

CARING IN A FAMILY WITH PARKINSON'S

It takes time to adjust to Parkinson's disease (PD) in the family. PD is an unwelcome guest that is here to stay. However, its influence on your life and your relationships can be limited by lifestyle choices you can make.

PD causes trouble with voluntary movement because there is not enough of a chemical called dopamine in the brain to send consistent signals to muscles in the body. As a family member or friend of a person with PD it is natural to wonder how to be supportive.

It is important to remember that the progression of PD is different for each person. This can add to the ambiguity of the situation and the challenge of dealing with it, as there is no set pattern of what will happen in the future.

However, learning about PD can give you information that will equip you and your family to cope with day-to-day situations that may arise. Contact Parkinson Society Southwestern Ontario about resources and support groups in your area.

Humour, love and a positive attitude in the family can go a long way towards coping well with PD. Accept that there are moments in time when you may be discouraged on this continuing journey. As with life in general, the journey will involve moments of coping, surviving and thriving. Remember that you are not travelling alone.

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 suggestions that may help in your journey as a PD Carepartner:

- 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. Such discussion may take a concerted effort.
- Be aware that symptoms can vary widely from minute to minute. The amount of care and the type of care can sometimes vary widely 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.
- Recognize the signs of depression, in both yourself 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.
- Each person is valuable. 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 Parkinson Society Southwestern Ontario. We are here to help navigate these challenging waters.

Carepartner and Caregiver

Initially the term carepartner is usually appropriate to describe the relationship between the spouse, adult child or friend who helps the person with PD. Caregiving 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 becomes 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 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. With appropriate support, there can be benefits to the roles of both carepartner and caregiver.

Self Care

- Nurturing yourself can become a habit if you let it! Acknowledge the importance of your well-being each day.
- Physical: Eat well-balanced meals; do exercise you enjoy; get a good night's rest.
- Mental and Emotional: Keep up a hobby. Treat yourself once a week. 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).

Caring for a person with PD means caring for yourself.

Parkinson Society Southwestern Ontario gratefully acknowledges Parkinson Society British Columbia for sharing their resources and information.

Source: Resources Guide for Family Caregivers, Family Caregiver Network Society, (2003)