



 Parkinson Canada

Managing My  
Parkinson's Disease  
in Healthcare Settings

**ACT**»  
*on time*™

# Acknowledgements

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  2018 Parkinson Canada

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## Forward

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*“Good communication is at the heart of every interaction between people with Parkinson’s, their care partners and health professionals. Healthcare professionals committed to clear and compassionate communication can make a meaningful difference to their patients. When people with Parkinson’s know what healthcare professionals recommend and why, they can anticipate what to expect; they are better prepared to navigate the system, ask the right questions, and make the best personal choices.”*

**Canadian Guidelines on Parkinson’s Disease, 2012**

The purpose of this book is to help you garner valuable information that you can apply to help manage your Parkinson’s disease in various healthcare settings. It may also guide conversations with the members of your healthcare team. Open communication will facilitate your experience and ensure your needs are met.

It is up to your healthcare providers to ask you the questions necessary to gain a clear understanding of your needs. And, it is up to you to engage and work with your healthcare providers to ensure they fully understand the experience of your unique journey with Parkinson’s disease.

Remember, **you** are **your** Parkinson’s disease expert.



**Note:** The term care partner is used throughout this book for simplicity. It refers to anyone who is an unpaid provider of care to a person living with Parkinson's disease.



# Introduction

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A Parkinson's disease diagnosis does not mean your quality of life diminishes with disease progression. Although it may not feel like it at first, you do have choices in how your disease and your life are managed. To do that you will need a variety of tools to manage your disease symptoms, and understand and monitor the various treatments you will receive. Subsequently, these choices may improve the quality of your life.

An important part of managing your Parkinson's disease is your understanding of the medications, their dosages and timing schedules. This can feel overwhelming, especially as the disease progresses. Increases in dosages, changes in dosing times, and the introduction or removal of medications can be difficult to track. And having to attend multiple healthcare appointments or visiting a hospital for another condition or injury can further complicate things.

This booklet is designed to help you manage your disease effectively in various healthcare settings. Each chapter covers a different area of the management of your disease. It provides you with specific information regarding your visits and interactions with various healthcare providers and settings. It will advise you on:

- **what you should know**
- **what you need to bring with you**
- **what questions to ask, and**
- **what you should do before, during and after any contact with a healthcare provider or facility**

This booklet will also help you learn to self-advocate so that you are in control of what happens to you, and you have a say regarding your treatment.

Near the back of this book you will find a **Parkinson's Disease Daily Diary**. Make several copies of this diary and complete one of the copies. Be sure to bring this diary with you to all your medical appointments. Keep the other blank copies for future changes and/or updates to your symptoms, medications and/or dosing schedule. Visit our website or contact us for additional copies.

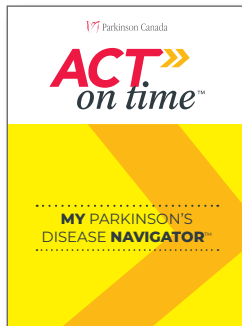
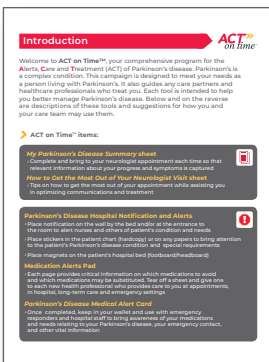
# My Parkinson Canada ACT on Time™ Kit

The Parkinson Canada **ACT on Time™** kit was designed with you and your healthcare providers in mind. It contains information and tools that will help you better manage your disease and improve your overall health.

It was also designed to help guide the care you receive from your home care partner, as well as anyone on your healthcare team (i.e. general physician, movement disorders specialist, neurologist, nurse, dietician, psychologist or psychiatrist, physical and occupational therapists, speech-language pathologist, and others).

There are many items in the **ACT on Time™** kit that you will use as you move between the professionals of your healthcare team. For each section in this booklet, we suggest you use one or more of these tools to help you manage your disease symptoms.

# ACT on time™



# Responsibilities of Each Provider on Your Care Team

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## ➤ Your Primary Care Provider

Your primary care provider or family physician, also called a 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, also called an 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 support any other needs 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 referrals 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.

You 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 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***<sup>™</sup> 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 a copy of ***My Parkinson's Disease Navigator***<sup>™</sup>. Call 1-800-565-3000 or email [info@parkinson.ca](mailto:info@parkinson.ca).

# Visiting My Primary Care Practitioner

*(Family Doctor, Nurse Practitioner)*

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## **What You Should Know:**

Not all healthcare providers are familiar with the many, complex symptoms of Parkinson's disease, the medications used to treat it, nor the importance of making sure a patient gets their medications on time, every time. Only a specialist—such as a neurologist, movement disorders specialist, specialized nurse or pharmacist—receives that level of training and information. So, it's up to you, as the person living with Parkinson's disease, to help educate any healthcare provider who needs to know.

