



Care Partnering

Managing Parkinson's together

About this book

This book was created to support you and the person you care for in navigating daily life with Parkinson's. Use it as a tool to spark meaningful conversations, strengthen your partnership, and work together with health care providers in managing care.

In this book you'll find tips for self-care and maintaining your own well-being, communication advice for navigating changes and decision-making, and strategies for managing daily life with Parkinson's together.

Visit parkinson.ca/carepartners or go to carerscanada.ca for more tools and information on caregiving.

Acknowledgments

Parkinson Canada thanks the Parkinson's Foundation for permission to adapt their book, *Caring and Coping: A Caregiver's Guide to Parkinson's Disease*.

We also thank each care partner who humbly shared their stories, tips, and insights so that you may benefit from their wisdom and experience.

We gratefully acknowledge the following individuals for their review of the content for this publication:

Pascal Girard (Personal support worker and social worker)

Elaine Book, MSW

Sheryl Hague (Care partner)

We also wish to thank the care partners from across the country who took the time to share feedback and suggestions.

This resource is supported by Rexall Care Network.



This resource was also made possible through the generosity of Parkinson Canada donors. If you would like to support quality resources like this, please consider making a gift to Parkinson Canada. Visit parkinson.ca/donate.

Disclaimer

The information contained in this book does not represent medical advice. Consult your health care team and Parkinson Canada to help you make informed decisions that are best for you and your care recipient.

A message for you

A person's life story changes after a Parkinson's diagnosis. There begins a chapter of collaboration in care that eventually evolves into more hands-on caregiving. And whether you are caring with or for that person, it is guaranteed to involve you more and more over time, and increase your understanding of the experience of another person.

Caregiving is a part of the societal fabric of most cultures. You may have witnessed others taking care of people in your family and community. Care partnering is often adopted and learned based on a change in life circumstances by those who face illness or injury. You may or may not be prepared. Having the knowledge, practicing the skills, and using the tools available to you will help.

Reading this book is a positive step towards successfully meeting both your needs and those of the person you're caring for.

Whether you are just beginning on this journey or have been on it for some time, we hope these pages unveil some of the answers you need to make care partnering more collaborative, manageable, and rewarding.



*"If you want to go quickly, go alone.
If you want to go far, go together."*

African proverb



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Care team provider contact information

Provider	Name	Phone	Email	Address	Notes
Primary care physician					
Neurologist					
Parkinson's nurse					
Pharmacist					
Neuropsychiatrist/ psychologist					
Ophthalmologist					
Optometrist					
Social worker					
Occupational therapist					

Physiotherapist					
Speech-language pathologist					
Massage therapist					
Dentist/Dental hygienist					
Personal support worker					

Other	Name	Phone	Email	Address	Notes



Introduction

Whether the Parkinson's diagnosis is new or the person you're providing care for has been living with Parkinson's for some time, together, the two of you can make the care partnership as productive and stress-free as possible. You will likely encounter emotional, financial, physical, and even spiritual challenges along the way. Preparation is an integral component of success as a care partner. We hope the tips and tools in this book will help you prepare and successfully manage each challenge that you encounter along the way.



Caregiving often calls us to lean into love we didn't know possible.

Tia Walker



What is caregiving?

A precise definition of caregiving remains elusive, despite growing numbers of people serving in the role of care partner. One definition describes a care partner in Canada as a person who takes on an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury, or a chronic life-limiting illness.

It is estimated that there are over 13 million care partners in Canada. Many of these care partners are also juggling jobs: over 6 million people in Canada are balancing paid work with caregiving, which adds up to roughly 35% of the workforce.

Just over half of all care partners in Canada are women and about 1.8 million people are what have been called “sandwich caregivers,” providing care for both children and adults at the same time. Among this group, women are more likely than men to be sandwich caregivers – 62% versus 38%.

What does caregiving look like? The simple answer is it takes many forms. It may involve assistance with personal maintenance and hygiene; transporting, shopping and driving; housekeeping and chores; advocating and arranging health care; handling of financial and legal matters; or it may simply be having regular check-ins (in-person, by phone, or virtually) to support and bring social connection to the care recipient.

Unpaid care partners save the Canadian health care system tens of billions of dollars annually by doing the work that they do.

“Am I in this for the long haul, or is it a short haul? No one knows. I sometimes feel that I am on a treadmill trying to figure out how to live my life and his life as well. But the more I try to bring normalcy back into my life, the more difficult the balance becomes. As I begin to try to live my life, I sometimes feel that he is fading away as a result.”

Diana – Ottawa, Canada



Chapter 1: The care partner identity

Who are you?

How to talk with your family about Parkinson's

The 7 strengths of care partners

The 7 needs of care partners

Balancing work and caregiving

Parkinson's is a progressive condition. The degeneration and changes that take place over time can make it hard for you to define your role within the journey both of you are on. Your responsibilities and challenges will change with time. You may find yourself contemplating whether or not you actually want to be a care partner. This section includes information on how Parkinson's fits into your life. Including sharing the diagnosis with family, assessing your work life, and prioritizing your own needs.

Taking on the responsibility of being the primary care partner will likely impact every part of your life, your health, and your overall well-being. It will be helpful to incorporate this role gradually. You may wish to assess how the responsibilities associated with it might affect your physical and mental health, your career, your social life, your finances, other family members and their needs/desires, and finally, your relationship with the person receiving the care.

This next section deals with how these changes will come to define your involvement and will show you how you can continually redefine how Parkinson's fits into your life. This includes assessing your personal and professional needs along the way, and prioritizing and sharing your responsibilities with others. That may mean deciding how much caregiving you will take on, and who will be sharing that role with you.

Who are you?

A Parkinson's diagnosis changes a person's life almost overnight. In fact, it has dramatically changed yours, too. Being a care partner is a role that you take on and grow into.



Caregivers are often the casualties, the hidden victims. No one sees the sacrifices they make.

Judith L. London



Each person with Parkinson's is unique, and so is each care partner. As you start your care partner journey, take time to define caregiving for yourself. For some people, being a care partner is one of many roles, or it may be a group they belong to. For others, it is a central characteristic of who they are and who they become.

Many people do not like the term “caregiving.” Particularly early on in the Parkinson's journey, you might not feel like you are actually giving care. Similarly, the person whom you care for might not see themselves as someone in need of care. Remember that care is not limited to physical tasks; care can also take the form of emotional and spiritual support, as well as physical.

Care can also be a spectrum – changing and progressing as the condition progresses. You may find yourself going from being a care partner to a caregiver. And further down the line, you may feel and act more as a substitute decision-maker. However you define it, and whatever term you choose – caregiver, care partner, carer, etc. – it is important that you define what this role will look like for you. It does not have to erase or replace any existing ways you self-identify; it is an addition, a new facet of your identity that will help you and the person whom you care for face Parkinson's together.

Early on, learn all you can about Parkinson's so you can anticipate changes, participate in health care discussions, make informed decisions, and provide emotional and physical support now and in the future. Expect that there will be changes in your relationship as the condition progresses, and that there may be times when your relationship will experience strain and pressure. Mood changes such as depression and anxiety are common with Parkinson's, and you may find yourself constantly adjusting your approach and manner of communicating with your care recipient in order to avoid conflicts and problems. This, too, may cause you grief and strain.

Consider your own support needs, wellness, and self-care. There are several warning signs of care partner strain. If you begin to feel angry or irritable, are sleeping poorly, feel constantly fatigued and overwhelmed, or possibly seeking solace in medications or alcohol, then get help immediately.

"It is true; we once had some independence from each other. We were never 'joined at the hip.' We shared much, but we both had our own interests and activities. But then, we were always able to come back together. Our mini separations were never permanent. That is no longer the case. The old life is over and must be replaced, his independence now gone. A new balance must be established, one that fulfill our very different needs."

Diana – Ottawa, Canada



How to talk with your family about Parkinson's

Family members—children, siblings, and other relatives—want to understand and help. How do you begin to explain Parkinson's to them?

First, you must understand the condition yourself. Ask for information and do some research on your own. Be sure to understand the specific needs and wishes of the person you're providing care for. Only then can you call in your family for a discussion on what those are; how they can contribute and support the two of you; the extent of their involvement in decision-making; and what you need from them.

This does not have to be a one-time, all-encompassing talk. You will find that ongoing discussions will better address needs as things change and progress.

Engage your family and help them understand both your needs:

- Include your family in care discussions and ask for their observations about how the person living with Parkinson's is doing
- Make specific, concrete requests to family members about how they can help you or the person with Parkinson's
- If your family members live out of town, provide them with information about Parkinson's and tell them about where they can learn more about Parkinson's
- Refer them to Parkinson Canada for support group information or answers to other questions they might have

Visit Parkinson Canada's website or contact us for more information about talking to family and friends about Parkinson's.

 parkinson.ca  1-888-664-1974  support@parkinson.ca

The 7 strengths of care partners

Care partners are strong. They must be to support the person they care for and still manage the various tasks and activities of daily living for themselves and for any others who may rely on them. It is in these strengths that they find the courage to meet the varied needs of the person with Parkinson's. It is also these strengths that come to define who they are as a care partner, and as a person.

"The first requirement is patience. Get used to moving at a more 'relaxed' pace! Anticipate the unexpected. It's a way of life!"

You will probably have to repeat instructions and comments often. Making eye contact is a good thing. Keep reminding. Communication is often one-sided. Learn to ask your partner if you have understood them properly. For example, a response of silence and an expressionless face used to mean something entirely different from what it means now. Don't misinterpret responses of silence as indications of disapproval or disagreement, as you might once have done. Usually this means that they have heard you and simply forget, neglect, can't find the words or don't have the energy to communicate back. Ask if you are confused or unclear, and explain why you are doing so. Checking might help your partner to understand better how you are feeling, too."

Marjorie - Ottawa, Canada



1. Patience

- They can control their own emotions and wait it out without becoming upset
- They accept the hurdles they encounter unexpectedly along the way

2. Compassion

- They can be both empathetic and proactive as they face the daily challenges with the person they care for
- They understand the challenges the person with Parkinson's faces

3. Organization

- They plan effectively, execute those plans to achieve desired outcomes and get things done
- They utilize time efficiently and squeeze in as much as they can into each hour

4. Adaptability

- They change modalities and approaches in every situation to ensure that the care recipient's needs are met
- They are flexible and go with the flow

5. Resilience

- They bounce back from setbacks and reset their focus so they keep moving forward
- They don't let things get them down because they know how much the care recipient depends on them

6. Positivity

- They are optimistic and can find humour or the silver lining in life
- They employ hope and expect good outcomes

7. Self-assuredness

- They know what they can handle even when doubt creeps in and with each day their confidence grows
- They learn and improve their skills and knowledge so they can be more supportive to the person whom they care for

The 7 needs of care partners

Just as the person with Parkinson's has specific needs, so does their care partner. Here, we have broken down those needs into seven categories. Each has a focus and includes tips on how to balance your needs to better manage the health of the one you care for. Be aware of something referred to as "caregiver burnout." Do not let yourself reach the point of total exhaustion before you ask for help or your health may be seriously compromised.

1. Educational needs

- **Understand the symptoms** of Parkinson's
- **Learn about available treatments**
- **Consider the impact** of Parkinson's on everyday life
- **Access resources**
- **Explore your role** as a care partner
- **Encourage the one with Parkinson's to learn** as much as they can about their condition
 - ◆ Encouraging people with Parkinson's to take an active role in managing their condition can ease the burden on care partners and families while reducing health care usage and preserving good health outcomes



2. Time management needs

- **Make daily and weekly lists of things to do**
 - ◆ Make the tasks manageable and realistic. You don't want to feel like you are failing to complete them
- **Keep a monthly calendar** with important events/appointments written down
 - ◆ Give yourself an overview of the month to come
 - ◆ Coordinate help
- **Prioritize** and do the most important things first
 - ◆ Check off what's been done
- **Save up errands** and do more of them at the same time
 - ◆ Plan out your 'run' and how you will execute it
- **Take a small task with you** if you are going someplace — like an appointment — where you will likely wait
 - ◆ Reading, sewing, knitting, or some other task can be done in any waiting room
- **Delegate what can be delegated**
 - ◆ You don't have to do everything yourself
- **Take breaks** when the pressure gets too great
 - ◆ Reward yourself for those periods of hard work
- **Don't do so much in one area that you can't be effective in another**
- **Break large tasks into smaller, more manageable parts**
- **Establish and stick to routines** and schedules
 - ◆ It takes away the mental stress that would otherwise be there each time
- **Recognize that some amount of time and effort will be spent on things that are out of your control**
 - ◆ Just let go and accept, rather than resist

3. Self-care, health, and respite needs

- **Build quality time for yourself** into your daily schedule
 - ◆ Aim for 1 – 1.5 hours per day, if possible, and protect it
- **Keep up with your own needs, hobbies, and regular activities**
- **Exercise regularly** to increase your energy, decrease any tension or depression, and improve your sleep

- **Eat a balanced and nutritious diet**
- **Drink plenty of water** to stay hydrated
- **Recognize when you are stressed** and take steps to manage it
- **Get enough rest** and sleep
- **Take time to relax**
- **Maintain your sense of humour**
- **Get regular check-ups** and keep your own medical appointments
- **Think about your future**
 - ◆ What goals do you hope to achieve?
 - ◆ How can you achieve them?
 - ◆ Can the care recipient help you achieve them?
- **Set limits and boundaries and stick to them**
 - ◆ Bring in outside help (family, friends, or paid workers) to take care of some of the work so you can take a break or attend to other responsibilities
- **Engage the support of a social worker** or counselor to guide you to community resources that support you and address care partner stress and strain

“The most important thing I learned as a caregiver was that I needed to care for me first—if I didn’t help myself through self-care, I would be of no use to anyone else. Self-care allowed me to put aside the ‘stressors’ in my life in order to open my awareness to what was really important, and what needed my attention. I was fortunate enough to discover a self-care course for caregivers where I live. The course facilitator encouraged me to take time daily to stop and quiet my mind so I could experience rest and peace while caring for my father with Parkinson’s. I also learned how to ‘pause’ and reflect before making an important decision. I tell my friends that the self-care course saved my life, because without these important tools I may have been the one that ended up in the hospital.”

