



## CAREGIVERS

It takes time to adjust to Parkinson's disease in the family. Just like other serious chronic conditions, no one is ever ready for a diagnosis such as Parkinson's disease. If you are caring for a loved one with Parkinson's, coping with this new role can be quite challenging.

The purpose of this pamphlet is to provide a brief overview of various ways in which the caregiver and the person living with Parkinson's disease can adapt to this new situation (or to the progression the disease) in ways that are healthy for both of you. As a family member or friend of the person with Parkinson's, it is natural to wonder what they require, how to be supportive and respond to their needs.

The progression of Parkinson's disease is different for each person. Since there is no way to know for sure what will happen in the future, this makes the situation even more uncertain and also makes the challenges facing the caregiver a little bigger. In order to develop the necessary skills and better understanding of how you and the family members may cope with day-to-day situations, learn about Parkinson's disease: symptoms, medication and progression.

*Learning about community resources in addition to who you can rely on for support is also essential to coping with your new role.*



# P A R K Ì N S O N QUÉBEC

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To find the appropriate resources,  
visit the Info Centre Parkinson at

**parkinsonquebec.ca**

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## CAREGIVER: SEVERAL LEVELS OF INVOLVEMENT

“Caregiving” describes the relationship between the person living with Parkinson’s disease and the person who helps and supports. The act of caregiving creates an intimate, two-way relationship between caregiver and the person needing care. You are partners in caring for each other.

For some people, this relationship shifts as Parkinson’s disease progresses. In later stages of the disease, the emotional ties may remain but the physical amount of caring is no longer reciprocal. This transition is very gradual and can be more difficult due to the loss of autonomy of the person living with Parkinson’s disease. It can be difficult to know how much help should be given and when it should be given.

**Open communication, compassion and understanding from both the caregiver and the person living with Parkinson’s disease can make this transition smoother.**

The person living with Parkinson’s disease is responsible for asking for help when help is needed.

Caring in a family where Parkinson’s disease is present poses challenges but it will also allow new learning opportunities on providing care. Learning is necessary, as is seeing the positive side of these difficult situations.

## REMINDER

Parkinson’s disease is a long-distance run, not a sprint. In order to care for a person with Parkinson’s disease, you must also take care of yourself!



## FITTING YOURSELF TO YOUR NEW ROLE

Do not let your status of caregiver define you! This new role is only one part of who you are as a complete person.

**Here are a few thoughts to consider as you learn to live as a Parkinson’s disease caregiver:**

People with Parkinson’s disease should continue to do as much for themselves and live as independently as possible, with some support from you. Your role needs to be discussed and agreed upon in advance and on a continuing basis.

Be aware that symptoms can vary widely throughout the day. The amount and type of care can also vary because of these fluctuations.

Accept that although there is as yet no cure, appropriate management of Parkinson’s disease symptoms can offer a full and productive life.

Accept that there are moments in time when you may feel discouraged.

Recognize when feeling discouraged begins to look like depression, in both you and the person living with Parkinson’s disease. Do not wait: seek help as soon as possible.

Adjust your favourite activities or find new ones you can enjoy together to remain close.

Realize that your emotional reactions to a complex situation are natural.

Compromise, encouragement and strength are needed from all family members to maintain a good quality of life.

Ask for help from your healthcare team, family, friends, and from Parkinson Québec.

## SELF-CARE

*“If you don’t take care of yourself, you won’t be able to care for someone else.”*

This advice is never more important than when dealing with a progressive illness. If you are not used to making time for yourself, now is the time to start. Even 10 minutes a day of reading in a quiet corner can make a difference.

**Take care of every aspect of your life:**

**Physical:** Eat well-balanced meals, do exercise you enjoy, and get a good night’s rest.

**Mental and emotional:** Maintain a hobby, treat yourself once a week, and acknowledge your feelings.

**Social:** Find at least someone you trust you can talk to on a weekly basis.

**Spiritual:** Set aside time each day to find peace within yourself in ways that suit you (meditation, yoga, reading).

Nurturing yourself can become a habit if you let it! Acknowledge the importance of your well-being each day.