

Caring in a Family with Parkinson's

It takes time to adjust to Parkinson's disease (PD) in the family. Like other serious chronic conditions, PD is an unwelcome guest that is here to stay. If you are caring for a person with PD, coping with this new role can be a challenging.

The purpose of this help sheet is to provide a brief overview of ways in which anyone in a caring role can adapt to the new situation (or to the progression of PD) in ways that are healthy for both of you. As a family member or friend of a person with PD it is natural to wonder what is needed and how to be supportive and respond to that need.

The progression of PD is different for each person and this can add to the ambiguity of the situation and the challenge of dealing with it because there is no way to know for sure what will happen in the future. Learning about the symptoms of PD, medications and general disease progression is one of the best ways to develop skills and understanding to help you and your family members cope with day-to-day situations that may arise. 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 and Caregiver

Initially the term care-partner is appropriate for describing the relationship between the spouse, adult child or friend who helps the person with PD. Care partnering is part of an established, reciprocal caring relationship. You are partners in caring for each other.

For some people this relationship shifts as PD progresses. In later stages of PD the emotions of caring for each other may remain but the physical amount of caring is no longer reciprocal. The spouse, adult child or friend of the person with PD is now a caregiver. This transition is very gradual and can be more difficult due to the fluctuation in the abilities of the person with PD. 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 carepartner/caregiver and the person with PD can make this transition easier. The person with PD is responsible for asking for help when help is needed. Caring in a family with PD will present challenges but it will also present new opportunities and learning opportunities, many with very positive outcomes.

Fitting Yourself to New Roles

Some people let words like PD 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 PD caregiver/care partner:

- People with PD 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 PD symptoms can lead to 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 PD, and 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 health care team, family, friends, and from Parkinson Canada.

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 wellbeing each day.

Remember PD is a long distance run, not a sprint.
Caring for a person with PD really does mean caring for yourself.