Paul - Brantford, Canada

4. Supportive needs

- **Share the care.** Explore ways to get the assistance and support that you need. This includes physical, emotional, and spiritual help.
- **Develop your coping skills.** Care partners experience a wide variety of emotions. Give yourself permission to feel sad or frustrated at times but also take time to enjoy life. Focus on the present, and the needs and rewards of the day. Try not to be critical of yourself in moments of anger. Give yourself credit, not guilt, and try to forgive any mistakes. Use positive self-talk. For example, tell yourself you are doing a good job. Know that it is okay to grieve the losses that you and the care recipient may experience. Writing in a journal or other format can help you work through your feelings and emotions. What causes you to mourn? Where do you find satisfaction and pleasure?
- **Develop your emotional and spiritual support networks.** Include your health care team (physician, nurse, social worker, etc.), family, friends, neighbours, support group and individual support group members, clergy, volunteers, and online support forums. Seek comfort from your faith, faith community, and spiritual practices, if you have them. Find meaning, insight, understanding, and your own inner strengths. Adjust your expectations: life and you are not perfect. Accept changes as they occur. Get help if necessary. It is strength, not a weakness, to ask for help — including emotional help or counseling. Each person experiences depression in a unique way. It is important to take seriously any symptoms you experience that could signal depression; you should not feel embarrassed or ashamed.
- **Be aware of the core symptoms of depression.** They may include the following:
 - ◆ Sleeplessness
 - ◆ Loss of appetite
 - ◆ Difficulty concentrating
 - ◆ Feelings of hopelessness and worthlessness
 - ◆ Feeling slowed down or restless inside
 - ◆ No interest in once-pleasurable activities
 - ◆ Thoughts of death or suicide

If you think you may be depressed, talk to a doctor or mental health professional about your symptoms. Find a supportive professional that you trust and with whom you feel comfortable. In most cases, depression is effectively treated with psychotherapy, antidepressant medications, or a combination of both, plus activities such as regular exercise, spirituality, supportive social interactions, and meditation.

If you are thinking about hurting yourself or ending your life, help is available. In Canada, call or text 988 (Suicide Crisis Helpline) or go to your nearest emergency department.

5. Relationship needs

- **Maintain open communication** with the person living with Parkinson's
- **When conversing, remove any distractions** and turn off any loud noises
- **Express care and appreciation, along with any feelings of frustration**, so they don't turn into resentments
- **Share special time together** apart from caregiving tasks

6. Medical, financial, and care needs

- **Define and clarify any care decisions** regarding family participation in caregiving, power of attorney for personal care (POAPC), power of attorney for property (POAP), representation agreements, wills, and long-term care options
- When making decisions about hands-on care, **ask yourself if the decision promotes the care recipient's independence**
 - ◆ Be sure that their wishes are guiding those decisions
 - ◆ Any decision must be a balance between the desires of the person with Parkinson's and the care partner's well-being
- **Devise and plan the steps for carrying out these decisions**



Never let the stumble in the road be the end of your journey.

Anonymous



7. Community resource needs

- Take advantage of physical and practical assistance, and any products that may be available
- See what resources local associations have to offer
- Seek out educational materials and information
- Organize and get all your legal documents (POAPC, etc.) in order
 - ◆ Don't wait for the last minute
- Explore options and resources for financial assistance (e.g., disability insurance benefits, etc.) that may be available now, or down the road, to plan your budget
- Reach out to a variety of health care professionals, social workers and clergy

Visit Parkinson Canada's website or contact us for more information on accessing community resources in your area.



parkinson.ca



1-888-664-1974



support@parkinson.ca



How to categorize and prioritize needs

1. Identify your concerns according to the need categories in this section
2. Place your needs and concerns in your priority order
3. Consider and then write down your 'action steps'
4. Discuss the priorities with others who can help
5. Devise a step-by-step action plan
6. Implement the steps with help from the others you have consulted with

Balancing work and caregiving



The major work of the world is not done by geniuses. It is done by ordinary people with balance in their lives, who have learned to work in an extraordinary manner.

Gordon B. Hinckley



Caring for someone with Parkinson's can be a full-time job, especially as the condition progresses to a more advanced stage. At first, you may be hesitant to tell your employer about your situation. However, it may be helpful to see if your workplace offers any special accommodations for care partners.

- **Look into your company's benefits policies.** Check your employee handbook or staff website, or talk to someone from the human resources department to learn if your company offers programs or special assistance for care partners. If you are a union member, ask a union representative to help you negotiate with your employer
- **Arrange a meeting with your boss, and prepare for it in advance.** Before you approach your boss, decide if you want to discuss your situation as a care partner, or if you want to go further and request specific job accommodations. Jot down the most important points you want to address
- **Be upfront and positive.** When you meet with your supervisor, highlight your strengths and contributions to the company. Indicate your willingness to work together to identify potential accommodations to help you continue to do your job while maintaining your role as care partner
- **Get it in writing.** Send an email to your manager or HR representative with your understanding of the agreed-upon conditions. This will give everyone a reference point

Later, if you consider leaving work altogether to accommodate your caregiving duties, consider the following steps:

- **Explore your options**
 - ◆ What are your alternatives to resigning?
 - ◆ Can you take a career break or retire early?
 - ◆ Will your employer let you work remotely or part-time?
 - ◆ Could you consult or freelance your work so you can have the flexibility that suits your needs?
- **Take the time you need**
 - ◆ As employment is governed by provincial legislation, look to current labour laws on your provincial government's website for more information
 - ◆ Understand the repercussions of each of your options
 - Can we manage with less money?
 - Will this affect my pension or retirement plan?
 - ◆ Think about your current income and what might happen if you leave your job
 - ◆ Consider the potential loss of independence, social contacts, and valuable skills

For more information on your rights regarding leaves of absence, contact your provincial Ministry of Labour.





Chapter 2: Care for the care partner

Caring for you
Finding meaning in caregiving
Managing care partner stress
Care partner self-assessment

Care partners have an enormous and often underappreciated job. The job is unique for each care partner but carries concerns, fears, stressors, and rewards. This section is designed to help you understand and handle your own caregiving situation, so that caregiving can continue to be – or return to being – a healthy, viable, even rewarding role for you.

Caring for you

You may be involved in assisting the person living with Parkinson's many activities of daily living and with medical tasks while still maintaining your household; shopping and preparing meals; organizing records, papers, and appointments; transporting them to their health care visits; keeping up with family and social events; and many other tasks. At the same time, you may be working outside the home, raising children or grandchildren, or coping with your own health issues.

The burden of all these responsibilities can cause something known as caregiver strain. It is not an imagined condition, but a recognized medical syndrome. Caregiver strain can affect health in many ways including causing depression, fatigue, apathy, and an overall negative impact on the care partner's mood.

"I'm told I must reclaim my life. Get out and do things. Invite friends for tea. Every comment intended to be helpful and in most cases reflecting genuine concern. But weaving our lives together from pieces seems to be the pathway now; pieces for him and pieces for me. When I'm trying to reclaim my life, I must remember him and what he's going through every day. Not easy."

Diana – Ottawa, Canada

Here are some tips to help combat caregiver strain:

- Accept that your daily routine will likely change. You will probably have to compromise some of your personal standards of housekeeping, meal preparation, and other tasks. Caring for someone with a chronic condition means your world has been turned upside down. "Something's gotta give!" as they say
- Forgive yourself for not being perfect. Accept your own humanity. Give yourself a pat on the back for doing the best that you can under your particular circumstances
- Acknowledge your right to feel emotionally off balance some days. Recognize the hidden grief component of your anger, anxiety, guilt, and depression. Work towards resolution of your grief. Accept it and seek out the support of someone who understands it
- Determine your limits – physical, emotional, and psychological. You cannot be everywhere or be everything to everyone. Limitations are a part of the human condition. Ask yourself:
 - ◆ What are your limits?
 - ◆ What is your comfort level providing care?
 - ◆ What types of assistance do you need?
 - ◆ What responsibilities are you willing to pass on to someone else?
 - ◆ What are you experiencing today physically, emotionally, and psychologically?
- Build in regular breaks from caregiving and make them a priority. You will be a better care partner if you take care of yourself. The person whom you care for will be fine if you take a respite leave from your responsibilities. Don't hesitate to ask for help

- Share the workload. Assess where and what the person with Parkinson's can do to help. Discuss household chores, errands, and activities that they can take on
- Be kind to yourself. You are experiencing normal reactions to abnormal circumstances. You are not being selfish if you express your challenges and need for help and support
- Seek out joy in your relationship with the person with Parkinson's. Your hands-on duties might feel like work, but these tasks also bring you closer together. Add some fun to your care. Sing, tell jokes, share stories, goals, and dreams
- Develop a habit of participating in activities together outside of care. Shared time outside of your care partner and care recipient roles allows you to enjoy each other and build cherished memories
- Communicate constantly with your partner. Share what you feel is working and what isn't. Discuss what needs to change and how the two of you can work together to make those changes
- Try to forgive the care recipient for past hurts. Resentment toward past wrongs and injustices will make your present caregiving role difficult
- Let go of what was and concentrate on making the present healthy and productive. Talk to a social worker or other health care professional who can help you through this process

Benefits of support groups

- Commonality among members
- Education and information
- Learning to adjust to diagnosis
- Practical techniques and strategies
- Safe environment for sharing in confidence
- Feelings of understanding
- Reduction of stigma
- Socialization and friendships

Finding meaning in caregiving

Caregiving offers trials and triumphs, as well as challenges and joys. It can be more rewarding than expected. If given support and assistance, a care partner can surmount hurdles and can potentially find more positives in their caregiving experience.



From caring comes courage.

Lao Tzu



What are some rewards of being a care partner?

Connection

Care partners don't start out being care providers. It often happens unexpectedly. Joining care partner support groups provides a network of support from others who find themselves in the same role. You may find similar interests and endeavours.

Relationships

Families often come together — or break apart in fights — when a member is in need of care. Appreciate the time you have with them while sharing responsibilities. Conflicts can arise. By setting clear and agreed-upon boundaries of who is responsible for which aspects of care, these conflicts may bring positive changes, and even bring family members closer together. Likewise, your caregiving experience will often bring you closer to the one you are caring for. However, it is important when providing long-term care to learn how to develop skills of delegation, negotiation, and planning.

Growth

Caregiving is a learning journey. Take pride in the skills and knowledge you acquire. Discover your strengths and share your new insights about life. Find positives in everyday experiences. Feel empowered and recognize your accomplishments.

Appreciation

When someone is ill, the natural experience of those around them is to reflect and become more appreciative of their own health and the good things that they have in their life.

Subsequently, the person with Parkinson's often comes to appreciate things similarly, especially the things that they may have previously taken for granted. Share your insights on appreciation with the person you care for to bring you closer to what really matters.

The rewards of being a care partner are not limited to the points above. You may also experience some of the following:

- Taking pleasure in giving
- Seeing positives where you once saw deficiencies
- New or renewed spirituality
- Feeling proud and purposeful.

Managing care partner stress

Some health professionals call care partners 'hidden patients.' Stress is inevitable with all your responsibilities. And the longer you are in the role of a care partner, the harder it is to manage stress. You need emotional support and practical services as much as people with Parkinson's. Here are some techniques to help you more effectively manage stress. Whichever techniques you choose to use, be sure to do them consistently as you will not benefit from sporadic use.

Stress reduction techniques

Exercise

- Talk to your doctor or physical therapist about setting up an exercise regimen that meets your health needs and begin exercising away any anxiety or stress
- Exercise with others so you can enjoy your sessions and the social interaction

Empowerment

- Socialize with those who uplift you and stay away from anyone who is negative
- Get involved in community activities and organizations, charities, and support groups

Laughter

- Keep your sense of humour
- Watch funny shows and movies
- Read funny articles and books

Meditation and breathing

- Find or create a relaxing space with minimal distractions/noise/ interruptions
 - ◆ Turn off/turn down all phones
 - ◆ Dim the lighting or close the curtains/blinds
 - ◆ Play soft, spa-like music if you wish
- Sit or lie down in a comfortable position with your body well supported
 - ◆ If you are lying down, make sure to extend your limbs, place arms at your sides, and support your knees and head with pillows if that is more comfortable
 - ◆ If you are seated, be sure to have proper support and equal weight on both sides of the body (i.e. an armchair that will support your arms)
- Close your eyes and focus on breathing in and out slowly and steadily
 - ◆ Inhale through the nose and exhale through the mouth
 - ◆ Breathe deep into your lower abdomen
 - ◆ Feel it expanding and contracting
 - ◆ Keep the breath moving in slow, smooth movements with no pauses
 - ◆ Do this for 3-5 minutes
- Mentally begin to identify each area of your body beginning with your feet and working up toward your head
 - ◆ Focus on each of those areas for a few seconds to assess if you feel any muscle tension or pain
 - ◆ Tighten each area for several (5-7) seconds and then release the muscle (be sure to tighten only the one area you are focusing on at a time, leaving the other muscles relaxed)
 - ◆ Each time, imagine the tension to be water draining from your body until all of the tension is gone (you can imagine a water balloon emptying its contents)
- Feel your body 'sink' into the floor or chair upon which you are sitting
 - ◆ Focus back on your breathing and continue the slow, smooth motion of inhaling and exhaling
 - ◆ Do this entire exercise for a total of 15-20 minutes

John's Story

"We have been at this for a long time – 28 years from the time we got word it was Parkinson's – not including the time before the actual diagnosis. Roles have changed and we have built a team, my wife and I. But some things remain the same. This includes doing things for me. You have to remember, you still have a life and you cannot do the care partnering if you do not take time for it.