## **What to Bring:**

When planning a visit to your family doctor, be sure to bring along all your Parkinson's and non-Parkinson's medications, in the original packaging you received from your pharmacy. You may also ask your pharmacist to print out a list of all your medications. This is so the doctor can see the name of the medication, the prescribed dosage and dosing schedule, and ensures that there are no discrepancies. Medications for Parkinson's are often prescribed by the specialist and so your family doctor may not always be aware of changes to your medications or their dosing schedule.

You may also wish to bring any notes or reports you may have from a specialist's visit, the pharmacist and/or any other healthcare provider you may have been to see prior to your doctor's visit.

Often, when a patient is seeing more than one provider, there is a break in communication. Your physical therapist will not likely be sending information to your psychiatrist. Your family doctor will not be sending updates to your dietician. And so on. You have to be the link between them and make each of them aware of the treatments you may be receiving, any findings or observations, and any recommendations they may have made to you.

Use **My Parkinson's Disease Navigator™** (part of the **ACT on Time™** kit) to collect and record all types of information about you and your medical history. Share the *Navigator* with the appropriate healthcare provider during each visit.

## Checklist:

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- My Parkinson's Disease Navigator™
- Parkinson's Disease Medical Alert Card™
- Pharmacist's list of all medications (prescription and over-the-counter) and any supplements you may be taking
- Medications in their original containers with your name clearly identifiable
- Managing My Parkinson's Disease in Healthcare Settings™ booklet with completed copy of the **Parkinson's Disease Daily Diary**

## What to Ask:

Some questions you may wish to ask your family doctor are:

- **How is my disease progressing?**
- **What changes do you observe since my last visit to you?**
- **How do your observations compare with mine?**
- **What recommendations do you have for me to better manage this change?**
- **Who should I be seeing to deal with these issues?**
- **What other members of my healthcare team should I be advising of these issues?**
- **What are my options at this point?**
- **Do I need further testing or assessment?**
- **What should I, or my care partner, be doing differently?**

# Visiting My Neurologist or Movement Disorders Specialist

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## What You Should Know:

There are often long wait times to see a specialist and appointments may seem too short or rushed.

It may come as no surprise that our healthcare system has its challenges. It is up to us to manage it the best that we can and seek out the help we need when we need it. Doing so may require some extra resources on your part, or that of your care partner.

That's why Parkinson Canada has created the **Getting the Most Out of My Neurologist Visit™** information sheet (printed on the reverse of the **My Parkinson's Disease Summary™**). This resource provides tips for good communication. It also provides ideas on how you can get the most out of your appointment.

## What to Bring:

Prepare for your visit with the neurologist or movement disorders specialist by arming yourself with the items in the following list.

## Checklist:

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- My Parkinson's Disease Summary™/How to Get the Most of My Neurologist Appointment™ (double-sided sheet)
- My Parkinson's Disease Navigator™
- Parkinson's Disease Medical Alert Card™
- Pharmacist's list of all medications (prescription and over-the-counter) and any supplements you may be taking
- Managing My Parkinson's Disease in Healthcare Settings™ booklet with completed copy of the **Parkinson's Disease Daily Diary**

## What to Ask:

Questions you might ask include the following:

- **Are you affiliated with a specific hospital? And if yes, which one?** (Consider going to that hospital first for any unplanned or emergency visits)
- **Is there anything I can stop, start or change that will help with my Parkinson's disease?**
- **Can there be another cause for my symptoms?**
- **What strategies can I employ to manage them?**
- **What other specialists or health providers should I be seeing to treat my Parkinson's symptoms?**
- **Am I a good candidate for deep brain stimulation (DBS) or the Duodopa Infusion System® (intestinal pump)?**
- **What is the prognosis or outcome of such a surgery?**
- **What should I expect in terms of my symptoms after this surgery?**
- **What is the timeframe for healing after placement of the device?**
- **What are some of the risks associated with this type of surgery/treatment?**

## What to Ask Yourself:

There are many ways to gather valuable information that can be shared with your physician, and one sure way is to ask yourself how your body responds to your medications. Record your answers to the following questions:

- **How long does it take my body to absorb my medications?**
- **How long do I feel the effects of each dose?**
- **What can I take, or not take, with each dose?**
- **Which of my symptoms recur when my medications wear off?**
- **Which vitamins or nutritional supplements appear to be affecting my medications?**
- **Are the other medications that I take affecting my symptoms or the effectiveness of my Parkinson's medications?**

# Visiting My Other Treatment Providers

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## What You Should Know:

Properly managing your Parkinson's disease, and its symptoms, takes a team of healthcare providers including, but not limited to, your family doctor, neurologist, movement disorders specialist (MDS), occupational therapist, physical therapist, speech-language pathologist, dietitian, pharmacist, psychologist/psychiatrist, Parkinson's nurse, and others.

If you are being treated by an interdisciplinary team of healthcare providers, then you are more likely to be in better control of your disease symptoms. An interdisciplinary team will have several health professionals, treating you and working together to make sure you achieve the best health outcomes and quality of life.

If the local clinic or hospital does not have an interdisciplinary team, you may be using your family doctor as your primary care practitioner. Be sure to ask members of your healthcare team to connect with your family doctor on a regular basis to provide updates and reports.

