.

What causes it?

The cause of Restless Leg Syndrome is not known.

How is it treated?

- Ask your doctor about medication available for RLS.
- Baths and massages can relax your muscles.
- Apply warm or cool packs. Alternating warm and cool packs can lessen the sensations in your limbs.
- Relaxation techniques such as meditation or yoga. Stress can aggravate RLS.
- Establish good sleep hygiene. Fatigue tends to worsen symptoms of RLS.
- Getting moderate, regular exercise may relieve symptoms of RLS.
- Avoid caffeine.
- Reducing alcohol and tobacco intake may help.

Obstructive Sleep Apnea

Obstructive sleep apnea is a sleep disorder in which breathing repeatedly stops and starts during sleep. The most noticeable sign of obstructive sleep apnea is snoring.

What causes it?

Obstructive sleep apnea occurs when the muscles in the back of your throat relax too much to allow normal breathing. When the muscles relax, your airway narrows or closes as you breathe in and breathing may be inadequate for 10 to 20 seconds.

How is it treated?

Continuous Positive Airway Pressure (CPAP) is the most consistently effective treatment. CPAP is a machine connected to a facemask that is worn by the person through the night and controls the pressure in the throat to prevent the walls of the throat from collapsing. In addition, you might want to try the following:

- Lose excessive weight. Losing even a few pounds may help.
- Avoid alcohol and medications such as tranquilizers and sleeping pills. These relax the muscles in the back of your throat, which interfere with breathing.
- Sleep on your side or abdomen rather than on your back. Sleeping on your back can cause your tongue and soft palate to rest against the back of your throat and block your airway.
- Keep your nasal passages open at night. Talk to your doctor about using nasal decongestants or antihistamines, because, unlike saline sprays, these medications are generally recommended for short-term use only.

REM Sleep Behavioural Disorder

REM (rapid eye movement) is a normal part of the sleep cycle during which people dream. Usually the only part of the body that is moving during REM is the eyes, thus the name rapid-eye movement sleep. People with Rapid-Eye Movement Sleep Behaviour Disorder (RBD) do not have the normal relaxation of the muscles during their dreams. Therefore, they act out their dreams during REM sleep. With RBD, a person may shout, kick, grind their teeth and, in some instances, become aggressive.

How is it treated?

- Environmental adjustments to protect the person and bed partner from injury are important. This may include padding the floor, using bed rails or sleeping in separate rooms.
- Certain medications may help. Ask your doctor.

Sleep Hygiene: Tips for Getting a Good Night's Rest

- Maintain a regular sleep schedule; get up and go to sleep the same time every day.
- Get plenty of bright light exposure, particularly natural daytime light.
- Decrease fluids several hours before bedtime.
- Go to the bathroom before going to bed.
- Use your bed only for sleeping and intimacy with your partner.
- Set the thermostat for a slightly cool bedroom temperature for sleeping.
- Make a regular, relaxing bedtime routine a habit.
- Lie down to sleep only when you're sleepy.
- If you are unable to sleep after 15 minutes, get out of bed and engage in a relaxing activity like listening to music, meditation or reading until you are sleepy.
- Keep lighting and noise at comfortable levels when trying to sleep.
- Sleep as much as needed to feel refreshed, but avoid spending too much time in bed.

Your Bed: Tips for Getting Comfortable

- Your bed should be high enough to allow you to easily sit down on it.
- The mattress should be firm.
- Use a soft pillow so you can position it for the greatest comfort.
- Bedcovers should be light but warm. Don't get weighted down under heavy blankets.
- If you sleep with a partner, you may find separate covers easier to deal with.
- If you have difficulty turning over in bed, try to reduce the friction between your pyjamas and your sheets. Avoid brushed nylon and flannel sheets. You might want to try silky sheets or pyjamas but be careful they are not too slippery.
- See a physiotherapist to learn how to safely turn and get into and out of bed and an occupational therapist for aids such as grab bars and bed rails.

