The Guide

Everyday life with Parkinson's disease

Parkinson Québec

www.parkinsonquebec.ca



The Guide

Everyday life with Parkinson's disease

Parkinson Québec

www.parkinsonquebec.ca



Bibliothèque et Archives nationales du Québec and Library and Archives Canada Cataloguing in Publication		
	Main entry under title:	
The InfoParkinson (Guide: Everyday life with	n Parkinson's disease
	Contains an index.	
 Parkinson's disease. Parkinson's disease - Treatment. Parkinsonian - Health and hygiene. Parkinsonian - Care. I. Parkinson Québec. 		
RC382.G84 2016	616.8'33	C2016-940898-1

All rights reserved. Any unauthorized reproduction or redistribution, in whole or in part, and by any means whatsoever, is strictly prohibited.

Copyright © Ottawa 2016 Broquet Inc.

Legal deposit — Bibliothèque et Archives nationales du Québec, $3^{\rm rd}$ quarter 2016



TABLE OF CONTENTS

FOREWORD	9
PARKINSON'S DISEASE	15
Parkinson's disease	16
Available medical treatments and side effects	27
Surgery and Duodopa [®]	
Alternative approaches	47
RESEARCH	49
Fundamental medical research	50
Multidisciplinary research	57
LIVING LIFE TO THE FULLEST	63
Learn to live in the moment: psychological aspects	64
Sleep and rest	72
Exercises	77
Exercise program	84
Walking and getting around	

TABLE OF CONTENTS (CONT'D)

Diet 10	05
Driving a car1	16
Micrographia1	19
Managing medication12	21
Motor fluctuations and dyskinesias12	27
Difficulty speaking	31
Swallowing disorders13	36
Urinary and bowel elimination disorders13	39
Cognitive impairment14	42
Sexuality14	47
Young adult1	51
Maternity1	54
LIVING LIFE TO THE FULLEST15	59
Parkinson's disease: learning how to live again	60
ABOUT PARKINSON QUÉBEC17	75
Parkinson Québec1	76
GLOSSARY	80
	00
INDEX	82





Colleagues (2002 edition)

Line Beaudet, RN, PhD, chapters 1 to 5 Chantal Beauvais, chapter 1 Chantal Besner, chapter 3 Pierre Blanchet, MD, FRCPC, chapter 2 Sylvain Chouinard, MD, FRCPC, chapters 1 to 3 Brigitte Damien, chapter 3 Manon Desjardins, chapters 1 to 5 Mélanie Doyle, chapter 5 Christiane Dubois-Lévesque, chapter 3 Isabelle Fontaine, chapter 3 Marie-Josée Fortin, chapter 3 Martine Gaudreault, chapter 3 Marie-Mireille Gagnon, chapter 3 Luce Gosselin, chapter 3 Annie Lavigne, chapter 3 Ginette Lavigne, chapter 3 Hélène Matteau, chapter 3 Philippe Nguyen, chapter 3 Michel Panisset, MD, FRCPC, chapter 1 Emmanuelle Pourcher, MD, FRCPC, chapter 1 Jean Rivest, MD, chapter 3 Éric Simard, chapter 3

Valérie Soland, MD, FRCPC, chapter 1 Sylvie Trépanier, chapter 3

Drafting and review committee (2016 edition)

- Line Beaudet, RN, PhD, Senior Consultant in Specialized Care and Clinical Research (neurosciences department), Centre hospitalier de l'Université de Montréal (CHUM)
- Sylvain Chouinard, MD, FRCPC, neurologist, Co-Director of the André Barbeau Movement Disorders Unit, Centre hospitalier de l'Université de Montréal (CHUM)
- Pierre J. Blanchet, MD, FRCPC, neurologist, André Barbeau Movement Disorders Unit, Centre hospitalier de l'Université de Montréal (CHUM)
- Guillaume Fortin, PhD, Training Officer, Parkinson Québec
- Hélène Piette, MSc, Training Officer, Parkinson Québec

Coordination

Annie Turcot, Parkinson Québec

Acknowledgements

Parkinson Québec would like to gratefully acknowledge the financial support of the **Société Parkinson de Lanaudière** in republishing this guide.

We would like to thank **Mr. Lucien Quesnel** for carefully reading the manuscript. We would also like to thank Mrs. Johanne Lamothe and Chantal

Pelletier, who trusted in us by agreeing to be photographed to illustrate the exercises. As well as Jean-Marie Charbonneau, Sylvain Dubé, François Guérin and Marie Tremblay for agreeing to appear in this guide.

FOREWORD

A reliable resource to find the freedom to move!

The first edition of *the InfoParkinson Guide* was written by a group of specialists in 2002. This team, under the direction of Dr. Sylvain Chouinard and his colleagues Line Beaudet, Manon Desjardins and Mélanie Doyle, wrote a very thorough guide that, for several years, was the main point of reference in the Parkinson's community. It was also used in educational and health institutions as a reference tool.

Mindful of giving people access to a modern and reliable guide that surpasses all expectations, Parkinson Québec is updating the original reference tool. In collaboration with Dr. Sylvain Chouinard, Line Beaudet RN, PhD and Dr. Pierre J. Blanchet, who volunteered to undertake the scientific review of the first version of this guide, I am pleased to unveil this new edition.

The new and improved edition includes all of the key elements on what there is to know about Parkinson's disease. More closely targeted at those affected by the disease and members of their families, this guide debunks, informs and answers the most commonly asked questions that people have about Parkinson's disease. The guide aims to gives the person reading it the tools they need to inspire them to find the freedom to move and encourages readers to take a more active role and to develop a strong support system. It also aims to educate medical professionals responsible for assisting those affected by Parkinson's disease throughout their journey.

It is thanks to the active and voluntary involvement of skilled people and the generosity of donors that this second edition could be brought to life. I would like to

thank all of those who helped make this possible by volunteering their time, sharing their knowledge and donating their money. I would also like to extend a heartfelt thanks to all of the people who helped bring Parkinson's disease out of the shadows and who took the time to share their practical research-based strategies.



Nicole Charpentier Executive Director



I am optimistic

My life changed several years ago, when, one night in October, my hand refused to sign my name. This was the first sign of what was to come and what would lead me to become involved with Parkinson Québec. I didn't ask for it, but I accepted this challenge that life threw at me with open arms. I was lucky enough to have a mother who instilled in me this philosophy: when life challenges you or when you are faced with adversity, you will stumble and fall, but you must pick yourself up, dust yourself off and keep moving forward. As a father of four children, I want to leave them that same legacy.

Those that know me well would tell you that I am always cheerful and energetic. Of course, like anyone else, I have my moments of doubt and things aren't always great, but I don't let that hold me back. I want to keep fighting and continuing to see the world through optimistic eyes. I firmly believe that staying cooped up at home would get me nowhere.

I am also convinced that by staying active, not just physically, but psychologically and socially as well, I can live a full and meaningful life. Of course, I have to make some changes here and there, but I do so by keeping in mind just how much I love life and what it has to offer.

Pessimists see challenge in opportunity. Optimists see opportunity in challenge. And guess what? I'm overflowing with optimism and hope!

I urge you to find the freedom of movement within yourself!

Gérard Tardif Living with Parkinson's Chairman of the Board of Directors at Parkinson Québec









PARKINSON'S DISEASE AND TREATMENTS

15



PARKINSON'S DISEASE

What is Parkinson's disease?

Parkinson's disease is a neurodegenerative disease that mainly affects movement. Unlike many other neurological disorders, the abnormality that causes Parkinson's disease is known. It can be explained as a loss of cells in an area of the brain called the substantia nigra (black substance). These cells are responsible for producing a chemical called dopamine, which acts as a messenger between brain cells that control movement, which is why it is considered a neurotransmitter. It is estimated that by the time a diagnosis is made, almost 80% of the dopamine-producing cells have already stopped working. This sharp drop in dopamine is what triggers the first symptoms of Parkinson's disease. Fortunately, there are now various medications available that can help offset this lack of dopamine. It is therefore possible to effectively manage the symptoms of this disease and maintain an excellent quality of life for many years after being diagnosed. Unfortunately, there are no medications out there that can slow down or stop the progression of the disease.

What causes Parkinson's disease?

The cause of Parkinson's disease remains unknown. Some theories offer interesting explanations, but for now, it's important to understand that the exact cause is unknown.

One theory suggests that certain environmental factors (toxic) increase the likelihood of developing Parkinson's disease. Some researchers believe, for example, that people living in rural communities are at a higher risk of developing Parkinson's disease; their research calls into question things like well water and pesticides. Once again, these claims have never been proven; they are only assumptions.

The genetics theory is based on recent discoveries about the genes associated with Parkinson's disease. We know that a person who has a parent with the disease carries a greater risk of developing the disease themselves. Recent studies have shown that genetic contribution is particularly high in those that develop Parkinson's disease at a young age.

Who is wrong? Who is right? The reality is that it is probably a combination of toxic and genetic factors. For example, people who have a higher risk of developing Parkinson's disease might be those who have a genetic predisposition and who, once exposed

to certain environmental toxins, would develop the symptoms of Parkinson's disease.

People affected by Parkinson's disease

It is estimated that 100,000 people in Canada have Parkinson's disease; 25,000 of them live in Quebec. This disease occurs in young adults just as often as in older adults and affects more men than women. Symptoms most commonly appear around the age of 64. However, we know that this number increases with age. Parkinson's disease will affect 1% of people aged 65 and up and 2% of people aged 70 and up. Additionally, it is estimated that the number of new cases will increase by 50% among people aged 65 and up in the next 20 years. In general, no matter the age at which the disease appears, the symptoms are fairly similar. However, some clear differences can be seen if the onset of the disease happens before the age of forty. It appears that dystonia (involuntary muscle contraction) is more common in younger people and that they respond better to levodopa treatments, as they experience motor fluctuations and dyskinesias (involuntary movements) much earlier. Conversely, both tremor and cognitive disorders (memory loss, difficulty concentrating) are much less common in younger people.

Diagnosing Parkinson's disease

Parkinson's disease is not always easy to diagnose. As is the case for other health problems, there is no specific blood test or radiological exam that can pinpoint its existence. Being able

to diagnose this disease depends solely on patient-reported symptoms and on a thorough neurological exam performed by a doctor.

For some, diagnosing Parkinson's disease is easier if they experience common symptoms such as rest tremor, slowed body movements and stiffness on one side of the body.

However, things aren't always that simple. Some people with Parkinson's disease do not experience—and will never experience—rest tremor, or what we call "akinetic-rigid" forms, which differ from "trembling" forms where rest tremor is experienced. Moreover, several other diseases can cause similar symptoms to Parkinson's disease in their early stages; this is referred to as a parkinsonian syndrome, a subject we will tackle later on. It is often very difficult to tell the difference between Parkinson's disease and a parkinsonian syndrome. It is believed that even experts, such as neurologists who specialize in treating Parkinson's disease, misdiagnose one out of every three patients when making their first diagnosis. Without a targeted test, the neurological exam done by the doctor is the most important diagnostic tool.

For someone living with Parkinson's disease, radiology imaging tests come back normal. However, the doctor may still want to try certain tests, like a CT scan for example, in order to eliminate the possibility of other complications such as mild strokes. More specialized imaging tests, in nuclear medicine, can be useful in detecting Parkinson's disease, but in reality they are mainly used as research tools and not as diagnostic tests.

Symptoms of Parkinson's disease

The clinical symptoms of Parkinson's disease are marked by four key signs:

- rest tremor;
- akinesia and bradykinesia;
- rigidity;
- postural instability.

1- Rest Tremor

Rest tremor is the most common symptom of Parkinson's disease. For 70% of people, it is their first symptom. The tremor usually starts unilaterally (on one side of the body) in the hand or foot. It appears as alternate flexion and extension of the fingers; adduction and abduction of the thumb like when crumbling something. As the disease worsens, the tremor may eventually affect limbs on the opposite side of the body. The distinguishing feature of this tremor is that it lessens when executing voluntary movements, which is what sets it apart from other types of tremors.

2- Akinesia and Bradykinesia

Akinesia and bradykinesia are symptoms that are clinically defined by an inability to initiate movement (akinesia) and an implied slowed speed of movement (bradykinesia). In the face, this appears as a decrease in facial expression and blinking. Some people may experience an excess of saliva, as a direct result of slowed swallowing. The voice may become monotone and low. There may also be difficulties when executing movements and a slow execution. This appears as impaired fine motor skills; the person may struggle with buttoning their clothes or shaving, and they may take smaller, slower steps when walking.

3- Rigidity

Rigidity refers to increased muscular tone. Most of the time, the person will report feeling stiff, but will not experience any other clinical symptoms of rigidity. This symptom is most often observed by the doctor during the physical exam and is extremely useful when determining a diagnosis. Rigidity may appear as a decrease in arm swing on the side of the body affected by Parkinson's disease.

4- Postural Instability

Postural instability is a later symptom of Parkinson's disease that appears after the disease has had time to progress for many years. The person will experience balance disorders, which will cause increasingly frequent falls. This is probably the most debilitating symptom because it reduces mobility and compromises the person's safety when moving. If postural instability appears early on, there is a strong possibility that it is not related to idiopathic Parkinson's disease and could be a symptom of something else.

In summary, the main symptoms that enable a diagnosis of the disease are the presence of two of the following three factors: rest tremor, bradykinesia and rigidity.

Finally, it is important to know that a person with Parkinson's disease may also experience the following symptoms:

- seborrheic dermatitis (greasier skin, especially around the nose and eyebrows, as well as a greasier scalp);
- increased sweating;
- decreased sense of smell;
- constipation;
- increased urinary frequency;
- dizziness when standing up (orthostatic hypotension);
- non-specific sensory symptoms: numbness, pain, burning sensation, restlessness and fatigue;
- difficulty sleeping;
- feelings of depression.

Progression of Parkinson's disease

Since Parkinson's disease is caused by a progressive loss of dopaminergic neurons that control voluntary movement, people generally seek help because of motor difficulties. The most common reason for seeking medical attention is usually because of a rest tremor. Some of the other most common reasons are reported loss of fine motor skills or micrographia (handwriting that gets progressively smaller). Occasionally, some people may seek medical attention if they notice a change in posture or if they experience trouble walking. It is also common for people to experience pain, most often in the arms, during the onset of the disease. Finally, depression, fatigue and changes in personality are all signs that may appear before the onset of any mobility difficulties.

It is estimated that people seek medical attention one or two years after their first symptoms appear. Based on the challenges caused by the disease, the doctor will decide whether or not to prescribe medication at the time of diagnosis. Not all specialists agree on which type of treatment is best or when it is advisable to start. However, one thing is certain, in most cases, patients report a noticeable decrease in the intensity of their symptoms, which can last for years, following their initial treatments: this is commonly referred to as the "honeymoon" phase.

It is extremely difficult to predict how the disease will progress over time. Some people with Parkinson's disease will notice their symptoms slowly progress over several years, whereas others may notice that their condition deteriorates more quickly. Chart 1, found below, summarizes the typical progression of Parkinson's disease in a person who is not receiving treatment. This chart provides a highly simplified "snapshot" of the typical progression: the disease starts on one side, eventually begins affecting both sides and finally balance problems will appear. However, thanks to modern medicine (medications or surgeries) very few people actually reach stage 5.

Nowadays, Parkinson's disease is not considered a fatal disease. In other words, you won't die as a direct cause of it. However, in the more advanced stages of the disease, certain problems related to infection, pneumonia or fractures caused by a fall can have serious implications and become causes of death attributed to Parkinson's disease.

STAGE 1	The symptoms are unilateral and include at least two of the
	following three symptoms: rest tremor, stiffness, akinesia.

STAGE 2	The symptoms start to become bilateral and can include
	speech problems, bad posture and difficulty walking.

STAGE 3	Bilateral symptoms worsen and difficulties with balance	
	may appear. The person's autonomy is usually not affected.	

STAGE 4	Disability is evident, but the person's autonomy is usually not affected. Bradykinesia and fluctuations (if present)
	become more pronounced.

STAGE 5	The person is confined to a wheelchair or is bedridden.
---------	---

Chart 1: The "typical" progression of Parkinson's disease Hoenh and Yahr Scale (1967)

Conditions often mistaken for Parkinson's disease

Essential tremor

When most people think of Parkinson's disease, the first thing that comes to mind is the tremor. Additionally, this disease is often mistaken for essential tremor, a hereditary disease where, unlike Parkinson's disease, the tremor is the only symptom that appears. One with essential tremor does not experience the characteristic slowness and rigidity that comes with Parkinson's disease.

The fundamental difference between these two afflictions, Parkinson's disease and essential tremor, comes down to the type of tremor. With the former, the tremor is most often observed at rest and disappears when the person attempts to move. In the second case, the tremor is predominately observed when performing an action such as holding a glass. Despite this theoretical distinction, distinguishing essential tremor from rest tremor, associated with Parkinson's disease, can be difficult to do.

Parkinsonian syndromes

Parkinsonian syndromes refer to a handful of diseases that produce similar symptoms to Parkinson's disease, like slowness, tremor, stiffness and balance disorders, but also produce other symptoms commonly referred to as "Parkinson's-plus."

Here is a list of some of the diseases that are commonly mistaken for Parkinson's disease: supranuclear palsy, multisystemic atrophy, striatonigral degeneration, olivopontocerebellar atrophy, Shy-Drager syndrome, corticobasal degeneration and Lewy body disease.

It can be very difficult for the neurologist to make a diagnosis during the onset of the disease. The differences between Parkinson's disease and a parkinsonian syndrome are subtle. Symptoms not typical of Parkinson's disease, such as vision loss, early falls, significant cognitive impairment and discovering atypical signs during the clinical exam, might point to a parkinsonian syndrome. Confirming the diagnosis of a parkinsonian syndrome often happens during levodopa treatments because, in such cases, there is little to no response to this type of pharmacological treatment. Parkinsonian syndromes often progress much quicker than Parkinson's disease, and, unfortunately, most therapeutic treatments do not offer any relief.

Other situations that may cause confusion

Some medications may lead to movement disorders and cause symptoms almost identical to those of Parkinson's disease. Some examples include: medications used to treat psychoses such as haloperidol (Haldol[®]) and chlorhydrate found in chlorpromazine (Largactil[®]) or those prescribed to treat nausea like metoclopramide (Maxeran[®]) and prochlorperazine (Stemetil[®]). Furthermore, experiencing many mild strokes is also a frequent cause of parkinsonism. A CT scan would be able to determine the causes and confirm a diagnosis.

AVAILABLE MEDICAL TREATMENTS AND SIDE EFFECTS

Many classes of medication can now alleviate the symptoms of Parkinson's disease. It is a good idea to understand what may lead the doctor to favour a certain treatment over another. It is equally important to be well-informed of any side effects caused by taking these types of medications.

Six classes of medication are currently available: levodopa, dopamine agonists, anticholinergic medications, amantadine, monoamine-oxidase-B inhibitors (MAO-B) and COMT inhibitors. These classes of medication use two different strategies:

Replenishing the missing neurotransmitter, i.e. dopamine, using four types of medication:

- dopamine precursors: levodopa;
- dopamine degradation inhibitors: MAO-B inhibitors (selegiline and rasagiline) and COMT inhibitors (entacapone and tolcapone);
- dopamine agonists: medications that mimic the actions of dopamine by attaching themselves to dopamine receptors;
- dopamine release: (amantadine hydrochloride).

Balancing acetylcholine and dopamine levels:

 anticholinergic medications (trihexyphénidyl, procyclidine, ethopropazine and diphenhydramine).

Levodopa

It is currently the most effective Parkinson's disease medication. Levodopa is absorbed into the intestine and travels through the bloodstream until it reaches the brain. Once in the brain, it is converted into dopamine and stored in nerve cells to replace depleted dopamine. Levodopa is always combined with another peripheral inhibitor like carbidopa found in Sinemet[®] or benzerazide found in Prolopa[®], which slows the peripheral transformation of dopamine allowing more levodopa to enter the brain. This also reduces the risk of any side effects like nausea and vomiting.