I do many things that keep me strong; photography, playing musical instruments. I only need a few minutes on the ukulele to change how I might be feeling. I have raced sail boats on Wednesday nights for the last 30 summers. I did not have my own boat most of that time, but instead, joined a crew at a club. It was, and still is, a night out with the boys; except now our daughter is one of the crew, so it's a father-daughter activity, too. For me, almost nothing comes close to being out on the water, sailing and racing. It gives me a feeling of being away from it all (and not just the Parkinson's). Do I miss some nights? Yes, but very few. My wife knows how much this means to me and supports this time away, so we just make it happen.

My wife is up early and gets her day in. She is not a night owl anymore, so by 6 or 7 pm she has had it for the day. I would love to have her there sailing with me, but that just can't be. We try not to have [stand-ins for care] at home, so at the end of the day we both try to live as full a life as we can. For me, it's sailing, photo trips, and this year, a ukulele weekend away.

I like to think we have been successful in balancing my needs and hers."

John P. – Tiny, Canada

Care partner self-assessment

The care partner role is one where there are both rewards and challenges; days of positive progress and periods of decline. Parkinson's is chronic and progressive, and the inevitability of degeneration is unavoidable. You don't have to join the care recipient on that decline. In fact, they need you to remain strong and healthy for their sake, as well as yours.

The demands of caregiving can have a negative impact on your health. The more time you spend providing care, the less you will have for yourself. Take an inventory of your own needs – physical, mental, spiritual, and social – so that you can make decisions that will best meet them.

- Become more self-aware, now and over time, to guide your actions and decisions
- Measure your reactions to various aspects of caregiving to assess your support needs
- Bring to light the areas of greatest concern to you so you can deal with them
- Acknowledge and validate the importance of your role, experiences, and feelings
- Define experiences and acquire insights, skills, and knowledge about you and your role

Fill out the self-assessment on the next page at regular intervals to identify your risk factors and shed light on your needs. There is great value in assessing yourself. You can get additional copies of the self-assessment at parkinson.ca/carepartners.

Review your self-assessment for new insights. Share the results with family, friends, or others you trust and who are close to you so they can better understand the scope of your caregiving (i.e. emotional support, physical demands, financial resources, and social and spiritual connections). This may lead to a deeper engagement and involvement on their part, and more support for you and the person with Parkinson's.

Explore more care partner planning and assessment tools at
parkinson.ca/carepartners.

 parkinson.ca  1-888-664-1974  support@parkinson.ca



Care partner self-assessment

Rate each item below from 1 (never) to 5 (almost always) according to how much of the time each statement applies to you. Add all the numbers you have selected to determine your results.

☐ 1 Never
 ☐ 2 Rarely
 ☐ 3 Occasionally
 ☐ 4 Frequently
 ☐ 5 Almost always

STATEMENT		RATING				
1	I exercise on a regular basis.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2	I make and keep preventive and necessary medical and dental appointments.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3	I have a job or regular volunteer activity that is gratifying.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4	I do not use tobacco products.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5	I do not consume alcohol or use drugs.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6	I get an adequate amount of sleep each night.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7	I have a hobby or recreational activity I enjoy and spend time doing.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8	I eat at least two to three balanced meals a day.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
9	I have at least one person in whom I can confide (tell my problems, discuss my successes).	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
10	I take time to do things that are important to me (e.g., church, garden, read, spend time alone).	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
11	I am optimistic and have a healthy outlook on life.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
12	I have personal goals and am taking steps to achieve them.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Total

Assessment results

12-24 You are at extremely high risk for personal health problems. It is important for you to talk to your personal health care provider as soon as possible. Remember, you can only provide good care for someone else if you take good care of yourself.

37-48 You have room for improvement. Assess where you experience challenges and seek help from family, friends, or professionals and make some changes.

25-36 You are at moderate risk for personal health problems. Talk to your health care provider or others who can help you create and stick to a plan to take better care of yourself.

49-60 You are doing very well at taking care of yourself.

Adapted from *Caring and Coping, A Caregiver's Guide to Parkinson's Disease*, published by the Parkinson Foundation, 2016. Original version adapted from "Checklist for Caregivers: Do you take care of yourself?" Bass, D.S. 1990, *Caring Families: Supports and Interventions*, p. 35, National Association of Social Workers



Take some steps that will help you stay healthy:

Eat a balanced diet

Eat a balanced diet of lean meats, fish, fresh fruits, and vegetables, along with whole grain breads, cereals, and dairy. Unprocessed, whole foods are better choices (these are the foods you find if you were to only shop the outside aisles of the grocery store). Stay away from unhealthy snacks such as potato chips or cookies.

Follow Canada's food guide at food-guide.canada.ca

Move your body

You may want to schedule short but regular periods of exercise into your day. Aim for 30 minutes, three times a week and gradually increase to every day, if and when possible. Choose a variety of forms of exercise. You may decide to walk one day and then bicycle the next day. Yoga is a great option as it will help stretch tired and stiff muscles, improve breathing, and decrease the effects of stress on the body.

Follow Canada's movement guidelines at participation.com

Prioritize sleep

Take steps to get a good sleep every night. That time is crucial for your body to regenerate itself and revitalize for the day to come. Many care partners do not get enough sleep, and this impacts their health and the way they manage their caregiving tasks. Just as a new mother may sleep when her newborn sleeps, you may want to consider napping when the care recipient naps. Try to avoid napping too late in the day as this will further disrupt your nighttime sleep.

You may also want to consider sleeping in another bed or room (if you normally would have slept in the same room and bed) to allow you to fully relax during the night. One of the non-motor symptoms of Parkinson's is REM-sleep behaviour disorder (or RBD). This is when someone with Parkinson's physically acts out their dreams. This can result in them possibly waking you by flailing or shouting, or unintentionally hitting or otherwise harming you during the night. It is absolutely necessary for your safety that you sleep separately if this is an issue.

Explore more care partner planning and assessment tools at
parkinson.ca/carepartners



parkinson.ca



1-888-664-1974



support@parkinson.ca





How to develop good sleep habits

- Maintain consistent sleeping and waking times, and do this every day, even on weekends.
- Establish a comforting bedtime ritual that helps you relax before bed.
 - ◆ Turn off the television. Remove it from the bedroom. Bedrooms should only be used for sleep and sex.
 - If weaning yourself off the television-before-bed habit is challenging, try substituting relaxing music in its place.
- Invest in a good mattress and pillow; create a relaxing and comforting sleep environment.
- Keep noise and light levels low. If you need a reading light, buy a book light.
- Maintain a slightly cooler temperature at night. You will sleep more comfortably.
- Keep pets off the bed, and ideally, out of the room.
- Avoid strenuous exercise, alcohol, caffeine, nicotine and heavy foods within four hours of your bedtime.
- Condition yourself to not check the clock all night.
- Limit your use of prescription sedatives (if you use them) to a two-week period.

If you still find that you are feeling overwhelmed with your caregiving responsibilities, you may want to assess your care partner burden level. You can do this using the care partner burden calculator on the next page. This scale measures your experience of burden. If, after completing this worksheet, you rated higher than you expected, you may wish to seek out the services and support of a social worker to assist you in managing your care partner burden and mitigating any risks to your own health and well-being. You can get additional copies of the care partner burden calculator at parkinson.ca/carepartners.

Care partner burden calculator

Rate each item below from 1 (never) to 5 (almost always) according to how often you feel this way. Add all the numbers you have selected to determine your results.

☐ 1 Never
 ☐ 2 Rarely
 ☐ 3 Occasionally
 ☐ 4 Frequently
 ☐ 5 Almost always

I feel my care recipient...		1	2	3	4	5
1	Asks for more help than they actually need.	☐	☐	☐	☐	☐
2	Takes up so much of my time, there's none left for me	☐	☐	☐	☐	☐
3	Behaves in a way that is embarrassing.	☐	☐	☐	☐	☐
4	Makes me angry.	☐	☐	☐	☐	☐
5	Makes the future look bleak.	☐	☐	☐	☐	☐
6	Depends on me too much.	☐	☐	☐	☐	☐
7	Causes me additional strain and stress.	☐	☐	☐	☐	☐
8	Affects my relationship with other family members in a negative way.	☐	☐	☐	☐	☐
9	Has needs that mean less privacy for me.	☐	☐	☐	☐	☐
10	Has impacted my social life in a negative way.	☐	☐	☐	☐	☐
11	Makes me embarrassed to invite others over.	☐	☐	☐	☐	☐
12	Attempts to control me.	☐	☐	☐	☐	☐
13	Expects a lot from me, and me alone.	☐	☐	☐	☐	☐
14	Doesn't understand the financial burden placed on me as a result of providing them care.	☐	☐	☐	☐	☐
15	Doesn't know that I am exhausted and cannot take care of them for much longer.	☐	☐	☐	☐	☐

Total

Assessment results

15-30 Little to no burden

Your experience of the burden is manageable.

31-45 Mild to moderate burden

Your experience of the burden is somewhat stressful.

46-60 Moderate to severe burden

Your experience of the burden is increasingly stressful and may have an impact on your health.

61-75 Severe burden

Your experience of the burden is extremely stressful and puts you at a high risk of stress-related health issues.

Adapted from the FTLDA Caregiver Burden Scale; Zarit, S.H. et al (1980).





Chapter 3: Living alone with Parkinson's

Stay active – physically and mentally

Stay engaged – personally and socially

Identify hazards around the home – lower your risks

Know who to call on

Prepare for the future

Care partners: This chapter is primarily written for people living with Parkinson's who do not have a primary care partner. Even so, you may still find a lot of valuable information here. Topics such as the benefits of exercise for people with Parkinson's, strategies to reduce the risk of falls, advance care directives, and more can help you better understand what supports and approaches may benefit someone with Parkinson's.

Many people with Parkinson's are their own care partners. This is because many more people today are living alone, without a primary care partner, than ever before in our history. Caring for yourself when managing a condition has become the norm rather than the exception.

What does that mean to the person with Parkinson's? Naturally, a newly-diagnosed person with Parkinson's may experience a great deal of uncertainty and fear as they look to the immediate and long-term future. They may also experience feelings of helplessness if they ponder the question of their future ability to care for themselves as their Parkinson's progresses. Because Parkinson's is a chronic and progressive condition, those fears may persist for years, and even decades, especially if the person's support system and social network is limited.

Most people with Parkinson's manage to cope fairly well with their circumstances, even when they live alone. But as the condition progresses, it presents additional challenges that need to be addressed and more risks that need to be mitigated.

Insightful planning and being proactive in your efforts to improve your quality of life can help alleviate much of the uncertainty you may be feeling and help you to build a network of support that will sustain you throughout your journey. Here are a few tips to get you started.

Stay active – physically and mentally

There is not enough that can be said about the benefits of exercise and getting your body moving vigorously to help you manage the symptoms of Parkinson's. Exercise has been shown to have potential neuroprotective effects. It is an important contributor to improved balance, strength, endurance, flexibility, and walking. Research has even shown that it is good for the non-motor symptoms of Parkinson's, such as low mood, as well as being a non-medicinal way to alleviate the constipation that often predates and accompanies the condition.

Research shows that exercise improves so much more than one's physical capacity – it has positive effects on cognitive functional capacities as well. This stresses the importance of 'working out' both your body and your mind. A multi-site study demonstrates that high-intensity exercise three times a week is not only safe, but slows the progression of the condition and the worsening of symptoms for people with early-stage Parkinson's.

Motivation, or the lack thereof, may present an obstacle to doing any type of exercise. We all know that the motivation to work out, even for the best of us, can be fleeting. Joining an exercise group or sports team (e.g., boxing group, Zumba class, tennis club, etc.) can help you stay committed, and it may find you a 'workout buddy' who will help you stay motivated. Who knows... you may discover they need you to get them going just as much as you need them!

And remember, the body is not the only thing you need to keep active. You can exercise your mind and mental abilities by reading, doing puzzles, and other mental exercises. Begin writing and contributing to a journal of your experiences. Keep a log of your symptoms and progression. Stay engaged in social and personal relationships that will stimulate your mind and keep it sharper for longer, bring you joy and contentment, and improve your overall quality of life.

Stay engaged – personally and socially

Staying engaged personally and socially are basic human needs. We all need to feel connected to significant others, to a group, or to a community that cares about us and for whom we care. According to Abraham Maslow, in his 1943 paper, “A Theory of Human Motivation,” humans have five basic categories of needs, and they form a hierarchy beginning at the bottom with physiological needs such as the need for food, water, shelter, and sleep. Somewhere in the middle – the third need up in the pyramid – is the need for love and belonging. This includes the need for an intimate relationship with a significant other, as well as a connection to family and friends.

This need may be fulfilled, even if you live alone with Parkinson's, by staying engaged in your already existing relationships, and avoiding isolation which can trigger depression and worsen your Parkinson's symptoms. Find ways and avenues for interacting with people, including others with Parkinson's. Here are some ideas:

- **Consider joining a support group**, or communicating with others online through email or social media. Join online forums and contribute your thoughts, feelings, and life hacks. You never know who you might be helping or inspiring
- **Keep working for as long as you can.** Speak to your employer about disability accommodations as your condition progresses
- **Volunteer in your free time** – if you have any – to help others who have Parkinson's or are newly-diagnosed. You have much to contribute to the improvement of quality of life for yourself and others
- **Join a book club or an exercise group** which will help you with your symptoms while opening you up to the possibility of meeting new and like-minded people

Identify hazards around the home – lower your risks

Your home ought to be your sanctuary, but with a Parkinson's diagnosis, it may present hazards that increase your risk of injury. People with Parkinson's are generally at a greater risk of falling due to walking and balance issues. Falling will complicate your condition and possibly put you in hospital. Being in hospital brings yet another set of challenges relating to your medication dosing schedule and the fallout of not getting your medications on time, every time.