## What to Bring:

One of the most important items in the **ACT on Time™** kit is **My Parkinson's Disease Navigator™ (Navigator)**. This tool allows you to track and record recommendations, changes, treatments, and observations—yours and those of your healthcare providers. It also provides a means of communication between you, your doctors and your other healthcare providers. If an observation is made by one healthcare provider, it can be noted in the **Navigator**. If a healthcare provider recommends changes in your routine, exercises, supplements or other treatments, it can be written down so you can have a clear record of it. That way, nothing is forgotten and information can be shared among you, your family and your care team, in an efficient way.



Bring along your **Parkinson's Disease Medical Alert Card™**— which should be kept in your purse or wallet—and any medication list or information that may be important to share with attending providers.

## Checklist:

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- My Parkinson's Disease Navigator™
- Parkinson's Disease Medical Alert Card™
- Act on Time™ Medication Alerts!  
(a pad of tear-off sheets)
- Managing My Parkinson's Disease in Healthcare Settings™ booklet with completed copy of the **Parkinson's Disease Daily Diary**

## What to Ask:

Questions you might ask include the following:

- **What can you recommend to me that will improve my overall functioning with Parkinson's disease?**
- **How often do I need to do that for it to be effective?**
- **What should I avoid doing that could potentially negatively affect my Parkinson's?**
- **Are there any things you have observed today that I should report to my family doctor or neurologist?**
- **What information do you need from my doctor or specialist to improve the quality of care you are providing to me?**
- **Do you provide regular reports to my doctor? If not, then what should I be taking back to him/her?**

# Visiting the Hospital

*(Planned Stay or Emergency Visit)*

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## What You Should Know:

A person living with Parkinson's disease is more likely to visit a hospital during the course of their disease than the average person of their age. The reasons for this include a fall, pneumonia, a urinary tract infection or any number of side effects of some of the medications. People with Parkinson's are also admitted to hospital more frequently and have significantly longer stays as a result of the complications of their disease, whether it is the reason for their stay or not.

Any type of hospital stay can cause anyone a certain level of anxiety. And for someone living with Parkinson's disease, anxiety can make Parkinson's symptoms worse. Preparedness is critical. Just knowing what to expect can lower any anxiety and help make the experience less difficult.

For the person living with Parkinson's disease, hospital visits are more often spent in the emergency department. There may be other conditions that require planned hospital stays for surgeries, tests and treatments.

Be aware that regardless of the type of hospital visit, your medications must continue to be taken **on time, every time**. When you are admitted to a hospital and while you are awaiting care in the emergency department, the hospital will not allow you to take any medications they did not order for you. Hospital staff will also need to monitor and record when you take any medications.

Taking charge of your care by educating hospital staff about your Parkinson's disease may alleviate the challenges you may face. Doctors, nurses and others working in the hospital need to know what medications you are taking and when you must take them.

**If you are visiting the hospital on an emergency basis, tell them right away or have your care partner bring your needs to their attention upon reaching the emergency department.**



Share the following table of drug alerts with the attending physician, nurse or other healthcare providers. It will assist them in making informed decisions regarding your treatment while at the hospital.

# Drug Alerts!

If a Parkinson's patient needs...	...Use or avoid these drugs (generic)
<b>Antipsychotics</b>	<p>Use the following <b>safer alternative(s)</b> instead:</p> <ul style="list-style-type: none"> <li>• <b>Seroquel</b><sup>®</sup> (quetiapine) or</li> <li>• <b>Clozaril</b><sup>®</sup> (clozapine)</li> </ul>
<b>Narcotic Analgesics</b>	<p>If patient is taking <b>Azilect</b><sup>®</sup> (rasagiline) or <b>Eldepryl</b><sup>®</sup> (selegiline), <b>AVOID Demerol</b><sup>®</sup> (meperidine)</p>
<b>Anesthetics</b>	<p>If patient is taking <b>rasagiline</b> or <b>selegiline</b>, <b>AVOID</b>:</p> <ul style="list-style-type: none"> <li>• <b>Demerol</b><sup>®</sup> (meperidine)</li> <li>• <b>Ultram</b><sup>®</sup> (tramadol)</li> <li>• <b>Tramacet</b><sup>®</sup> (tramadol with acetaminophen)</li> <li>• <b>Inapsine</b><sup>®</sup> (droperidol)</li> <li>• <b>Methadose</b><sup>®</sup> or <b>Dolophine</b><sup>®</sup> (methadone)</li> <li>• <b>Halothan</b><sup>®</sup> or <b>Fluothane</b><sup>®</sup> (halothane)</li> <li>• <b>Flexaril</b><sup>®</sup> (cyclobenzaprine)</li> </ul>
<b>Anti-nausea and stomach medications (GI meds)</b>	<p><b>AVOID</b> the following:</p> <ul style="list-style-type: none"> <li>• <b>Compazine</b><sup>®</sup> or <b>Stemetil</b><sup>®</sup> (prochlorperazine)</li> <li>• <b>Maxeran</b><sup>®</sup> (metoclopramide)</li> <li>• <b>Histantil</b><sup>®</sup> (promethazine)</li> <li>• <b>Insapsine</b><sup>®</sup> (droperidol)</li> </ul>
<b>Antidepressants</b>	<b>AVOID Abilify</b> <sup>®</sup> (aripiprazole)

## Planned Hospital Stays:

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For planned hospital stays, quite often you will be scheduled for a pre-operative assessment visit. Make the hospital aware of your needs **BEFORE** you are admitted for your stay by using this appointment to educate staff and discuss your condition in greater detail.