Sinemet[®] is the most frequently used medication in Canada. The most common Sinemet[®] preparations include 100/10, 100/25, 250/25 and controlled-release preparations like Sinemet CR[®]



100/25 and 200/50. Sinemet CR[®] is absorbed more slowly and the effects are more intense, meaning that fewer doses are required. However, absorption can sometimes vary.

Taking levodopa improves rigidity and bradykinesia in most patients. In other respects, its effect on tremor is extremely variable and it is not very effective in treating balance disorders. When patients taking high doses of this product (above 1,500 mg) do not see any noticeable improvements, they may be diagnosed with something other than idiopathic Parkinson's disease.

Dopamine agonists

Dopamine agonists work by stimulating the dopamine receptors in the brain and mimicking or imitating the action of natural dopamine. It is the second most effective class of medication after levodopa.

There are currently four dopamine agonists available in Canada: bromocriptine (Parlodel[®]), pramipexole (Mirapex[®]) and ropinirole (Requip[®]). Ritigotine (Neupro[®]), an agonist that delivers dopamine through a transdermal patch, recently became available. However, this medication is not yet covered by the public RAMQ plan in Quebec.

Agonists are distinguished by their action, as each one is able to stimulate subclasses of dopamine receptors and their molecular structures in a different way.

Although there have only been a limited number of studies done to compare them directly, there does not appear to be any major differences between the different agonists when it comes to their effectiveness, ease of use or side effects. They must be prescribed in very low doses and increased very slowly to avoid any side effects.

Agonists have been proven to be a very effective form of initial treatment for Parkinson's disease and just as effective when combined with levodopa in the more advanced stages of the disease where people experience motor fluctuations. Agonists have been recommended as an initial treatment ahead of levodopa in Parkinson's disease sufferers under the age of 65. Studies suggest that it could reduce the incidence of motor complications caused by the progression of the disease (dyskinesias). That being said, the very-long term effects of relying on dopamine agonists to initially treat the disease remains a controversial topic. In addition, this class of medication frequently causes side effects, such as impulse control disorder. For these reasons, dopamine agonists are now prescribed less often than before.

Monoamine oxidase-B inhibitors (MAO-B)

Selegiline is an irreversible monoamine oxidase-B inhibitor. MAO-B is partly responsible for dopamine degradation in the brain. Consequently, selegiline increases the symptomatic effects of levodopa. It can also worsen symptoms like dyskinesias, hallucinations, nausea and more.

In the mid 90s, the question arose as to whether selegiline had a neuroprotective effect, meaning, it could slow the progression of Parkinson's disease. The first large multicentre Datatop study followed 800 people in the early stages of Parkinson's disease who didn't require levodopa treatment. Unfortunately, this study did not prove that selegiline had an effect on the progression of the disease.

Selegiline can be used alone in young people at the onset of the disease, as they do not have any disabling symptoms, or it can be used in combination with levodopa to treat those experiencing motor fluctuations.

Rasagiline (Azilect®) is a new generation monoamine oxidase-B inhibitors. This molecule has generated a lot of hope following the publication of the Adagio study, which suggested a positive effect on the progression of the disease, though this neuroprotective effect has not been demonstrated with certainty. Moreover, its safety profile (tolerance of the drug) is better than that of selegiline. Studies have also demonstrated the effectiveness of rasagiline when used alone in young people at the onset of the disease or in combination with levodopa in people experiencing motor fluctuations.

COMT inhibitors

Catechol-O-methyltransferase (COMT) is one of the molecules responsible for the degradation of levodopa and dopamine. COMT inhibitors block the action of this enzyme in the intestine and the brain. By slowing its degradation, levodopa becomes more easily available to the brain.

Tolcapone (Tasmar®) is a potent COMT inhibitor. It was removed from the Canadian market, saved for a handful of patients who were already taking it, due to liver toxicity.

Entacapone (Comtan®) is a peripheral COMT inhibitor, taken in 200 mg doses in combination with levodopa. For people

experiencing motor fluctuations, it helps reduce "off" time and increase "on" time, while also prolonging the motor response to levodopa. There are now pills (Stalevo®) that combine levodopa, entacapone and carbidopa. These pills make it possible to take levodopa in various dosages (50-75-100-125 or 150 mg of levodopa), which an be extremely beneficial for certain patients.

Anticholinergic medications

Anticholinergic medications were the first medications to be used to treat Parkinson's disease. Even when other, more targeted medications became available on the market, they still proved to be useful, mainly for treating tremors. It should be recognized, however, that tremor is often a difficult symptom to control using medication.

Here is a list of some of the different anticholinergic medications: trihexyphenidyl (Artane[®]), orphenadrine (Disipal[®]), benztropine (Cogentin[®]), procyclidine (Kemadrin[®]), diphenhydramine (Benadryl[®]) and ethopropazine (Parsitan[®]).

Amantadine

Amantadine (Symmetrel®) is an antiviral agent whose antiparkinsonian properties were discovered by accident. The mechanisms of its action are not completely clear. It can stimulate dopamine release in the brain. It can be used alone, during the onset of the disease or in combination with other medications once the disease has progressed. It is usually taken in 100 mg doses, two or three times per day. Recently, it has been proven that amantadine can also reduce the severity of dyskinesias.

Choosing a treatment

The decision to start a treatment depends on multiple factors. It usually happens when symptoms begin preventing the person from leading a normal personal, professional or social life. Other factors, such as the age of the patient, the affected side (dominant or non-dominant) and the presence of any common symptoms like tremor, bradykinesia and difficulty moving, should also be taken into consideration.

The main purpose of treatment is to relieve the symptoms of Parkinson's disease in order to allow the person to go about their daily activities. Regular medical follow-ups can help to more clearly understand the progression of the disease and ensure that the medication remains effective and that any side effects are safely controlled.

Once the decision has been made to start medical treatment, the next step is to choose which medication or medications to take. Today, there are no over-arching recommendations, and treatment must be personalized as symptoms may differ from person to person. In 2012, the Canadian Neurological Sciences Federation published the Canadian Guidelines on Parkinson's Disease. http://www.parkinsonclinicalguidelines.ca

When tremor is the most prominent symptom and rigidity and bradykinesia are relatively minor, anticholinergic medications may be considered as an initial treatment. Amantadine could also be a great choice for people who are in the early stages of the disease.

Some people might need a stronger antiparkinsonian effect if their symptoms are more severe. Levodopa is currently the most

effective Parkinson's disease medication. Many people are afraid to use levodopa because they mistakenly believe that it can speed up the progression of the disease. There is also the misconception that if it is taken prematurely, the effects will wear off over time.

As mentioned earlier, until recently, it was recommended that people under the age of 65 should use dopamine agonists instead of levodopa. This practise is still controversial as dopamine agonists have been known to cause much more severe side effects.

Unfortunately, there is currently no treatment that has been shown to effectively slow the progression of Parkinson's disease.

Side effects of medications

Levodopa

Levodopa is currently available in two forms: Sinemet[®] and Prolopa[®]. The most common side effects include: nausea, vomiting, loss of appetite and constipation. Taking this medication with food may reduce the likelihood of experiencing any nausea or vomiting. Levodopa can also cause orthostatic hypotension, which causes dizziness when standing up or feelings of fatigue.

Using levodopa can cause visual hallucinations. In the beginning, the hallucinations are not threatening, but may become more disturbing over time. Nightmares, restlessness and fragmented sleep may happen before the onset of any visual hallucinations.

Dopamine agonists

There are currently two families of dopamine agonists. "Old" agonists, such as Parlodel[®], can cause the same type of side effects as when using the "new family" of agonists, which includes Requip[®], Mirapex[®] and Neupro[®]. All dopamine agonists may cause the same complications as levodopa, including orthostatic hypotension, constipation, nausea and vomiting. Just like with levodopa, as the body becomes accustomed to the medication, side effects may begin to disappear over time. This tolerance can be built up more easily if the medication is introduced gradually and slowly. It is important to know that, in rare cases, using Parlodel[®] has been attributed to the development of pulmonary fibrosis. If this happens, it is a good idea to stop taking the medication. Agonists have also been known to cause swelling in the ankles (edema). Certain side effects, the same ones caused by taking levodopa, are also common when taking any type of dopaminergic medication. They run the risk of visual hallucinations, delirium and confusion.

In the last few years, there has been a lot of interest around one serious side effect, impulse control disorder. This side effect, which can happen with any class of antiparkinsonian treatment, appears much more frequently when taking dopamine agonists. The incidence of this problem is still unknown, but the latest figures estimate that more than 20–30% of agonist users may experience this symptom. This impulse control disorder can take on various forms, including pathological gambling, hypersexuality, excessive spending, increased appetite, compulsive shopping and repeated and compulsive hobbies. Those affected lose all self-control.

Dopamine degradation enzyme inhibitors

The medications found in this category are rasagiline, selegiline and COMT inhibitors (entacapone and tolcapone). Selegiline is an MAO-B inhibitor that indirectly enhances dopamine stimulation. In addition to the dopaminergic effects described above, selegiline may have a stimulative effect, cause anxiety or lead to insomnia. Insomnia has not been reported as a side effect in people taking rasagiline.

Entacapone and tolcapone are COMT inhibitors that indirectly enhance dopaminergic activity and prolong the effectiveness of levodopa. As with MAO-B inhibitors, COMT inhibitors can worsen dopaminergic effects such as dyskinesias, nausea, vomiting, dizziness when standing and even hallucinations. Users may occasionally experience diarrhea.

Anticholinergic medications

Medications, such as Cogentin[®], Artane[®] and Parsitan[®], are used most often during the onset of the disease in order to control tremor. They have numerous side effects: dry mouth, difficulty urinating, urinary retention, constipation, vision troubles, negative effects on attention and memory, hallucinations, confusion and delirium. Given this long list of side effects, these types of medications are not used in the more advanced stages of the disease, especially in older people or those experiencing cognitive impairment.

Additional considerations

Antiparkinsonian medications must first be taken slowly and in small doses. Additionally, you should never abruptly discontinue antiparkinsonian medications.
It is also important to know that some medications may not be well tolerated by certain people suffering from Parkinson's disease, including those that have a direct effect on the brain and block dopamine, thus worsening the symptoms of the disease. These medications are mainly used to treat psychoses or as tranquillizers. The same is true for neuroleptic medications such as haloperidol, mellaril and nozinan, to name a few. Other medications used to treat digestive issues (Maxeran®) or mental health problems (Epival®) can also cause or worsen parkinsonian symptoms. The brands listed above are just a handful of examples of medications that users should pay a close attention to when using. It is also possible that certain medications used to treat Parkinson's disease may interact with other medications such as antibiotics.

Recently, a rare complication initially associated with new agonists was reported to cause sudden sleep attacks. The reaction can occur when the person is in the middle of an activity, such as driving their car. This form of sudden drowsiness, which is not preceded by any feelings of mild sleepiness, was causing accidents and forced the Ministry of Health to issue a warning to patients who were taking Mirapex® or Requip®. Those taking either medication had to stop driving their cars. It is important to note that this complication does not seem to be specific to new agonists and that other medications used to treat Parkinson's disease have also been the cause of similar situations.

STRATEGIES

For nausea

Nausea is a problem frequently reported with the use of any dopaminergic agent. If the nausea is directly related to the absorption of levodopa, it is a good idea to take the medication with food. Controlled-release preparations like Sinemet CR[®] are also less likely to cause this side effect. If the nausea continues, it is a good idea to take carbidopa, an exception drug that you can order free of charge. Finally, if nausea persists due to difficulties absorbing agonists or levodopa, taking domperidone, a prescribed medication, can help reduce the problem; it is sold under the name Motilium[®].

For orthostatic hypotension or dizziness when standing

Parkinson's disease can be the sole cause of these types of situations. Different medications could also be the cause of these types of problems. In general, experimenting with non-medicinal ways of treating these problems, like wearing compression stockings and adding salt to your diet, can help put you back on track. If nothing works, you should consider taking a medication, such as domperidone, sold in pharmacies under the name Motilium[®], or even a sympathomimetic, like Amatine[®].



SURGERY AND DUODOPA®

Surgical treatments for Parkinson's disease

Treating Parkinson's disease with brain surgery is nothing new. Before even discovering a medication that effectively treated Parkinson's disease, the medical community experimented with treating tremor and rigidity by damaging certain parts of the brain. Levodopa made its debut in the 1970s and turned out to be so effective that the number of surgeries being performed began to decrease. It was only many years later that surgeries came "back in style." Pallidotomy surgeries started being performed again after the 1990s, not to help treat rigidity, but to counteract dyskinesias that were appearing after extended use of levodopa and other antiparkinsonian agents. Thalamotomy surgeries continued to be recommended to help treat cases of severe tremor. Around 1995, another neurosurgical target was discovered, which, when neutralized, makes it possible to control not only tremor and dyskinesia, but rigidity, as well as posture and gait disorders. It is referred to as the subthalamic nucleus. Implanting electrodes is the best way to target this area. Subthalamic stimulation is the most highly recommended way of treating this type of situation. It can significantly decrease the amount of medication needed to control the disease. Since the stimulator device is adjustable, the stimulation strength can be changed in order to respond to the progression of the disease.

Surgical procedures

Because of the serious risk of complications, rare as they may be, accurately assessing suitable candidates is extremely important. Only if there is no doubt at all about the diagnosis of the disease and if the person's chances of success are relatively high, are they a good candidate for surgery. The person should generally meet the following criteria to be considered for surgery: experience rest tremor, rigidity, bradykinesia and asymmetrical onset, have a good response to dopaminergic agents and present no symptoms suggestive of another diagnosis. Additionally, the person has to have demonstrated that pharmacological treatments no longer adequately control the symptoms of the disease. Patients experiencing significant memory disorders, hallucinations or untreated severe depression are not considered suitable candidates.

However, each surgical procedure has its own requirements. Thalamotomy surgery is most often performed to treat tremor. It may also be used to treat dystonias caused by Parkinson's disease. Pallidotomy surgery is only for patients whose dyskinesias are their main problem. Thalamotomy and pallidotomy surgeries have not been shown to significantly improve posture and gait problems.

Subthalamic stimulations are recommended for patients suffering from dyskinesias, motor fluctuations, posture and gate disorders, as well as tremor. Since patients experiencing either severe tremor or dyskinesias will sooner or later experience other signs and symptoms of the disease, several groups recommend subthalamic stimulation over other types of surgical procedures.

Surgical complications

Despite the impressive results achieved by performing surgical procedures, it should not be forgotten that they don't actually cure Parkinson's disease and can carry certain risks. Fewer than 7% of surgical procedures result in major complications. Inserting the leucotome or electrode can sometimes cause blood vessels to burst, leading to bleeding in the brain. These hemorrhages can be fairly minor and be reabsorbed into the body with limited consequences, but they can also be more severe and cause permanent disability.

Despite accurate preoperative localization, neighbouring structures may also be affected, which may cause unwanted neurological conditions.

Implanting foreign objects into the body, such as stimulators, may increase the risk of infection. The electrodes may also move around and surgery may be required to put them back into place. Batteries usually need to be replaced within two to seven years.

Outcomes

So far, the outcomes of different groups that practise surgical procedures to treat Parkinson's disease have been consistent. Thalamotomy surgeries eliminate hand tremor in 90% of cases. However, a tremor in the other hand will require a second thalamotomy surgery, on the opposite side. Similarly, dyskinesias are better managed through contralateral pallidotomy surgery. It should be pointed out that the right side of the brain controls movements on the left side of the body and vice versa.

When it comes to subthalamic stimulations, all patients notice improvements, however, the results are more variable. Almost all patients report feeling more stability after taking their medications and experience less "off" time. Some patients experience a dramatic improvement in how they walk and talk and in their fine motor skills (those used to write, for example). Others see painful syndromes completely disappear.

In summary, the results produced by all of these surgeries are relatively consistent. Additionally, another interesting feature is that stimulators can be more easily adjusted to meet the needs of this ever-changing disease.

Duodopa®

Duodopa[®] is an effective treatment for people with Parkinson's disease who have developed motor fluctuations that can no

longer be controlled by adjusting their oral pharmacological treatment. This treatment has been available in Europe for more than twenty years and was commercialized in Canada in 2013.

Duodopa[®] is a gel mixture of levodopa and carbidopa that is administered directly into the digestive system (small intestine). This innovative device allows levodopa to be delivered continuously, thus sustaining dopaminergic stimulation. Adjustments can also be made to levodopa dosages, which would be impossible to achieve with an oral medication. Inserting a temporary nasogastric tube is recommended in order to find out if the patient responds well to this form of treatment and to adjust the dosage before the indwelling catheter is put into place.



Recent studies have shown that Duodopa® was more effective than levodopa pills for controlling motor fluctuations. It should be understood, however, that this treatment is more invasive and is therefore reserved for people who cannot control their fluctuations with oral pharmacological treatment options.

There are two types of Duodopa[®] side effects. There are the effects caused by dopamine, which are common with all dopaminergic agents. Examples include hallucinations, nausea, hypotension and others. Moreover, there are also side effects that are associated with inserting a tube into the digestive system such as the tube moving from the intestine into the stomach (this causes an irregular response to treatment), a local infection at the puncture site of the tube and occasionally more serious infections (peritonitis). These side effects usually occur before the tube is put into place. Finally, Duodopa[®] users are at risk of developing severe neuropathy.

The way forward

Although treating Parkinson's disease is done mainly through pharmacological treatment, adding in complementary therapies on top of using medications has proven to be extremely effective in helping to better control certain symptoms or even delay their onset. Things like posture, gait, balance, rigidity, endurance and pain control may improve through physiotherapy. Occupational therapy monitoring may help to improve autonomy in all aspects of day-to-day activities. Communication and speech can be maintained or corrected by going to speech therapy. Consulting a nutritionist could result in improving the overall health of the affected person by ensuring they are getting the nutrients that they need and to improve the effectiveness of medications or counteract any side effects. A comprehensive approach therefore greatly improves treatment for people living with Parkinson's disease and can provide them with a better quality of life.





ALTERNATIVE APPROACHES

Alternative medicines and therapeutic approaches

Interest in alternative medicine continues to grow. We often hear about massage therapy, chiropractic, acupuncture, osteopathy, homoeopathy, phytotherapy, aromatherapy, pressure therapy and reflexology. These alternative medicines are becoming more and more accepted as alternatives to traditional medicine. While it is true that there is no harm in doing good, when considering these therapeutic approaches it is necessary to do so with care and attention. For example, choosing a type of massage that is well suited to meeting the person's needs, condition and energy level.

It is important that the person with Parkinson's disease understands the advantages and benefits of all of these approaches, as some might be better suited to their needs than others. The best therapeutic choices, whether traditional or alternative, are those that are well-informed. A visit to the doctor may help the affected person decide which approaches they should consider and which they should avoid, thus helping them to create a plan of action that could prove to be beneficial to their health and well-being.



RESEARCH

49



FUNDAMENTAL MEDICAL RESEARCH

Even though the disease was first medically described by English surgeon James Parkinson in 1817, its exact cause is still unknown and its diagnosis still relies heavily on clinical criteria because all generic tests are unable to pinpoint its existence. However, research has come a long way over the last thirty years and now focuses on answering three fundamental questions:

- What causes Parkinson's disease?
- Is it possible to slow or even stop its progression?
- Is there a way to prevent and permanently reverse the motor complications that result from the extended use of levodopa?

Cause of the disease

People suffering from Parkinson's disease gradually lose dopaminergic cells ten times faster than healthy people of the same age. Some studies suggest that people begin to lose dopaminergic neurons four or five years before they notice their first symptoms.

It is, however, important to clarify that people who have Parkinson's disease will never lose all of their dopamine-producing cells. In some areas of the brain, outside of the substantia nigra, many cells will remain intact. Other types of nerve cells are also affected. This loss explains some non-motor symptoms associated with the disease, such as cognitive impairment and depression.

