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**MY PARKINSON'S
DISEASE NAVIGATOR™**

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My Parkinson's Disease Navigator™

This booklet belongs to:

Name: _____

Address: _____

Phone: _____

Mobile/Other: _____

In case of emergency, please contact:

Name: _____

Address: _____

Phone: _____

Mobile/Other: _____

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How to use My Parkinson's Disease Navigator™

My Parkinson's Disease Navigator™ is provided to you by Parkinson Canada. Please bring this with you when you visit **any** healthcare providers, including your:

- Family Physician (Primary Care Provider)
- Neurologist or Movement Disorders Specialist
- Parkinson's Nurse Specialist
- Pharmacist
- Physiotherapist
- Occupational Therapist
- Speech-Language Pathologist
- Dietitian
- Psychiatrist, Psychologist or Neuropsychologist
- Social Worker
- Other Specialists

My Parkinson's Disease Navigator™ lets you record the management of your disease. It will also facilitate communications between you, your care partners and your healthcare providers.

Please ask each of your healthcare providers to use their respective page(s) to record any treatments, medications, recommendations and referrals. Use these same pages to record **your** symptoms, experiences and reactions as they relate to that particular treatment. **Tip:** Add new pages when these are filled. Need help? Contact info@parkinson.ca

We **HOPE** this tool will **HELP** make your Parkinson's journey more manageable at every stage.

What are the responsibilities of each provider on your care team?

➤ **Your Primary Care Provider**

Your primary care provider or family physician, or GP, is the person you will likely see the most often. This is the expert you will go to first when something is wrong or if you are not feeling well. Your doctor will assess your signs and symptoms and attempt to identify what the issue may be. Your doctor may provide you with a prescription, recommend treatments, and make referrals to specialists and order tests for specific purposes. You can also ask questions of your family doctor and learn about your Parkinson's disease, medication side-effects or other health issues you may be experiencing.

➤ **Your Neurologist/Movement Disorders Specialist**

A neurologist is the specialist that will deal more directly, and knows more about, your Parkinson's disease. Some neurologists are also movement disorders specialists as well. This means that they have additional training in the area of movement disorders such as Parkinson's and parkinsonisms. Your neurologist is likely the one who will have diagnosed you with Parkinson's disease.

A neurologist will assess what symptoms you are experiencing, to what degree you are experiencing them, and what medications you need to manage them. You will not likely see your neurologist very often, but they will be the one who decides on the need for changes to your medications or other treatment needs.

➤ **Your Parkinson's Nurse Specialist**

This healthcare provider is a registered nurse who specializes in Parkinson's disease and other parkinsonisms. They will also be another expert you will likely see more frequently than your neurologist. Sometimes the nurse specialist works in the neurologist's office or clinic. They monitor Parkinson's patients to ensure their medications are working, assess side-effects and their impact, provide support, and are a source of information on the disease, the medications and other therapies that may improve quality of life for you.

➤ **Your Pharmacist**

Your pharmacist is a healthcare provider who works in a community setting, most often at your local pharmacy (drug store), hospital or medical clinic. A pharmacist will dispense medications based on prescriptions received from physicians and specialists. In some provinces, pharmacists are also permitted to prescribe medications to individuals. Your pharmacist is also the person who can best counsel you – and your physicians – on the use of your prescription and over-the-counter medications. They will also provide you with information on nutritional supplements and advise you of their side effects as well as any contraindications.

Your Physiotherapist

If you are addressing all of your needs, then you are likely also seeing a physiotherapist, also called a “PT”. Through targeted exercises, this health provider will help you to build strength and better control the movement of your muscles. They will also work with you to gain more flexibility, improve walking and balance, and prevent falls and freezing.

A physiotherapist will also train you to do exercises at home that will help to maintain your mobility so you can continue to do many of the things you did before. They will provide you with tips and techniques to better manage actions like getting in and out of a car, your bed and various chairs.

Your Occupational Therapist

The focus of an occupational therapist, or OT, are the activities of daily living such as eating, sleeping, eating, bathing, dressing, toileting, as well as working and leisure activities. They will assist you by strategizing on how best to manage these activities while remaining safe and reducing the risks of injury.

An occupational therapist can also recommend appropriate devices and technology to fill any gaps identified. Another part of the scope of work for the OT is to assess driving and evaluate when it’s no longer safe for you to drive. And if funding for any device is a challenge, they will be able to guide you to the right support network and information.