If you are having surgery, there are several other things you need to know. Day surgery—admission, surgery, and release all on the same day—is not usually a problem for those living with Parkinson’s disease. But when surgery requires the use of general anesthetic (GA) and any type of hospital stay, some factors need to be considered. Please refer to the previous table of **Drug Alerts**.

Fasting is a requirement of general anesthesia surgeries and people are usually asked not to eat or drink anything after a stated period of time prior to surgery. This time is often the night before. Many people with Parkinson’s take their last dose of medication the night before surgery. Then, all medications are stopped until after the surgery. This means that the person does not get the medications they need when they need them which can lead to symptomatic setbacks.

**Neurologists will often ask that their patients receive a morning dose of Sinemet® (levodopa/carbidopa or levocarb) with a very small amount of water the morning of any surgery.** If absolutely nothing is permitted orally, then a nasogastric tube prior to surgery may be requested and dosing can be administered through it, directly to the stomach.

The routines (or rounds) in hospitals may be different from the medication routine you have at home. Knowing this ahead of time will help you navigate the dosing schedule.

## Emergency Department Visits

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The time leading up to an emergency department visit is an important factor for those living with Parkinson’s disease. Being prepared is essential and it can make a difference on your health outcomes.

Have your Parkinson Canada **ACT on time™** kit prepared, ready and waiting for when you might need it. Much like an expectant mother prepares her bag as she nears her delivery date to avoid any unnecessary delays when having to suddenly depart for the hospital, you must do the same. But in your case, you will have to **have your bag ready at all times**.

If possible, do not go to the emergency department alone. Bring your care partner or trusted friend with you to ensure there is someone who knows your care wishes if you are unable to express them. Make sure the person who accompanies you is well versed in your particular symptoms, needs and medications. Ask them to advocate on your behalf if you are unable to. Ask them to hold your **ACT on Time™** kit and your medications until you are certain that the hospital will be providing you with the necessary medication **on time, every time**, for the duration of your visit.

## **Special Note: Deep Brain Stimulation**

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**Deep Brain Stimulation (DBS)** devices are similar to pacemakers in that they send electrical impulses to a specific part of the body—in this case, targeted parts of the brain. This is done through surgically implanted electrodes that stimulate the parts of the brain necessary to address the symptoms of such diseases as Parkinson’s, dystonia, essential tremor and others.

DBS is generally not considered as a treatment for Parkinson’s until the later stages of disease progression, especially if the symptoms cannot be adequately controlled with the medications. The benefits are strictly related to the motor symptoms, with an alleviation of the issues related to “off” periods or dyskinesias. This treatment does not work well on issues relating to balance, freezing, or the spectrum of non-motor symptoms associated with Parkinson’s.

### **Considerations when you have a Deep Brain Stimulation device:**

If you have deep brain stimulation (DBS) implants, then you must make hospital staff aware of this immediately. Tests, such as an MRI, can only be used under very strict conditions, and antibiotics have

to be prescribed if there is any risk of bacteria entering your bloodstream during a test or treatment (this includes dental procedures). Furthermore, some equipment in the operating room can cause the DBS stimulator to turn off. Always check with your neurologist or movement disorders specialist prior to undergoing any invasive procedures, tests or surgery.

Be aware that some of your Parkinson's disease symptoms may affect your tests, treatments or surgery, and in some cases, may cause it to be postponed or cancelled. Inform the hospital staff (particularly the attending physician, surgeon and anesthetist) if you experience any of the following:

- **Dyskinesias or involuntary movements that may require you to be sedated or placed under GA for any tests**
- **Orthostatic hypotension or low blood pressure that causes you to faint if you get up too quickly**
- **Excess salivation or swallowing problems which may require you to be intubated during surgery (if not otherwise used)**

## **Special Note:**

### **Duodopa Infusion System®**

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**The Duodopa Infusion System®** has been highly beneficial to persons with advanced Parkinson's disease when their oral medications no longer provide stable relief from their symptoms. With this gastric infusion system, there is less variability in the levels of levodopa and, therefore, fewer motor fluctuations and dyskinesias. It has been successful in eliminating the extremes of the on/off periods of medication effectiveness and has been instrumental in improving the quality of life and social functioning of people with Parkinson's. Research shows that a year after having the pump installed, patients feel the neurological benefits of this system offset any procedurally related problems or technical issues.

If you have a Duodopa® pump, you know that maintenance and monitoring are a part of your daily routine. While changing of the gel cassette once a day reduces the frequency of taking strict doses of oral

medication, monitoring of the percutaneous endoscopic gastrostomy (PEG) tube site must be done several times a day. Any adjustments to the dosing and programming of the pump device must ideally be done by your movement disorders specialist. So, if you are visiting a hospital for any period of time, your MDS should be made aware and steps ought to be taken to ensure your pump continues to operate optimally.