With Parkinson's disease, the neuronal loss in the substantia nigra is associated with the appearance of abnormal rounded inclusions, called Lewy bodies, in affected neurons. This phenomena is the main pathological feature of the disease. Researchers have long believed that Lewy bodies play a part in this process. Since they are rarely seen in other degenerative diseases, some researchers initially believed that they were a result of the disease instead of what was causing it. It has only been in the last few years that it was discovered that these inclusions contained a protein called alpha-synuclein. This protein, which gained significance following 1997, is to Parkinson's disease what beta-amyloid is to Alzheimer's disease. Genetic mutations or damage caused to cells by this same protein can make them insoluble and lead to toxic deposits. This can cause the hereditary form of parkinsonism, which is directly passed down from one generation to the next. In order to develop ways to reverse these conditions, we are currently working toward identifying factors that could be

causing the alpha-synuclein protein to be insoluble and toxic to most individuals suffering from Parkinson's disease.

The incidence of genetic factors is currently being studied. According to various studies, even though there is a very low risk of passing the disease on from one generation to the next, the possibility increases two to fourteen times in a family where one person has Parkinson's disease.

The factors involved in the death of dopaminergic cells in people with Parkinson's disease have also been the focus of intensive research. Various distinct mechanisms have been studied specifically:

- the inability of the affected cells to counteract or eliminate the harmful effects caused by certain toxic molecules called free radicals;
- energy disorders stemming from the abnormal functioning of mitochondria, also known as the powerhouse of the cell;
- the damage is likely caused by an excess of a substance called glutamate, which the cells are unable to get rid of;
- the death programmed by the cell's genes, referred to as apoptosis, might be triggered by various factors and lead to their loss;
- the possibility that a sick cell may transfer their protein content, now abnormally insoluble and toxic (like alpha-synuclein) from one cell to the next, therefore contaminating other cells and aiding in the spread and progression of the disease.

Neuroprotection and neurorestoration

All of the previously mentioned mechanisms could interact with one another creating more and more toxicity, eventually leading to the death of dopaminergic and non-dopaminergic cells. As such, they would be an interesting subject that could lead to research studies focused on developing new treatments targeted at slowing or even stopping the progression of the disease. These types of neuroprotective strategies need to be introduced early on, hence the importance of detecting the disease as guickly as possible. Some people may show unrecognized non-motor symptoms before experiencing resting tremor and other traditional motor symptoms, which can delay diagnosis and treatment. These initial non-motor symptoms, such as restless sleep or taste and smell disorders, are the focus of studies being done by various teams. The introduction of these neuroprotection strategies early on is also being undermined by the absence of a biomarker and a diagnostic test specific to this disease; this is another subject of many studies currently being carried out.

Even if, in the past, molecules like vitamin E and selegiline weren't able to slow the progression of the disease, many other antioxidant approaches, such as free radical scavengers, glutathione promoters, chelators and medications acting on the oxidative metabolism of dopamine, may be the subject of future clinical studies. Glutamate inhibitors, growth agents or factors (called neurotrophic) and other apoptosis cascade inhibitors are also being studied. These medications should be tested as soon as possible over the course of the disease, in order to protect the healthy dopaminergic cells in the brain, seeing as the loss appears to happen more quickly in its advanced stages. Clinical trials testing antibiotic vaccines that target alpha-synuclein are currently being carried out in the hopes that they can slow the spread of the disease from one cell in the brain to the other. However, researchers still don't know at which stage of the disease this type of vaccine should be used in order to be effective.

Since 1987, it has been possible to transplant replacement cells in the brain to treat the more advanced stages of the disease. The demonstration that embryonic dopaminergic cells can survive and function in an adult host brain was a major first step toward using cell replacement therapy to treat Parkinson's disease. However, in 2003, an international moratorium was proposed because of its unpredictable clinical benefits and adverse effects. Before the moratorium was called, more than 100 people were operated on using vastly different protocols. However, a review of the data gathered from these instances suggested that the best outcomes were experienced by younger patients, those operated on at an earlier stage, and those in whom at least 100,000 dopaminergic cells of fetal origin had been transplanted. The dopaminergic cells of at least three fetuses are needed in order to gather such a large number of cells, which raises ethical, practical and safety concerns. In 2014, the moratorium was lifted in Europe in favour of practising fetal cell transplants that followed an approved and standardized protocol developed by researchers. During the moratorium, research on so-called pluripotent immature stem cells (which have the potential to produce several types of mature cells) sky-rocketed, so much so that it is now possible to program and transform such cells into dopaminergic neurons. The best source of cells to use in transplants to treat Parkinson's disease is still unknown. Directly transferring certain genes into the brain using viral vectors to deliver them, in order to allow molecular synthesis, is also being studied.

Preventing or deprogramming complications associated with levodopa

The introduction of levodopa in the treatment of Parkinson's disease was truly revolutionary for the medical community. What's more, this medication remains the most powerful weapon to control the clinical symptoms of the disease. However, the patient's response to the medication can change over months or even years, and there are many complications associated with the chronic use of levodopa. Over time, the length of relief experienced after each dose begins to shorten. This is known as the "end-of-dose" effect. In some cases, the response to different doses of levodopa can become unpredictable and chaotic. This is called the "on-off" phenomenon. These fluctuations are partly related to a "lazy" or slow stomach whose emptying varies from one moment to the next, leading researchers and pharmaceutical companies to try to create medications that can be administered alternatively, including through the skin (by patch like Neupro®), direct infusion into the small intestine (Duodopa®) or even the bronchial tubes (by inhaler). There is still a lot of hope for this form of treatment.

Long-term use of levodopa is also associated with the development of abnormal, uncontrolled involuntary movements, of varying intensity, called dyskinesias. These movements can be tolerated in most cases, but can also be extremely bothersome to a certain number of patients. To minimize the effects, levodopa doses must be adjusted accordingly and combined with other medications like dopamine agonists, controlled-release levodopa or enzyme inhibitors like selegiline, rasagiline and entacapone.

Studies using animal models have shown that the loss of dopamine and its conventional intermittent oral replacement with levodopa throughout the day could lead to a series of biochemical disturbances in the brain that can cause and sustain dyskinesia. Clinical trials testing amantadine, a well-known glutamate inhibitor, have shown that this medication could reduce dyskinesia by 50% in some people. The antidyskinetic effects that some other medications have on glutamate are currently being studied. We also want to find out if it is possible to prevent other harmful biochemical changes that are responsible for causing intermittent dopaminergic stimulation. Continuously taking dopaminergic medications (through the skin, for example) that consistently stimulate dopamine receptors in the brain, may also reduce the intensity of dyskinesia. These studies raise hope of one day being able to counteract or even prevent the complications of this degenerative disease that impact a person's quality of life.

A lot of progress has been made over the last thirty years in understanding the cellular mechanisms associated with Parkinson's disease. New therapeutic and neuroprotective strategies have been developed. Knowledge is being acquired so quickly that we are not far off from making a link between genetic mutations, alpha-synuclein accumulation, Lewy body formation and energy disturbances that lead to the loss of dopaminergic cells. The goal of stopping the progression of the disease and preventing complications associated with erratic absorption of levodopa looks more promising than ever.



MULTIDISCIPLINARY RESEARCH

Although the medical and pharmaceutical aspects of Parkinson's disease are central to clinical and fundamental research, research is not limited to these aspects alone.

Physiotherapy is a heavily studied area. There is still a lot to learn and understand about the complexity of motor and non-motor disorders associated with Parkinson's disease. A better understanding of these phenomena will allow for more effective treatment strategies to be created, focusing on maintaining mobility and autonomy.

Occupational therapy research focuses on identifying ways in which people living with Parkinson's disease can maintain functional abilities in their day-to-day activities and continue to lead

rewarding social lives. Motor difficulties such as rigidity, involuntary movements and overall slowness are realities that force patients to review the way they do things and how they get work done, as well as reorganize their environment. Studying all of these signs is particularly interesting to occupational therapists.

Neuropsychology also focuses on a long list of research subjects. In fact, Parkinson's disease and its associated treatments cause changes that can also affect cognitive functions such as memory, planning, organization and problem solving. Some intellectual tasks may become more difficult to perform and the ability to learn may become more challenging. It is also important that researchers collectively analyze these phenomena in order to better address them.

The psychological impacts of Parkinson's disease are also at the heart of many intensive research studies. People living with the disease often experience depression and anxiety, a subject that is also studied by researchers all over the world. Feelings of overall well-being



and quality of life are also subjects that are closely examined in various areas of health sciences.

Many people living with Parkinson's disease suffer from altered speech. **Speech therapists** are specialists who focus on studying this phenomenon in order find ways to better address changes that affect communication.

In nursing research, subjects as diverse as the patient's experience with the disease, direct care, pain control, quality of life, assistance interventions throughout the entire progression the disease, support for people and caregivers and so much more are also being explored.

In **nutrition**, the work being done mainly analyzes elements in the affected person's diet that could increase the risk or progression of Parkinson's disease, as well as the impact or effectiveness that different diets have on the disease and managing motor symptoms.

All in all, multidisciplinary research represents the hope that a better understanding of the reality of Parkinson's disease will give those suffering from it the opportunity to regain control over their lives and their bodies. A joint effort in contributing to areas that are both diversified and interdependent is vital. The abovementioned fields of research are just some of the areas being studied. Medical libraries are just one possible way to consult the main scientific journals that publish the results of this research. Websites belonging to various universities in Quebec and around the world, the governments of Quebec and Canada, as well as the Parkinson's Québec website all offer a wealth of information on projects and research findings. The development of new medications, before even becoming available in pharmacy, generally takes 15–20 years. It involves various clinical phases that start with animal testing and end by being tested on humans. Out of the 10,000 potential active principles to come out of the first clinical phase, only one will eventually become an effective and non-toxic medication capable of treating Parkinson's disease in humans. It is therefore recommended that people living with the disease take a critical look at scientific studies being glorified by the media.





LIVING LIFE TO THE FULLEST WITH THE DISEASE

63



LEARN TO LIVE IN THE MOMENT: PSYCHOLOGICAL ASPECTS

When Parkinson's disease takes over someone's life, it can drastically change their future plans. Of course, overcoming it can sometimes seem impossible. It can seem like quite the challenge, but it is possible to tackle the disease head on and learn how to live with it, in order to handle anything it throws at you.

Learning how to live with Parkinson's disease happens slowly over a number of years. Coping with the disease does not mean just sitting back and letting it win. It is consciously finding the strength to fight for and reinvent your life and, above all, not giving up.

Don't lose control of the situation

Since Parkinson's disease is a neurodegenerative disease, various different symptoms will appear over time. The progression of the disease has a significant impact on the physical and mental health of those affected, as well as those around them. Anxiety, pressure, frustration, arguments and stress can all complicate the situation. All of these major changes can lead to expecting the worst. Even though the road ahead is filled with uncertainty, many success stories have shown that it is possible to stay in control of your life.

Understanding

Above all else, in order to understand what is happening to you and to better manage the situation, it is critical to really make sense of Parkinson's disease.

People living with this disease that are able to stay on top of their condition by consulting resources and understand what is happening to them are able to maintain better control over their lives. It is possible that a decrease in the number of medical appointments, missed days at work and social isolation due to the disease may be noted. A general improvement in mood and an increase in autonomy may also be observed.

On top of all of the usual physical symptoms related to Parkinson's disease, psychological impacts may also develop and should not be ignored. Moreover, a large number of people with Parkinson's disease experience depression. It can be attributed to chemical changes in the brain, as well as the physical and cognitive limitations that gradually appear over time.

While not all people with Parkinson's disease are depressed, they are a lot more likely than most to experience periods of depression. Certain events, such as when their diagnosis is announced to them, the appearance of new symptoms, their medication becoming less effective and adjusting to new forms of treatment, can all contribute to the development of depression. There are many other difficult changes to overcome that could trigger feelings of depression, including giving up their hobbies, quitting work and losing important roles in their lives.

The chart below proves just how difficult it can be to identify symptoms of depression in someone with Parkinson's disease, as the symptoms of both diseases are strangely similar.

	PARKINSONIAN Symptoms	SYMPTOMS OF DEPRESSION	
Mobility	Fixed expression. Bradykinesia (slowed speed of movement). Stooped posture.	Little to no emotion. Slowed movements. Slumped posture. Insomnia. Shortened sleep. Fatigue. Constipation. Weight loss.	
Sleep	Insomnia. Fragmented sleep. Fatigue.		
Gastrointestinal system	Constipation. Weight loss.		
Concentration	Bradyphrenia (slowness of thought).	Difficulty concentrating.	

Chart 2. Comparison of the symptoms of Parkinson's disease and depression

Sadness and pessimism, an urge to cry for no reason, a loss of interest in those close to you, indifferent behaviour, lethargy, a loss of motivation and interest and tense or edgy feelings are all symptoms associated with depression. Under these circumstances, the person's view of the world and their perception of themselves and others is rather negative. These symptoms may be fleeting and disappear in people who are very strong-willed. However, some people may experience many symptoms that do not go away so easily. Inactivity allows depression to creep up and settle in.

It is crucial to speak with a doctor or a nurse about these different symptoms in order to find out if you are depressed. It may be easier to screen elderly people for depression by using the Geriatric Depression Scale¹ on the next page.

It is a good idea to consult a doctor or another healthcare professional if the score obtained on the screening test is 7 points or higher, because it could mean a diagnosis of depression.

Depression, it's treatable!

Pharmacological treatment may be recommended; the affected person will be offered antidepressant medication. Psychotherapy may also be suggested. A combination of a pharmacological and therapeutic approach may be used to treat depression.

¹ Reference: P. Bourque, L. Blanchard and J. Vézina. "A psychometric study of the Geriatric Depression Scale." *Canadian Journal on Aging*. Volume 9, Issue 4 (1990).

Choose the best answer for how you have felt over the past week.				
QUESTIONS		YES	NO	
1.	Are you basically satisfied with your life?	\bigcirc	\bigcirc	
2.	Have you given up many of your activities and interests?	\bigcirc	\bigcirc	
3.	Do you feel that your life is empty?	\bigcirc	\bigcirc	
4.	Do you often get bored?	\bigcirc	\bigcirc	
5.	Are you in good spirits most of the time?	\bigcirc	\bigcirc	
6.	Are you afraid that something bad is going to happen to you?	\bigcirc	\bigcirc	
7.	Do you feel happy most of the time?	\bigcirc	\bigcirc	
8.	Do you often feel helpless?	\bigcirc	\bigcirc	
9.	Do you prefer to stay at home, rather than going out and doing new things?	\bigcirc	\bigcirc	
10.	Do you feel you have more problems with memory than most?	\bigcirc	\bigcirc	
11.	Do you think it is wonderful to be alive now?	\bigcirc	\bigcirc	
12.	Do you feel pretty worthless the way you are now?	\bigcirc	\bigcirc	
13.	Do you feel full of energy?	\bigcirc	\bigcirc	
14.	Do you feel that your situation is hopeless?	\bigcirc	\bigcirc	
15.	Do you think that most people are better off than you are?	\bigcirc	\bigcirc	

Give yourself a point if you responded NO to questions 1, 5, 7, 11 and 13. Give yourself a point if you answered YES to questions 2, 3, 4, 6, 8, 9, 10, 12, 14 and 15.

Add up your points.

If you scored between 0 and 6 points, it is highly unlikely that you are depressed. If you scored 7 or more points, you may be depressed. People who have been diagnosed and treated for depression often notice an overall improvement in their autonomy. They may also experience better control over their emotions, an increase in energy, a reduction in pain, better mobility and improved sleep, as well as a desire to participate in social activities and hobbies.

Life is stressful

In addition to depression, stress is also one of the psychological symptoms associated with Parkinson's disease.

Living with a progressive disease that has no cure is considered one of life's most stressful events. Stress occurs because the disease is seen as dangerous. This can happen without warning, making you feel as though you have suddenly lost control. Your balance is completely thrown off, but you have to try to get things back on track or try to strike a new balance in your life. Things have absolutely changed; look for different solutions, muster up your strength and use new techniques to reduce your stress.

While it may no longer be possible to function the same way you did before the disease, it is possible to find other ways to manage stress. Doing tai chi, relaxing, listening to music and reading a good book are just a few examples of ways to reduce stress. Having access to new strategies provides you with endless ways to control particularly stressful situations.

A sometimes fragile situation

Anxiety is another psychological factor associated with Parkinson's disease. It is often experienced in response to different stressful

situations. From feeling insecure to a full-blown panic attack, anxiety can take on many forms depending on the person and whether or not they have a strong support system, including family, friends and acquaintances. While all degenerative diseases may cause a certain amount of anxiety, it is more prevalent among people living with Parkinson's disease when compared with the general public. The same goes for phobias and panic attacks. However, if the person is taking an antiparkinsonian medication that is well-suited to their needs, stays well-informed, is supported and develops effective management strategies (tips and tricks), they can be prepared to face the disease head-on and tackle anything that comes with it.

Possible loss of self-esteem

Motor disorders caused by Parkinson's disease can affect body image. All physical changes impact body image and can influence what is called self-esteem. This sense of personal identity directly affects the way that each person determines their own self-worth. Self-esteem begins developing from birth and can be torn down or built up based on different life experiences, including illness.

Being diagnosed with Parkinson's disease inevitably and irreversibly changes the life of the person affected and can destroy their self-esteem. For example, if their job defines them and then the disease forces them to stop working, they may feel as though they have lost a part of their identity. A part of them is now missing and their self-esteem will take a hit. Giving up activities that are important to them, such as playing golf, driving their car, doing the cooking, going about their daily tasks and needing someone to help them do things that they used to be able to do alone are a handful of examples of changes that could lead to a loss of self-esteem and identity.

However, it is possible to maintain good self-esteem and build it back up despite living with the everyday challenges of the disease. For example, not letting the disease define them and take over their life. As humans, we are more than just a diagnosis, we are, above all, people with strengths, qualities, faults, quirks, habits, passions, interests, families and both friendly and professional relationships.

Combat isolation

Of course, many changes will begin to creep in bit by bit, and it is normal to feel crushed under the weight of all that's going on. Warding off indifference and resignation in order to take hold of each situation is a strategy for success. When things get to be too much, it might seem easiest to close yourself off by voluntarily choosing isolation. The benefits of surrounding yourself with people that make you happy and continuing to maintain an active lifestyle are indisputable. Consciously choosing to live your life by staying in touch with your family and getting involved in your neighbourhood and community will not only let you fully enjoy yourself, but will help you live longer.



SLEEP AND REST

Most people living with Parkinson's disease report experiencing difficulties sleeping and resting. There are so many different types of sleeping disorders that it can be difficult to tell them apart (see the following chart). It should be noted that insomnia remains the most frequently reported problem during medical consultations.
MAIN SLEEPING AND RELAXATION DISORDERS	CHARACTERISTICS
Insomnia	 Difficulty falling asleep and staying asleep. Waking up frequently, waking up too early or too late.
Sleep apnea	 Intermittent breathing that repeatedly stops and starts during sleep. Duration: 10 to 60 seconds. Frequency: up to 30 times a night.
Night cramps (dystonia)	• Involuntary muscle contractions or spasms (calves and thighs). Mainly occurs in the early hours of the morning when dopamine levels are low.
Hypersomnolence	 Extreme feelings of fatigue and drowsiness. Excessive daytime sleepiness.
Nightmares, sleep hallucinations, vivid dreams	• Disturbing dreams, periods of agitation and unconscious activities. Often a side effect of medication.
Difficulty entering REM sleep	 Loss of paralysis associated with certain stages of sleep. Agitation, unconscious activities.

Chart 3. Sleep disorders

Things like taking medications (antiparkinsonian or others) as well as drinking alcohol and stimulants (tea, caffeine, etc.) should

be taken into account. If someone with Parkinson's disease is having trouble sleeping, look into how much of each of these they are consuming. Making changes to your therapeutic regimen is just as essential as changing certain lifestyle habits, especially in cases of excessive daytime sleepiness.