Chapter 11

Caregiving and Parkinson's

Caring for yourself while you care for others

Parkinson's is a Family Affair

While you may have suspected that the health of a person you love was changing, hearing the words “I have Parkinson's” can be overwhelming. The diagnosis may answer some questions, but it can raise others. There's no doubt that Parkinson's changes the life of the diagnosed person, but it also changes your life if you are a spouse, partner, close family member or friend. It will take time for you and your family to adjust to this unexpected and unwelcome change.

It is useful to remember that all people who care for someone with Parkinson's will react differently. You may be experiencing a wide range of emotions; fatigue, numbness, sadness, anger, fear and frustration are normal and understandable feelings when faced with this diagnosis.

If you are caring for someone who has had Parkinson's for some time, you may still be experiencing some of these emotions. It's part of a healthy process of dealing with change.

Carepartners and Caregivers

These terms are often used interchangeably but they can mean different things. In many relationships, both people start out as carepartners. They participate equally in caring for each other. With a progressive illness, the role of a carepartner can become that of a caregiver. While the emotional care may remain the same, the day-to-day responsibilities will change. This is a shift that some carepartners find unsettling.

When and Where to Start

Now is the time to begin the process of living well with the changes Parkinson's will bring to you and your family. A good place to start is to talk about it! Maintaining open lines of communication with the person with Parkinson's and other family members is fundamental to reducing caregiver stress. Family meetings in person, by phone or using Skype are an excellent way for each person to maintain a good understanding of what is needed and how to help.

Whether you are new to living with Parkinson's or you have been a carepartner or caregiver for a while, it is never too late to begin taking better care of yourself.

Find Out What You Need to Know

- **Symptoms of Parkinson's** – Find a credible source for information, such as our website, and learn about the motor and non-motor symptoms of Parkinson's. Many caregivers tell us that it is more difficult to cope with the non-motor symptoms so learning about these symptoms is particularly important.
- **Medications** – At present, medication is the primary treatment for Parkinson's. A variety of medications, in a variety of dosages, can be prescribed and having a reasonable understanding of the medications is important.
- **Progression** – No one can accurately predict disease progression for a person with Parkinson's and symptoms can vary a great deal. Even though there may be frequent symptom fluctuations, Parkinson's is usually a slowly progressing disease and you will have time to adjust to the changes as they occur.
- **Who is in your corner?** – Now is a good time to connect with people in your personal support network. If you don't have one, now is the time to start building one. Family and friends can all play a role in helping you deal with this disease. For starters, practise asking for help now. The more accustomed you become to asking for and receiving help, the easier it will be to request help when you truly need it.

Continue to research and learn but resist the temptation to share every detail with the person you care for. A person with Parkinson's can feel overwhelmed with too much information.

A Member of the Healthcare Team

A person with Parkinson's may have a number of healthcare professionals involved in their care. As a carepartner or caregiver, you are an important member of the healthcare team. To make the most of appointments and to remain up to date with the treatment your loved one is receiving, it is recommended that caregivers participate in as many appointments as possible. In addition to learning more about the treatment options, it's important that your healthcare professionals receive current information about symptoms, medication side effects and other health concerns. The more details the doctor has, the more accurate his or her care plan can be.

A person with Parkinson's is strongly encouraged to maintain a list of notes and questions in preparation for a medical appointment. As a caregiver, your daily or regular observations of the person with Parkinson's are critical pieces of the healthcare puzzle. The person with Parkinson's may not accurately describe or disclose this information or he or she may think it is not important enough to mention.

To keep track of your loved one's medical information, keep a notebook. Jot down questions that arise between appointments. Before an appointment, prioritize with your loved one the information you want to share with the doctor and what questions you want to ask. Take notes during an appointment. Some doctors provide a summary of information and action points at the end of an appointment.

You are a vital member of the healthcare team!