## **Considerations when you have a Duodopa®**

### **Infusion pump:**

A detailed discussion with your movement disorders specialist or neurologist is critical prior to any stay in hospital. Having a Duodopa® pump requires attention during your hospital stay and you and your care partner will need to know as much as you can before you are admitted. Hospital staff should be familiar with PEG tubes in general but may not be aware of the Duodopa® system. They may appreciate the ease of administering one cassette, rather than frequent oral medications. Ask all relevant questions (see subsequent section on **What to Ask**) and make sure you understand what is required of you or your care partner.

Also, find out if the hospital pharmacy will be supplying the gel cassettes during your hospital stay. If not, you will have to make arrangements for your care partner to deliver a fresh cassette each day for the duration of your hospital stay, or see if the hospital can store—refrigerated—several gel cassettes for you.

If you have to make an unscheduled visit to the emergency department, you or your care partner must advise the hospital staff of your Duodopa® pump. If they are unfamiliar with its maintenance and monitoring, ask for someone who is experienced in the use of the pump and who understands your needs as a person living with Parkinson's. Ask if your care partner will be permitted to continue to manage the pump and monitor the PEG site. Some hospitals will allow this. Again, you may have to supply the gel cassettes if the hospital pharmacy does not have them.

It may be up to you to educate some staff on your condition, your particular needs and what they can do for you.



## IMPORTANT ALERT:

It is vitally important that your Duodopa® dose continues and is not lowered. Advise your attending staff that if this happens, it may result in a very serious condition called **Neuroleptic Malignant Syndrome**. The signs, symptoms and results of this may include:

- **Increased heart rate (tachycardia)**
- **Increased breathing rate**
- **Increased protein levels in your blood**
- **Fluctuating blood pressure**
- **Sweating and fever**
- **Muscle stiffness**
- **Altered mental status**
- **Loss of consciousness**
- **Coma**
- **Death**

### **What to Bring:**

When you know you are going to the emergency department or being admitted to hospital, bring someone with you that you trust. This person—care partner, friend or family member—should be someone who will speak to staff on your behalf if you are not able to, and may advocate for you to ensure your particular health needs are met. If you happen to be alone, be sure to bring all the necessary documentation from your Parkinson Canada **ACT on Time™** kit to inform the healthcare providers who will be attending to you.

Assist hospital staff by having a record of your medications and your dosing schedule. Bring your **Parkinson's Disease Medical Alert Card™**—included in the Parkinson Canada **ACT on Time™** kit. This card should be complete and include all the medications you are presently taking (including any over-the-counter medications and natural supplements). Note the dosages and when you take them. This card also contains a table of contraindicated medications which will inform hospital staff of what NOT to give you.



Bring your medications in their original packaging. Also bring several updated copies of your medication list printed by your pharmacy. This detailed list should include all supplements and over-the-counter medications you may be taking. Having several copies of the list will ensure you have the information if the hospital copy is lost or misplaced. The hospital staff will want to confirm what you are taking and what dosages have been prescribed.

You will also want to bring with you the **Parkinson's Disease Alert Stickers™**, part of the **Act on Time™** kit. Give these to the attending nurse and ask that a sticker is placed in your chart immediately. In this way, anyone who treats you will automatically see that you have Parkinson's disease and allow certain considerations to be made.

Bring your **My Parkinson's Disease Navigator™** as well and continue to document any symptoms you may be experiencing while you are in the hospital. Such things might include difficulty swallowing, or a return of tremors.

Although something most people don't think about regularly, an authorized **Power of Attorney for Personal Care (POAPC)** is just as important as any of the other documents that you will be bringing to the hospital with you. Have your care partner retain this document—but have it available if reference to it becomes necessary.

Anytime anyone is admitted to hospital for medical reasons or undergoes surgery under general anesthetic, there is a risk that the person may experience difficulties, become incapacitated, or, in the worst case scenario, not recover. A POAPC provides your trusted substitute decision-maker with the power to make healthcare decisions on your behalf, ensuring your wishes are followed and that you continue to receive the care you want.

## Checklist:

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- Parkinson's Disease Medical Alert Card™
- Parkinson's Disease Alert Stickers™ (and magnets)
- Parkinson's Disease Hospital Notification™ sign
- My Parkinson's Disease Navigator™
- Act on Time™ Medication Alerts!  
(a pad of tear-off sheets)
- Medications in their original containers
- Pharmacist's list of all medications (prescription and over-the-counter) and any supplements you may be taking
- Power of Attorney for Personal Care (POAPC)
- Personal and hygiene items for an overnight stay in your Parkinson Canada ACT on Time™ kit bag

### What to Ask:

Ask hospital staff to take a photocopy of the **Parkinson's Disease Medical Alert Card™** to place in your hospital file (if you haven't already provided them with a copy). Ask them to bring this information to the attention of any nursing staff that will be attending to your needs so they can be sure to give you the right medications and dosages on time. Suggest they use the **Parkinson's Disease Alert Stickers™** in your chart so anyone looking at it will be aware of your condition. Ask your nurse or your care partner/family member to place the **Parkinson's Disease Alert Magnet™** at the end of your bed and the **Parkinson's Disease Hospital Notification™** on the wall by your bed where it will be noticed by all staff.