Additionally, a variety of biological, psychological and social factors can also impact sleep and rest. Biologically, a lack of physical activity and intellectual stimulation, not having a chance to unwind, taking naps, as well as illnesses and pain seem to have a major impact. Psychologically, stress, anxiety, depression, worry and lifestyle greatly influence the quality and quantity of sleep and rest. Social factors that can influence sleep include changes in daily routine, a new or turbulent environment or tense and combative relationships with loved ones.

It is widely described in scientific literature that the use of sleeping pills and anti-anxiety medications is a short-term solution that can quickly lead to dependence and cause falls. After only a few weeks of use, the solution can actually become part and parcel to sleep and rest problems.

Above all, the key to success is changing your environment, habits and attitude. Satisfying, stimulating and supportive relationships are also the key to getting a better sleep and more rest.

Developing strategies

Do some form of physical activity every day (gardening, housekeeping, walking, adapted exercises or various sports) when you are feeling your best. Enjoy tea, coffee, soft drinks and chocolate during the day, as they are strong stimulants; drink fewer liquids after 7 pm to reduce the number of trips to the bathroom at night; drink alcohol in moderation, because even though it makes you sleepy, it doesn't help provide a solid sleep; indulge in a light snack before bed like cookies, crackers or fruit.

Maintain a healthy weight in order to avoid feeling fatigued throughout the day.

Take up a method of relaxation, such as meditation, visualization, reading, listening to music, massage or taking a shower or warm bath.

To facilitate sleep, keep the bedroom at a cool temperature, limit ambient noise, wear loose-fitting clothes (not too hot and not too cold), make sure your pillow and mattress are firm and comfortable, make sure your bedding is crisp and clean, use a night light and avoid reading or watching TV in bed.

Forget about the myth that says you need to get eight hours of sleep to feel refreshed. This doesn't take into account individual differences and natural aging. Sleep long enough so that you wake up feeling refreshed.

At night, go to sleep as soon as you feel tired. After waking up a few times, get up and wait 15 to 20 minutes before going back to sleep.

If you are having trouble falling back asleep, get out of bed, go into another room and do something that relaxes you and normally makes you sleepy. As soon as you feel tired again, go back to bed. If you still can't fall asleep, repeat the two previous steps. Continue following this routine until you can get back to sleep.

Don't try to make up for lost sleep the next day; wake up and fall asleep at your usual times, wait until nighttime to go back to bed, avoid taking naps during the day and especially at night in front of the TV.

Keep an up-to-date list of the medications you are taking and speak with your doctor to avoid any conflicting combinations. This could also help establish a schedule that fits your sleeping habits.

If, even after trying the methods mentioned above, serious difficulties persist, it is recommended you consult a doctor to assess the sleep problem itself, its extent, any aggravating factors, daily activities and suggested medications. An in-clinic consultation with a sleep disorder specialist may be advised. It is important to remember that simply keeping lines of communication open about this subject may prove to be an excellent source of relief.



EXERCISES

Treatment of Parkinson's disease is based on multiple factors, including integrating an exercise program into your daily life in order to retain mobility and autonomy and to prevent, delay or reduce any functional impacts of the disease. Additionally, exercising daily increases self-confidence and fosters a general sense of well-being that has a direct impact on your overall quality of life. Exercising has countless functions and benefits, namely because it helps improve various motor and non-motor symptoms. More specifically, exercise can help:

- improve muscular flexibility, range of motion, coordination, balance, gait, speech and dexterity;
- strengthen the extensor muscles, which not only help keep your back straight, but prevent you from overworking your flexor muscles;
- improve rigidity and posture problems;
- reduce fatigue;
- promote muscle relaxation and relieve cramps;
- address certain problems associated with the disease, such as stress, depression, insomnia and constipation;
- maximize the therapeutic effects of medication.

Studies also suggest that physical exercise may slow the progression of Parkinson's disease in animals. It is important to mention that exercise is a therapeutic approach that complements medication. It is not a substitute for pharmacological treatment.

Choosing an exercise program

Before starting an exercise program, it is recommended you have your condition evaluated by a healthcare professional, especially if motor fluctuations are developing and worsening. It could also help in developing a personalized program tailored to your individual needs.

It is suggested that people living with Parkinson's disease try to include aerobics, stretching, strengthening, coordination, posture, balance, fine motor, breathing, facial gymnastics and relaxation exercises into their daily routines.

The best time to exercise

Ideally, exercises should be done when medication is most effective. The morning is often the best time to do a full exercise program. However, facial gymnastics can easily be incorporated into your daily routine, especially when flossing and brushing your teeth. Short exercise sessions (5 to 10 minutes) can also be scheduled into your daily routine in order to improve mobility, fluidity of movement, relaxation and to conserve energy.

Engage in regular exercise

Consistency is the key to succeeding in an exercise program. Integrating one thirty-minute session into your everyday routine is ideal. If that's too much, exercising three times a week is an acceptable compromise. It is also important to take breaks during an exercise session so that you don't overdo it; this will help avoid fatigue, as well as any aches and pains.

Maintain an exercise routine

For those that are more disciplined and can easily stay motivated to follow an at-home exercise program, it is possible to watch exercise videos specifically designed for people living with Parkinson's disease. Listening to music can also make exercising more enjoyable. However, for some, exercising in a group seems to be the best way to stay motivated and is essential to their long-term success. Having a regular routine that is supervised by a professional is popular among people who feel supported by being around others who are going through the same issues as them. It is possible to participate in activities like this, designed specifically for people with Parkinson's disease, by contacting Parkinson Québec.

STRATEGY

To get the most out of each activity:

- 1. wear comfortable clothing;
- wear flat, closed-toe shoes and never wear slippers;
- breathe deeply while exercising;
- 4. exercise such that no pain develops.

Make the most of life by continuing to enjoy the activities you love

To make the most of life, it is very important to continue doing the activities, hobbies or sports that bring you the most joy and satisfaction. Instead of depriving yourself of these activities, find ways to modify them in order to prevent fatigue and make doing them more safe. Using a golf cart or choosing to play 9 holes instead of a full 18, will allow you to continue playing without exhausting yourself. Doing water aerobics and swimming in the shallow end of the pool are just a handful of other suggestions. Before thinking about quitting an activity, you should consider whether it is possible to modify it in order to continue doing what you love.

Activity recommendations

Stationary bicycle, treadmill

Fitness equipment must be used with caution. When using a stationary bicycle or treadmill, make sure to pay attention to the speed and pace of the machine, as well as to keeping your back straight and upright the entire time. In order to avoid any falls, you may need to have someone help you.

Tai chi

Tai chi is a great exercise for people with Parkinson's disease as it focuses on concentration, coordination and balance. Some people love this Chinese martial art for the same reason that some people hate it: for how slow each movement is performed. This activity can also been done while seated.

Yoga

Yoga is an exercise that combines breathing techniques and stretching in order to promote well-being and relaxation. People living with Parkinson's disease can benefit from this type of activity, as it can be adjusted to meet their health needs. If certain postures are too difficult, ask the instructor for modifications that suit your ability level. Don't miss out on enjoying all of the benefits!

Dancing and singing

Moving and singing to the rhythm of music is simultaneously therapeutic, creative and fun! Doing these types of activities with others who share similar experiences and who have developed



all sorts of tips and tricks for living better with Parkinson's disease creates an atmosphere of pride, support, friendship and hope.

Boxing

Fighting Parkinson's disease by boxing is a great activity that is offered in some areas of Quebec and aims to improve or preserve coordination, balance, concentration, well-being and quality of life. It involves exercises that engage all parts of the body and incorporates a long warm-up period. Boxing that has been adapted to people living with Parkinson's disease also includes breathing techniques and proprioceptive training, which intensifies body markers and promotes better body awareness.





EXERCISE PROGRAM

Flexibility exercises

It is important to have good joint and muscle flexibility in order to accomplish everyday tasks. When beginning a period of physical activity, it is best to start with movements that are not too intense, but which help combat the muscle stiffness typically experienced by people with Parkinson's disease. The following exercises are highly recommended.

Exercise 1

While sitting or standing:

- slowly tilt your head forward and backward;
- 2. tilt your head from left to right;
- 3. move your chin forward and backward;
- 4. end by bending and straightening your upper body.

Perform each movement 10 times. Increase or decrease the frequency according to your tolerance.

85

Exercise 2

While sitting or standing:

- 1. bend your arms while holding a stick;
- 2. extend your arms while holding a stick.

Perform each movement 10 times. Increase or decrease the frequency according to your tolerance.



Exercise 3

Exercise 3

While sitting:

- 1. bend and extend your knees;
- 2. point and flex your feet.

Perform each movement 10 times. Increase or decrease the frequency according to your tolerance.







Stretching exercise

During the next stage of physical activity, it is recommended to maintain a posture that stretches the muscles that will be used throughout the more intense portion of the workout. The muscular release that happens after stretching is particularly beneficial for people with Parkinson's disease. These exercises are mainly recommended for the flexor muscles of the upper body, arms and legs.

Exercise 4

While standing:

- 1. let your arms hang by your side;
- 2. join your hands together in front of your chest;
- raise your arms over your head; hold this position for 10 seconds;
- 4. separate your hands and bend your upper body from side to side while holding the same position.

Repeat the exercise 6 to 8 times. Increase or decrease the frequency according to your tolerance.

Posture exercise

People with Parkinson's disease generally have a posture where their body and head are bent forward and their knees bend, which brings their centre of gravity forward. Our centre of gravity is what enables us to maintain or change positions without worrying about falling and without using much effort. Here is an easy exercise that you can do to counteract this situation.

Exercise 5

While standing:

- press your back against a wall, moving your shoulder blades backward;
- 2. keep your head straight and chin tucked in;
- 3. hold this position for 30 seconds;
- 4. relax.

Repeat the exercise 6 to 8 times. Increase or decrease the frequency according to your tolerance.

To make the exercise easier, you can put a small foam ball behind your head, holding it in place against the wall with your head.





Coordination exercises

To counteract the slowness and bradykinesia frequently associated with Parkinson's disease, try exercises that require using the arms and legs at the same time in a series of alternating or opposing movements, gradually increasing the speed. These exercises require a great deal of concentration. It is easier to do them slowly and by following a model.

Exercise 6

While sitting:

- simultaneously lift your left arm to the side and raise your right knee;
- 2. relax;
- simultaneously lift your right arm to the side and raise your left knee;
- 4. alternate these two movements.

Repeat the exercise 10 to 12 times. Increase or decrease the frequency according to your tolerance.

Exercise 7

While sitting:

- place your hands on your thighs, with one palm facing up and one palm facing down;
- 2. alternately switch the position of your hands;
- 3. gradually increase the speed.

Repeat the exercise 10 to 12 times. Increase or decrease the frequency according to your tolerance.

Manual dexterity exercises

To maintain dexterity and grip strength, try wrist and finger movement exercises.

Exercise 8

While sitting or standing:

- touch each finger in turn to your thumb;
- 2. alternate this movement using your left and right hands or do both hands at the same time.

Perform each movement 10 times. Increase or decrease the frequency according to your tolerance.





Exercise 8







While sitting or standing:

- 1. make a tight fist;
- 2. open your hand and extend it completely;
- 3. alternate this movement using your left and right hands or do both hands at the same time.

Perform each movement 10 times. Increase or decrease the frequency according to your tolerance.

Facial gymnastics and phonation exercises

People with Parkinson's disease can benefit from doing facial exercises to improve their facial expressions and more effectively communicate with those around them. To maintain clear speech, it is a good idea to do speech therapy exercises. It is also possible to turn daily activities into opportunities for exercise: read aloud, sing in the car or in the shower or make faces in front of the mirror when flossing or brushing your teeth.

While sitting or standing, using a mirror:

- 1. make an exaggerated smile showing your teeth;
- 2. pretend to drink from a straw (breathe in);
- puff out your cheeks, simultaneously or alternately;
- 4. frown;
- 5. stretch your tongue up and down and from side to side.

Perform each exercise 10 times.





Exercise 11

While sitting or standing:

- 1. makes the sounds a, e, i, o;
- 2. make an ooh sound;
- 3. alternate between the different sounds.

Perform each exercise 10 times.

Walking exercise

Walking is an excellent form of exercise. It is always a great option. Ideally, taking a thirty minute walk every day is suggested. However, walking for shorter periods of time, according to your ability, is also recommended. Going for regular walks is better than going on the occasional long walk.

Exercise 12

While standing:

- 1. walk in place, lifting your knees as high as possible;
- swing your arms back and forth in an exaggerated manner. Keep your head straight, looking far ahead;

 try incorporating spoken commands; for example, as in a military march: say, "one, two" or "right, left" to improve your rhythm.

Do this exercise for 2 or 3 minutes—or longer—depending on your tolerance.

Exercises to improve balance

Balance is made up of many physical components: posture, muscle strength, mobility, vision, proprioception (the body's ability to perceive its own position in space) and the vestibular system, which is responsible for balance reflexes. Several of these components are affected by Parkinson's disease and decrease a person's ability to react when off balance. When doing exercises to improve balance, make sure you have a stable support nearby at all times.



Exercise 13

Exercise 13

While standing:

 with your feet slightly apart, shift your weight from one hip to the other.

Repeat the exercise 15 to 20 times. Increase or decrease the frequency according to your tolerance.





Exercise 15





Exercise 14

While standing, using a chair for support:

- 1. swing one leg back and forth;
- 2. repeat with the other leg.

Perform the exercise 10 times for each leg.

Strengthening exercises

Adding weight or resistance to increase physical strength must be done with caution. Remember that the goal is to promote greater range of movement and improve joint flexibility, as both of these tend to decrease as the disease progresses. Repeating exercises helps maintain strength. These exercises are really great for the extensor muscles of the arms and legs.

Exercise 15

While sitting, with 1 kg or 2 kg weights on the wrists:

- 1. extend then bend your right arm;
- 2. repeat the exercise with your left arm.

Perform the exercise 10 times for each arm.

Exercise 16

While sitting, with 1 kg or 2 kg weights on the ankles:

1. bend your left leg;

2. extend your left leg.

Repeat the exercise with your right leg. Perform the exercise 10 times for each leg.

Breathing exercise

Maintaining breathing capacity is vital. Learning to breathe, which means breathing in and out deeply, is important for good oxygenation of the body and to counteract increased rib cage rigidity.

1. While sitting or lying down, breathe in deeply through your nose, inflating your abdomen, then breathe out deeply through your mouth, pulling in your abdomen. Put one hand on your stomach to monitor abdominal movement.

Perform the exercise 10 times.



Aerobic exercises

It is a good idea to include activities that are more demanding on your cardiovascular system, especially in the early stages of Parkinson's disease. These counteract the effects of stress all while keeping you in good overall physical condition. Examples include: cycling, stationary bicycle, dance, various sports, swimming (with supervision in case of "freezing" of the feet or "off" time).

Relaxation exercises

These can help stimulate the release of muscle tension caused by rigidity. Several different methods are available on video; you should familiarize yourself with those that seem the easiest and best-suited to your needs. Learning how to manage stress improves your overall well-being and provides lasting benefits. While comfortably seated or lying down, close your eyes and try to relax by listening to soft music while imagining a pleasant place or moment.

STRATEGY

Conserve your energy

Parkinson's disease often causes extreme fatigue. Various factors contribute to this situation. Rigidity, slowness of movements and depression are some of the main causes. Incorporating energysaving practices into your life can help you complete all of your day-to-day activities.

Planning your day

- establish a schedule and accept that it may have to be modified depending on your energy level;
- strike a balance between working, doing hobbies and resting;
- alternate between more intense physical activities and light exercises;
- separate your to-do list into sections. For example, make a meal while sitting down and in various stages throughout the day, spread out your housework, the big "spring cleaning" and your gardening over a few days, for example, by cleaning one room or one wall at a time or by tending to your flower-beds, one by one;
- get things done when your medication is most effective and your energy level is at its highest;
- avoid pushing through "off" periods and just return to finish the task later;
- after long periods of inactivity in front of the TV or computer or after waiting in a long line at the bank or in your car, do some stretches and ease back into moving to counteract rigidity and prevent fatigue;
- establish daily priorities and determine what is essential to accomplish that day and what isn't.

Organizing your environment

 make your workspace functional and well-adjusted to your needs, for example, put the things you use most often in easy-to-reach spots;

- choose an armchair that works for you; one that is comfortable but not too soft, so that you can easily get up;
- make your surroundings safe by adding ramps, installing grab bars in the bath, using a shower chair, etc.;
- choose to complete certain tasks while seated, things like cutting and pealing vegetables, washing the dishes and folding the laundry;
- meet with an occupational therapist if necessary.

Modify certain habits

- avoid getting up and moving around unnecessarily by using a wireless phone, a cell phone or an answering machine;
- order what you can by phone using a catalogue or online by using the Internet;
- use a home delivery service to have your groceries, medications or restaurant meals delivered to you;
- choose products that make your life easier, such as readymade or frozen meals, frozen vegetables, pre-washed bagged salads, clothes that don't need to be ironed, etc.;
- use equipment that has wheels, like a shopping cart, a luggage cart, a kitchen cart or a gardening bench;
- use electric devices rather than manual ones, for example, can opener, blender, toothbrush, razor, etc.

Prevent falls

Falls are the leading cause of accidents and fatal trauma for people aged sixty-five and up. It is a well-known fact that people are more likely to get injured at home or close to home, than anywhere else. The majority of falls happen during everyday activities like getting out of bed, getting up from a chair, getting off the toilet or even when moving from one room to another.

Creating a safe environment

Lighting: install accessible light switches at the entrance of each room and put night lights in the bedroom, the hallway and the bathroom, in order to avoid creating any shadows and reflections;

Flooring: use non-slip area rugs, make sure your carpeting is securely installed, use non-slip floor wax, avoid any clutter on the floor by putting away electrical cords, clothing, shoes or anything that could be dangerous;

Stairs: ensure there is adequate lighting, install light switches at the bottom and top of the stairs, ensure that ramps are securely attached on both sides, use brightly coloured tape to mark the first and last steps, keep your stairs in good condition and make sure they are clear of any objects;

Kitchen: store food and accessories in easy-to-reach areas to avoid leaning or climbing, use a stable stepping stool, use a solid, fixed table;

Bathroom: install grab bars in the bath, the shower and near the toilets, put a rubber mat or non-skid strips in the bath and shower, use a non-slip area rug, remove any locks from your doors, in case of emergency;

There are several programs and plenty of information available on this subject at Parkinson Québec, on the health websites of the governments of Quebec and Canada, at your neighbourhood CLSC, or from a local healthcare professional (e.g. occupational therapist, physiotherapist, nurse).



WALKING AND GETTING AROUND

Walking is usually something that happens automatically, but is actually quite complex and requires good muscular strength, flexibility and mobility.

Walking sticks, canes and rollators (walker): why and how do you use them?

A walking aid, such as a walking stick, a cane or a rollator, can be used to provide extra support when a person is having trouble keeping their balance. However, it is necessary to make sure the device is being used correctly. Using a walking stick when walking outside or doing outdoor exercises helps control arm swing and increase stride length. Additionally, your steps will become more constant and consistent, and your speed, posture and stability will improve. Using a cane held by the stronger side of the body could be great for supporting the weaker side. It is not always easy, with any of these devices, to coordinate movement and keep a steady pace. Additionally, it is strongly encouraged that you see a physiotherapist so that they can evaluate your physical condition and teach you how to take your first steps with these new sidekicks. Some people only use a cane when going outside or only during certain seasons. When walking outside during the winter, it is necessary to attach an ice pick to the end of your cane.

Your cane or rollator must be adjusted to your height when you are standing straight with your arms at your sides and while wearing your shoes. The hand rests should be at wrist height.

In some cases, following the recommendation of a healthcare professional such as a physiotherapist, an occupational therapist, a neurologist or an orthopedist, the cost of a rollator can be covered by RAMQ, the public health insurance board in Quebec.

It is important to move around as safely as possible and to wear comfortable, low-heeled shoes that fit your feet and have flexible soles. Never walk in just your socks and never wear ill-fitting slippers or backless mules or sandals.

