

Diagnosis and useful information

There will be questions about Parkinson disease that you may be concerned about after the announcement of the diagnosis. In the following information, you will find, in a general way, answers related to the questions that you are likely to ask yourself.

1- Who is affected by this diagnosis?

Parkinson's mainly occurs in people over the age of 60. Men are more affected than women, in a ratio of 3 men to 2 women. About 25 000 people live with this disease in Quebec.

This illness also affects other family members or those around the person living with Parkinson's. It is estimated that for one person with the disease, nearly three people around them are involved.

2- What are the causes?

Parkinson's disease is caused by a slow and gradual loss of cells called neurons, located at the base of the brain. It is mainly the neurons of the substantia nigra producing dopamine that are affected. Over time, symptoms become visible at the motor level such as slowness, stiffness in movement, tremor, but rarely all three at the beginning. There are also less visible non-motor symptoms that may be present, for example, fatigue, sleep disturbances, difficulty concentrating and organizing one's thoughts. This can also contribute to anxiety and depression.

The exact cause of the disease is not known, but research points to predisposing factors such as genetics and environmental factors. Parkinson's is not a hereditary disease in itself, but a certain favorable family background can contribute to it. Research results show that toxic substances, among others, certain pesticides, herbicides and heavy

metals aggravate the loss of dopaminergic neurons. A combination of these two factors (genetics and environmental) is probable in this illness, which also evolves with ageing.

3- Are there any treatments?

The treatment of Parkinson's mainly involves taking drugs that compensate for the decrease in dopamine in the brain, and also monitoring the control of motor and non-motor symptoms.

At each stage of the disease, it is important to reduce motor difficulties by prolonging the effectiveness of the medication as much as possible. Combined with a well-balanced diet and daily physical activity, the goal is to delay the transition to the next stage of the disease.

We are not talking about a cure but about an alleviation and better control of the symptoms of Parkinson's in order to preserve your quality of life and to continue doing the activities that are important to you.

4- How does this disease develop?

Parkinson's is a chronic illness, but not fatal disease. Its development generally takes place over several years and varies from one individual to another depending on the characteristics of each person and the other health problems present. The person living with Parkinson's must be vigilant with regard to the already existing symptoms, at the motor and non-motor level, such as the loss of smell, writing disorder, and fatigue as well as with the appearance of new symptoms.

There are certain phases that are common to all persons, including the adaptation phase following the announcement of the diagnosis, which is a phase of equilibrium where the symptoms are relatively well controlled and, a phase of symptom's fluctuations.

5- Is there anything we can do to improve our quality of life?

According to clinical and research knowledge, four elements are essential to consider, including taking medication on a regular schedule, a balanced diet, daily exercise and socialization. These elements aim to improve symptom's control, comfort and quality of life for people living with Parkinson's.

In addition, certain strategies tailored to your current situation, to you and your partner or relative, could improve your well-being, make the diagnosis more “digestible” and also help you use your own tools to bounce back better.

6- To find out additional information:

Parkinson Québec website provides accurate, evidence-based and regularly updated **information** concerning the disease, in particular about the period following the announcement of the diagnosis. You can access to this information on the section Parkinson's disease > Newly Diagnosed, or by clicking on the following link:

<https://parkinsonquebec.ca/en/living-with-parkinsons/newly-diagnosed/>

An **Information and support line** is also available at 1-800-720-1307 or by email at info@parkinsonquebec.ca.

Furthermore, various free of charge services are offered by the organization. You will find them on the website <https://parkinsonquebec.ca/en/> at tab «**Services offered**».

They offer, among other things, training programs and the opportunity to participate in support and exercise groups. Furthermore, you can access to the EMPATIC program. This program contains three online interventions: [TAVIE™ in motion](#), [Expert' advice](#) and [Inspiring testimonials](#).

Also, Parkinson Québec offers a free reference guide «**The infoParkinson Guide: Everyday life with Parkinson's disease**». This guide developed by specialists, attempts to answer various questions asked by people living with Parkinson's. It also invites you to use various strategies to cope with the illness on a daily basis. This guide can be downloaded from the Parkinson Québec website, at the «Parkinson's disease» section or by clicking on the following link:

<https://parkinsonquebec.ca/en/services/guide-info-parkinson/>

Finally, on the **Parkinson's Canada** web site, on the «Resources» section, you can access the Canadian edition of the «[Every victory counts](#)» manual and worksheets or click at the following links:

<https://www.parkinson.ca/resources/every-victory-counts-canadian-edition/>

<https://www.parkinson.ca/wp-content/uploads/EVC-Canada-worksheets-2022-05-20.pdf>

To answer further questions, we add the following references:

Marie, L. (2020). The complete guide for people with Parkinson's disease and their loved Ones. West Lafayette: Purdue University Press.

Marie, L. (2020). Everything you need to know about caregiving for Parkinson's Disease. West Lafayette: Purdue University Press.

Hague, Tim (2018). Perseverance: the seven skills you need to Survive, thrive and accomplish more than you ever imagined. Toronto: Viking Canada, 2018, 272 p.