Minimizing your risk of falling

- Check your floors for improper or rough transitions from one type of flooring to another and have them fixed or replaced
- Remove any floor mats that slide and fix/replace any wrinkled areas in your carpeting
- Remove any furniture that is unnecessary and causing clutter, especially coffee tables that you may bump into and throw you off-balance
- Rearrange your furniture so you have clear pathways through your living spaces
- Move or lift all wiring off the floor and secure them to the walls
- Install better and brighter lighting everywhere, especially over stairs and in walk-in closets
- Install nightlights in your bedroom, hallway, and bathroom
- Resurface stairs with a non-slip material or surfacing
- Install an additional handrail along the stairs to provide you with support on both sides
- Declutter any closets that might cause you to fall or have something fall on you
- Change any handles on your kitchen cupboards that might catch your clothing as you walk by and cause you to lose your balance
- Install a slip-prevention mat in your shower or bathtub
- Install grab bars in your bathroom next to the toilet and on the wall of your shower or tub

- Use a shower seat or bench so you can sit while showering or bathing
- Install a comfort height toilet or a raised toilet seat with strong armrests
- Remove any wheels or coasters from the legs of your bed or chairs to stop any movement that may occur when you get in and out of them
- Place satin sheets on your mattress to ease your turning over and getting out of bed
- Add bedrails to the side of the bed so you have support when getting into and out of bed



- Carry a cordless telephone or cell phone with you at all times, inside and outside your home
- Check your smoke alarms and carbon monoxide detectors to be sure they are working properly
- Invest in a monitored fall detection device that contacts 911 should you fall or need emergency assistance. Installing a lockbox – and providing the monitoring company with the code – near your front door with a spare key inside will allow first responders to be able to enter your home to help you, should you not be able to get to the door to open it yourself
- Check other areas of your home for issues that need to be remediated to prevent you from falling and injuring yourself:
 - ◆ Clutter in, or cracks in the floor of, the garage
 - ◆ Bumps or cracks in the driveway or walkways
 - ◆ Irregular surfaces or potholes in the lawn
 - ◆ Tree roots that have risen through the lawn
 - ◆ Interlocking brick that is loose or raised
 - ◆ Steps that are cracked, tipped, or loose
 - ◆ Patio railings or handrails that are loose

Safety around the home isn't just about the home. It's also about you. Here are a few steps you can take to improve your overall safety:

- Select clothing with clasps, snaps, magnets, or Velcro® to facilitate dressing
- Swap your high-heeled shoes for flats or ballet-style shoes for easier walking and better security
- Wear slippers that have non-slip soles
- Don't carry around anything that impedes your line of sight (i.e. boxes, bags, etc.)
- Take regular bathroom breaks to prevent having to rush to the bathroom

Visit Parkinson Canada's website or contact us to learn more about preventing falls and access home safety resources.

 parkinson.ca  1-888-664-1974  support@parkinson.ca

Know who to call on

Although you may be living alone with Parkinson's, your personal network of family and friends is a fountain from which you can draw, when you need it. Know who can and is willing to do what. Create a contact list with details of what each person is willing to assist you with and when they are available to help. It may take the form of driving you to and from certain appointments; it may be mowing your lawn one day a week. Don't hesitate to accept offers of assistance when they are presented. Others want to help, so let them. The key to maintaining a balanced and healthy support network is acknowledgment of their efforts and kind acts of gratitude. What that looks like is up to you, your resources, and your abilities.

When it comes to your health, keeping a detailed contact list of all your health care providers is essential. Use the table at the front of this book to jot down all the information you will need. Place copies of the contact list contained within, in several easily-accessible places. You can place this book on your bedside or coffee table. You can place copies of the contact list on your refrigerator, on your desk at home (if you have one), on your bathroom mirror, and by your telephone (if you have a landline). If you have a cell phone, be sure to enter all this information into your contacts list.

If you don't already, get to know your neighbours. Speak to them about your circumstances, and if you trust them, provide them with a spare key in case of an emergency. Exchange contact information such as home, work, and cell numbers. Let them know your routines so they can be watchful of anything out of the ordinary. Ask them to check in with you from time to time. And, remember to acknowledge and show appreciation for their support.

Prepare for the future

Living with Parkinson's affects each minute of every day. The condition progresses differently for everyone, but typically, it does so slowly. That doesn't mean that you have plenty of time to get your affairs in order. It is not wise to wait until an emergency requires you to make pressured decisions and quickly produce necessary documentation. The question that often begs to be answered is, "When is the best time to plan?" The answer is always, "Now!"

Take the time to reflect on your future health care preferences. Speak to family or friends you trust. Speak to a financial planner or lawyer regarding your care wishes, resources, and disbursement of property after death. This is especially important to avoid serious issues should you become incapacitated and unable to make decisions for yourself.

For example, you may want to remain at home and age in place despite the stage of your Parkinson's. That might mean instructions regarding home care nursing and end-of-life care. You may want to have pain medications ceased when you reach a certain stage; you may want to express your desire to pursue life-extending treatments; or, you may choose to sign a Do Not Resuscitate order (DNR).

Property is another thing to consider. Who would you like to leave your home to? How much of your investment portfolio will go to each of your children, or to that favourite niece? These and many other questions will need to be answered.

You will need to put all your wishes into writing to ensure they are respected and carried out. The paperwork you may need to complete includes a properly executed will, a power of attorney for personal care (POAPC) and a power of attorney for property (POAP). Depending on the province or territory that you live in, you may also need an Advance Directive. In Canada, there are two types of Advance Directives: (1) an Instructional Directive, and (2) a Proxy Directive.

An Instructional Directive is a document that states what and how health care decisions are to be made on your behalf when you are unable to make them yourself. This document is also known as a 'Living Will.'

Alternatively, a Proxy Directive is a document that names your substitute decision-maker (SDM) – someone you trust who will make the decisions for you based on your wishes – when you are unable to do so yourself. This type of directive is also known as a 'Durable Power of Attorney for Healthcare.'

By taking the necessary steps now to plan ahead, you will decrease any stress you may be feeling about your future. You will also have prevented any possible future conflicts for the people who care about you should they ever be put in a situation where you are unable to express your wishes.

For more information on these and other planning documents, please see Chapter 9: Planning ahead and decision-making, and visit the websites of your respective provincial Attorneys General.



Chapter 4: Making life easier

Getting organized

Communicating with health care professionals

Your partner's general health

Your partner's energy levels

Parkinson's symptoms, exercise, and activity

Changes in how you and your partner communicate

Changes in and around the home

Safety considerations

Skin protection

Parkinson's is unique to every person who has it. It takes skill and patience to know when to assist with a task and when to simply allow the person more time. This section offers tips and strategies to manage each day as it comes.

Getting organized



The shoe that fits one person pinches another; there is no recipe for living that suits all cases.

Carl G. Jung



A Parkinson's diagnosis means you will need to get yourself organized, if you aren't already. There will be many medical and health appointments that you will need to take them to, as well as sort, store, and refer to reports/documents that you may be given. Being organized will help you avoid potential pitfalls. It will improve your ability to manage and care for the person with Parkinson's.

There are many practical tools and supports that exist to help you with this. Explore Parkinson Canada's website to get connected with the tools and supports that can help you maintain records, manage medications, monitor symptoms, and address the needs of the person with Parkinson's and your own. With the right tools and supports, you will soon find that it will ease your workload. Keep these tools accessible in case of an emergency.

To help prepare you for any potential life-changing events, use the What-if plan, where you can complete a series of what-if statements that will prompt you to consider some possible events in your life. Along with the person you care for, you can then formulate effective responses/actions for each. There are several statements to start you off, but then there is room in the template for your own personal What-If statements.

Explore more care partner planning and assessment tools at
parkinson.ca/carepartners



parkinson.ca



1-888-664-1974



support@parkinson.ca



Communicating with health care professionals

Open, direct, and respectful communication with any health care professional is very important. They depend on you and the person living with Parkinson's to provide them with relevant information at each visit so that they can provide and recommend appropriate supports and treatments. With the person you are providing care for, decide in advance of the visit what needs to be shared with the health care team so that nothing is forgotten. Advocate for the person living with Parkinson's, if need be, to help contribute to better health outcomes.

You may also need help and support, yourself, with such things as knowing how and when to administer medications, adapting your home to mitigate the risks of falls, knowing how to transfer someone into and out of the car or bed, and understanding how to manage

Parkinson's non-motor symptoms such as hallucinations, delusions, depression, anxiety, or any other mental health or mood issues.

Prepare a list of questions before each visit to the family physician or other health care providers. Working with a full complement, interdisciplinary team will make things easier for you and your care recipient. If that's not possible, ensure that each member of the person with Parkinson's multidisciplinary team is aware of any changes or new needs that have arisen.

Building a comprehensive, interdisciplinary health care team is a goal that people with Parkinson's and their care partners should strive toward. Here are the types of providers that can make up a care team:

- Primary care physician
- Neurologist or movement disorders specialist (MDS)
- Nurse practitioner or nurse specializing in Parkinson's
- Pharmacist
- Physiotherapist (PT)
- Occupational therapist (OT)
- Speech-language pathologist (SLP)
- Psychologist or psychiatrist
- Social worker (SW)
- Registered dietitian
- Massage Therapist
- Personal support/home care worker

Visit the Parkinson Canada website or contact us to learn more about building your care team.

 parkinson.ca  1-888-664-1974  support@parkinson.ca

If any of the members of your health care team need to know more about Parkinson's, refer them to the Parkinson Canada website where they can get the answers to their questions along with other valuable information.

Open communication is essential. Your ability to communicate with health care providers may influence treatment options and health outcomes. In fact, some health professionals insist that a care partner be in the room at each visit. Those who have Parkinson's will often say they are 'fine' when they are not. The person living with Parkinson's needs you to share the whole truth about their condition, their symptoms, and their needs. This will help the health care professional address the issues with greater awareness and understanding.

It is important to make sure the person with Parkinson's feels empowered to speak and advocate on their own behalf. Encourage them to be open, honest, and express their needs and concerns, if they can. Be there to support their communications and to add your own observations. Ask honest and direct questions. If you cannot get all your questions answered at one visit, ask if you can contact the clinic to have them answered over the phone, on a virtual call, or through email.



Integrating a person-centred care approach

Palliative care is often misunderstood as being only for end-of-life — but in reality, it ideally begins at the time of diagnosis and continues through all stages of a condition. It offers holistic, person-centered support within any setting and ensures both the individual with Parkinson's and their care partner remain central in decision-making. Read the 'Palliative care' section in **Chapter 9: Planning ahead and decision-making** to learn more about how palliative care optimizes quality of life.

Take the time to get to know the entire care team. Learn what each team member's role is in the care and treatment of the person with Parkinson's. Understand the services they provide and how that helps the person living with Parkinson's.

These health care professionals can teach you how to provide better care to the person living with Parkinson's. As the condition progresses, the symptoms will increase and worsen. Ask the team members for guidance and techniques to properly perform tasks like lifting, transfers, and bathing. Learn skills that will build your confidence in the role you have in caring for someone.

Three out of four people with Parkinson's do not receive their medications on time when staying in a hospital or visiting an emergency department. This may result in complications and a longer hospital stay. You can be ready for such events by preparing ahead of time. Contact Parkinson Canada to find out more about the tools and resources available to you.

Your partner's general health

People with Parkinson's may have other health conditions, too, and they all require regular medical management. They may get a cold or the flu, develop a bladder infection, or be diagnosed with arthritis, diabetes, a heart or lung condition, cancer, or other ailment. Be proactive in caring for all health concerns, not just Parkinson's.

Parkinson's is not a condition in which the symptoms change quickly. It is slow progressing. If sudden changes occur, this may indicate the existence of another medical problem such as an infection. See your primary care physician right away. If you wait, the results may adversely affect their Parkinson's. The emotional stress, worry, and anxiety can also worsen their symptoms.

Some things to consider:

- Parkinson's medications tend to cause dry mouth, which can result in dental health issues
 - ◆ Visit the dentist or dental hygienist at least twice a year
 - ◆ Stay on top of their oral care at home and encourage more frequent brushing and flossing
 - ◆ Switch to an electric toothbrush and water flosser
 - ◆ Add adjunctive home therapies such as an antiseptic mouth rinse or a rinse for dry mouth
- Diet can affect the symptoms of Parkinson's. Although there is no one special diet for people living with Parkinson's, here are some general recommendations that can help:
 - ◆ Encourage them to drink 6-8 glasses of non-caffeinated fluids a day
 - ◆ Encourage them to consume high fiber foods such as fresh or frozen fruits, vegetables, and whole grain pasta and bread
 - ◆ Protein can interfere with the absorption of some Parkinson's medications, so talk to your specialist, nurse, or pharmacist about medication timing and meals

- Blood pressure
 - ◆ Parkinson's and some Parkinson's medications can cause sudden drops in blood pressure that result in dizziness when the person sits up or stand up (i.e., orthostatic hypotension)
 - ◆ Have the doctor test for orthostatic hypotension by measuring blood pressure in prone (laying flat), sitting, and standing positions
- Skin cancer
 - ◆ People with Parkinson's are at a higher risk of skin cancer
 - ◆ Apply sunscreen before going outside
 - ◆ Point out any skin changes to their doctor and have their doctor check/monitor any skin changes of concern

Your partner's energy levels

Many people with Parkinson's experience excessive daytime sleepiness. They report a loss of energy and chronic fatigue, which may be disruptive to planned activities and schedules.

