

You probably clearly remember the day when someone close to you was told “You have Parkinson’s disease”. Now you are considering how you can develop your role as an effective caregiver/ carepartner to this person with Parkinson’s (PWP).

No one is really prepared to be a caregiver. You may feel overwhelmed with your new responsibilities. You know there is no cure for Parkinson’s and the PWP will need even more help as the disease progresses. You know your lives will never be the same.



How can I help? Where do I start?

The first step is to discuss and agree with the PWP on the role you will play. The PWP will make the decisions but you want to be there – to offer physical and emotional support when it’s needed. You need to talk about how your involvement can change as Parkinson’s evolves.

Then form a partnership with the PWP, health care team, family members and friends. Each has a contribution to make and a role to play in meeting the challenges of Parkinson’s.

The more information you and the PWP have, the better equipped you will be to cope with day-to-day obstacles.

Listen to the doctor’s advice. Review what he/she recommends. Talk about available treatment options. Learn how the symptoms of Parkinson’s can be managed.



You will hear about medical breakthroughs in the media. These can sometimes create unrealistic expectations about ‘miracle cures’ for Parkinson’s. Get up-to-date, reliable information by contacting your doctor, calling us or visiting www.parkinson.ca.

Medication management is the most important part of controlling Parkinson symptoms. The doctor will provide guidelines on when medication should be taken. You can help by keeping a record of medication effectiveness as well as side effects including nausea, confusion, hallucinations or abnormal movements. Does the PWP feel better when the medication is taken before or with a meal or on an empty stomach? Does a new drug cause undue anxiety? Share any observations with the doctor.

A PWP will have ‘good’ and ‘bad’ days. So will you and that’s okay. Listen, be patient and understanding. Look for signs of depression which could include anger, change in personal habits, withdrawal. Seek support if needed, and encourage socialization.

Exercise, especially walking, is essential therapy for someone with Parkinson’s. It’s good for you, too. Make exercise a part of the daily routine. You might look into a stretching program or a tai chi class - ideal exercises for people with mobility issues.

As Parkinson’s progresses, one of the toughest hurdles you both will face will be coping with emotions. Talk about ways you can help relieve stress, provide physical assistance and meet special needs.



You may need to adjust or find new activities to enjoy together to remain close.

The PWP may experience problems with medication and potential side effects, constipation, sleep problems, speech and communications difficulties and mobility issues. We can help – ask us for information on these topics.

How can I take care of myself?

- Contact us to determine what kind of support groups are available in your area for you and the PWP. These are a good opportunity to listen, learn and share experiences.
- Know your limitations. Parkinson’s is progressive so it may be increasingly difficult to care for a PWP by yourself. Look into homecare, day programs or help from your family members.
- Every caregiver needs ‘time out’ on a regular basis. Take a break and see friends. Ask for and accept support. Make a list of tasks others can do. People want to help – include them in the caregiving plans.
- Find someone you trust when you’re feeling low or need to talk about some of your feelings. Get help when you are feeling stressed. And, remember, you are not alone!

What does it mean to be a caregiver/carepartner?

A caregiver can be a partner, spouse, friend and/or adult child caring for a person with Parkinson's (PWP)

Caregiving can be a demanding job involving compromise, encouragement and strength

It means realizing the PWP is in control and needs and wants your support to live as independently as possible



It means accepting that although there is no cure yet for Parkinson's, management of its symptoms can lead to a full, productive life

It means looking for ways to help a PWP cope with the daily challenges of living

It involves gathering information and working with a health care team to ensure the right treatment balance is achieved

It requires recognizing the signs of depression in a PWP and seeking help as soon as possible

It leads to a variety of emotions - especially frustration and possibly guilt ... a very normal reaction to a complex situation



It means asking for help from your doctor, family, friends and local Parkinson's organization



Parkinson Society Canada is a national organization with regional partners from coast to coast. We share a vision to ease the burden and find a cure through research, education, advocacy and support services to improve quality of life for all those affected by Parkinson's.

Call your local Parkinson office for information, programs and services in your area, or to make a donation.

 Parkinson Society Canada
Société Parkinson Canada

Parkinson's: How you can be a supportive caregiver

Ease the Burden; Find a Cure

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