Finally, some people with Parkinson's disease experience a particular phenomenon when walking, called gait festination. It can be described as short, quick, involuntary steps forward.

Freezing phenomenon

For someone with Parkinson's disease, various actions, such as taking their first steps, walking through a doorway and using an escalator or a swinging door, can become difficult. For this reason, it is important to become familiar with different techniques that will make these types of movements a lot easier. Caretakers can also encourage the affected person to use these strategies without pressuring or forcing them:

- remind them to stay calm;
- remind them to take deep breaths;
- remind them to bring their heels all the way back before taking a full step forward;
- have them concentrate on one thing at a time, such as lifting their knees up high;
- have them practise saying, "1-2-3 go" while taking brisk steps;
- tell them to imagine that there is an obstacle in their way that they have to try to avoid;
- have them practise balancing on one side and then the other or leaning forwards and backwards;
- tap their thigh and have them concentrate on moving it forward;
- have them hum to keep rhythm.

This phenomenon may happen when the person's medication is no longer effective. Write down on a calendar the time, the length and the frequency at which you are experiencing limited movement. Write down when you took your medication and how effective it was. This information will help the doctor adjust pharmaceutical treatment, if necessary.

Move more easily from an armchair, a bed or a car

To sit down and get up from an armchair more easily, you have to first make sure that it isn't too deep, too low or too soft and that it has armrests. Good shoes will give you a solid base.

To sit down:

- turn your back to face the armchair with your feet spread apart;
- back up until your legs are touching the armchair;
- lean forward and bend your knees;
- press your hands into the armrests or into the seat;
- move your buttocks backward and gently lower yourself into the chair, while continuing to lean forward;
- sit all the way back into the armchair.

To stand up:

- press your hands into the armrests or into the seat;
- move your buttocks forward so that it is in line with the middle of the seat;
- lean back and spread your feet apart;
- lean forward;
- stand up by pressing into your hands and feet while keeping your weight forward, then straighten up;

- gently rock forwards and backwards or say aloud "1-2-3 go";
- remain upright for a few seconds before starting to move.

To get out of a bed, it is best if you are lying down on your side, near the edge of the bed. Start by pushing yourself up using your elbow, forearm or your other hand. Swing your legs out and around the outside of the bed. Sit down and complete the movement as if you were getting up from a chair. Satin sheets and clothing might help make it easier to move around the bed.

To get into a car, it is recommended to first sit down and then bring both legs inside the vehicle. To get out, swing your legs out of the car while remaining seated and then follow the same steps as though you were getting up from an armchair. Sitting on a plastic bag might make it easier to rotate your body.



DIET

Just like with regular physical exercise, a healthy, varied and balanced diet is crucial to maintaining good health and overall well-being. It is important that people with Parkinson's disease eat enough healthy and nutritious foods in order to:

- reach or maintain good nutritional status and drink enough liquids;
- maintain a healthy weight (as close to normal as possible);
- keep their energy levels up;
- maintain good muscle and bone strength;
- prevent constipation;

- improve the effectiveness of antiparkinsonian medications;
- reduce the likelihood of getting infections.

In the early stage of Parkinson's disease, studies recommend eating a significant amount of vegetables, fruits, legumes (chickpeas, beans and soy), multigrain cereals, nuts, fish and poultry, in addition to reducing consumption of saturated fats and alcohol. A "Mediterranean" diet, as well as consuming more calcium and vitamin D, is often suggested in different writings.



Over time, as the disease progresses, it is sometimes necessary to make diet adjustments in order to improve the effectiveness of medications or to reduce any side effects and to overcome possible problems, such as difficulty swallowing (see the Difficulty swallowing section). In order to create a suitable personalized diet plan—when these problems occur—do not hesitate to consult a healthcare provider (nutritionist, speech therapist or occupational therapist).

Parkinson Québec recommends that people suffering from Parkinson's disease follow the Canada Food Guide in order to enjoy a healthy and varied diet.

Common nutritional issues associated with the progression of Parkinson's disease

Weight loss

Involuntary weight loss often worsens as the disease progresses. This weight loss can be attributed to not eating enough and using 20 to 35% more energy. Therefore, it is important for the person living with Parkinson's disease to make sure that they are eating enough.

Possible causes for increased energy needs:

- muscular rigidity;
- tremor;
- involuntary movements caused by taking certain medications.

Possible causes for not eating enough:

- becoming tired when preparing a meal;
- loneliness;
- loss of appetite;
- difficulty chewing and swallowing;
- difficulty picking up the food and lifting it to the mouth;
- changes to taste and smell attributed to the disease itself.

To increase appetite

- cook ahead of time with a loved one, a friend or a neighbour and freeze portions so that they are easily available to you when you want them;
- make your food beautiful—we first eat with our eyes;
- eat with someone;
- season your dishes well with herbs, spices, sauces and such;
- eat more frequently; eat smaller meals that include healthy snacks;
- have pre-cooked dishes and other prepared foods available to you if making your meals becomes too difficult. Seek help from the CLSC, use Meals on Wheels or hire a caterer;
- ask for help when cutting your meat or buttering your bread;
- if necessary, take multivitamin and mineral supplements or enjoy a meal replacement pudding, drink or bar like Ensure[®], Carnation[®] Breakfast Essentials, Boost[®], Ressource[®] or Nubasics[®];
- reduce fatigue during mealtimes by choosing foods that are easy to chew and swallow.
Constipation

Constipation is a side effect of the disease itself but may also be caused by taking certain medications. It is recommended you incorporate a fibre supplement into your diet in order to reduce the problem.

STRATEGY

You should try to consume 30 to 35 g of fibre-rich foods every day. Foods such as:

- cereals that have more than 10 g of fibre per serving;
- wholegrain breads and other multigrain bakery products;
- fresh, dried or cooked fruits (for example, plums, prunes, kiwis and grapes);
- raw vegetables are best, but cooked vegetables will also do the trick;
- nuts and seeds, ground up if necessary, like peanuts, almonds and sunflower seeds;
- legumes like pea soup, baked beans and lentils.

And drinking plenty of liquids: a minimum of 6 to 8 cups per day in various forms such as water, juice, broth, tea and milk, just to name a few.

Food interacting with medication

Levodopa is absorbed into the intestine. It stays longer in the stomach, so breaking it down is extremely important. To improve its absorption and maximize its effectiveness, levodopa should be taken 30 to 60 minutes before a meal.

If levodopa or other medications cause nausea or dyskinesias when taken on an empty stomach, try taking them with a lowprotein food like crackers, fruit or juice. Avoid taking medication with high-protein foods such as milk, cheese, meats, poultry, fish, eggs, nuts, seeds and legumes, and try to avoid taking any medication after indulging in a large meal.

Over the past few decades, various studies have shown that it is important to consume a varied diet rich in fruits, vegetables and fibres. Results have also revealed that the protein content in your diet as well as the time when the high-protein foods are eaten can significantly reduce or slow down the absorption of levodopa, thus decreasing its therapeutic effect.

Dietary proteins can compete with medication. In other words, when someone living with Parkinson's disease eats high-protein foods, their medication may become less effective. In order for the medication to be more effective, especially during times when you want to be active, it is important to control your protein intake. In order to not compromise your nutritional status and cause deficiencies, it is necessary to make up for this decrease in high-protein foods by increasing the amount of carbohydrates, i.e. sugars, in your diet. High carbohydrate foods promote insulin secretion by diminishing certain protein constituents in the blood, therefore reducing the competition between them and levodopa.

Eating a diet low in protein and high in carbohydrates can, in some cases, increase levodopa absorption. If this diet causes an increase in side effects, levodopa doses can be reduced. This type of diet may also reduce motor fluctuations and extend levodopa effectiveness, allowing you to enjoy longer periods of increased mobility and activity.

Various modifications can be made to reduce your protein intake. **However, you should reach out to a qualified nutritionist before following this type of diet.** If not followed correctly, this type of diet may be ineffective or, worse, may cause significant nutritional deficiencies: increased risk of protein, calcium, vitamins D, B2 and iron deficiencies.

Diet with a modified intake of carbohydrates and proteins (7:1 diet)

The combination of carbohydrates (sugars) and proteins that seems to be most effective in about two-thirds of people who experience fluctuations because of taking levodopa, is commonly referred to as the 7:1 diet. Once caloric requirements are established, each meal and each snack are balanced so that the amount of carbohydrates consumed is proportionally higher than the amount of proteins, in a ratio of at least 7 grams of carbohydrates for every 1 gram of protein. This approach can reduce any negative side effects caused by medication. A ratio of 6:1 or even 5:1 may also help reduce the "end-of-dose" effect (see motor fluctuations and dyskinesias).

The 7:1 diet allows most people to maintain fairly normal eating habits as they are allowed to eat small portions of meat—or an equivalent—at each meal. Vegetarian meals that include tofu and

legumes as protein sources are preferred, because they naturally provide the perfect balance between carbohydrates and proteins.

Good sources of carbohydrates (sugars)

Breads, rice, cereals, pasta, fruit juice and fruit, white sugar, syrup, brown sugar, honey and sweet desserts like tarts, cakes, cookies, pastries, sorbets and ice cream.

Good sources of protein

Meats, poultry, fish, eggs, legumes, milk and other dairy products like cheese and yogurt.



The menu below follows this particular balance between proteins and carbohydrates.

Example of a 7:1 diet	plan
-----------------------	------

	QUANTITY	FOODS
8:00 am	1 cup (250 ml)	Cold or hot cereal
	2 tablespoons (30 ml)	Brown or white sugar or honey
	1 slice	Toast with butter and honey
	1 cup (250 ml)	Fruit juice
	1 oz (30 g)	Cheese
	or	or
	1 tablespoon (15 ml)	Peanut butter
10:30 am	1 cup (250 ml)	Milk or yogurt
	1	Fresh fruit
	1 tablespoon (15 ml)	Honey or syrup
1:00 pm	1 cup (250 ml)	Carbohydrate: potatoes, noodles, or rice
	1 or 2 slices	Bread with butter or margarine
	2 oz (60 g)	Meat, poultry, fish or 2 eggs
	1 cup (250 ml)	Raw or cooked vegetables
	1 cup (250 ml)	Fruit juice
	3 tablespoons (45 ml)	Syrup, molasses, honey or jam
	1 serving	Sweet dessert: pastry, ice cream, canned or fresh fruit
	1 cup (250 ml)	Tea or coffee with sugar
3:30 pm	1 cup (250 ml)	Milk or yogurt
	1	Fresh fruit
	1 tablespoon (15 ml)	Honey or syrup
6:00 pm	Similar to lunch	
8:30 pm	1 cup (250 ml)	Milk or yogurt
	1	Fresh fruit
	1 tablespoon (15 ml)	Honey or syrup

This diet is not recommended for those suffering from severe malnutrition, as it would be difficult to consume enough protein without having to drastically increase calorie intake. It is also not recommended for people suffering from diabetes, lung disease or hypertriglyceridemia, as well as those who are significantly overweight. The diet is even less suited to people who want to lose weight, since it is virtually impossible to maintain the recommended balance without incorporating a significant amount of overly sugary foods. For all of these reasons and as mentioned before, you should contact a qualified nutritionist before considering this type of diet.

Taking vitamin and mineral supplements

Taking supplements is not recommended for everyone and is only suitable after carefully considering the person's overall diet. If you have been prescribed a supplement, here are some details you should know.



Iron

Iron supplements run the risk of reducing the effectiveness of levodopa.

Avoid taking iron supplements and Sinemet[®] pills at the same time.

Take iron supplements at night.

Calcium and vitamin D

The risk of falls associated with balance disorders increases the likelihood of hip fractures. Additionally, people with Parkinson's disease have a lower bone density than most and are more likely to develop osteoporosis, a disease that weakens bone strength. Calcium and vitamin D play an important role in maintaining good bone health.

Consume three to four servings of dairy products per day.

If dairy products aren't an option, take a 1200–1500 mg supplement of calcium and 400–800 IU of vitamin D every day.

Antioxidants

Vitamins C and E, selenium and beta carotene are well-known antioxidants. These products, along with a handful of the others that can be found in the natural products section of the grocery store, like coenzyme Q10 and NADH, claim to be able to slow the progression of Parkinson's disease. Up until now, the results of these studies have been mixed and none have succeed in scientifically proving that these products can effectively slow the progression of the disease. However, consuming a moderate amount is still recommended as many studies have shown that these antioxidants can benefit overall health.



DRIVING A CAR

Driving a car is one of the most important things that we do on a daily basis. Driving is a complex task that requires a combination of visual, cognitive and motor skills.

When driving a car, being able to detect the presence, speed and direction of another object is crucial. You have to be aware of everything around you in order to anticipate certain situations like slowed traffic. Reacting quickly and appropriately when avoiding an unexpected obstacle is critical. The person not only has to be aware and capable of analyzing each situation, but they have to be self-critical in order to assess their own driving skills. The manoeuvres performed while driving a car require good limb coordination, as well as fast, accurate movements so that the steering wheel, pedals and turn signals can all be used safely. The clinical symptoms of Parkinson's disease may affect a person's ability to drive a car. Additionally, some medications used to treat the disease may cause drowsiness, insomnia or sleep attacks. In these cases, driving is not recommended.

Some people living with Parkinson's disease have reported feeling their foot "freeze" on the brake, when sitting at a red light or street corner, and were unable to move in order to push down on the gas pedal. The stress became worse when people behind them began honking their horns.

If you suspect any issues with driving safely, you should speak with those close to and your doctor. Visiting an occupational therapist, whether in the public health sector or private sector, that specializes in driving assessments, might help reassure you of your driving abilities. It is important to be aware of what those around you might be noticing. Feeling as though you have lost control of the situation and experiencing dyskinesias are two factors that you should consider before driving your car. Everyone with a driver's licence should take it upon themselves to regularly reevaluate their ability to drive a car.

It is sometimes necessary to find other ways to get around. Family members or friends may offer rides or help the person with Parkinson's disease get where they need to go. Depending on the area, it may be possible to use public or adapted transport or take a taxi. Some community organizations, such as Volunteer Bureaus, also offer chauffeur services to make it easier to get to and from medical appointments, for example.

Anyone who has been diagnosed with a chronic disease, such as diabetes, a heart condition or Parkinson's disease, must notify the

Société d'assurance automobile du Québec of their condition. They must do so within thirty (30) days following their diagnosis, as outlined in Article 95 of the Highway Safety Code. The driver's licence renewal form has a "Declaration of Illness or Functional Impairment" section. The form is available by calling the SAAQ Medical Services toll-free at 1-800-561-2858 or by going to a SAAQ service outlet. It is very important to note that disclosing this information does not automatically suspend your driver's licence.



MICROGRAPHIA

Micrographia is a change in handwriting that often occurs at the onset of Parkinson's disease. It is characterized by handwriting that gets progressively smaller on a single line or from one line to another. Micrographia can impact one's social and professional life when it begins to impair their written communication.

Rigidity and the slowed speed of movement impacts writing speed, letter size and readability, to varying degrees. The person's handwriting may become slightly slower or micrographic, but remain legible. However, it could also become so bad that entire sentences become illegible. Specific exercises, such as muscle relaxation, wrist and finger movement coordination and handwriting rehabilitation can help slow the progression of this phenomenon. In rehabilitation, emphasis is put on exaggerating movements and letter size. For example, drawing large "0s" or "8s" in the air. Various other techniques can be used to counteract the effects of micrographia.

Using graph or lined paper can help with alignment and make letters more uniform. In some cases, simply stopping in the middle of a sentence if the letters are becoming too small, and then continuing after a short break, can make all the difference. In other cases, when hand and finger movements become too limited, using the shoulder to help form letters could prove effective.

Using block letters may be easier if cursive writing becomes too difficult. Using crayons can help with writing fluidity. Pens that glide smoothly on paper and that are easy to hold are recommended. Using a computer or a tablet with a keyboard and a touch screen can help the affected person communicate more effectively with their loved ones and make banking transactions and payments when and where they please.

In summary, it is important to train regularly, on different surfaces and by using stimulating and varied material. And, above all, despite any changes to your writing, continuing to practise written communication with loved ones is key to staying in touch.

MANAGING MEDICATION

The importance of taking your medication on time

Even though there is no treatment that can cure Parkinson's disease, several symptoms can be reduced or controlled with the help of medications. To do so, it is crucial to follow a schedule for taking your medication at all times.

In fact, changes to a consistent schedule can have a direct impact on a person's quality of life, by preventing them from moving, getting out of bed, or walking. It can also cause serious complications such as aspiration pneumonia.

The irregular release of dopamine can also cause sleep disturbances, bowel disorders, mood swings or the inability to communicate.

Having pillboxes equipped with timers or alarms to help you take your medications on time is a great idea. You can also get a medication card from Parkinson Québec to help you keep track of all of the medication you take.

Preparing for a medical exam

Doctor's appointments are extremely important for people living with Parkinson's disease. In fact, it is these exams that lead to a diagnosis and establishing a medicinal treatment. It is also essential to prepare for each visit beforehand by writing down any questions, things you noticed following your last appointment and the effectiveness of your medications, just to name a few. This will help the doctor choose the most effective treatments and arrange the appropriate care in order to provide better symptom control. To help you better prepare yourself, use the "Preparing for your appointment" file available on the Parkinson Québec site.

After meeting with a doctor, ask yourself if they were able to answer all of your questions, if they explained why they made changes to your medications and if they really took the time to listen to you. If you feel unsatisfied in any way, you can improve the situation by taking things into your own hands. Consider speaking directly with your doctor about any doubts you have during your next appointment or, if the experience was particularly upsetting, you can always go see another doctor.

Preparing for hospitalization

The person with Parkinson's disease may be admitted to the hospital for a planned procedure, such as a one-day hospital stay or a surgery, they may need to start a new treatment or have their medication adjusted because their symptoms have become difficult to control or they may even have to be rushed to the hospital for something urgent. Upon arrival, a number of important pieces of information must be shared with the medical staff and nursing team to allow them to properly plan the person's treatment, care and discharge from the hospital. Wearing a MedicAlert bracelet or keeping a list of the following information in your wallet is advised:

PERSONAL INFORMATION

Name, address and phone number

Date of birth and Health Insurance Card number

Occupation

Languages spoken

Religion and practices you follow

Emergency contacts and their phone numbers

Known conditions

Current medications: name, dosage, frequency, how you take them

Known allergies (medications, food, chemical products, etc.)

PLANNING FOR ADMISSION AND DISCHARGE

Main issues

Onset of signs and symptoms, intensity and length

Treatments and solutions given

Main reactions and results

Support, environment and available resources

Day-to-day activities

	AUTONOMY	AND MOBILITY
--	----------	--------------

Communication and facial expression

Main signs and symptoms

Specific problems

Fine movements and coordination

Walking and moving around

Freezing, loss of balance, falls

Motor fluctuations ("on-off") and dyskinesias

Necessary equipment and assistance

Other essential information will need to be verbally conveyed to the healthcare team. This information is related to the person's health, their daily habits, as well as their priority needs.

Special care should be taken when a person with Parkinson's disease is hospitalized. It is a good idea to consult with the attending neurologist about which antiparkinsonian medications are safe to take before and after surgery.

Additionally, using narcotics or analgesics to control pain during the post-operative period should be closely monitored, as they can cause confusion and hallucinations. The general consensus is that Demerol[®] should be avoided as morphine is usually better tolerated.

If the person must absolutely abstain from taking their antiparkinsonian medications for approximately 12 hours due to surgery, it must be written down on their patient checklist so that they don't go too long without taking their medication.

After surgery, as soon as the person is able to sit upright and swallow safely, they should immediately take their levodopa (Sinemet® or Prolopa®), if applicable. This medication is extremely important because it prevents certain complications associated with immobility: blood clots, pneumonia, pressure ulcers, constipation and more. Afterwards, as soon as the person's condition improves, other antiparkinsonian medications should be taken.