Caring for Yourself

Caring for a person with Parkinson's means caring for yourself. Many caregivers don't have time for themselves while others say they feel guilty when they do something on their own without the person they're caring for. Many people do not recognize the benefits of caring for one's self as an important way to renew their energy and commitment.

A break does not have to be a week, several days or even a full day. Having an hour to yourself each day can make a significant difference. Scheduling activities on a weekly basis, such as attending yoga class every Wednesday morning or meeting a friend for coffee every Saturday afternoon, ensures you make time for yourself. By making it a habit now, even if you don't think you need it, you will benefit later when you really need time to rest and rejuvenate.

It is important for your loved one to learn that your needs are important and that he or she is capable of doing things without you. Time away from each other benefits both of you.

Consider how you can incorporate the following aspects of self-care into your day:

- **Physical Health** – Exercise, eat well and get enough sleep.
- **Mental and Emotional Health** – Maintain your interests and pay attention to how you are feeling. Talk to a friend to de-stress. Visit a counsellor for practical tips on how to stay well.

- **Social Support** – Maintain social contact with friends and family. Stay intellectually stimulated and current by reading the newspaper, watching the news or joining a book club.
- **Spiritual Health** – Try activities such as yoga, reading, prayer, meditation, walking in the forest or by the beach. Whatever works best for you, do it. Even 15 minutes of quiet time by yourself every day can make a world of difference.

Key Concepts for Healthy Caregiving

- Learn to ask for help.
- Learn to accept help. If someone offers to help, give them a practical task such as driving both of you to an appointment so you won't have to deal with traffic and parking.
- Learn to say “no.” Many find this a difficult task but there are times when it is essential; don't overload yourself with responsibilities that aren't important.
- Set goals so you become proactive rather than reactive.
- Be flexible. Caregiving can be an unpredictable job.
- Accept feeling down and discouraged for periods of time.
- Recognize when feeling down moves toward depression and seek help as soon as possible.
- Recognize that you can't do it all. Be realistic.
- Join a support group and talk with others in a similar situation. In some areas, there are support groups for caregivers. These groups are helpful sources of information, inspiration and compassion.

Give yourself permission to have your own life. The need for private time and relaxation is a basic human need and a caregiver right.

Toolkit

For home and community care contact information, see the Resources section.

For pamphlets, help sheets and support group information, go to www.parkinson.bc.ca/services

Pamphlet: *Caregiving and Parkinson's*

Help Sheets: *Caregiving, Grieving and Loss*

Caring in the Family

Communication Challenges in Parkinson's

Chapter 12

Joining a Support Group

To attend or not to attend

Support groups bring together people facing similar issues, whether it be an illness, relationships or major life changes. People with Parkinson's and caregivers often find it helpful and comforting talking with other people who are living with Parkinson's. Even if you have support from your family and friends, you may find it beneficial to connect with others outside of your immediate circle.

Benefits of Support Groups

In a Parkinson's support group you will find people with challenges similar to yours. Members typically share their personal experiences and offer one another emotional comfort and support. They may also offer practical advice and tips based on their own experience.

A support group does not replace standard medical care. Participants are cautioned against recommending specific medication regimes or giving others advice.

The benefits of participating in a support group include:

- Feeling less lonely, isolated or judged.
- Making friends and meeting people with whom you have something in common.
- Gaining a sense of empowerment and control.
- Improving your coping skills.
- Talking openly and honestly about your feelings in a confidential setting.
- Reducing stress, depression or anxiety.
- Getting practical information about treatment options to discuss with your doctor.
- Comparing notes about resources.
- Tips and strategies for coping with specific aspects of Parkinson's.
- Sharing humour and personal anecdotes.
- Supporting a group member going through a difficult time.
- Listening to guest speakers.
- Having a regular outing.

Self-Help Model

Our groups are self-help groups with a volunteer facilitator who often shares the leadership role with two or three other people. All group members are encouraged to participate in organizing the meetings.

