

CAREGIVING 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 supporting a loved one with PD, coping with your new caring role can be challenging.

The symptoms and progression of PD are different for each person, and this ambiguity can make it difficult to adapt to your caring role in a healthy way. Learning about the disease, its treatments, and medications, is one of the best ways to develop the skills and understanding necessary to help you and your family cope with day-to-day situations that may arise. Building a support network of friends, family, community resources, and healthcare partners, is also essential to the caring role.

Carepartner and Caregiver

The caring role of a spouse, adult child, or friend is usually that of the carepartner, who supports the person with PD in the early stages of disease progression. Carepartners are part of an established, reciprocal caring relationship – you are partners in caring for the person with PD, as well as each other.

For some, the carepartner relationship may shift as the disease progresses. In the later stages of PD, caring duties may no longer be reciprocal, and your loved one with the disease may not be able to handle much of their daily self-management. In this case, the spouse, adult child, or friend becomes the caregiver. The transition is gradual, and can be difficult due to the fluctuation in the abilities of the person with PD. It is not always apparent what kind of support is needed, and when.

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. Caregiving in a family with PD will present challenges, but it will also present new learning opportunities, including many with very positive outcomes.

Adjusting to New Roles

It is important not to let terms like *carepartner* or *caregiver* become labels that guide your identity. Your caring role is only one part of who you are as a complete person. Many other life aspects define who you are – find a way to express these in your daily activities. Here are a few thoughts to consider as you adjust to your role as a PD carepartner:

- People with PD should continue to do as much for themselves as they can, and live as independently as possible, with some support from you.
- The caring role is flexible, and depends on the needs of your loved one with PD, as well as on your abilities. Discuss your respective roles often, and redefine your carepartner duties accordingly.
- Symptoms can vary widely throughout the day. The amount and type of care needed can also vary as a result of these fluctuations.
- Although there is no cure for the disease, appropriate symptom management can lead to a full and productive life with PD.
- There will be moments in time when you may feel discouraged – be vigilant. Recognize when discouragement begins to look like depression, and seek help as soon as possible. Talk to your doctor, and contact PSBC for local counselling services.

- You do not need to give up your hobbies and interests because of a PD diagnosis in the family. Adjust your favourite shared activities, or find new ones you can enjoy together.
- Your emotional reactions to a complex situation are natural and valid.
- Compromise, encouragement, and strength are needed from all family members to maintain a good quality of life with PD.

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. Remind yourself of the following self-care strategies:

- 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 someone to talk to, who can support you on your carepartner journey.
- Spiritual: Set aside time each day to find peace within yourself in ways that suit you (e.g. meditation, yoga, reading, prayer).
- Nurturing yourself can become a habit if you let it! Acknowledge the importance of your wellbeing.

*Remember, Parkinson's is a marathon, not a sprint.
Caring for a person with Parkinson's means caring for yourself.*