If the person must undergo a major surgery, such as a thoracic, cardiac or gastric surgery, or if they remain unconscious or sedated for a prolonged period of time, a nasogastric tube should be put into place so that levodopa can be administered. This is necessary as there are no antiparkinsonian medications that can be administered by injection or suppository. It is also essential in order to prevent the complications listed in the previous paragraph.

After the procedure, when the person is once again alert, they can ask the healthcare team for permission to self-administer any of their antiparkinsonian medications. They have better control over when and how each dose needs to be taken in order to most effectively control their symptoms.

Hospital discharge should always be carefully planned to ensure a safe return home.

Several details should be clarified before the person leaves the hospital, and any measures deemed necessary should be properly coordinated. The less worry and stress that comes from leaving the hospital, the better the recovery period.

Check for:

- Specific needs in terms of diet, exercise, recovery, accommodation, special facilities or equipment, home care services, etc.;
- Medication regimen once discharged from the hospital;
- Medications that need to be taken, their dosage and why they need to be taken;
- Specific advice or recommendations to follow after being discharged;
- Follow-up provided by the healthcare team at the patient's home or in their living environment;
- Making an appointment with a doctor or other healthcare professional in advance.

Vaccines

Fall brings with it colds, flus and pneumonia. People living with Parkinson's disease should get a vaccine to help prevent any of these respiratory problems and complications.

In Quebec, flu vaccines are usually given out around the end of October right up until the end of January. Vaccines are available at CLSC centres, medical clinics and some hospitals. All you have to do is make an appointment.



MOTOR FLUCTUATIONS AND DYSKINESIAS

Motor fluctuations

At the onset of the disease, levodopa treatments are effective. The brain is able store this substance and turn it into dopamine. Unfortunately, as the disease progresses, the brain loses its ability to store dopamine or use its dopamine stores, causing motor fluctuations to appear. Essentially, it is as if the medication loses its effectiveness over time. Several hours after taking the medication, the positive effects begin to wear off and are gradually replaced by the characteristic symptoms of the disease such as slowness, loss of dexterity and stiffness, as well as difficulty moving and walking. The tremor may also return or worsen. Another phenomenon, called "freezing," makes it feel as though the affected person's feet are stuck to the ground. During these "off" times, some people may develop painful cramps (dystonia), usually in their calves and feet. This phenomenon can sometimes happen in the early hours of the morning because the brain has been deprived of medication for the entire night.

As the disease progresses, the medication gradually becomes less effective and for a shorter amount of time. It is therefore important to know and recognize these phenomena so that you can speak with a neurologist. Generally, if the prescribed doses are carefully and appropriately adjusted, this can eliminate or minimize any of these difficulties.

Dyskinesias

Dyskinesias are involuntary movements that generally affect the side of the body that has been more severely impacted by Parkinson's disease—usually the same side that first experienced symptoms. This phenomenon usually occurs after many years of taking levodopa. It is more common and appears earlier on in younger people. These involuntary movements can affect the face, tongue, respiratory muscles, torso and limbs. They are characterized by jerky, sudden contractions followed by stretches, twists and turns. People who suffer from motor fluctuations are more likely to experience this symptom. The underlying mechanisms responsible for the development of dyskinesias are still not well understood. Dyskinesias occur most often halfway through a dose and are caused by an overload of levodopa in the brain. Finally, some people may also suffer from biphasic dyskinesias; these occur at the beginning and at the end of a dose.

Strategy to counteract the limited effect of medications and dyskinesias

It is important to write down for how long you felt the effects of each pill and discuss it with your doctor on your next visit.

Taking the medication one hour before a meal can increase its effectiveness, seeing as research has shown that protein can interfere with levodopa (Sinemet[®]; Prolopa[®]) absorption.

When this happens in the early hours of the morning, it is recommended a controlled-release form of levodopa (Sinemet CR®) be taken before bed and a regular form of fast-acting levodopa (regular Sinemet[®], Prolopa[®]) be used after waking up.

If the medication is taking a long time to work, taking it when sober and with plenty of water will help increase its effectiveness.

Adding in one or several antiparkinsonian medications, such as amantadine, rasagiline (Azilect®), selegiline (Eldepryl®), a dopamine agonist (Mirapex®, Requip®, Permax®, Parlodel®) or a COMT inhibitor (Comtan®), usually helps to reduce motor fluctuations. However, levodopa doses must be adjusted accordingly.

Sometimes levodopa doses (Sinemet[®], Prolopa[®]) must be increased gradually or taken in frequent intervals and in smaller amounts to produce better results. However, sometimes levodopa doses need to be reduced in order to minimize the dyskinesias that frequently accompany motor fluctuations.

If fluctuations begin happening sporadically, it is a good idea to keep regular levodopa pills on hand so that you can take them when you need, like on a night out for example. If fluctuations begin happening more closely together and for longer periods of time, it is recommended this be discussed with a nurse and a doctor in order to consider other forms of treatment.



DIFFICULTY SPEAKING

Many people with Parkinson's disease suffer from dysarthria, a speech disorder that affects language centres in the brain. According to recent studies, at least 75% of people with Parkinson's disease will experience dysarthria—to varying degrees—as the disease progresses. The difficulties essentially stem from a limitation or a lack of coordination of the muscles involved in speech activity. To understand the extent of the phenomenon, you have to remember that speech is facilitated by breathing, which involves other factors such as voice, articulation, rhythm, intonation and speed.

Although they vary from person to person, the speech characteristics observed in people with Parkinson's disease are essentially as follows:

Voice and breathing

Voice quality changes: the voice may become hoarse, faint and sometimes tremble. Voice volume decreases, resulting in a weak, muffled voice. The breath capacity needed to speak also becomes limited and the person may feel as though they are running out of breath when speaking.

Articulation

The amplitude of articulatory movements is reduced. Articulation becomes less precise and some sounds may get lost.

Melody of speech

The speed at which a person speaks may be sped-up or slowed down. The person living with Parkinson's disease may express themselves in short bursts, and words near the end of a sentence may come tumbling out. They may also hesitate or involuntarily repeat sounds, syllables or words (disfluidity). Periods of silence may occur in the middle of a conversation. They may have trouble starting a word or sentence and their tone of voice may become monotone.

When speaking, the person may also experience other unpleasant symptoms such as a diminished or mask-like facial expression, inconsistent eye contact, a bent posture, fewer gestures, lapses in memory, difficulty expressing their ideas or an excess of saliva in the mouth.

Recent studies have shown the positive and lasting effects of using speech therapy to help treat people suffering from Parkinson's disease whose neuromuscular and cognitive abilities are good enough to keep up with an exercise program and follow specific instructions. For this reason, early intervention is key.

In order to prevent these stressful situations, the speech therapist will evaluate the overall situation of the person suffering from speech impairment and will establish certain objectives that align with their specific needs. In some cases, to help prevent or ease these symptoms, an exercise program involving the mouth and facial muscles might be prescribed. In other cases, if the voice is extremely weak, using a voice amplifier or an adapted telephone might prove to be helpful. In severe cases, usually in the more advanced stages of the disease, the speech therapist will help in a more indirect way by suggesting compensatory strategies and technical aids to help improve verbal communication. For those who need specific devices to improve their condition, it is once again up to the speech therapist to find out about any existing government programs and the possibility of receiving financial compensation to cover any costs. The speech therapist's job is to help maintain or improve the person's breathing, voice, articulation and melody of speech, in order to maintain good communication skills.

To be better understood

Environment and placement

Try to:

- reduce ambient noise (e.g. lower the volume on the TV or radio);
- have conversations in well-lit areas (e.g. avoid dark areas in restaurants);
- stand close to the person who you are speaking with (e.g. avoid speaking to each other from across the room);
- make sure you have the attention of the person with whom you are speaking and stand facing them (e.g. wait until the end of a sentence or when they have finished what they are doing before speaking with them);
- always maintain good eye contact with the person with whom you are speaking;
- make sure your face and mouth are visible (e.g. avoid putting your hands in front of your mouth or face).

Speech control

Try to:

- think about what you are going to say before speaking;
- make your face as expressive as possible, exaggerate any expressions as needed;
- take a deep breath and slowly ease into speaking;
- project your voice as far as possible;
- exaggerate the movements of your mouth;
- use short sentences;
- pause in between phrases;
- speak more slowly (speed).

Ask for feedback

To avoid any breakdowns in communication:

- ask the person you are speaking with to let you know when they don't understand something;
- always make sure the person you are speaking with has understood you.

Above all, it is important that you stand your ground, not let others speak for you and remain communicative.

STRATEGY FOR LOVED ONES AND ANYONE SPEAKING WITH SOMEONE LIVING WITH PARKINSON'S DISEASE:

focus all of your attention on the person who is speaking;

pay close attention to their mouth and face;

ask them to speak louder if their voice is too soft;

avoid interrupting them when they are organizing their thoughts, or starting or stopping a sentence;

let them know what you did or didn't understand;

ask them to repeat or, if needed, rephrase any parts that you didn't understand.

In any case, the speech therapist we be involved in order to suggest the most appropriate strategies.



SWALLOWING DISORDERS

Swallowing involves moving food and saliva from your mouth down into your stomach. Around 50% of people living with Parkinson's disease will experience varying degrees of difficulty swallowing.

The main symptoms of a swallowing disorder

Swallowing disorders can differ greatly from one to the next and with varying degrees of severity. Here are some examples:

 saliva accumulation in the mouth and drooling caused by poor lip closure and swallowing less frequently;

- taking longer than expected at mealtime because of one or more of the following reasons: difficulty moving food around the mouth, difficulty chewing. Both of these phenomena can be attributed to a decrease in the mobility of the muscles being used;
- coughing and choking because solid or liquid foods, as well as medications go down the respiratory tract instead of the digestive tract;
- experiencing a blocked feeling caused by the reduced mobility of the throat muscles;
- oral or nasal regurgitation;
- aspiration pneumonia.

STRATEGY

Accumulate saliva in the mouth and increase salivary flow

Think about swallowing more often; make a conscious effort to swallow more regularly; make it a habit to wipe your mouth more frequently.

Swallowing disorders

This type of disorder requires the intervention of a team of specialists including the following professionals: a doctor, a nutritionist, a speech therapist and an occupational therapist. Depending on the results of the evaluation, some professionals may make the following suggestions:

- facial exercises, prescribed by the speech therapist, in order to help make moving food around the mouth and chewing easier;
- changing food consistency, based on the recommendations of a nutritionist: solid foods should be softened, chopped up, eaten with a sauce or mashed; eating thickened liquids as needed; consistencies and viscosities that should be avoided;
- splitting up mealtime: having more small meals throughout the day;
- changing eating habits: taking smaller mouthfuls and sips, eating slowly, avoiding speaking when eating, choosing quiet environments;
- technical aids suggested by the occupational therapist;
- improving posture and head position during mealtime.

It is important to speak with someone as soon as any of the above mentioned symptoms appear. In addition to interfering with your diet, a swallowing disorder can also cause health problems.



URINARY AND BOWEL ELIMINATION DISORDERS

Changes that occur as a result of normal aging can affect urinary and bowel function. Other factors that can also contribute to developing an elimination disorder include Parkinson's disease and the medications used to treat it, infections, childbirth, menopause, an enlarged prostate and stress. In broader terms, not drinking or eating enough, a lack of exercise, bathrooms that are too far away or an environment that does not promote the person's elimination needs are all factors that can greatly contribute to increasing the probability of changes to urinary and bowel function.

IMPAIRED URINARY FUNCTION	IMPAIRED BOWEL FUNCTION	
 Strong need to urinate more often Urgent need to urinate Difficulty starting urine flow Only passing a small amount of urine at a time Sensation of incomplete bladder emptying Slow urine stream Urine leakage Waking up often to urinate at night 	 Infrequent and difficult passage of small hard stools Frequent loose stools Bowel leakage 	

Chart 4

Secondary signs that frequently accompany elimination disorders include: nausea, vomiting, dizziness, abdominal stiffness, a bloated feeling, abdominal or lumbar pain, a burning sensation when urinating, difficulty breathing, changes in blood pressure, fever and chills.

THERAPEUTIC APPROACHES

Speaking with a doctor to evaluate the situation and undergo physical and cognitive function exams; identifying the main causes; undergoing diagnostic tests, if necessary; addressing any factors that could be contributing to the problem, if possible (infection, dehydration, lack of exercise and more.); evaluating antiparkinsonian medications and others; speaking with a medical specialist; Drink more liquids (1 to 2 litres) and consume more dietary fibres during the day; drink fewer liquids after 7 pm or when going out; drink fewer diuretics (coffee, tea, soft drinks, alcohol and the like.);

Abdominal and pelvic muscle exercises;

Bladder training (start by emptying the bladder every hour for several days and then begin emptying it every hour and a half and finally every two hours);

Take antiparkinsonian medications and others on a regular schedule and control motor fluctuations as best as possible;

Wear appropriate and adapted clothing (baggy, with Velcro or large zippers); bring an extra set of clothes with you wherever you go; use pads or protective underwear;

Modify your environment (ensure there is good lighting, remove obstacles that interfere with walking, keep a bedpan or a urinal beside the bed, use warmer covers in the early hours of the morning, ensure that your bathroom is safe and has adapted equipment).

Urinary and bowel disorders tend to worry and frustrate many people living with Parkinson's disease. Beyond simply understanding the possible difficulties and how to address them, the key factor to success is patience. The methods suggested in the previous paragraphs are effective, however, the expected changes will appear gradually. Using a trial and error method gives you the experience you need to develop a collaborative approach that actually works. With the help of a doctor and a health team, it is possible to gradually take control of the situation and overcome any elimination disorders.

COGNITIVE IMPAIRMENT

Although Parkinson's disease mainly affects a person's mobility, the general slowdown it causes also affects cognitive functions. Memory, orientation, attention, concentration, learning ability, abstract thinking, decision-making and language may all be affected.

Even today, the cause of these cognitive disorders is not clearly defined. Some researchers speculate that they may be caused by chemical changes or problems connected to nerve impulses in the frontal area of the brain.

Cognitive impairment can occur at any time during the illness and may happen gradually or suddenly. It can vary from one individual to the next and can even fluctuate over time in the same person. It isn't always dependent on the severity or duration of the disease. Risk factors associated with the onset of cognitive disorders include old age, diagnosis after the age of 65 and people who experience the quintessential clinical symptoms of the disease such as rigidity and slowness of movements.



The changes that occur are often barely noticeable. Most people complain about cognitive disorders that mainly affect their memory. Only a small percentage of people develop more severe cognitive impairment associated with what is called dementia (see glossary). If the changes become so severe that they begin impacting the person's social and professional behaviour, or there are major changes to their personality, they should be looked into. Several healthcare professionals are trained to assess cognitive functions, including neurologists, neuropsychologists, psychiatrists, psychologists, nurses and occupational therapists. Other members of the care team (licensed practical nurses, patient attendants), family and loved ones of the person living with Parkinson's disease can also do a great deal to help by sharing their observations.

The following chart outlines the primary cognitive functions that are affected by Parkinson's disease.

MEMORY	Occasionally forgetting where familiar objects were left. Difficulty remembering certain people's names, phone or identification numbers, words or phrases, appointment dates and more. Feeling as though the answer is on the "tip of your tongue." Learning new things may also become more difficult.
ABSTRACT REASONING	Doing complex activities that require analysis, organization, planning, setting priorities and creating a plan, can prove to be quite difficult. Doing calculations and expressing ideas may take longer. Decreased spontaneity, sense of initiative and humour.
PROCESSING INFORMATION	When information comes from various sources at once, response time may be slowed. Organizing and filing new information may require a lot more effort.
VISUAL ORIENTATION	Occasional difficulty finding your way, using a map or diagram, or following assembly instruc- tions.
ATTENTION AND CONCENTRATION	More easily distracted. Difficulty concentrating on the words when reading or remembering what you just read.
Some factors may also contribute to a decrease in intellectual performance. Physical illnesses, infections, depression, stress, anxiety, wanting to do too much at once, fatigue, pain, lack of sleep, malnutrition, constipation, "off" times and side effects of some medications all play a key role.

Developing strategies

Even if there are no signs of cognitive impairment, you must still be vigilant. There is a growing understanding of how cognitive changes associated with Parkinson's disease occur and evolve, which can lead to discovering adaptive and compensatory strategies.

Many different methods can be used to help alleviate certain cognitive issues. Limiting distractions, such as the radio and TV, can minimize any sensitivities to interference. Putting aside some quiet time or finding a quiet place to work can help make it easier to accomplish tasks that require your full attention.

Other tools may also be particularly useful: checklists, all kinds of lists, bulletin board, notebook, calendar, diary, storage boxes, key hooks, computer, dictaphone, alarm for medications and the oven or even dosette packaging, just to name a few.

Grouping together information that needs to be memorized is another effective strategy. The best example is for grouping numbers together; this formula makes it easier to remember phone numbers. It is easier to memorize 328-12-67 as 7 separate numbers: 3-2-8-1-2-6-7. The same goes for remembering things on a grocery list. Using general food categories such as dairy products or grain products, makes it easier to remember items that fall under these subcategories. When thinking of the category "dairy products," it is easier to remember words like milk and butter.

Creating associations between information that needs to be memorized helps to slowly strengthen the link in the memory by creating a mental image. In real terms, it can be done by associating two concepts that have something in common. Visualizing one concept helps make it easier to remember the forgotten information. For example, to help remember the name Mrs. King, you might want to try thinking of an image of a crown. Thinking of the word "crown" might help you to remember the name "King."

It may also be useful to stimulate memory using common activities such as playing cards and board games, doing puzzles, crosswords or mystery words, reading an article or watching a movie and discussing it with a partner or friend, memorizing stories or poems, singing, making music, exercising, dancing or learning a new language.

Of course, this list doesn't include everything. All in all, you should make an effort to try out some of these methods, or better yet, invent new ones that are just as efficient and practical. Celebrating the small wins is a great way to maintain your selfesteem and help you feel as though you have more control over the situation. These strategies are designed for everyone and can help achieve positive results.



SEXUALITY

For any adult, being in relationship also means enjoying a fulfilling sex life. Being intimate is a great source of pleasure. Even if the psychological aspects of seduction remain a mysterious puzzle, attraction and desire are nothing short of physical.

Given the long list of symptoms of Parkinson's disease, the person's body goes through many changes that can also have a lasting impact on their body image. Because of this, their perception of themselves may drastically change, causing them to feel less attractive.

The person's self-esteem may also take a hit, as they may feel undesirable, among other things, from leading a less active lifestyle. Some people may also feel as though they have lost their identity after quitting their job or giving up their hobbies, as they no longer see themselves as a "real man" or a "real woman." All of these changes are likely to upset their sex life, as the perception they have of themselves and others is an extremely important factor in sexual activity. Feeling desired or desirable is vital, however, this feeling can change as a result of some of the symptoms of Parkinson's disease, such as a decrease in facial expression, changes in body odour or difficulties swallowing.

Additionally, some sexual dysfunctions may develop, such as difficulty achieving or maintaining an erection, insufficient vaginal lubrication, hypersexuality and difficulty ejaculating or reaching orgasm. In addition, the stress, depression, fatigue and lack of energy often experienced by people living with Parkinson's disease will undoubtedly affect their interest and desire in having sex. On top of all that, other factors such as taking medications, aging, menopause, andropause or co-existing health problems such as heart, stroke and endocrine diseases can also affect sexual activity.

It is also important to understand that the autonomic nervous system plays an essential role when engaging in sexual activities. For people with Parkinson's disease, the system responsible for the mechanisms associated with erection and ejaculation is often compromised. Rigidity, tremor, slowness and involuntary movements can also impact sexual expression: some positions or touches may become more difficult to do.

All of these changes can cause tension to build between a couple. There is still plenty of prejudice around sexuality. It is still difficult to speak freely about any problems or concerns, especially when they are related to the disease. This is really unfortunate as communication is still the best way to readjust to this new reality.