Parkinson Society British Columbia support groups are based on the following values:

- The purpose is to help each other develop a positive approach to living well with Parkinson's.
- Each person's input is valuable and important.
- Group members learn from each other.
- Each person's experience of Parkinson's and caregiving is unique.
- The group leader is not the expert nor is any individual member an expert.
- Diverse definitions of family, caregiving and the meaning of 'help' are respected.
- Everything discussed in the meeting is confidential.

Getting the Most Out of a Support Group

When you join a support group, you may be unsure about sharing personal issues with people you don't know. At first you may wish to simply listen. Over time, though, contributing your ideas and experiences can help you get more out of a support group. In addition, your contribution may help or encourage other participants.

Concerned about Attending?

A person considering attending a Parkinson's group for the first time may be concerned about the possibility of seeing people in more advanced stages of the disease. Some people actually choose not to attend because they believe they will be "seeing their future" and would "rather not know." Whatever your perspective, it is valid and understandable. Attending a support group is a big step for some people so take your time and attend when you feel ready.

Consider attending one meeting to see what it's like. That will give you a more accurate idea of how you may benefit from the group and whether or not you would attend again. Remember that you don't need to make a commitment or pay any fees to attend.

Choosing a Group

Parkinson Society British Columbia has a network of more than 50 support groups throughout the province. Groups are often comprised of an equal number of people living with Parkinson's, caregivers and friends. In larger cities, you are welcome to attend different groups to find one where you feel comfortable. Many people contact the group facilitators to ask about the average age within the group, the average length of diagnosis and the focus of the meetings. The contact information for the facilitators may be obtained by calling our office.

If your area does not have a support group or would benefit from having an additional group (eg. Young Onset, New Diagnosis, Caregivers, etc.), call our office so we can discuss the possibility of getting one started.

Chapter 13

Parkinson's Research in Canada

Across Canada

Parkinson Society Canada National Research Program funds high-quality innovative research by established and promising Canadian investigators. Together with our regional partners across Canada, Parkinson Society British Columbia contributes annually to the research program in order to support our national research objectives.

The research program in Canada spans a variety of health disciplines such as nursing, occupational therapy, speech-language pathology and social work. It also aims at building capacity among the next generation of Canadian researchers and contributing on an international scale to the collective understanding of this complex disease and to the global search for a cure. The National Research Program has four research pillars – biomedical, clinical, health services and population health.

In British Columbia

In the past number of years, Parkinson Society British Columbia has independently funded research undertaken at the Pacific Parkinson's Research Centre, University of British Columbia and Simon Fraser University.

Participating in Research

When the Pacific Parkinson's Research Centre conducts research, they often require people with, and without, Parkinson's to participate. Some people choose to participate in research studies as a way of supporting the search for more effective treatment and, ultimately, a cure.

If you are interested in knowing about or participating in current or future research projects at the Pacific Parkinson's Research Centre, go to www.parkinsons.ubc.ca, then to Participate and click Recruiting Subjects.

“Patient participation is the corner stone of clinical research and makes such a difference in moving us toward a better understanding of the many facets of Parkinson's disease.”

Dr. Claire Hinnell, Neurologist, Jim Pattison Outpatient Care and Surgery Centre

“At the Centre for Applied Neurogenetics and the Pacific Parkinson's Research Centre at the University of British Columbia, researchers are working with the latest technologies in human genetics to find specific gene(s) responsible for Parkinson's disease. Each discovery provides remarkable molecular insight. We believe knowing the root of the problem will enable us to fix it. Our approach hinges on the participation of affected and unaffected individuals, and especially families in which two or more persons have been diagnosed with Parkinson's disease or another related neurological condition (dystonia, dementia, essential tremor or REM sleep disorder). We can be reached by phone at 604 822 0322 or email: about@can.ubc.ca”