Ask the hospital staff if you or your care partner can self-administer your medications, if the dosing schedule becomes an issue with hospital rounds and resources. Ideally, you should enquire about this prior to admission—especially if you have had a pre-operative assessment visit. It's better late than never.

Once the hospital staff understand the importance of getting your medications on time, many will allow you or your care partner to manage the dosing (if you are capable), but will monitor and record those doses in your chart.



### **Cautionary Note:**

People with Parkinson's with **dysphagia** (trouble swallowing) should advise every health professional who attends to them. Care partners should ensure that a dietitian and/or speech-language pathologist is involved. This will address dietary restrictions and modifications for the person with Parkinson's during their hospital stay.

Ensure that all Parkinson's medications are taken at least 30 minutes prior to or two hours after any meal containing protein to avoid complications.

Ask the hospital the following questions:

- **How will my Parkinson's disease be affected by: this surgery, the anesthesia, medications, treatment, or tests associated with this surgery?**
- **Where will my supply of medications be stored during my hospital stay?**
- **What policies does the hospital have regarding self-administration of patient medications?**
- **When will my first dosage of Parkinson's disease medications be provided to me by the hospital? (See section on **Advocating for Myself or My Care Recipient.**)**
- **Who will update my hospital chart if/when I take my scheduled dosages?**
- **Can the hospital accommodate my dietary needs, schedules and/or restrictions?**
- **Is staff familiar with Parkinson's disease and how to manage it in a hospital setting?**
- **Does the hospital pharmacy have the necessary medications for me or should I bring my own supply?**



- **What types of physical therapies will be expected after surgery to reduce the risk of aspiration pneumonia and maintain my flexibility and mobility?**
- **What are the overall expectations after surgery?**
- **What recovery time should I expect?**
- **When will I be discharged and to whom or where?**

### **What to Do—Before:**

- Have your family physician or pharmacist send your medication regimen and dosing schedule to the hospital prior to your being admitted, or bring a current copy with you to hospital
- Pack your medications—in their original packaging—in your **ACT on Time™** kit bag with several copies of your list of prescription and over-the-counter (OTC) medications, and bottles of any supplements you may be taking
- Ask your care partner to hold on to any extra medications for you
- Pack any documents that you will need during your stay, such as a POAPC, etc.
- Pack any tools/items you will need from your Parkinson Canada **ACT on Time™** kit

### **What to Do—During:**

- **Make attending staff aware of the following:**
  - What you can or cannot do during your on/off periods
  - On/off periods are not in your full control but are managed better when medications are taken on time
  - Your lack of facial expression is due to your Parkinson’s disease
  - Mental or verbal slowness is due to the medications, but may be worsened by your surgery, treatment or medications for either
  - Dexterity may be compromised by your condition and may affect tasks such as hygiene or eating
  - Your risk of falling is higher than normal so movement to and from the bathroom, for example, may require assistance (equipment or personal support)
  - Your need for assistance with eating or dressing

- Explain to staff that although your dosing schedule and theirs may not be the same, you **MUST** get your medications on time
- Explain what missing a dose would mean for you—and for them
- Schedule any in-hospital rehabilitation sessions around your medication administration (at least 30 minutes after a dose)
- Talk to the attending physician about getting authorization to self-administer your medications (or having your care partner administer your medications)
- Provide the hospital with the list of contraindicated medications so they are aware of what drug interactions may occur
- Advise the staff of any particular needs you may have regarding sleeping, diet, walking, equipment, etc. (this can also be done at the pre-operative assessment appointment)
- Advise the staff of any challenges with speech and swallowing so they can anticipate and accommodate
- Advise staff of what to do/not to do and what you require if you have an episode of dystonia
- Do not consume any proteins (e.g. dairy, meats, fish, eggs, high protein drinks, etc.) within a half hour of taking your medications as protein will affect the absorption (You may need to wait to eat; ask to keep the meal tray longer, if necessary)
- Document any issues, symptoms, or difficulties, and whom you spoke to about it, or who addressed it (the more detailed the notes, the better)
- Ask for clarification regarding any instructions or recommendations hospital staff may make as you may have some difficulties with understanding or attention, especially if you have had surgery under general anesthetic
- Ask your attending doctor to request physical and respiratory therapies during your hospital stay to reduce the risk of pneumonia, urinary tract infections and deep vein clotting, as those living with Parkinson's disease tend to be at a higher risk of these issues
- If you are unhappy with the level of care or treatment you are receiving in hospital, you can raise your concerns to the staff directly
- If that doesn't improve the quality of care, then you may also reach out to the hospital administration through the means provided