Other considerations should also be taken into account, such as the person's state of health and the effect of their medications. A person who feels good physically tends to feel more sexual desire, and when their medications are most effective it allows them to enjoy greater mobility. Moreover, taking turns initiating sex allows the person suffering from the disease to enjoy being touched even when they feel as though they aren't able to return the favour. It is just as important to stay positive by focusing on the gains and not the losses, otherwise, this situation will only cause anger and sadness. The complete opposite of pleasure! Sexual dysfunctions, such as insufficient vaginal lubrication, can be treated using hormonal replacement therapy. Similarly, the pharmacological market offers several options that can help treat erectile dysfunction. Various medications can be taken orally or inserted into the tip of the penis. Intrapenile injections and penile implants are also possible solutions. The choice of treatment depends on the type of difficulty being experienced, the overall health of the person requiring treatment, their personal preferences and the opinion of their doctor or the professional being consulted.

Although these sexual dysfunctions can be solved in a more technical way, it is also possible to look at the situation from a different angle, that is to say, by exploring different parts of your sexuality with your partner. If penetration is pleasurable and creates intimacy, other forms of touching, that have yet to be discovered, may also bring a certain level of sexual satisfaction, making it possible to downplay the presence of any sexual dysfunctions.

A family doctor, nurse or neurologist can refer people who need help to resource persons who can assess their situation and provide treatment. Urologists, psychologists, sexologists or gynecologists are specialists who can offer their expertise on any difficulties or sexual dysfunctions.

Finally, adapting to the changes caused by Parkinson's disease may eventually require you to modify your habits. Foreplay and touching might take up more time, night-time intimacy might have to take place in the morning, satin sheets may need to be replaced by cotton sheets, and so on. Strong communication will be required in order to create a space where respect, collaboration, kindness and love can be expressed freely and without fear of judgement.



YOUNG ADULT

Being in your twenties means being happy to be alive, falling in love and doing crazy things, it is dreaming about what you will accomplish in ten or twenty years and thinking you can change the world. Turning thirty means being on top of your game and being happily in love, it means being at an exciting time in your career, it is thinking about starting a family, it is going on travel adventures and having your whole life ahead of you. Your forties is all about professional accomplishments, enjoying activities with those you love, feeling boundless energy and the satisfaction of being where you are at. It is when you just start sinking your teeth into what life has to offer. The disease has no place in these rites of passage. Being in the prime of your life and then getting diagnosed with a degenerative disease is a curve ball that no one can every truly be ready for. Especially since Parkinson's disease mainly affects people over the age of sixty. It is estimated that 5 to 10% of people with Parkinson's disease will have already shown some symptoms of the disease by age forty. Michael J. Fox, a Canadian actor who has been working in the US for many years, has to be the most well-known young adult to suffer from Parkinson's disease. He has also been extremely vocal in finding a treatment that could slow, control or cure the disease. This visibility has made many young people more aware that the disease exists.

It is difficult to determine how the clinical signs of Parkinson's disease in people under the age of forty differ from those found in older people, as there have only been a handful of studies done on this subject. However, researchers have discovered a handful of specific distinctions associated with the early onset of the disease:

- dystonia is more common and may be the first symptom to appear;
- tremor seems to be less common;
- dyskinesias may appear earlier on and in a larger number of people;
- motor fluctuations are more common and often appear earlier on.

The disease is like an intruder. The challenge is daunting and it is difficult to head into the future with confidence. It is absolutely normal to have questions about how the disease may affect your future plans or how the diagnosis will impact your personal, physical, social and economic life. Deciding how to broach the subject with your children and their living environment, such as school and friends, will also have to be thought about.

Studying Parkinson's disease and its short- and long-term effects in people under forty years old deserves careful consideration. Hopefully reading this guide will help answer most of your questions and encourage you to stay optimistic yet realistic. Among the subjects being tackled that focus on younger people suffering from Parkinson's disease, there is one that should be given special attention: maternity.

For any other subject related to this age group, it is possible to talk with a medical team or a therapist. You can find out additional information by visiting scientific libraries. Joining support groups and finding different ways to meet your personal needs are also good steps toward becoming more well informed in order to take action.



MATERNITY

Choosing to have a child will always be a big decision and one that is made even harder if you have a degenerative disease. Ten to twenty percent of people living with Parkinson's disease will experience their first symptoms before the age of fifty, which may lead some couples to second guess their dream of having a child. It is completely normal to have some worries. The biggest concerns associated with how medications affect the fetus or the pregnancy as a whole, as the disease progresses, are usually related to the amount of energy needed to take care of the child over many years.

Most animal studies have not been able to demonstrate with any level of certainty that levodopa has a negative effect on the embryo. In laboratory experiments, the medication is always used in combination with a type of decarboxylase inhibitor (carbidopa or benserazide), agents associated with visceral or skeletal abnormalities in guinea pigs. However, in humans, none of these inhibitors seem capable of crossing the placental barrier.

In addition, dopamine agonists (bromocriptine, pergolide and lisuride) appear to be harmless to animal fetuses. Two medications give cause for concern: amantadine, under the registered trademark Symmetrel[®], and selegiline, known as Eldepryl[®]. Amantadine has been found to be teratogenic, i.e. toxic, in rats and embryos. Whereas when selegiline was used in rats, it caused biochemical imbalances in the brain, behavioural disorders and convulsions. Finally, there is no data that supports the safety of using anticholinergic medications (Kemadrin[®], Artane[®]).

Clinical trials

The results of clinical trials, that have been reported in literature, highlight the following points:

Currently, there is insufficient clinical evidence to assess the possible effects of levodopa on the fetus when the medication is used during pregnancy. However, it is recommended to hold off on introducing levodopa after the first trimester. If it is impossible to start treatment before becoming pregnant, comprehensive prenatal monitoring is required. The same goes for dopamine agonists. Antiparkinsonian medications are not recommended during pregnancy unless the expected benefits to the mother outweigh any potential risks to the fetus.

Data collected on the impact of antiparkinsonian medications on lactation showed that levodopa and dopamine agonists actually suppress lactation. Other studies revealed that some women living with Parkinson's disease experienced a deterioration in their neurological state during or after pregnancy. Is this directly linked to the disease? If it is being taken at face value, other factors could potentially be the cause. Significant metabolic changes associated with pregnancy and hormonal imbalances, particularly the postpartum estrogen drop, may contribute to changes in neurological state. This imbalance may lead to an increase in medication.

Additionally,

- pregnant women taking levodopa (Sinemet[®], Prolopa[®]) or a dopamine agonist (Mirapex[®], Requip[®], Permax[®], Parlodel[®]) can continue to do so during pregnancy, preferably after their first trimester. Comprehensive monitoring is necessary;
- taking amantadine (Symmetrel[®]) and selegiline (Eldepryl[®]) is not recommended;
- because of the effects that using antiparkinsonian medications have on lactation, it is recommended to use formula to feed the baby.

Bringing a child into the world and watching them grow up is one of life's greatest joys. However, certain circumstances, such as living with a progressive disease such as Parkinson's disease, may require further deliberation. It is normal to obsess over both the mother and father's health, as well as that of the unborn child for many years to come. Any nagging or worrying questions or concerns about a potential pregnancy or parenthood are completely legitimate for both women and men living with Parkinson's disease. By being open with their healthcare and medical teams about their desire to start a family, any concerned couples can find answers to all of their questions in order to make an informed decision around Parkinson's disease.



LIVING LIFE TO THE FULLEST WITH SOMEONE WHO HAS THE DISEASE

159

PARKINSON'S DISEASE: LEARNING HOW TO LIVE AGAIN

Being diagnosed with a chronic degenerative disease such as Parkinson's disease is just as upsetting for the person affected as it is for those around them. Living with someone suffering from this disease becomes a challenge in and of itself. You have to familiarize yourself with their disease, understand it and be ready for the unexpected. This new reality becomes a shared experience. Physical, psychological, cognitive and social changes require everyone involved to develop strong coping mechanisms. However, it is possible to mitigate the uncertainty of the future, so that life can regain its sense of meaning.

The diagnosis

Being diagnosed with Parkinson's disease is always a huge step for the person who is directly affected. But what about their loved ones, or their family and friends? At first, there might be some relief. Finally, there is answer to all of the physical and psychological symptoms that were plaguing the affected person. Then comes confusion and doubt. Is the diagnosis inaccurate? Has there been a mistake? Things would be so much easier if it weren'ttrue. But no one can escape reality. Quickly, other emotions begin to take over. Sadness and grief become overwhelming. Anger also begins to bubble up. Why him? Why her? Why us? What did they do to deserve this? Could it have been avoided? Was the disease detected early enough? Worry, fear and anxiety also become increasingly paralyzing and unsettling. Finally, you accept that the situation is permanent and begin to slowly work toward coping with the disease.

Let's talk about you

Parkinson's disease has just come crashing into your life. And even though you aren't the one with the disease, you know that your life will never be the same. With the diagnosis confirmed, you now find yourself in one of the most distressing situations of your life. It will have a significant and lasting effect on your relationship with your loved one. You are faced with a series of stressful situations and the idea of having to overcome multiple losses over several years can seem like too much.

After the diagnosis has been confirmed, you dread the next symptoms of the disease. The uncertainty of the future and feeling helpless against the disease often cause frustration, worry and a host of other emotions. It is normal to question everything: the progression of the disease, the future, any obstacles you need to overcome, the need to understand and support your loved one, accepting your own pain, how to contain your anger, the strength and resources you need in order to handle this situation, your readiness for change, when to start making changes in your life and how to rethink the future when the present is so all-consuming. These questions are valid and will become the topics of frequent discussions. Differences of opinion about what decisions to make and how to cope with critical events can lead to conflict between you, your partner, and other members of your family. You will have to reach agreements, look for ways to maintain meaningful connections and integrate these multiple changes into your life, in order to keep moving forward. This means continually making adjustments around the disease and looking for ways to make up for the losses and limits that it poses. Meeting your own needs, the needs of the affected person, as well as the demands of the situation are just some of the heavy responsibilities you will have to shoulder.

Living for today when the future is uncertain

Parkinson's disease crushes your dreams and ambitions, as well as any future retirement plans you have made together. It is often a race against the clock and involves running back and forth from your home, the hospital, the pharmacy, the office, the CLSC and community resources. You have to deal with regular doctor visits, frequent medication adjustments and physiotherapy treatments; a jam-packed schedule that doesn't leave much breathing room. Even amidst all of the daily hustle and bustle, it is normal to feel worried about yourself and your loved one.

As this disease is neurological and progressive, various clinical symptoms appear over time and deterioration settles in, but usually over the course of many years. Health problems may worsen causing the uncertainty of it all to intensify. Leaning on various support services will be required. Fears associated with physical changes can sometimes cause financial and legal worries.

Several studies have examined the difficulties experienced by the partner or spouse of a person living with Parkinson's disease. The range of issues reported by partners includes worry, tension, frustration related to communication difficulties, stress resulting from direct and daily care, role conflicts, differing expectations of on the part of both partners, economic worries, insufficient resources and, finally, the overall weight of the situation.

The idea of having to deal with all of these changes makes you fear the worst. You may feel as though you have lost everything. You are not immune to fatigue and exhaustion. Depression may also creep into your life. But there is hope.

Adapting to changes

Some partners choose to cope with Parkinson's disease by continuing to maintain their same level of activity for as long as possible. When major changes happen, they get things moving and lean on their loved ones or seek out other resources in order to get the help and support they need at home. As they go along, they develop the skills they need to recognize not only their needs but those of their partner and find ways to deal with several eventualities with the help of a CLSC health team.

Others try and fill in the gaps at all costs. They do everything themselves and rarely ask for help. If help is offered to them, they have a really hard time accepting it. They strictly stick to their schedules and don't ever let themselves slip up. Many partners reach a point where they just fall apart, are completely exhausted and crumble under all of the responsibilities they put on themselves. Stringent rules can stifle growth and become unbearable. Even though this step is hard to overcome, the temporary discomfort that it causes will allow you to bend the rules by learning how to respect each other's needs and how to openly express any pent up feelings. It is often at this point that both partners are able to reevaluate their life's purpose, their quality of life and their relationship with their loves ones. It is these things that ultimately make them truly happy. They then try and find new ways to adapt to their current situation by changing what they can control and letting go of what no longer serves them.

You may start feeling comfortable enough to make choices and important decisions. Transforming yourself is sometimes necessary in order for you to continue living a life that has been forever changed. This transitional phase is completely normal and expected under these circumstances. Life has now led you to these important questions. Rethink your values and beliefs, reevaluate relationships with those close to you and keep those that make you feel good, talk about your dreams and your worries and put your own needs first. All of these things will help you regain balance and consistency in your life, as well as control over different situations.

To help keep your strength and energy levels up, you can also give yourself more time to do everyday tasks. Establish new priories, set limits for yourself and stick to them and let others take on certain tasks; these are just some things you can do. With a little organization and willingness to be flexible, you can block out periods of activity, exercise, work and rest, in order to manage your stress levels. Writing in a diary, using a calendar, a filing system or a payment routine, keeping up-to-date medication and phone number lists, keeping your legal papers in order and maintaining a comfortable environment with adapted equipment are valuable tools that save time, conserve energy, reduce worries and avoid conflict.

As life changes, you also have to think about redefining yourself in your relationship, as an individual, a parent, a grandparent or a friend. When everyday life almost exclusively revolves around keeping the house and care organized, it can seem daunting. During difficult times, you have to remember to take care of yourself and give yourself some time to just be. Otherwise, letting the stress pile up can negatively impact your health and cause various physical and psychological problems, sometimes requiring hospitalization. If the cornerstone of your relationship as a couple were to crumble, your family would get nowhere. It is clear that the road ahead is fraught with difficulties. But if the road is winding, then that means there will also be interesting stop-offs and hidden gems along the way.

Familiarize yourself with the disease

In order to be able to overcome all of the critical moments you will inevitably have to face, you have to first understand what Parkinson's disease actually is. It is a good idea to read up on the subject, ask questions and look for answers. It is also useful to:

- recognize the clinical symptoms of Parkinson's disease in your partner;
- understand how their medication works and any possible side effects they may experience;
- recognize when they are experiencing motor and non-motor fluctuations (e.g. how it affects their mood);
- consider the psychological impacts of the disease on the person who has it, on yourself, as well as those close to you.

Frustration, misunderstandings and tension often lead to a poor understanding of the disease and the changes that come with it. Thus, the phenomenon of fluctuations related to taking medications and the progression of the disease is sometimes interpreted as a lack of will, manipulation or even a lack of initiative. A better understanding of the situation, i.e. realizing that fluctuations are a part of the disease, that they happen after taking certain treatments and that they are completely out of the control of the person affected will allow you to focus all of that anger and negative energy you originally felt toward finding a solution.

Communicate

If talking comes naturally, then understanding usually takes a lot more time to master. Good communication is not always easy to establish or maintain. In fact, it can sometimes lead to misunderstandings. Additionally, it can be more difficult to express yourself when stress, intimidation and anxiety are thrown into the mix.

You should speak openly about any topics that are bothering you or any questions that you would like to have answered with members of the care team (doctor, nurse, occupational therapist, physiotherapist, nutritionist, neurologist, psychologist, speech therapist and social worker). Sharing information is a win-win situation for everyone. Open lines of communication promote better conversations and make it easier for the affected person to get the follow-up and family support they need.

Moreover, in order to face Parkinson's disease together, it is important to remember that your feelings are just as important as those of the person suffering from Parkinson's disease. Lines of communication need to stay open in order to allow mutual expression of each other's fears, desires and needs.

Parkinson's disease should not take up every minute of every day. It is normal to spend a lot of time talking about how the disease has impacted your life and your day-to-day activities. However, you have to make sure that these subjects are not the only ones you talk about. It is best to stay in touch with all that life has to offer. It is also crucial to enjoy moments of peace and quiet, when the disease isn't taking up your every waking moment. Happiness is in the small things. It is important to stay in touch with life by talking about the rain and how good the weather is, by agonizing over just how long winter has been, by criticizing the decisions of the Prime Minister and other elected officials, by getting excited about the Golden Globe worthy performance of an actor in Spielberg's latest movie, by complaining about the price of gas, by picking out which garden seeds to use, by remembering how delicious a meal tasted on your last vacation, by laughing at yourself, by getting excited about the amazing deal you got on an outfit... and so much more!

Have a positive outlook on this new reality

The disease becomes part of your everyday life and it is obvious that various changes are slowly taking place. Sometimes things are easy and sometimes they are extremely difficult. This new reality is not always easy to deal with. Even with the best of intentions, it is easy to be too hard on yourself or on those around you. Everyone has the right to make mistakes, to get mad, to feel overwhelmed and helpless or to be impatient at times. Everyday responsibilities are complex and demanding. Don't be afraid of making mistakes and remember to apologize and forgive each other, because nobody is perfect. Standing together, as a couple or a family, will help you face any problems that are thrown at you by adapting and finding solutions.

You can try to incorporate different strategies that will help you on your journey. Focused thinking is an effective technique that will allow you to consciously ignore the negative aspects of a situation and only focus on the positive. Focusing your energy on what has been preserved, that is, residual abilities rather than lost ones, will also allow you see your reality in a more positive light. Looking on the bright side of things and bringing a little bit of lightness and optimism into your life can make a huge difference. It is important to continue seeking out the company of people and things that bring you happiness and joy, and make you feel comfortable and relaxed. The old popular proverb "it is better to laugh than to cry" is just common sense. Use humour every day to detract from and downplay any difficult situations.

Parkinson's disease can be sneaky. In the same day, a person can experience highs, making them almost forget about the disease. However, they may also experience so much difficulty in moving, talking or thinking that it is impossible for them to ignore their state of health and the feeling of being trapped inside their body may resurface.

While motor and non-motor fluctuations are the bane of many people living with Parkinson's disease, they also impact those around them. You have to take advantage of the good times. Planning daily activities around the most productive times of day requires reorganizing your schedule almost every day. In this adventure that we call life, each person must demonstrate respect, tolerance, flexibility and adaptability. For example, going over what will happen tomorrow morning, by discussing it the night before.

Taking care of yourself so that you can take care of others

In order to face the toughest situations and continue to provide the necessary care to the person affected, it is a good idea to regularly take time to relax and take care of yourself. This decision is the opposite of being selfish. It not only allows you to provide better care over a longer period of time, but helps you maintain a higher level of satisfaction. By doing so, you can help prevent various physical, mental and emotional health problems for you and your partner. The following measures may prove to be helpful:

- establish boundaries for your well-being and that of the affected person, including respecting your space, your privacy, your alone time and your differences;
- take care of your physical, emotional, cultural and other needs;
- give yourself a break: take rest, escape from reality, or go for a walk;
- appreciate the small things;
- be kind and forgive yourself;
- lean on your family as well as your personal, professional and community resources;
- be grateful for any help from those around you;
- ask for, accept and be grateful for any help and support you receive;
- give your body and soul time to relax;
- take a step back from your responsibilities and relationships with others;
- make room for listening, kindness and collaboration;
- accept your shortcomings, your limits and your hidden strengths.

Doing any one of these actions every day will help you take on your daily responsibilities, keep up your strength and vitality and allow you to thrive. They improve and enrich not only your life, but that of your partner. Taking care of yourself in order to be able to take care of someone else becomes an act of compassion, a ritual of healing.

Loving for someone while helping and caring for them

As Parkinson's disease progresses over the years, a lot of energy will be put toward providing care, comfort, safety and support to your partner. What motivations will allow you to continue taking on this role every day?

Emotional commitment is without a doubt the most significant element to consider. Willingly offering your help is the most satisfying. All actions and gestures of love, deep respect and affection will be shared, even if one person seems to be giving more than the other. On the other hand, if the commitment is artificial or emotionless, that is, if you do things because you feel you have to, it could just compound your stress and bring up a whole range of other feelings that are tinged with frustration, anger, guilt and resentment. In this context, caring for someone else and offering your support becomes very difficult.