Dr. Matthew Farrer and the CAN/PPRC team

Chapter 14

Regional Partners

Parkinson Society Canada

4211 Yonge Street, Suite 316

Toronto, ON M2P 2A9

416 227 9700

1 800 565 3000

www.parkinson.ca

Parkinson Society British Columbia

890 West Pender Street, Suite 600

Vancouver, BC V6C 1J9

604 662 3240

1 800 668 3330

www.parkinson.bc.ca

Parkinson Society Saskatchewan

610 Duchess Street

Saskatoon, SK S7K 0R1

306 933 4478

www.parkinson.ca

Parkinson Society Manitoba

414 Westmount Drive, Suite 7

Winnipeg, MB R2J 1P2

204 786 2637

1 866 999 5558

www.parkinsonmanitoba.ca

Parkinson Society Central & Northern Ontario

4211 Yonge Street, Suite 321

Toronto ON M2P 2A9

416 227 1200

1.800 565 3000, extension 3301

www.parkinsoncno.ca

Parkinson Society Southwestern Ontario

4500 Blakie Road, Unit 117

London, ON N6L 1G5

519 652 9437

1 888 851 7376

www.parkinsonsociety.ca

Parkinson Society Eastern Ontario

200 Colonnade Road, Unit 1

Ottawa, ON K2E 7M1

613 722 9238

www.parkinsons.ca

Société Parkinson du Québec

550 Sherbrooke Street West, Suite 1080

Montreal, QC H3A 1B9

514 861 4422

1 800 720 1307

www.parkinsonquebec.ca

Parkinson Society Maritime Region

7071 Bayers Road, Suite 150

Halifax, NS B3L 2C2

902 422 3656

1 800 663 2468

www.parkinsonmaritimes.ca

Parkinson Society Newfoundland & Labrador

136 Crosbie Road, Suite 305

St. John's, NL A1B 3K3

709 754 4428

1 800 567 7020

www.parkinsonnl.ca

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Resources

HealthLink BC

www.healthlinkbc.ca/abouthealthlinkbc/contactus/
Dial 811

PharmaCare

www.health.gov.bc.ca/pharmacare
Metro Vancouver 604 683 7151
Toll-free 1 800 663 7100

Physiotherapy Association of British Columbia

www.bcphysio.org
Metro Vancouver 604 736 5130
Toll-free 1 888 330 3999
Email info@bcphysio.org

Massage Therapists' Association of British Columbia

www.massagetherapy.bc.ca
Metro Vancouver 604 873 4467
Toll-free 1 888 413 4467

College of Occupational Therapists of British Columbia

www.cotbc.org
Victoria 250 386 6822
Toll-free 1 866 386 6822
Email info@cotbc.org

BC Association of Clinical Counsellors

www.bc-counsellors.org
Victoria 250 595 4448
Toll-free 1 800 909 6303
Email hoffice@bc-counsellors.org

BC Coalition for People with Disabilities

www.bccpd.bc.ca
Metro Vancouver 604 875 01888
Toll-free 1 800 663 1278
Email feedback@bccpd.bc.ca

LSVT Global

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www.lsvtglobal.com

Toll-free 1 888 438 5788

Canada Revenue Agency

www.cra-arc.gc.ca

www.cra-arc.gc.ca/ndvdl-fmls

Toll-free 1 800 959 8281

BC Ministry of Health

www.hlth.gov.bc.ca/health

Health Canada

www.hc-sc.gc.ca

Dial-A-Dietitian

www.healthlink.bc.ca/healthyeating

Toll-free 811

Northern Health Authority

www.northernhealth.ca

Phone 250 565 2649

Email hello@northernhealth.ca

Interior Health Authority

www.interiorhealth.ca

Phone 250 862 4200

Vancouver Island Health Authority

www.viha.ca

Toll-free 1 877 370 8699

Vancouver Coastal Health Authority

www.vch.ca

Metro Vancouver 604 736 2033

Toll-free 1 866 884 0888

Fraser Health Authority

www.fraserhealth.ca

Metro Vancouver 604 587 4600

Toll-free 1 877 935 5669

Willis-Ekbom Disease Foundation (formerly RLS Foundation)

www.rls.org



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