Consider the following:

- People with excessive daytime sleepiness feel fatigue during the day and then have poor quality sleep at night. Adding regular exercise to the routine will help improve the quality of nighttime sleep and daytime wakefulness
- Lower energy levels of people with Parkinson's will increase fatigue, so schedule fewer activities each day
- Breaking up tasks and activities with rest periods in between will also help reduce feelings of fatigue, as long as the rest periods are not too long (or they, too, will impede proper nighttime sleep)
- Remain flexible in your scheduling and respond to how the person with Parkinson's is feeling each hour of each day. If you need to postpone or cancel activities, then do so.
- Have a back-up plan if a scheduled activity falls through
- Make sure that any travel plans include enough rest periods to accommodate the needs of the person with Parkinson's
- Encourage the person with Parkinson's to avoid tasks that require significant coordination, focus, and attention, especially when fatigued to avoid accidents or falls

Parkinson's symptoms, exercise, and activity

Staying active is important for people with Parkinson's. In fact, people with Parkinson's, who start exercising earlier, experience a significantly slower decline in quality of life than those who start later. Regular exercise can help combat muscle stiffness, posture changes, and weakness; reduce balance, walking and other mobility issues; and even alleviate constipation, which is commonly seen in people with Parkinson's.

You can encourage regular exercise and activity in the following ways:

- Establish a regular exercise routine early on. Offer to join them for a walk, bike ride, or visit to the local gym
- Allow independence as much as possible and be patient, as it will take them longer to complete tasks
- Provide assistance when needed. Parkinson's symptoms can fluctuate throughout the day, so your care recipient will need more help at some points throughout the day and less at others
- Remind the care recipient to move around or change position at least once an hour. Loss of automated movements can make them less inclined to move and cause pressure sores
- Suggest the pursuit of hobbies and activities. Parkinson's can cause apathy and loss of motivation. Find ways to prevent this
- Seek a referral to a physiotherapist for recommendations on an exercise regime and monitoring



Changes in how you and your partner communicate

Communication challenges

Parkinson's can impact communication in many ways. Several motor and non-motor symptoms can affect the person with Parkinson's ability to process, comprehend, and respond to what is being said.

At some point, most people with Parkinson's experience a softened voice volume and it may be difficult to hear them. Loss of automatic facial expression (or masked face) can be misinterpreted as boredom, anger, or sadness. Mood changes in Parkinson's such as apathy, depression, or anxiety can also affect communication. The following tips can make communication easier.

- Have conversations one-on-one or in small groups in order to pause during the conversation and allow the person with Parkinson's time to form their thoughts and words
- Reduce or remove any distractions or noises from TVs, radios, or music so there are no obstacles to communication
- Sit close to the care recipient so it's easier to hear them when they speak, and they can focus on what you are saying, too
- Encourage the person with Parkinson's to take a deep breath each time they are about to speak to enhance the volume of their voice
- Give the person with Parkinson's time to respond or participate in the conversation as their thoughts, as well as their movements, are slowed by Parkinson's
- Don't make any assumptions. People with Parkinson's are no longer able to express their emotions through their facial muscles, so their feelings can be hard to read
- Monitor their mood. Mood changes can be symptoms of Parkinson's, especially depression or anxiety
- Seek referrals to a speech-language pathologist to help with their voice and assess swallowing, if needed

Cueing strategies

Parkinson's impacts the ability to perform movements that are usually done automatically and without conscious thought. As the condition progresses, someone with Parkinson's will experience smaller and less automatic movements. Parkinson's can also result in an inaccurate perception of movement size and quality, so they may not fully recognize these changes. You can use cues to help the person whom you care for move more easily. Simple cues can make the brain less dependent on its automatic systems and reroute messages so movement improves.

- Keep your instructions short and simple:
 - ◆ "Stand tall," if posture becomes too flexed forward
 - ◆ "Big steps," to decrease shuffling when walking
 - ◆ "March," when turning to keep knees high
- Repeat cues on a regular basis



Physiotherapist

Ask the doctor for a referral to a physiotherapist who can tailor cueing strategies to individual needs; in particular, ways to help with walking challenges, including freezing episodes.



Changes in and around the home

Even simple, routine tasks can become more challenging as Parkinson's progresses. These suggested changes can make home tasks easier to perform:

- Move frequently-used items in the bedroom, kitchen, and bathroom to places where they can be readily accessed
- Label drawers, cabinets, containers, and boxes to easily identify their contents
- Use electric shavers and power toothbrushes to make hygiene tasks easier to perform on their own, or with assistance from you
- Substitute Velcro® closures for buttons on shirts, cuffs, waistbands, and other clothing to make them easier to fasten, and purchase shoes with Velcro® instead of laces
- Ask for a referral to an occupational therapist for a self-care or independence assessment

Safety considerations

As a care partner, it can be hard to recognize changes that occur slowly over time in the person with Parkinson's. If symptoms begin to significantly affect mobility, memory, or thinking skills, it may be time to consider if it is still safe for the care recipient to perform tasks that he or she once did easily as part of their daily routine.

While each person experiences Parkinson's differently, there are still some commonalities. It is important to recognize that even familiar tasks can become difficult or unsafe. Making necessary changes can be difficult for them, so it is important for care partners to acknowledge these losses and offer support as needed. Here are a few examples:

Driving

The loss of flexibility in the neck and trunk along with reduced reaction times, and cognitive changes affecting the ability to multitask, may affect a person's driving ability and safety. Though it may be difficult to raise the subject, it is important to be realistic and seek medical advice and input if you notice any of these changes.

Use of power tools

The person living with Parkinson's may have been a do-it-yourselfer. Tremor, combined with balance and coordination challenges, can impact the safe use of power tools, even if they were used a great deal in the past. Decreased strength, slowed reaction time and a lack of control can add to existing safety concerns. Consider all these factors when helping the care recipient determine if they should be using power tools at all.

Kitchen appliances

Cooking is often a multi-step process, and a person with Parkinson's may begin to have difficulty managing kitchen tasks, such as cutting foods safely. Balance changes can make opening a refrigerator or oven door difficult; not to mention carrying a pot of boiling water very dangerous. Falls can occur when attempting to reach high or low shelves or carrying objects from counter to table and back. You may need to modify how the care recipient participates in the preparation of meals, and in the kitchen, in general.

Climbing

Reductions in balance control and protective reflexes increase the risk of falling for people with Parkinson's. Attempts to climb ladders, step stools, or other apparatus should be avoided altogether. This may change which tasks one can perform in and around the house.

Explore more care partner planning and assessment tools at
parkinson.ca/carepartners



parkinson.ca



1-888-664-1974



support@parkinson.ca



Occupational therapist

Ask the doctor for a referral to an occupational therapist who can conduct safety assessments and make recommendations on safer ways to carry out daily activities.

Skin protection

Parkinson's symptoms can impact the skin. People with Parkinson's have an increased risk of developing melanoma – a type of skin cancer linked to sun exposure. The person with Parkinson's may also have more difficulty changing positions, which can result in skin breakdown. Consider the following recommendations:

- Avoid the hot midday sun and seek shade when outside
- Make sure to apply lots of sunscreen to their skin and provide them with a hat and sunglasses
- Avoid skin contact with plastic coating and tapes from incontinence products which can irritate their skin
- Help them change positions – whether seated or lying down – every two hours to avoid pressure sores
- Check their skin regularly for redness, blisters, and/or open sores
- Use lotion to prevent dryness
- Consider an egg-crate foam or alternating pressure mattress pad to reduce pressure points





Chapter 5: Medication management

Medications – On time, every time Medication swallowing problems

Managing medications is one of the most important aspects of caring for someone with Parkinson's. Medications are central to treatment, but the schedules, doses, and side effects can sometimes feel overwhelming. As a care partner, your role in supporting safe and consistent medication use can make a real difference — not only in how well symptoms are managed, but also in creating a smoother, less stressful daily routine. By understanding the basics of Parkinson's medications and working in partnership with health care providers, you'll be better equipped to support your loved one's independence and quality of life.

Medications – On time, every time

Receiving their medications on time is crucial to the effective management of Parkinson's for those who live with the condition. Providing medications late can lead to greater difficulties for them, and it can take days and even weeks for them to recuperate from this setback. You need to remain organized to ensure they get their medications on schedule.

Consider the following:

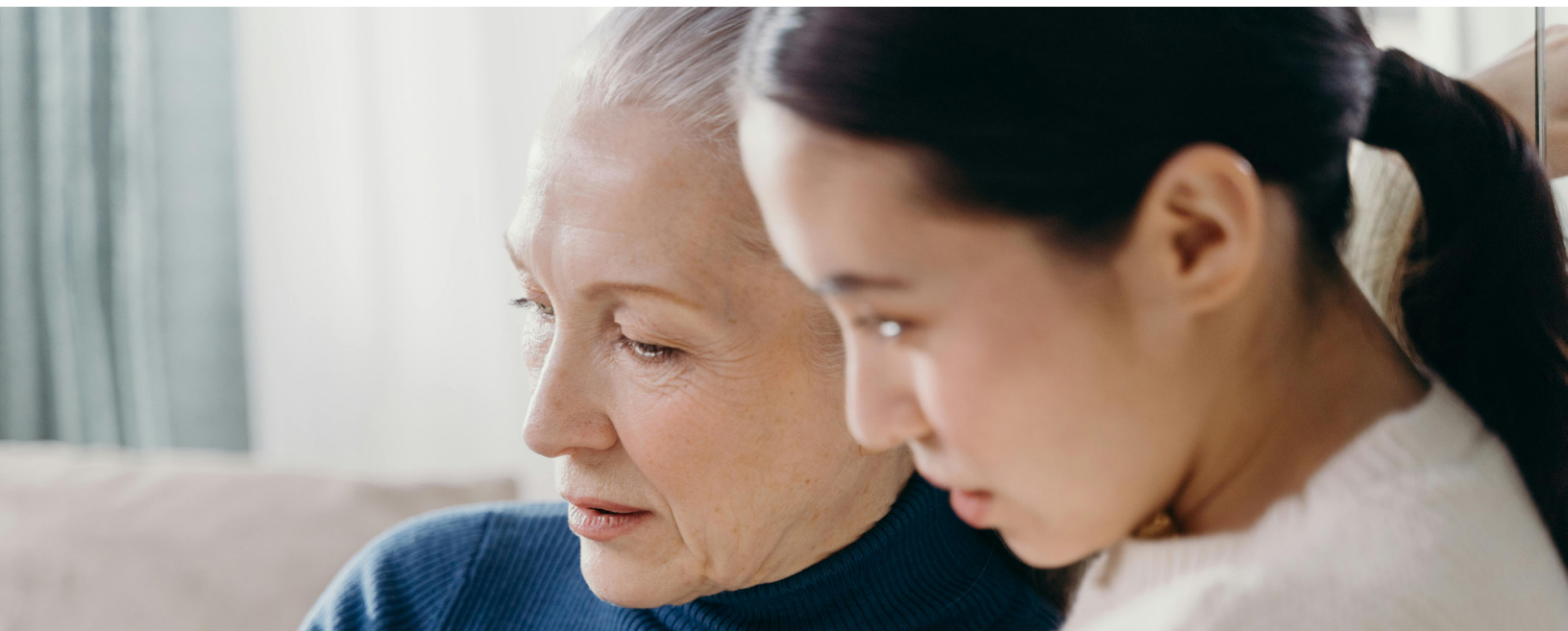
- Complete the various forms and use the tools for medication management on Parkinson Canada's website to ensure the medication and other information is up-to-date and accurate
- Share this information with anyone else who may occasionally be responsible for providing care
- Organize medications in a pillbox
 - ◆ If dosing is more than 4 times daily, then consider purchasing additional pillboxes to meet their needs
- Store additional medications in a secure place where they cannot be mistaken for food
- Set reminder times for dosing by using a...
 - ◆ Cell phone
 - ◆ Watch
 - ◆ Kitchen timer
- When the alarm sounds, stop what you are doing and give the medication right away
- When away from home, carry pills with you
- Check with the neurologist or primary care physician before adding new prescriptions or over-the-counter medications or supplements to their regimen
- Avoid any multi-symptom, over-the-counter medications such as those for colds and flu
- Do not suddenly stop the Parkinson's medications for any extended period of time

Medication swallowing problems

Swallowing changes seen in Parkinson's may result in difficulty taking pills. Since the majority of medications to treat the condition are in this form, this presents issues.

- Offer sips of water before giving pills
- Provide ample fluid to reduce swallowing problems and enhance absorption
- Avoid giving Parkinson's medications with pudding or ice cream as the protein content in them will interfere with the absorption of the medications
- Drop the pills into applesauce for easier swallowing, but check first if the particular pill is allowed to be crushed or dissolved
 - ◆ If not, then add it whole
 - ◆ If they cannot swallow whole pills, then consult with their primary care physician for options such as orally dissolving tablets
- For more serious issues with swallowing, consult with a speech-language pathologist for an assessment

There are many practical tools and supports that exist to help you with this. Explore the Parkinson Canada website to get connected with the tools and supports that can help you maintain records, manage medications, monitor symptoms, and address the needs of the person with Parkinson's and your own.





Chapter 6: Caring from afar

Secondary care partnering How to help a primary care partner Long-distance care partnering

Parkinson's affects the entire family, not just the person with Parkinson's. Whether you live in the same house as the person living with Parkinson's, or on another continent, Parkinson's and its impact can be felt. This section deals with that impact on family care partners who do not live in the same areas as the person with Parkinson's or those who do live in the same place, but would be considered secondary care providers. Share responsibilities with the primary provider of care and organize yourselves so no one person is responsible for everything.