### **Cautionary Note:**

**Consider keeping your medications with you when visiting an emergency department until you and/or your care partner confirm when you will be receiving your first hospital-provided dose of Parkinson's medications. Some medications may not be available through the hospital's pharmacy or dispensary.**

### **What to Do—After:**

- Make discharge preparations with your care partner or family member(s) BEFORE you are admitted to hospital and know who will be taking you home and what support you will be getting
- Ask the hospital staff to assess if you need a support plan in place before you are discharged and confirm any follow-up care you will be receiving at home
- Make sure you understand and have recorded any medical follow-up plans and appointments
- Confirm any medication additions/changes
- Speak to hospital staff to assess if you need rehabilitation therapy or at-home care
- If you are discharged to a rehabilitation facility, be sure to educate the staff there too
- If there has been a disruption in your medication schedule, immediately contact your doctor, neurologist and/or movement disorders specialist

# Living in a Long-Term Care Facility

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## What You Should Know:

If you, or your care partner, have made the choice to move you into a long-term care facility, there are several things you should know. The staff at long-term care facilities are healthcare providers—nurses, doctors, personal support workers and others—that specialize in the care of the elderly and some of the health issues that accompany aging. They may not, however, be fully familiar with the symptoms and challenges of Parkinson’s disease.

Your stay in a long-term care facility should involve preparation for and communication with, the healthcare providers working within that facility. Effective communication cannot be stressed enough. Most people living with Parkinson’s remain at home and in the care of their spouse or care partner. As a result, many long-term care facilities have not had enough experience caring for and dealing with residents living with Parkinson’s disease. Often, people living with Parkinson’s disease enter this type of facility at the later stages of the disease when their care partner can no longer manage their care effectively at home.

The most important thing that the staff should know is that your medications **MUST** continue to be administered **on time, every time**. This might mean having someone administer your medication outside of the normal medication rounds. Staff may be resistant to doing this. If this is the case, you or your care partner may wish to speak to the facility’s manager, or have your physician speak to them, to stress the importance of this need being met.

For people living with Parkinson’s disease, medication management is the most important part of controlling symptoms. A constant drug level in the bloodstream will support your ability to continue to care for yourself. This will ease the workload for the staff at a long-term care facility as you can continue—for as long as possible—to manage your own care and hygiene. Advise the staff of the benefits to them

if they allow you or your family member to administer your medications. **And be sure to confirm with your care partner that they will be able to do this for you each day.**

For more information on Parkinson's disease, managing it in a long-term care setting, strategies to optimize functioning of the resident, and critical information they need to know, refer them to the Parkinson Canada website ([www.parkinson.ca](http://www.parkinson.ca)).

### **What to Bring:**

As your disease progresses, your ability to communicate in an easy, effective and timely manner may change. It is important, especially if staff changes occur at the long-term care facility and new personnel are hired, that they be made aware of your condition and your needs. Post the **Parkinson's Disease Hospital Notification™** sign in your room on the wall by your bed to alert staff of your disease and how to better manage your challenges. You may also wish to put a **Parkinson's Disease Alert Magnet™** at the end of your bed; and, have the staff use the **Parkinson's Disease Alert Stickers™** in your chart to bring further awareness.

A long-term care facility may also benefit from having Parkinson's disease information posted up in areas where they will be read and referred to by staff. These are available through Parkinson Canada.

Contact Parkinson Canada to order any **ACT on Time™** resources. Some resources are available online. Please visit [www.parkinson.ca](http://www.parkinson.ca) and click on the Resources tab.

### **What to Ask:**

Questions you might ask include:

- **Has anyone at the facility received training and information specifically about Parkinson's disease?**
- **Are you aware of my non-motor symptoms as well as the motor symptoms you can see?**
- **Are you familiar with Parkinson's-specific medication and the importance of receiving medications on time?**



- Does my dosing schedule conflict with the general medication rounds of this facility?
- If yes, then how will this be managed considering the importance of me taking my medication **on time, every time**?
- Will you permit self-administration of medications as long as I, or my care partner, are able to do so?
- Have you had a Parkinson Canada in-service session?

# Advocating for Myself or My Care Recipient

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## What You Should Know:

In an earlier chapter we mentioned that people living with Parkinson's disease visit hospitals more frequently—emergency, ambulatory and inpatient visits—and we also emphasized the importance of continuing the medication dosing schedule regardless of the type of medical visit and/or treatment. When you take an active role in managing your health and Parkinson's, or you have someone advocating on your behalf, this leads to better health outcomes.

## What does it mean to advocate for oneself?

Self-advocacy applies to all aspects of your life, not just your health. It is a positive way in which to manage your life and health.

Self-advocacy means speaking up on issues and decisions that you may face. It also means being proactive in seeking out information about things that affect you, your health and your life. It entails listening, watching, reading, learning; and includes knowing your rights, understanding your condition, knowing yourself, your symptoms, and your needs. Developing a sense of self-determination, and working with those who can support and assist you, will give you the confidence to make choices and decisions that lead to you having the best possible quality of life.

