

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

**The purpose of this help sheet is to provide a brief overview of various ways in which the care-partner and the person with Parkinson disease can adapt to the new situation (or to the progression the disease) in ways that are healthy for both of you. As a family member or friend of a person with Parkinson's, it is natural to wonder what is needed and how to be supportive and respond to that need.**

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 the challenge facing the care-partner. 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.*

### **CARE-PARTNER: SEVERAL LEVELS OF INVOLVEMENT**

“Care-partner” describes the relationship between the person with Parkinson's disease and the person who helps. At early stages of Parkinson's disease, the care-partner is part of an established, reciprocal caring relationship. 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 links 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 fluctuation in the abilities of the person 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 care-partner and the person with Parkinson's disease can make this transition easier.***

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

Caring in a family with Parkinson's disease will present challenges but it will also present new opportunities in learning more on how to provide cares. 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 look after yourself!

## FITTING YOURSELF TO YOUR NEW ROLE

Do not let yourself become by your status of caregiver! Some people let words like Parkinson's disease or caregiver become labels that take over their identity. 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 care-partner:**

- People with Parkinson's disease should continue to do as much for themselves and live as independently as possible, with some support from you. What role this will take needs to be discussed and agreed upon 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 with Parkinson's disease. Seek help as soon as possible.
- Adjust 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.”*

How often have we heard this advice and how often have we ignored it? 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.

### Now is the time to consider some of the following:

- **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 as messages to yourself.
- **Social:** Find at least one friend 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.