Secondary care partnering

If you are a secondary care provider, your role will never be as demanding as that of the primary care provider — who may also be a spousal care partner, sibling, adult child, relative, or friend of the person with Parkinson's. However, your role comes with its own unique rewards and challenges. Whether you are providing support from afar or acting as back-up when the care partner needs time off, there are many ways you can support both the person with Parkinson's and the care partner.

The following ideas will need to be adapted to your individual family and financial circumstances.

Call every week

Set a designated day and time, and make the call consistently. Inquire about both the person with Parkinson's and the care partner. Make sure to include some topics not related to Parkinson's or caregiving to stay connected on multiple levels. Consider using FaceTime® or WhatsApp® for video calls so you can see each other. Just be there to listen.

Provide support and assistance

Many people will not ask for help — monetary or otherwise — no matter how dire their circumstances. Inquire tactfully but clearly if expenses are a problem and then offer a plan that can work for everyone. You could provide a regular monthly subsidy or cover a specific expense every month, like medications or a service that relieves the care partner of one or more chores (e.g. house cleaning, yard services, snow plowing, or other services).

Send a care package

Try to tailor the surprise to the individual to make it more special. It might be a bouquet of favourite flowers, a magazine subscription for a personal interest, or a gift card for a spa or dinner out. In any case, buy them something that they value and that will bring some relief and pleasure. Be creative. Never underestimate how much a personally-written thank-you note can mean to a care partner whose work goes mostly unrecognized.

Visit the person with Parkinson's

Budget funds and schedule time for regular visits. Find your own way to and from the airport and book a hotel room if quarters are cramped at the home of the person with Parkinson's. Your trip should not add to the workload, responsibilities, and strain of the care partner. Make the goal of your visit to provide a listening ear and a helping hand. Spending time with the care partner and the person with Parkinson's will give you a firsthand look at the specific challenges and issues they face and help you think about how to be involved.

Try to schedule at least one of your visits when the person with Parkinson's has an appointment with the neurologist. This will allow you to better understand the current medical status, see how the doctor, person with Parkinson's, and care partner interact and add your own valuable observations. During your visit, remember to ask about the health of the care partner. Are regular check-ups and screenings being overlooked because of caregiving responsibilities? Consider coordinating a visit so the care partner can schedule their own doctor, dentist, and other health care visits while you stay with the person with Parkinson's.

Provide respite

If you cannot fill in personally, find other options and offer to cover the costs, if possible. There may be free or low-cost services available that the primary care partner didn't know about. Many people who care for someone with Parkinson's say that their role started much earlier in the course of the condition than anyone else realized. If the person with Parkinson's can travel, invite them to visit you. This allows them to get all your attention and enjoy a change of scenery, while the care partner enjoys a welcome break from their caregiving routine.

Support decisions

Express your support for the health care team's care and safety recommendations. It is important that one feels that they are following through with good decisions, such as using a walker, accepting help from a personal support worker, wearing a medical alert bracelet, or making the decision to stop driving a motor vehicle. And, if the time comes when your care recipient needs to move to a long-term care facility or hospital, affirm the difficult decision. Be respectful of the fact that you are not the primary care partner and are not providing the day-to-day care. You may not fully appreciate how challenging the caregiving responsibilities have become. Always keep in mind that your goal and that of the primary care partner ought to be synchronized and focused on doing what is best for the person with Parkinson's as well as the people whose lives have been most affected.

How to help a primary care partner

It can sometimes be hard to know how best to help. You may wonder whether your support is welcome, or notice that the primary care partner prefers to handle many responsibilities themselves. These moments can feel challenging, but there are positive ways to contribute. Use the strategies mentioned above and keep in mind a few common situations where extra awareness can make your support even more helpful.

Understanding the reality of the condition

Many care partners will say that the person with Parkinson's is at their best when at a doctor's appointment or having visitors. What you see when you visit may be quite different from the daily reality. Research has found that people caring for someone with Parkinson's provide an average of 14 hours of care daily. This shines a light on how little time the care partner really has for themselves. Recognizing this difference in perspective can help you approach conversations with more understanding and empathy.

Sharing advice thoughtfully

Family and friends who aren't involved in daily care often bring a valuable outside perspective. This can be helpful, but it's most effective when shared with sensitivity. Instead of giving direct instructions, consider offering ideas in general terms, using "I" statements, and waiting until your input is invited. This keeps conversations supportive rather than overwhelming.

Respecting the care partner-care recipient relationship

The relationship between a person with Parkinson's and their primary care partner is often built on many years of shared routines, habits, and ways of doing things. For example, a spouse may have long managed certain tasks in a particular way. Respecting those established patterns, rather than trying to change them, helps preserve dignity, reduces frustration, and maintains harmony for everyone involved.



Communicating with the primary care partner

- Always listen to what is being said instead of thinking about what you are going to say next
- Be careful of what you say through email or text as these forms of communication are missing the non-verbal cues that enhance face-to-face conversations
- Do not expect any of the health care team members to speak to you if they have not received direct and express consent from the person with Parkinson's, or from a POAPC (Power of Attorney for Personal Care)
- Offer assistance to the primary care partner and wait for them to provide you with ways in which you can help
- Not all problems can be resolved, so, sometimes, all you can do is be patient and provide a listening ear, or a supporting shoulder

Long-distance care partnering

Many long-distance, primary care partners enter this role because the care recipient doesn't want to leave their home or familiar environment. This is understandable and very common. However, Parkinson's is a progressive condition, and the degeneration will mean that at some point in time, the person with Parkinson's may need in-home care or relocation to an assisted-living or long-term care facility.

Unless you can visit frequently, or have friends and relatives who can assist and report back to you — or you have the resources to hire a personal support worker — you may need to move the person with Parkinson's closer to you to ensure that they receive adequate and consistent care. And since travel can become more difficult as Parkinson's progresses, a move should be discussed earlier rather than later.

If the care recipient lives alone, consider making daily check-in calls or have a friend, relative, or neighbour check on them each day. You may wish to alternate the check-ins with them. Set your calls/visits for a specific time and be consistent. Have the person with Parkinson's consider wearing an emergency alert device as the risks of falls are higher for people with Parkinson's.

Educate yourself

Learn all you can about Parkinson's and/or the atypical parkinsonisms. Familiarize yourself with the motor and non-motor symptoms, the medications used to treat the specific conditions, their side effects, and other current treatments. You must be well-versed to help meet the needs of the person you care for. An occupational therapist can assess the person with Parkinson's needs and provide helpful strategies for managing their activities of daily living.

Stay in touch

If you cannot move the care recipient closer to you, stay in touch with them regularly. Communicate with their local care providers on a regular basis, too. If the care recipient's needs change, you will need to understand what that will mean to them and their care. You may need to have their medications reviewed or their care visits increased. It may mean higher costs. Staying on top of the situation will mean better planning as the future becomes the present.

Be kind to yourself

Long-distance care partnering has added challenges and can be emotionally draining. Make sure that you, too, have a solid support system in place.



Communicating with a long-distance care recipient

- Have any legal documents and forms properly signed by the care recipient so you are able to make decisions and ensure they get the care they need
- Talk about many things when you have conversations with the person with Parkinson's. It should not always be about the condition
- If the goal is to move the care recipient closer to you as the condition progresses, then have those discussions earlier rather than later. Be considerate of their feelings and encourage a mutually-agreeable decision
- Try to offer care suggestions and recommendations that allow as much autonomy as possible for the person with Parkinson's. Remember that they are and have been self-sufficient and have made decisions for themselves their entire adult lives. Choices come with responsibilities. Provide choices that do not put them or others at risk





Chapter 7: Paid help

Time to get help

Where to find help

Hiring in-home care providers

Using an agency or hiring privately

Preparing paid care providers

Respite care

Rehabilitation and Parkinson's

Far too often, long-term care partnering that transitions to caregiving happens without proper knowledge or support. Don't let this happen to you! Engage outside, third-party help early in the process to make it easier to add other resources as the condition progresses. This section will also help you decide when to get help, where to find it, how to effectively use paid caregivers, and when to begin to consider moving out of the home and into an appropriate care setting.

Time to get help

You cannot meet all of the needs of the person with Parkinson's all of the time. This becomes increasingly true as the condition progresses. As the person's needs change and increase, you must continually re-evaluate your ability to meet those needs, as well as how this might be affecting you and your own needs.

One of the first ways to relieve some of the stress of providing care is to add others to the mix. Take advantage of your personal network of friends and relatives. Asking for help may be hard for you. Consider trading tasks. When someone asks if or how they can help, have a list of ideas to suggest. Even occasional help can provide needed relief.

The best time to research home care options and other help is before those options are needed (i.e. an emergency or the condition has progressed so much that you can't meet the care recipient's needs). Making well-thought-out decisions early on will help prevent rushed decisions later when getting help becomes a necessity.

"There is at times a need to withdraw from feelings which are so painful and raw. I try to focus on something else, put on my protective shell and separate. Respite for a while is essential. I need a day off to replenish and recharge so that I can carry on with renewed resolve and energy. I frequently reassure him that my love for him has not changed. He needs to know this."

Diana – Ottawa, Canada



Integrating additional help

- Know how to contact outside resources, if needed
- Prepare for any illness or temporary disability on your part by including others in the care plan
- Discuss the emergency plan with the care recipient
- Maintain contact lists for health care providers and others who may need to be consulted
- Make sure everyone knows their part and their role in the care of the person with Parkinson's
- Take the time to train helpers if they don't know enough about the condition or the care recipient's needs

Be realistic — be prepared

If you are asked to promise to keep the care recipient at home, affirm that you are committed to doing this for as long as it is safe and practical to do so. Support this decision, but keep in mind that as the condition progresses, so do the risks of falls and injuries, both for the person with Parkinson's and for you.

In the later stages of Parkinson's — as well as with the atypical parkinsonisms — many people need more help with their own movements or activities of daily living. This will mean more heavy lifting and more challenges for you as the care partner. If you have to break your promise because of this, you may experience feelings of failure or that you betrayed their trust. To avoid this and to prepare properly, discuss the possible scenarios well in advance of the need. Talk about alternatives that may become necessary and encourage them to tell you which scenarios are most acceptable to them.

Sometimes, people with Parkinson's refuse to let anyone but their care partner provide help. Or, if there is outside help, they may insist on having their primary care partner present the entire time. This may be due to cognitive changes, medications, or an overall sense of fear or mistrust. Have a meaningful and direct conversation with them. Tell them what may happen to them if something happens to you. With resolve and continued exposure to the third-party care, the person with Parkinson's will eventually begin to trust and may even enjoy their interactions with this new care provider.

When it becomes too difficult to balance your own needs with those of the one you care for, your responsibilities will have to change. Their safety, as well as yours, will be at stake. Get the outside help you need right away.

Where to find help

In Canada, home care is organized by each province and territory, which means services can look quite different depending on where you live. Some regions may provide certain types of in-home personal care or equipment at no cost, while others may not. In most cases, an assessment is needed to determine what kind of help is available and how many hours of care will be publically funded. Because publicly funded care often doesn't cover everything, many families also choose to add private services to meet their needs.

In-home care providers

There are many home health care service providers in each province or territory. These agencies provide non-medical services and support for people who are at home and require assistance with personal care, housekeeping, or simply for companionship. Their services may be utilized for short- or long-term periods. If your province has provincially-funded home care services, there will likely be a cap on the number of hours of help you can receive. Your personal insurance plan (if you have one) may cover additional service hours. Otherwise, these types of services will be out-of-pocket expenses.

Hiring in-home care providers

There are specific traits you should be looking for when hiring in-home care providers. They must be able to perform all of the caregiving tasks you need accomplished, while being someone with whom the care recipient feels comfortable. Select carefully and be sure it is the right person for you — and for them.

Many people will use a reputable home care agency, which may provide personal support workers or nurses. A home care agency does the screening work for you, to ensure that a person is qualified, bondable, trained to deal with Parkinson's, and that issues around contracts are addressed. They may be able to send a different employee when one does not work out, or if one is sick, to ensure fewer gaps in the day-to-day care.

Some people might prefer to hire privately for certain hours of the day, or wish to have live-in help. It is important that you consider all the aspects of employing a paid care provider.

Here are some tips to help you out:

- List and define your needs and those of the care recipient
 - ◆ Do you need help with their bathing?
 - ◆ Do you need respite care a couple of times a week?
 - ◆ Do you need someone at night to help while you get uninterrupted sleep?
- Develop a job description and related responsibilities
 - ◆ Include a list of household, personal care, and leisure activity tasks
 - ◆ List all personal preferences as well (i.e. non-smoking household, hours of work, types of meals to be prepared, etc.)
 - ◆ Discuss this with the agency or company from which you are hiring the service provider

- ◆ Evaluate the worker based on this description, and terminate employment if it is not being followed
- Consult with the right person about legal, financial, and tax issues
 - ◆ Check with your insurance regarding your homeowner's policy for property damage, theft, and personal injury
 - ◆ Ask if your automobile policy will cover the homecare worker if they drive the car to run errands or take the care recipient to appointments
 - ◆ Understand employment laws and protect yourself from potential issues
- Screen and interview candidates carefully
 - ◆ Have a suitable questionnaire ready for phone screenings
 - ◆ Set up in-person interviews with the most promising ones
 - ◆ Have the job description and responsibilities ready for the interviews
 - ◆ If you don't feel the person is suitable, then let them know shortly after the interview
- Check references and backgrounds
 - ◆ When hiring from an agency or company, they will have done that, and you may request that information
 - ◆ If hiring privately, it will be up to you to do the investigating
 - ◆ Ask for at least 2-3 work and personal references

Check them thoroughly — ask pre-prepared questions

- Get the paperwork signed
 - ◆ Provide your selected candidate with a contract of your terms and conditions (if hiring privately). This should include pay rate, method of payment, hours of work, days of work, benefits, provisions, rules and termination requirements
 - ◆ Provide a copy of all necessary paperwork to the selected candidate

Using an agency or hiring privately

There are pros and cons to consider when deciding to use an agency or hire in-home caregiving help privately. Here are some important things to consider:

Administration

Hiring privately requires you to do all the legwork of running ads (online or in local papers), screening applicants, doing reference checks, ensuring the person is eligible to work in Canada, doing the payroll, paying taxes and deductions on their behalf, along with many other tasks. Agencies do all this for you and have access to information you may not.