When it comes to your life, you are the most invested stakeholder! Therefore, you should have the greatest control over it. Often, however, speaking up raises feelings of fear and avoidance, especially in the presence of those you may believe to be experts or specialists on the subject of your healthcare. Remember, **you** are the number one expert on **your** health, so arm yourself with the information you need and communicate those needs.

Communication—effective and respectful—is a key component of self-advocacy. And the key to success is making yourself heard no matter which method you choose to communicate your needs, choices or enquiries.

Here are a few things to keep in mind:

- **93% of communication is non-verbal; only 7% are the words you speak**
  - Tone, pitch, modulation, facial expressions, body language, eye contact and other visual and sound cues relay a great deal more than your words
- **Plan what you want to say**
  - Be aware of how you are saying it
- **Prepare yourself for health appointments, discussions, and potential challenges**
  - Keep records of everything including conversations, correspondences, and agreements
- **Listen and ask for clarification if you don't understand something**
- **You can respectfully disagree but don't be disagreeable** (both sides need to understand)
- **Be accountable for your actions and hold others accountable**
- **Mistakes will be made so forgive yourself and others and move forward**
  - Blaming will not achieve any positive outcomes
- **Work collaboratively**, especially with those who have the power to say, “yes”
- **Research, read, listen and learn** so you can gain a greater understanding of your condition, treatments and options
- **Improve your overall health literacy** so you can better manage your health
- **Be open to creative solutions to problems and challenges**

Advocating for yourself will increase the likelihood that you receive the care, attention and services that you need. Practicing self-advocacy with healthcare providers and other professionals will increase your confidence and improve your overall health outcomes.

## **What to Ask:**

Questions you might ask include:

- **Can you explain simply what you need me to do in between visits?**
- **From your professional perspective, what should be the number one thing on my list of priorities?**
- **In your experience, how can I maximize our appointment time?**
- **Is there any additional information you need me to provide the next time I come in?**
- **Can you please explain the circumstances for which I should be contacting you?**
- **What are your expectations of other members of my healthcare team?**
- **Is there anything I should be asking other members of my health team to do to facilitate your treatment of me?**
- **What is the usual response time if I leave a message at your office?**
- **If it was you needing this medication or treatment, would you take it?**

These are some of the numerous questions you may consider when advocating to ensure that you receive the best healthcare advice and treatments necessary to improve your quality of life with Parkinson's disease.

When you have a strong sense of self and are determined, you will experience more meaningful and productive relationships with each of the healthcare providers who treat you. You may also experience a higher level of engagement with the healthcare system in which you are being treated.

# Managing My Journey with Parkinson's Disease

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We hope you enjoyed reading this book. We encourage you to refer to this regularly, apply the knowledge and practice the suggested skills. And we hope that you have garnered the information that will help you more effectively manage your Parkinson's disease within your healthcare system and with the healthcare providers that you see.

Remember, your healthcare provider will ask the questions necessary to gain a clear understanding of your needs and make accurate clinical diagnoses. However, **you are the expert on you!** It is up to you to engage and keep everyone on your health team informed at every stage as the disease progresses. No detail is too small; it all contributes to painting an accurate picture of you and your health.

We wish you a safe and well-managed journey.

# Parkinson's Disease Daily Diary

[http://www.cmdg.org/MDC\\_tools/PDDIARY/pddiary.htm](http://www.cmdg.org/MDC_tools/PDDIARY/pddiary.htm)

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Name: \_\_\_\_\_

Date: \_\_\_\_\_

**Instructions:** This is a tool to track responses to medication and will be used to adjust the doses and timing of medications. For each time of day, place a check mark in the corresponding column that best describes your motor state. (i.e. in the 7:00 a.m. row indicate the average motor state from 7:00 to 7:59 a.m. or if asleep check **Asleep** in that column. If asleep, place a check mark under Asleep. If you take a medication dose at 7:45 p.m. write the time in the PD Medication column of the 7:00 p.m. row.

Motor State – Time of Day	"ON" with Dyskinesia Too Much Movement	"ON" Normal Movement	"OFF" Too stiff and slow	Asleep	PD Medication Time
6:00 a.m.					
7:00 a.m.					
8:00 a.m.					
9:00 a.m.					
10:00 a.m.					
11:00 a.m.					
Noon					
1:00 p.m.					
2:00 p.m.					
3:00 p.m.					
4:00 p.m.					
5:00 p.m.					
6:00 p.m.					
7:00 p.m.					
8:00 p.m.					
9:00 p.m.					
10:00 a.m.					
11:00 a.m.					
Midnight					

## You may also be interested in:

- [My Parkinson's Disease Navigator™](#)
- [Parkinson's Disease: An Introductory Guide](#)
- [Parkinson's Disease and Driving booklet](#)

## Where to find helpful information:

### Connect with Us

At Parkinson Canada, we offer you...

- Support one-on-one, and in a group setting via local community support groups
- A toll-free information and referral line at 1 (800) 565-3000
- Customized information packages
- Presence at local health fairs
- Opportunities to get involved in your community
- Educational workshops and conferences for individuals and families
- Continuing education and resources for health professionals at [ParkinsonClinicalGuidelines.ca](http://ParkinsonClinicalGuidelines.ca)

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