

## Preventing burnout

In most cases, we know what we can handle and how well we are coping. At times, however, it may be useful to listen to the caring feedback from others.

Preventing burnout means taking time for self-care. Caring for someone with Parkinson's is not about sprinting – it's about being able to provide support for the long haul.

This means looking after yourself in these four areas:

### Physical

Exercise, balanced meals and quality sleep.

### Mental and Emotional

Maintain your own interests and pay attention to how you are feeling.

### Social

Talk to family and friends.

### Spiritual

Yoga, reading, prayer or meditation.

Being a carepartner/caregiver may be one of the most challenging things you have ever done, however, it can be rewarding. Knowing your limitations, finding ways to look after yourself and receiving support while you care for another is key.

## Some ideas for day to day coping

- Ask for help from your healthcare team, family, friends and Parkinson Society British Columbia early in the process. Speak up!
- Find new activities you can enjoy together to remain close.
- Say “no” when you need to. Many carepartners/caregivers find this difficult but, at times, it is essential.
- Set goals for yourself so you become proactive rather than reactive.
- Accept that there are times when you may be discouraged.
- Recognize signs of depression, in yourself and/or the person you care for, and seek help as soon as possible.
- Compromise, encouragement and strength are needed from all family members.
- Be realistic in what you can accomplish. You can't do it all!
- Learn about Parkinson's so you can be more prepared for changes.
- Join a support group.

## You are not alone. We are here to help.

Parkinson Society British Columbia is here to help people with Parkinson's and those who care about them. The services provided include:

- Consultation at the PSBC office or by phone
- Free, confidential short-term counselling services for people with Parkinson's and their loved ones
- *Viewpoints*, quarterly newsletter with up-to-date information on scientific research, medication, caregiving, nutrition and other relevant topics
- Educational events throughout BC featuring experts in Parkinson's research and treatment
- PDLINK Program
- Information materials
- Library including books and DVDs
- A network of over 50 support groups province-wide
- Advocacy for improved healthcare and access to medications
- Partnership with Pacific Parkinson's Research Centre at UBC
- Workshops and training for healthcare professionals

## Our Mission

Parkinson Society British Columbia (PSBC) is the voice of British Columbians living with Parkinson's. Our purpose is to ease the burden and find a cure for Parkinson's disease through advocacy, education, research and support services.



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# Caring for Someone with Parkinson's



Caring for a person with Parkinson's means caring for yourself.



## What happened to my life? *I am now a carepartner/caregiver.*

In Canada today, there are an estimated 8 million caregivers.

If you are providing care and support for an adult family member, partner, friend or neighbour, you are a carepartner/caregiver.

You probably remember the day when someone close to you said “I have Parkinson’s disease”. You may have learned that there is no cure for Parkinson’s and that it comes with unpredictable physical and psychological changes. All of this may leave you wondering what it means to be a carepartner/caregiver.

*Parkinson’s changes lives forever and it takes time to adjust to Parkinson’s in the family.*

No one is really prepared to be a carepartner/caregiver and you may feel overwhelmed with your responsibilities.

It is possible, however, to successfully live with the influence of Parkinson’s on your life and your relationships through lifestyle and important self-care choices.

### Talking about Parkinson’s

We encourage you to talk to the person with Parkinson’s and your family about how you will navigate this together. Consider discussing what being a carepartner/caregiver might look like now and in the future as Parkinson’s progresses.

Talk about what each of your roles will be as you live with Parkinson’s. It might also be a good time to talk about future care and what each of you would like in the event that either one of you has a medical emergency and cannot speak for yourself.

### Changing Roles

At the beginning of the journey, the relationship you share with the person with Parkinson’s may not change much. You may be more of a “carepartner”, that is, you are partnering together to care for one another.

If Parkinson’s advances to a point that reduces a person’s independence, you may find yourself moving from a partnering role to a caregiving role.

It can be easy to let words like caregiver become labels that take over your identity. *This new role is only part of who you are as a complete person.*

As a caregiver, you also “have” Parkinson’s and common questions include:

- How will caregiving change my work, finances, independence and the dreams I had for our life?
- How quickly will Parkinson’s progress?
- How will my role as a partner, family member or friend change as Parkinson’s progresses?
- How can I adapt to these changes?
- Will I have the skills and strength to do what is needed?
- What will happen if I can’t manage?

### What do I need to know?

#### Symptoms

Parkinson’s is unique to each individual. Learn about the various symptoms, including movement, mood and cognitive changes. Look for signs of depression which could include anger, change in personal habits and withdrawal.

#### Medications

Medications remain the primary treatment for Parkinson’s. Learning about the variety of medications, the changes in dosage, side effects and the necessity of a strict medication schedule is an essential part of supporting a person with Parkinson’s.

#### Circle of Support

It is important to form a partnership with the person with Parkinson’s, the healthcare team, family members and friends. Each one has a role to play in meeting the challenges of Parkinson’s. You also need your own circle that can support you.

#### Progression of Parkinson’s

The progression of Parkinson’s differs with each person. There is no way to know what will happen in the future and symptoms can vary from minute to minute. Expect the unexpected.

At some point, it may become increasingly difficult to care for the person with Parkinson’s on your own. Know your limitations, talk about ways you can relieve stress, provide physical assistance and meet special needs.

With the average age of diagnosis being 60, the journey can be a long one. As Parkinson’s progresses, one of the toughest hurdles you may both face will be coping with emotions.



### Reactions to being a Carepartner/Caregiver

You may feel ill-equipped to be a carepartner/caregiver and begin to have a range of reactions such as:

- Anger
- Fear
- Stress
- Frustration
- Sadness or depression
- Guilt
- Hopelessness
- Loneliness
- Resentment
- Anxiety

*If you start to feel this way, accept that these feelings are normal, and ensure that you have the help necessary to support you in the role.*

You may find yourself putting your own needs aside in order to give care. There can be a high price paid for doing so. If unaddressed, the stress associated with being a carepartner/caregiver will impact your health.

Burnout may create a variety of physical and emotional symptoms including headaches, digestive problems, sleep deprivation, chronic back pain and fatigue.

If you are experiencing these symptoms, your body is letting you know that there is a problem.