Fill-ins

If a privately hired personal support worker becomes ill or has an emergency of their own, you are left to deal with finding someone to fill in. This will take time and tap your resources. Agencies can usually provide a back-up person relatively quickly.

Bonding

This is an insurance policy that protects both the employee and the employer against financial loss. Agencies usually bond their employees. Privately hired support workers may not be bonded. If you have private home or renters' insurance, you will need to check with your insurance provider to check whether your plan includes this type of coverage.

Accreditation

For many families, the most important factors in choosing an agency are the safety of the care recipient and the quality of care. One way to assess this is by checking whether the agency is accredited. Accreditation means a third-party authority has reviewed the organization and confirmed that it meets high standards and follows best practices. While it doesn't guarantee a perfect match for every family, it does provide added reassurance. In Canada, some common accrediting bodies include Accreditation Canada, CARF, ISO, FOCUS Accreditation, and the Canadian Centre for Accreditation.

Cost

In most cases, hiring privately will cost you less than going through an agency because of all the additional work and services that the agency provides.

Consistency

When you hire privately, you may choose to have them sign a yearly contract so the care recipient can enjoy the consistency of being cared for by the same person for a length of time. Agencies may not always be able to provide the same support person. You may find that having different support workers brings variety in personalities and can make social interactions more engaging. At the same time, not every match will be the right fit. Be sure to exercise your right to request a change if desired.

Preparing paid care providers

Part of your job when you hire an outside support worker is to take your care recipient through an orientation process that includes familiarizing the support worker with their particular needs. Only then can you feel comfortable leaving them in someone else's care.

Explore more care partner planning and assessment tools at

parkinson.ca/carepartners

 parkinson.ca  1-888-664-1974  support@parkinson.ca



You will also want to lay down the ground rules for what you want done, how you want it done, the boundaries and limitations, and a review of pertinent information.

Among other things, you will want to:

- Demonstrate how tasks should be done
- Share information about household routines
- Review emergency procedures and contacts
- Review the care recipient's routines, needs, and preferences
- Outline budgetary procedures and expenditure tracking

Keep in mind, even seasoned support workers may not know very much about Parkinson's and the unique set of needs, challenges, and symptoms that the person with Parkinson's may have. Provide the support worker with print and online information and have them review it.

Getting to know the care recipient

Once the support worker learns what they can about Parkinson's, it's time for them to get to know the care recipient. Take the time to discuss their particular needs and challenges and how they may be able to better deal with them. Explain your insights about the care recipient's occupation, favorite hobbies, likes and dislikes, and daily routines. Include information on family, friends, and health care providers that the person with Parkinson's visits.

Make a care plan

Collaborate with the support worker and the care recipient to create a care plan. Identify and discuss the care and support needs and the steps that are to be taken to address them. Write these instructions down for reference and a reminder. Revise as necessary. Having a simple outline of the regular routine is especially helpful when dealing with agency staff that may be unfamiliar with them, but are skilled in providing personal care. Ensure the support worker understands what the person with Parkinson's is accustomed to doing/having daily.

Stay in touch

If you are not living in the same home as, or near the care recipient, you will need to communicate with them and the support worker regularly. Make sure to ask about any changes that may be occurring. Change the care plan as needed. Evaluate the care recipient's relationship with the support worker. Voice any concerns about the quality of care being provided. Remain calm and be respectful during any conversation of this type. It may be necessary in the future to have a written record of the exchange, so after a conversation, follow up with an email or text to the care provider – and their supervisors if you are using an agency – summarizing your concerns, the support worker's responses, and action items. Follow up to make sure that the problem has been addressed.



Communicating with paid support workers

- Use short, concise sentences with common vocabulary for better understanding
- Focus discussions on the work, not the person, when addressing actions or behaviours of the support worker
- Use 'I' statements and avoid using "You always" or "You never"
- Provide regular, meaningful feedback and praise
- Ask for feedback and suggestions from the support worker
- If you need time to think about something, take it. You don't need to respond too quickly

Make expectations clear

When the person with Parkinson's spends time with a paid care provider, a bond is formed. It is important that it is nurtured, but at the same time, the support worker must maintain professional boundaries. They should not be involved in familial or financial conversations or decision-making. While your role as a care partner is much more involved, for the support worker, it is a job.

Respite care

Respite care involves short periods of relief from your care partnering duties. It is often short-term and temporary care provided so that you can take a break from your daily routine.

Care partner strain has a cumulative effect on the health of the care partner. To maintain your physical and emotional health and provide the best care you possibly can to the person with Parkinson's, you will need to take breaks from the long hours of caregiving. Respite care enables families to take time off – a few hours, or even a few days.

Informal respite care

You can receive a break from your caregiving duties by training a couple of willing friends or family members to fill in for you. You should try to have more than one person trained in case one is not available or something comes up.

Formal respite care

There are two forms of formal respite care: in-home and out-of-home services. Depending on the type, the needs of the care partner, and available funds, the services may include some or all of the following:

- **In-home respite care:** A bonded employee of an agency comes to the home and generally stays with the person for 24 hours a day, for the number of days you require or for a few hours at a time. In-home care involves assistance with the activities of daily living, such as dressing, eating, bathing, and the likes. These support workers can also be called companions, personal support workers, or aides. They often work for themselves privately or through an agency. This type of care is generally more expensive and is not covered by provincial plans. However, there may be tax credits available for caregiving. Ask your accountant about any tax credits that may be available to you.

- **Out-of-home respite care:** Respite is provided by support workers and others trained in this type of care. It takes place outside the home of the person with Parkinson's. There are two subtypes:
 - ◆ Adult day programs, which involve community-based, daytime social and recreational programs provided in safe, secure group settings. They are often held in community centers, places of worship (i.e. churches, synagogues), health care institutions, and other such facilities. Most programs offer health-related services and medication reminders. Adult day programs offer care partners a respite from the demands of full-time caregiving for someone who needs constant supervision. Services and fees vary from program to program and from province to province. They may include the following:
 - Transportation to and from the program
 - Meals and snacks
 - Assistance with, or supervision of, eating, walking, toileting
 - Exercise programs
 - Socialization and peer support
 - Social work services
 - On-site or on-call nurse
 - ◆ Residential facilities often offer rooms for short-term respite care.

Benefiting from respite care services

Beyond the immediate relief that respite care provides you as a care partner, there are several other benefits:

- Relaxation and peace of mind, and a renewed sense of humour and energy
- Stability in emotions and confidence in coping with the daily responsibilities of caring for someone with Parkinson's
- Involvement in community activities and decreased feelings of isolation
- Time off to enjoy a family vacation or just time spent alone doing the things you like
- Enrichment and nurturing of your own growth and development

“So much energy is required to keep all the pieces together for me and for him; frequent fatigue; emotional and physical. But I do occasionally have a day when there is more energy and when I can actually feel happy.”

Diana – Ottawa, Canada



Seeking respite services in your community

When seeking out respite services, ask yourself the following questions:

- What type of service(s) do I need?
- What do I plan to do during the respite period?
- How far in advance do I need to make respite care arrangements?
- Do I want to have in-home or out-of-home services?
- Are respite services available in and funded by my province or territory?
- Does an agency provide the services I need?
- What are the costs, and what payment arrangements can be made?
- What is the training and experience of the care providers?
- Are the care providers familiar with the needs of people with Parkinson's or do they require further training?
- Who supervises the care providers in my absence?
- Does the program require current health information?
- What procedures do they have in place in case of emergencies?
- What are the limitations of the service provided?
- Does the program provide transportation, meals, snacks, or other needs?

Rehabilitation and Parkinson's

Skilled rehabilitation therapies — including physiotherapy (PT), occupational therapy (OT), and speech and swallowing therapy (by a speech-language pathologist) — can help a person with Parkinson's maintain or re-stabilize functioning and offer helpful safety instructions for the care partner.

These types of skilled therapies are provided in multiple health care settings, as well as private practice. Some provincial health systems and most personal health insurance plans will cover all or some of these expenses, depending on the specific circumstances. Check with your primary care physician and private insurance company (if you have a plan) to see if your care recipient is eligible for coverage. Otherwise, these will be out-of-pocket health care expenses.

Inpatient rehabilitation

Large, dedicated rehabilitation facilities may offer inpatient rehabilitation stays as well as all other levels of rehab treatment facilities. These tend to focus their efforts on rehabilitation after acute injuries or surgeries, and even fewer are qualified to deal with Parkinson's. Some facilities may provide intensive day therapies, while some may have weekly appointments. To qualify, the person with Parkinson's must meet specific criteria related to their ability to participate in and benefit from multiple daily, intensive therapy sessions. Cost coverage will depend on whether the rehab is required after an injury (i.e. injury due to falling) or if it is preventive (i.e. fall prevention programs).

Outpatient therapy

Outpatient therapy is provided in a community clinic setting, so the person with Parkinson's must be able to leave the home and attend therapy. They may receive physical, occupational, or speech therapy, based on their specific needs. A person might be eligible for intensive day rehab; they may attend shorter weekly or biweekly appointments; or may be followed periodically.

In-home therapy

When there is a particular acute need (e.g., recovering from a broken hip after hospital discharge), there may be an opportunity for in-home therapy. In-home therapy usually refers to physician-prescribed rehabilitation therapy for patients who are home-bound and unable to travel to an outpatient therapy setting. In some areas, there may be the opportunity to hire a physical therapist privately for home visits, but this is usually not covered by provincial health care plans.



Chapter 8: Advanced Parkinson's

What is advanced Parkinson's?

Plans and scheduling

Movement challenges

Getting up from a fall

Dressing

Mealtime, swallowing, and unintended weight loss

Bathroom routines

Mind, mood, and dementia

Managing pain

Activities at home

Travel and transportation

Rest and sleep

Despite the challenges that advanced Parkinson's presents, there is still a lot that you can do to make life easier and more enjoyable. In this section, you will find tips and strategies on providing the best care possible. There is also information that may be helpful to professional care providers who work in the home.

What is advanced Parkinson's?

Advanced Parkinson's — with or without significant motor changes — includes serious cognitive impairments, including dementia, which impact a person's ability to perform tasks independently. Everyone with Parkinson's is different and will have a unique set of symptoms that progress at different rates. However, there are several scales used in research and by health care providers to measure how severe the condition has become and how far it has progressed. Generally speaking, advanced Parkinson's is described as when a person with Parkinson's is no longer physically independent.

This describes a person who has serious problems with mobility and cannot complete the activities of daily living all on their own. Cognition changes — specifically dementia — are also a hallmark of advanced Parkinson's with or without mobility impairment.

Each person with Parkinson's is unique, so any suggestions provided in this chapter will have to be modified to the particular needs and situation. It is strongly recommended that you seek to build an interdisciplinary team of professionals in your area to help you on this care partner journey.

Plans and scheduling

Care partners are busy people. Being organized and establishing a daily routine will help you save time and energy, while still providing the best care possible.

General tips

- Prioritize what needs to be done each day
- Stick to a daily routine that brings comfort and predictability
- Schedule rest time for yourself within the daily routine
- Write down the daily routine so it can be performed by others if you are unable to
- Use a calendar, planner, or some type of record for all appointments
- Maintain to-do and shopping lists and organize errands (or ask others to help)
- Store items in bins and label them so you can easily find what you need when providing care
- Make time for both of you that does not involve any caring for them
- Research options for home delivery of goods, groceries, medications, and household supplies

Record important information

- Use Parkinson Canada's and other Parkinson's organization's tools to keep accurate and up-to-date records of symptoms, medications, dosages, schedules, appointments, treatments, recommendations, contacts, etc.
- Keep paper and pens handy and by the phone to record messages and information
- Keep accurate and current records on financial and insurance information
- Review various Powers of Attorney documents to ensure they are up-to-date and readily available if needed
- Make sure a trusted family member or friend knows the location of important information in your absence

Movement challenges

It is essential to address your care recipient's physical and mobility challenges. As Parkinson's progresses, you will likely need to provide greater hands-on care and assistance. You will also have to learn safe and effective ways to provide help without injuring yourself or the care recipient while doing so. Talk to the health care providers for referrals to a physical and occupational therapists. These providers are trained in assessing needs and developing the best methods for the situation.

Standing and sitting

When at home, make sure that the care recipient uses a chair with sturdy arm rests and a stable sitting base. Avoid soft, low seating or upholstery such as velour or velvet which can make movements more difficult to perform. You can also raise seat height by adding an extra cushion to the chair or using a folded blanket.

To guide the care recipient out of a chair, talk them through the Nose-Over-Toes method. Have them scoot their hips forward in the chair. Ensure they plant their feet firmly on the floor, slightly separated, and use their hands to hold the armrests before standing. Get them to lean forward — nose over their toes — and place the pressure and weight on their feet.

If you are assisting them, avoid pulling on their arms or legs as they try to stand. If they are having difficulties standing, use a transfer belt (these can be purchased from a medical supply store or your local pharmacy). Standing in front of the care recipient, use the transfer belt with both hands to assist the care recipient down into and up from a seated position. Agree on a count or signal to coordinate both your movements.

To sit, make sure the care recipient places both hands firmly on the armrests of the chair and leans forward as they try to lower themselves into the chair. Remind them to feel the chair on the back of both their legs before they attempt to sit down. This helps maintain a smooth, controlled movement and avoids 'crash landings' which can hurt their spine.