Your Speech-Language Pathologist

A speech-language pathologist addresses your needs as they relate to your speech and swallowing. It’s best to retain the services of a speech-language pathologist immediately when you notice any issues with your voice. They may be trained in delivering a type of therapy called the Lee Silverman Voice Treatment (or LSVT) to improve volume, quality and intonation of your voice. This training also strengthens your breathing, works out your voice box (larynx) and improves your articulation of words so you don’t mumble.

A speech-language pathologist will also evaluate your control and ability to swallow. If there are problems with swallowing, known as dysphagia, they will address this through a change in diet and consistency of foods or exercises in altered swallowing techniques.

Your Dietitian

When it comes to your diet, the best person to work with you is a dietitian. They will look at your present diet, and make changes to it based on your needs and your disease progression. A dietitian will assess your weight and adjust your diet accordingly. If you are experiencing swallowing problems (dysphagia) or constipation – which is one of the most common symptoms with Parkinson’s – then that, too, will be addressed. A dietitian will consider any vitamin deficiencies, supplementation needs, and protein-related issues with medications.

➤ **Your Neuropsychiatrist/Psychiatrist or Psychologist**

This specialist will help you to manage any issues related to depressed mood or anxiety. They will ask whether or not you are experiencing any behavioural problems or psychosocial issues like withdrawing from family and friends. These problems may likely be treated with medications, talk therapy or both.

➤ **Your Social Worker**

When you live with Parkinson's disease, so does your family. A social worker is someone who will counsel you individually, with your family, or in group sessions. A social worker will connect you with community organizations and resources to meet your growing and changing needs through all phases of the disease. They will determine which healthcare providers you may still need to see and they will provide you with references to them. A social worker will help you plan for your future needs and health-related wishes. They may discuss home care services, housing options, assisted living, long-term care facilities, and respite services with you and your care partner.

A social worker will also provide support in times of crisis, and counselling for children who are living with a parent or grandparent who has Parkinson's.

➤ **Your Other Specialists**

You may be seeing other specialists or you may need to be as you may be experiencing other symptoms associated with your Parkinson's disease. If you are experiencing issues related to urination, erectile or sexual dysfunction, you may want to see a sex therapist and a urologist.

Sleep issues can be addressed by your neurologist or family doctor, and you may also be experiencing a coexisting illness or condition. A sleep medicine specialist can assess you and your sleeping patterns and recommend appropriate treatments.

Rigidity is one of the main symptoms of Parkinson's and for some, it can be very limiting. Some people find that going to a massage therapist decreases, and in some cases alleviates, the problem at least temporarily.

Others may wish to try acupuncture by seeing an acupuncturist. It has been documented to reduce the pain associated with Parkinson's and improve mood.

Other alternative specialists and therapies include dance therapy, art therapy, music therapy and boxing. Whatever you choose, be sure to assess its effectiveness against any risks to your health and safety by speaking to your doctor before starting anything new.

TIP: It's important to keep each member of your care team informed about challenges you experience and changes in your symptoms. Use each sheet provided in the **My Parkinson's Disease Navigator™** to track your personal experiences and bring these notes with you to your next appointment with any member of your team. Contact Parkinson Canada for additional pages. Call 1-800-565-3000 or email info@parkinson.ca

Family Physician/GP

Name: _____

Date	Clinician Notes

Attention

Symptom Log for My Family Physician/GP

Date	My Notes
Any challenges? When do they occur?	

Neurologist/Movement Disorders Specialist

Name: _____

Date	Clinician Notes

Attention

Symptom Log for My Neurologist/ Movement Disorders Specialist

Date	My Notes

Any challenges? When do they occur?

Parkinson's Nurse Specialist

Name: _____

Date	Clinician Notes

Attention

Pharmacist

Name: _____

Date	Clinician Notes

Attention

Symptom Log for My Pharmacist

Date	My Notes
Any challenges? When do they occur?	

Physiotherapist

Name: _____

Date	Clinician Notes

Attention

Occupational Therapist

Name: _____

Date	Clinician Notes

Attention

Speech-Language Pathologist

Name: _____

Date	Clinician Notes

Attention

Blank area for notes or comments.

Dietitian

Name: _____

Date	Clinician Notes

Attention

Symptom Log for My Dietitian

Date	My Notes
Any challenges? When do they occur?	

Psychiatrist, Psychologist or Neuropsychologist

Name: _____

Date	Clinician Notes

Attention

Social Worker

Name: _____

Date	Clinician Notes

Attention

Symptom Log for My Social Worker

Date	My Notes
Any challenges? When do they occur?	

Other Specialists

Name: _____

Date	Clinician Notes

Attention

If you require another
My Parkinson's Disease Navigator™
or if you need more
information, please contact:

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