There are no doubt other ways to feel rewarded in your caregiving role. Feeling useful, overcoming challenges, feeling as though you are the glue holding your couple and family together, being able to stick to your values, giving and taking and, finally, sharing something special are just a few examples. Some of your beliefs may also help you stand your ground as a caregiver by offering you new perspectives and innovative solutions to the challenges you face. Any tasks and challenges become easier if you truly believe that you can get through them together. The stability and strength of your family, the bond that holds together your relationship, the reminder of how you got through certain difficulties in the past and knowing that you will have the support you need and the strength to believe in your spiritual values can provide you comfort, reinvigorate you and renew your enthusiasm.

Feeling as though you have control over your life is something that should be mentioned, as it motivates you to continue loving your partner all while offering them care, help and support. This can be observed in many ways. For example, when you take a more positive approach to life and stop thinking that the person with Parkinson's disease is the "cause" of all your problems. When you are satisfied with yourself, your efforts, the good work you have done and your daily accomplishments, no matter how big or how small. When you feel capable of developing new knowledge and experimenting with new skills, that up until then, had remained unexplored. When you feel as though you have an influence on the quality of life of the affected person and on the care that they are receiving. Finally, once you know about the resources available to you, you can use them as needed.

Parkinson's disease is a complex neurological disorder that not only affects the lives of those who have it, but those around them as well. The upsets that it creates are intimately shared by the entire family. When you take the time to understand this process from your partner's point of view, you realize that there are so many obstacles that all influence one another. Living with someone who has Parkinson's disease brings up all kinds of thoughts, emotions, attitudes and behaviours. However, many partners share an understanding of life and illness, with its highs and lows, that many of us just can't grasp. It is crazy to think that most of them usually have some type of "inner spring" that allows them to find ways to bounce back with strength and energy, even when faced with adversity. This "invisible spring" seems to be able to help them cope with the unacceptable, to survive, to discover themselves and, finally, to take care of their own needs.



ABOUT PARKINSON QUÉBEC

175

PARKINSON QUÉBEC





"We aim to collectively compile more options, knowledge and references by improving our control over the quality of daily life and changing our role by becoming an active member in the fight against Parkinson's disease."

Nicole Charpentier, Executive Director

Parkinson Québec is a charitable organization, leader of the parkinsonian community, the point of reference for healthcare professionals and the provincial representative of the Regroupement des regions Parkinson Québec.

Parkinson Québec strives for excellence in research, advocacy, education and support for all people living with Parkinson's disease:

- We support the 25,000 Quebeckers suffering from Parkinson's disease and their caretakers.
- We contribute to biomedical research aimed at uncovering the causes and finding treatments for Parkinson's disease through the Quebec Research Fund on Parkinson's (QRFP).
- We encourage everyone to find the freedom to move by promoting educational services and programs that are consistent, effective and supported by reliable sources and follow best practices in Quebec.
- We represent the Parkinson's community in order to defend their rights and interests with decision-making bodies.
- We raise public awareness about Parkinson's disease.

Throughout Quebec

Parkinson Québec oversees various regional offices and works collaboratively with Parkinson Québec member organizations. Support services are offered throughout the province. Visit the www.parkinsonquebec.ca website or call 1 800 720-1307 to find out which organization serves your area.

Resources

Parkinson Québec has developed numerous information tools to empower and inform people living with Parkinson's disease, as well as those close to them, healthcare professionals and the general public.

Informative documents

A wide variety of flyers, brochures and videos created to meet your needs, are available at the Parkinson Québec office. Several documents can be consulted in the Parkinson Québec office or borrowed on a short-term rental. Others can be purchased locally or ordered by phone by calling 1-800-720-1307. Most are also available online.

Information and Referral Line

The Information and Referral Line is a toll-free, bilingual phone service. Specialized resources can help to answer any of your questions and refer you to the appropriate services. Our toll-free line is open from Monday to Friday, 8:30 am to 4:30 pm, by calling 1-800-720-1307.

Training Workshops and Seminars

Parkinson Québec offers training workshops and seminars that cover all kinds of topics related to Parkinson's disease. They are offered upon the organization's request. Training instructors and lecturers can travel to workplaces or support groups. Some training workshops are certified by the SOFEDUQ. Seminars may also be in webinar format or held as a conference.

The "Marcher sous la pluie" program is offered through a series of DVD-lectures on topics related to Parkinson's disease. You can order them directly from Parkinson Québec or watch them on our YouTube channel by going to the www.parkinsonquebec.ca website. Parkinson Québec offers the "Mieux Vivre avec le Parkinson" program, which is aimed at speakers, community leaders and healthcare professionals who want to develop their knowledge of Parkinson's disease. It equally provides them with simplified, up-to-date information, as well as well-known and accepted guidelines on Parkinson's disease. Any organizations that want to receive training can find out more information from Parkinson Québec.

Website

The Parkinson Québec website provides up-to-date, reliable information on Parkinson's disease that is accessible to everyone. You can find the latest news in research, the most up-todate information on Parkinson's disease, the activity calendar that is organized by Parkinson Québec and its members all across Quebec, and much so more! www.parkinsonquebec.ca.

Info Centre Parkinson

The Info Centre Parkinson is a virtual information centre that meets the information needs of people with Parkinson's disease, caregivers and healthcare professionals: links, videos, articles, health bulletins and more. There are tons of reliable and up-todate resources available on all aspects of the disease. Check them out at www.parkinsonquebec.ca.

Support and Exercise Groups

Various groups exist thanks to regional offices and Parkinson Québec member organizations. They are there to help those suffering from Parkinson's disease, as well as their caretakers.

GLOSSARY

Acetylcholine: chemical substance in the brain that can provoke tremor.

Adjuvant: treatment that helps to enhance or boost initial treatment.

Agonist: medication that mimics the action of another substance.

Akinisea: total or partial loss of movement.

Anticholinergics: medication that blocks acetylcholine from binding to its receptors on certain nerve cells.

Antioxidant: agent that prevents toxic products from forming in the brain.

Aphasia: language disorder that affects the production or comprehension of speech.

Bradykinesia: slowing of movements.

Cogwheeling: tremor in a limb when the doctor rotates it.

Cortex: outer layer of the brain.

Dementia: progressive decline in cognitive functions.

Dopamine: chemical messenger of the brain that controls fluid and coordinated movements, as well as cognitive functions.

Dysarthria: speech disorder caused by a neurological disorder.

Dyskinesia: involuntary and uncontrollable movements that occur with longterm levodopa use. These movements can be jerky or may look like a swaying dance. They differ from rhythmic tremor associated with Parkinson's disease.

Dysphagia: difficulty swallowing.

Dystonia: abnormal muscular posture in the hand, foot or other part of the body. Can be painful.

Edema: swelling.

Enzyme: substance that speeds up a chemical reaction—without being a reactant.

Festination: short, quick steps.

Freezing: feeling as though the feet are glued to the ground.

Hypersexuality: sexual dysfunction seen in people who use certain antiparkinsonian medications. It is characterized as unusual and excessive sexual behaviours, frequent sexual comments and a strong interest in sexual activity.

Hypokinesia: decreased bodily movements.

Idiopathic: of unknown cause.

Leucotome: device used to resection certain parts of the brain during surgery.

Levodopa: precursor to dopamine. Used to treat Parkinson's disease by offsetting the lack of dopamine.

Micrographia: smaller writing.

Molecular formulation: type of molecules that make up a pharmaceutical product.
Monotherapy: the use of a single medication to treat a particular disorder or disease.

Neuron: nerve cell.

Neuroprotector: prevents or slows neuronal death by providing protection.

Neurotransmitter: chemical substance in the brain responsible for communication.

On-offphenomenon: sudden loss of levodopa effectiveness after working for a period of time. Phenomenon can be cyclical.

Pallidotomy: surgical removal of a part of the pallidus.

Pallidus: area of the brain.

Parkinsonism: set of characteristic symptoms of Parkinson's disease; tremor, stiffness, slowness, balance disorders. Various other diseases and medications can cause these types of symptoms.

Placebo: inactive substance that replaces a medication.

Preclinical: before diagnosis.

Proprioception: sense of selfmovement and body position.

Rigidity: increased muscular tone that causes resistance to passive limb movement.

Striatum: area of the brain that controls movement.

Substantia nigra (black substance): small area of the brain that produces

dopamine. This area of the brain loses nerve cells in Parkinson's disease.

Subthalamic nuclei: structures in the brain that are targeted during surgeries to treat Parkinson's disease.

Symptom: a phenomenon that is experienced by an individual affected by the disease.

Teratogenic: what causes birth defects.

Thalamotomy: surgical removal of a part of the thalamus.

Thalamus: area of the deep brain that is targeted during surgeries to treat Parkinson's disease.

Vestibular system: a system located within the inner ear that is responsible for controlling reflexes and coordinating balance.

INDEX

A

abstract reasoning 144 abstract thinking 142 acetylcholine 27 activity 33, 57, 66, 68, 69, 70, 74, 76, 80, 81, 84, 86, 90, 96, 97, 99, 144, 146, 147, 163, 168, 179 acupuncture 47 adapted transport 117 aerobics 78, 80, 96 akinesia 20, 24 alarm 121, 145 alcohol 73, 75, 106, 141 alpha-synuclein 51, 52, 53, 56 alternative approaches 47 amantadine 27, 32, 33, 56, 129, 155, 156 analgesic 124 anger 160, 161, 165, 170 anomaly 16, 155 anticholinergic medication 27, 32, 33, 36, 155 antioxidants 115 antiparkinsonian medications 35, 36, 39, 73, 106, 125, 129, 140, 155, 156 anxiety 36, 58, 69, 70, 74, 145, 160 apoptosis 52, 53 appetite 34, 108 armchair 24, 98, 103

articulation 131, 133 Azilect[®] 31, 129

B

balance 21, 23, 24, 25, 29, 44, 78, 93, 100, 115, 124 bathroom 75, 99, 141 bed 75, 99, 103, 104, 121 benserazide 28, 155 body image 70 bowel function 140 Boxing 82 bradykinesia 20, 21, 24, 29, 33, 40, 66, 88 brain surgeries 39 breathing 73, 79, 81, 95, 102, 131, 133 bromocriptine 29, 155 burning 22, 140

С

calcium 106, 111, 115 cane 100, 101 car 37, 70, 103, 104, 116 carbidopa 28, 32, 38, 43, 154 cause of the disease 17, 50 chewing 108, 137 choosing a treatment 23, 33, 149 chronic 117, 160 class of medication 29, 30 cognitive impairment 25, 142, 143, 145 communication 44, 59, 90, 119, 124, 133, 134, 148, 150, 166 complications 30, 35, 40, 41, 50, 55, 56, 121, 125, 126 COMT inhibitors 31 concentration 18, 66, 81, 88, 142, 144 confusion 26, 35, 36, 124, 160 constipation 22, 34, 35, 36, 66, 78, 105, 109, 125, 145 coordination 78, 81, 88, 116, 119, 124, 131 corticobasal degeneration 25 cycling 81, 96 cycling 81

D

decision making 142 delirium 36 dementia 143 Demerol 124 depression 23, 40, 51, 58, 65, 66, 67, 78, 145, 148, 162 depression scale 67 dexterity 21, 22, 78, 89, 127 diagnosis 16, 18, 19, 21, 25, 26, 29, 40, 50, 53, 66, 67, 117, 121, 142, 160 diet 59, 105, 107, 109, 111, 114, 126, 138, 139, 156 dizziness 22, 34, 36, 38, 140 domperidone 38 dopamine 16, 27, 28, 30, 31, 32, 36, 37, 44, 51, 53, 55, 73, 121, 127 dopamine agonist 27, 29, 30, 34, 35, 55, 129, 155, 156 dopamine receptors 27, 29, 56 driving a car 116, 117 Duodopa 39, 42, 44, 55 dyskinesias 18, 30, 32, 36, 39, 41, 42, 55, 56, 110, 111, 117, 124, 127, 129, 152 dystonia 18, 40, 73, 128, 152

E

Eldepryl* 129, 155, 156 end of dose deterioration 55 energy 47, 68, 69, 79, 96, 97, 105, 107, 148, 164, 170 entacapone 27, 31, 36, 55 environment 17, 58, 74, 97, 99, 123, 133, 138, 139, 141 essential tremor 24 exam 18, 19, 21, 25, 140 exercises 74, 77, 78, 79, 80, 84, 96, 100, 119, 126, 132, 138, 139, 141, 146, 164, 179

F

fall 21, 25, 74, 81, 98, 99, 115, 124 fatigue 22, 23, 34, 66, 73, 75, 79, 80, 97, 108, 145, 148, 162 festination 101 flexibility 78, 84, 94, 100, 164, 168 flu 126 free radicals 52, 53 freezing 96, 102, 124, 128, 137 functional abilities 57

G

genes 17, 52, 54 genetics 17, 51, 56 glutamate 52, 53, 56

Η

hallucinations 30, 34, 36, 40, 44, 73, 124 hobbies 69, 80, 147 hospitalization 122, 124, 164 hypotension 22, 34, 38, 44

I

identity 70, 147 injection 125, 149 insomnia 36, 66, 72, 78, 117 iron 114 isolation 65, 71

Κ

kitchen 70, 98, 99, 108

L

language 131, 142 learning 58, 142, 160, 164 levodopa 18, 26, 27, 28, 30, 31, 33, 35, 36, 38, 39, 43, 50, 55, 56, 110, 111, 114, 125, 127, 128, 129, 154, 155, 156 Lewy bodies 25, 51, 56 lighting 99, 141 liquid 75, 105, 109, 137, 138, 140, 141

Μ

massage 47, 75 maternity 153 meal 97, 98, 107, 108, 110, 111, 129, 137, 138 memory 18, 36, 40, 58, 68, 132, 142, 144, 146 micrographia 22, 119 minerals 108, 114 Mirapex 29, 35, 37, 129, 156 mitochondria 52 mobility 21, 57, 66, 69, 77, 79, 93, 100, 104, 111, 124, 137, 149 morphine 124 Motilium 38 motivation 67, 170 motor fluctuations 18, 30, 31, 41, 42, 44, 78, 111, 124, 127,

128, 129, 141, 152, 165, 168 moving around 54, 103, 124 multisystemic atrophy 25 multivitamins 108

Ν

narcotics 124 nausea 26, 28, 30, 34, 36, 38, 44, 110, 140 Neupro 29, 35, 55 neuroprotection 53 neuroprotector 30, 31 neuropsychology 58 neurorestoration 53 neurotransmitter 16, 27 nursing 59 nutrition 44, 59, 105 nutritionist 107, 111, 113, 137, 166

0

occupational therapist 58, 98, 99, 101, 107, 117, 137, 138, 143, 166 olivopontocerebellar atrophy 25 on-off 55

P

pallidotomy 39, 41, 42 paralysis 25, 73 parkinsonian syndromes 25, 26 Parkinson's plus 25 Parlodel 29, 35, 129, 156 pergolide 155 Permax 129, 156 phonation 90 physiotherapy 44, 57, 162 planning 58, 97, 123, 144 pneumonia 23, 121, 125, 137 pramipexole 29 pregnancy 154, 155, 156 progression 21, 22, 24, 26, 30, 31, 32, 33, 40, 42, 50, 53, 56, 107, 131, 154, 165, 170 Prolopa 28, 34, 125, 129, 156 protein 51, 52, 110, 111, 112, 129

R

range of motion 78 regimen 59, 74, 107, 110, 113, 126, 162 relaxation 69, 73, 75, 78, 79, 81, 96 Requip 29, 35, 37, 129, 156 rest 25, 72, 74, 79, 97, 164 restlessness 22 retirement 162 rigidity 20, 21, 25, 29, 33, 39, 44, 58, 78, 95, 97, 107, 119, 140, 142, 148 rollator 100, 101

S

saliva 20, 132, 136, 137 schedule 76, 97, 121, 141, 163, 168 selegiline 27, 30, 31, 36, 53, 55, 129, 155, 156 self-esteem 70, 146, 147 sexuality 35, 147, 148, 149 Shy-Drager syndrome 25 Side effects of medications 34 Sinemet 28, 34, 38, 114, 125, 129, 156 singing 81, 90, 146 sleep 22, 34, 37, 53, 66, 69, 72, 74, 75, 117, 121, 145 Sleep apnea 73 sleep attacks 117 sleeping pills 74 smell 22, 53, 108 snack 75, 108, 111 speech therapy 44, 132 sports 74, 80, 96 stairs 99 Stalevo 32 stimulation 36, 40, 41, 42, 56 strengthening 78, 94 stress 65, 69, 74, 78, 96, 117, 125, 132, 139, 145, 162, 164, 166 stretching 78, 81, 86, 97, 128 striatonigral degeneration 25 substantia nigra 16, 51 subthalamic nucleus 40 surgery 23, 39, 122 swallow 108, 125, 136, 137 swallowing 20, 107, 136, 137, 148 sweating 22 Symmetrel 32, 155, 156 symptoms 16, 22, 25, 27, 33, 44, 51, 66, 77, 121, 122, 123, 147, 152

Т

tai chi 69, 81 Tasmar 31 taste 53, 108 technical aids 133, 138 test 18, 19, 50, 53, 67, 140 thalamotomy 39, 41, 42 tolcapone 27, 31, 36 toxicity 31, 53 transdermal patch 55 transplants 54 treadmill 81 treatment 15, 18, 23, 27, 33, 77, 123 tremor 18, 19, 20, 21, 22, 24, 25, 29, 32, 33, 36, 39, 40, 41, 42, 53, 107, 128, 148, 152

U

urinary function 140 urinate 36, 140

V

vaccine 53, 126 visual orientation 144 vitamins 106, 108, 111, 114, 115 voice and breathing 131 vomiting 28, 34, 140

W

walker 100 walking 21, 22, 24, 42, 44, 74, 78, 92, 100, 101, 121, 124, 128, 141 walking aid 100 weight 66, 75, 105, 107 weight loss 107 well-being 47, 58, 77, 81, 82, 96, 169 writing 22, 42, 119, 120

Y

yoga 81 yogurt 112 young 17, 18, 31, 54, 128, 152

PHOTO CREDITS

Every effort has been made to trace rights holders and obtain their permission for the use of any illustrated material. The publisher apologizes for any errors or omissions in the credit list and would be grateful for any corrections that should be included in any future reprints or editions of this book.

Shutterstock | STLLFX 2, 8, 15, 16, 28, 41, 49, 51, 52, 60, 65, 66, 74, 79, 102, 107, 118, 121, 123, 129, 133, 138, 141, 144, 149, 153, 156, 161, 162, 177; iStockphoto | Christopher Futcher 4; AdobeStock | didesign 7; Alexandre Claude 10, 11; Shutterstock | Alexander Raths 12; Shutterstock | SpeedKingz 14; Shutterstock | Zerbor 29; Alain Dionne 41; Shutterstock | Monkey Business 47; AdobeStock | JPC-PROD 48; iStockphoto | nicolas 50; Dreamstime | Newphotoservice 52; Shutterstock | Jacob Lund 60; AdobeStock | Photographee. eu 61a; iStockphoto | Steve Debenport 61b; Photoclub | MMonticello 61c; Francesca Cicchetti 61d; Photoclub | Jenifoto-Fotolia 63; Shutterstock | Diego Cervo 64; Cloé Jourdain 66; AdobeStock | JPC-PROD 74; iStockphoto | Kupicoo 79; AdobeStock | highwaystarz 84; AdobeStock | dglimages 85; Cloé Jourdain 86-97; AdobeStock | WavebreadmediaMicro 102; AdobeStock | ExQuisine 107; Shutterstock | gpointstudio 108; Photoclub | monticello 114; AdobeStock | Sea Wave 116; AdobeStock | Studio grand ouest 118; AdobeStock | michaeljung 132; AdobeStock | WayebreakMedraMicro 121; AdobeStock | Hunor Kristo 138; AdobeStock | goodluz 141; AdobeStock | Iily 144; AdobeStock | Daisy Daisy 149; AdobeStock | jminternet.co.uk 153; AdobeStock | Coy St. Clair 156; AdobeStock | Tyler Olson 160; Alexandre Claude 176.