If the care recipient uses a walker, make sure they continue to use this device to assist them in turning to sit down. If the Parkinson's stage is more advanced, then they will likely be bedridden and you will need assistance with transferring them in and out of bed when needed.

Walking

Walking changes are very common in Parkinson's and can become more difficult to manage as the condition progresses. People with Parkinson's often need verbal reminders or cues to take longer steps as what were once automatic motions become more difficult to perform.

- Help them focus when walking as distractions can make walking and balance more difficult
- Remind them to take larger steps as they are more stable than smaller ones
- Keep your instructions and cues short and simple
- To prevent festination (short, rapid steps), provide a cue to stop and then start again with large steps
- To prevent or manage freezing (feet glued to the floor), avoid tight turns and remind the person to take larger steps
 - ◆ Count out or clap to a rhythmic beat
 - ◆ Use a visual cue such as a laser or your foot and ask them to step over it
- Position yourself slightly behind them when walking to assist them if they lose their balance
- Watch out for pets in the home as even healthy individuals can sometimes trip over them

An occupational therapist can help determine if a mobility device is necessary and what type of device would be most effective. Canes, walkers, rollators, transport chairs, and wheelchairs may all be mobility devices to consider at different stages of Parkinson's.

- The assistive device must be fitted by a professional to ensure safety and efficacy
- A rollator (walker with wheels) is often recommended as the most suitable and safe assistive device

Wheelchair

If mobility changes do not allow the person with Parkinson's to walk, a wheelchair may be necessary. There are many wheelchair options, and these options should be reviewed with an occupational therapist before deciding on the best one. Here are some tips:

- Have the wheelchair professionally fitted to the care recipient to ensure best posture, positioning, and comfort
- Lock the brakes when they need to remove themselves from, or sit into, the wheelchair
- Ensure the wheelchair fits through your home's doorways, halls and the bathroom

Getting up from a fall

Even with safety precautions in place, sometimes falls do happen. It is important to have prevention or back-up plans in place before a fall happens. Determine if there is a friend, family, or neighbour nearby who can help. Consider installing an emergency call button or other system to summon help when needed. Familiarize yourself with the system and how to use it.

It is also important to learn a safe method for helping the person with Parkinson's up from the ground while avoiding injury to you both. Work with a physiotherapist to prepare a system in case of a fall.

- Remain calm!
- Assess if the care recipient is injured or is able to attempt getting up
- Have them scoot to a solid piece of furniture (such as a heavy sofa or counter)
- Plan together what you will both do to help them get up
- Using the transfer belt, take a firm grip and aid them as they rise
- If you feel it is unsafe or you suspect an unseen injury, call for help!
- Keep them comfortable while you wait

Visit Parkinson Canada's website or contact us to access Parkinson Canada's fall prevention resources.

 parkinson.ca  1-888-664-1974  support@parkinson.ca

Dressing

Advanced Parkinson's can make daily tasks more difficult to perform. Getting dressed becomes a slower, more challenging activity and care partners often need to provide assistance.

Changes to clothing and the dressing routine can improve safety and reduce frustration.

General tips

- Schedule adequate time for dressing; rushing can make symptoms worse
- Consider scheduling dressing time when the medications are working well – ON-time, rather than OFF-time
- Assemble all items of clothing before beginning, to eliminate trips to the closet while you are dressing them
- Allow as much independence as possible
- Offer limited choices to encourage participation in the task
- Incorporate a few extra arm or leg raises to keep muscles flexible and build range of motion



Facilitating dressing

- Have them sit down while dressing to reduce the risk of falls
- Select the best position and height possible to reduce your back strain
- Choosing clothing that is easy to put on, and that is made of fabrics that slide on and off
 - ◆ Oversized clothing
 - ◆ Soft, stretchy fabrics
 - ◆ Elastic waistbands
 - ◆ Front openings
 - ◆ Front hook bras
 - ◆ Tube socks
 - ◆ Velcro® closures on clothes and shoes
 - ◆ Coats with zippers instead of buttons
 - ◆ Mittens instead of gloves
- Avoid velour and fabrics that create friction
- Put the stiffest limb in first and allow the others to bend and follow



Mealtime, swallowing, and unintended weight loss

Advanced Parkinson's often causes difficulty with eating and drinking because of movement and swallowing issues. You may find that you will need to change the type and texture of the foods you serve, along with the utensils they are using. You may even find that they need more help with eating to consume adequate nutrition. Assessments can be performed by a speech-language pathologist, a movement disorders specialist, or even the primary care physician.

General tips

- Schedule mealtimes during ON-times when medications are working best
- Consider investing in adaptive utensils and cups. There are no one-size-fits-all approaches!
- Ask for recommendations from an occupational therapist regarding the types of adaptive utensils
- Give small bites when assisting with eating
- Allow plenty of time for them to chew and swallow thoroughly
- Increase fluid intake during the day to prevent dehydration and drying of the mouth
- Always give food or medications while the care recipient is in an upright, seated position

Mealtime set-up

- Choose a quiet, comfortable place without distractions
- Use small pillows or cushions to support posture
- Place the plate and cup on an elevated tray if the care recipient has neck immobility or vision changes
- Protect their clothing with a napkin, apron, or protective bib
- Consider using dark dishes when serving light-coloured foods and light dishes with dark food to improve visibility
- Cut food into bite-sized pieces

Types of foods to serve

- Avoid tough, dry, crumbly foods that might be difficult to swallow
- Consider foods that can be cut into smaller pieces or finger-food portions to maximize their independence
- Select easy to chew and swallow foods, such as:
 - ◆ Lean hamburger or tender beef stew
 - ◆ Baked or broiled fish
 - ◆ Eggs served any way
 - ◆ Cooked vegetables
 - ◆ Soft fruits such as berries and melons
 - ◆ Rice, whole grains, and beans
 - ◆ Gravies, sauces, or butter-moistened foods
- If weight loss is a problem, serve high-caloric, but nutritious foods
- Ask for a referral to a dietitian to ensure an adequate and nutritious diet is followed

Beverages

- Ensure they drink at least 48-64 ounces (6-8 glasses) of daily, non-caffeinated beverages
- Encourage sips between solid foods while eating
- Shorten the length of straws to decrease the volume of liquid being taken in
- Serve foods of a higher liquid content, such as soups, flavoured gelatin, ice cream or sorbet, fruits, and vegetables

Mealtime fatigue

- Serve smaller, more frequent meals if they experience weight loss, low blood pressure, or fatigue
- Maintain their upright position for at least 30 minutes after each meal to prevent food aspiration

Swallowing difficulty

- Report suspected swallowing difficulties, coughing or choking to the primary care physician
- Ask for a referral to a speech-language pathologist for a swallowing assessment
- Get your CPR and learn how to perform compressions for choking
- After a professional assessment by a speech-language pathologist, a feeding tube may be suggested. Learn about the pros and cons of this option before you provide your informed consent
- Consult with the pharmacist and primary care physician if there are issues with swallowing medications



Unintended weight loss

Weight loss may occur with advanced Parkinson's. This is often due to difficulties swallowing, feeling full or bloated and improperly fitting partial or full dentures. Discuss your concerns regarding weight loss with the health care team.



Managing unintended weight loss

- Switch from 3 regular meals to 5-6 smaller meals, daily
- Switch to higher-fat milk, yogurt, sour cream, and cheeses
- Provide fruit juices in place of water
- Add butter, nut butters, gravy/sauces, and avocado to their diet
- Serve fruits that are canned in syrup or frozen with sugar
- Serve vegetables with cheese spreads, sour cream, dips, salad dressings, or sauces
- Serve a high-calorie nutritional drink in between meals, at least 1-2 times daily
- Choose drink supplements that are high-calorie, not high-protein (as this interferes with the absorption of medications)
- Blend and serve smoothies made with fruits, supplements, syrups, and dairy products
- Serve milkshakes made with whole milk, fruit, and full-fat ice cream
- Offer ice cream or frozen yogurt as snacks, topped with syrup or fruit

Bathroom routines

Bathing, toileting, personal hygiene, and grooming are basic activities of daily living, yet these become challenging, if not impossible, with advanced Parkinson's.

Toileting

- Create a regular toileting schedule to avoid accidents during the day or assist with constipation issues
- Limit fluid intake during the evening hours to avoid having them get up during the night
- Use a stool softener to help produce more regular bowel movements
- Avoid laxatives as these require more fluid intake
- Install an elevated toilet or place an elevated seat adaptor on the existing toilet to make sitting on the toilet, and standing after use, easier
- Install a grab bar next to the toilet to assist with sitting or standing
- Mark the floor with coloured tape to assist with finding the correct position in front of the toilet before sitting down
- Provide moist, flushable towelettes for additional hygiene after toileting
- Ensure the care recipient washes their hands thoroughly after toileting even if they have to do it while seated
- Consider purchasing incontinence pads or underwear to manage accidents more effectively
- Larger pads can be used on the bed if the problem occurs at night

Bathing

- Make sure the bathroom is warm
- Make sure grab bars are installed in all the right places
- Gather all supplies before you turn on the water
- Use a walk-in shower with a hand-held nozzle or shower head (if available)
- Use a tub bench or seat with a backrest for safety

- Use a non-slip mat to decrease the risk of slips or falls
- Adjust the water temperature before the care recipient steps into the bath/shower
- Rinse skin and hair well
- Wrap them in a bathrobe or towel after bathing, making sure to dry their skin thoroughly
- Use powders and lotions to ensure good skin care
- Consider a bed bath if immobility prevents them from getting to the tub or shower
- Only expose the part of the body being washed and dried
- Use hand-sanitizer gels and good hand-washing techniques throughout the day to maintain your hygiene

Shaving

- Use an electric razor
- Rinse the skin well with a wet washcloth and pat dry
- Apply soothing lotion

Oral Care

- Assemble needed supplies before you begin
 - ◆ Soft toothbrush or, even better, an electronic/sonic toothbrush to promote better oral health and support autonomy and self-care
 - ◆ Fluoride toothpaste, ideally one with stannous fluoride for higher efficacy
 - ◆ Small basin for rinsing (if they are not at the sink and you are aiding them)
 - ◆ Dental floss picks or floss threaded onto a floss wand (has a specialized handle used to facilitate flossing)
 - ◆ Non-alcoholic, antiseptic mouth rinse (ideally, one containing essential oils)
 - ◆ Oral swabs (sponges on sticks)
 - ◆ Small towel for quick cleanups
- Choose a place that is comfortable, like the kitchen or dining room where they can sit in a solid chair with arms

- Make sure the lighting is good, and sit or stand where you can see all the surfaces of their teeth
- Support them as they brush their teeth, or brush for them twice daily, and verbalize each step as you are about to do it
- Use the mouth rinse and the oral swabs in between meals to clean and freshen the mouth
- If there are swallowing issues, consider techniques that will decrease the amount of excess product in the mouth that the person may swallow inadvertently, such as:
 - ◆ Using small amounts of toothpaste rather than gels (gels tend to foam more)
 - ◆ Using a dry toothbrush prior to adding toothpaste (this lessens the amount of build-up and foam)
 - ◆ Brushing with an antiseptic mouth rinse, rather than toothpaste in between the morning and evening brushing sessions
 - ◆ Applying mouth rinse to the gums, tongue and inside of cheeks using an oral swab rather than 'swishing' or gargling with the rinse (especially if the person with Parkinson's has swallowing issues)

Mind, mood, and dementia

Cognitive changes, from memory changes to problem-solving challenges are something 50% of people with Parkinson's will experience. A broad-spectrum of cognitive changes can occur including slowed thought processes, forgetfulness, confusion, judgment issues, compulsive behaviours, paranoia, delusions, hallucinations, anxiety, and personality changes.

General tips

- Remain calm, smile, and be pleasant
- Speak at eye level and maintain eye contact
- Use the same cues each time to provide instructions
- Do not leave them alone as this can be dangerous
- Use humor to defuse stress and avoid using sarcasm or negative humor which can be misinterpreted

Slowed thinking

- Ask one question at a time
- Give them time to respond before continuing
- Ask closed-ended, either/or questions instead of open-ended
- Try giving hints if they are having trouble finding a word
- Use short, simple phrases to provide cues

Forgetfulness and confusion

- Cross the days off on a calendar as a visual cue to the day of the month
- Keep frequently needed items in a consistent place
- Note the daily schedule or special events using a chalkboard or whiteboard
- Use simple remote controls or cover unnecessary buttons with tape to decrease confusion
- Limit distractions to, or diversions from, the daily routine

Hallucinations

Hallucinations may occur with Parkinson's progression or as a side effect of the Parkinson's medications. The most typical form of hallucination in Parkinson's is visual, where the person sees or feels something that is not physically present. It is not a dream or nightmare, and occurs while the person with Parkinson's is awake. Hallucinations should be reported to the medical team. People with Parkinson's may or may not find these events frightening, but any changes to the type of hallucination should be tracked and further reported.

- Acknowledge their experience and let them see you understand
- Do not argue about it
- Make sure that any medications prescribed to treat the hallucinations are safe (visit parkinson.ca for a breakdown of medications to treatment to treat Parkinson's, including hallucinations)

Reactive behaviour and personality changes

People living with all forms of parkinsonisms may experience changes in personality, becoming anxious, moody, irritable, or aggressive, even if they were not like this before. Some people develop paranoia (an extreme distrust or suspicion that is not based on reality). Some behaviours, such as paranoia, may actually be side effects of certain medications, while others may indicate changes in cognition. At times, they may say or do things that can be hurtful to you as their care partner. It may be extremely difficult to accept or understand this new person; and it may cause you to feel helpless, sad, depressed, or anxious.

Share any observable changes in behaviour with the care team. Don't assume they are being stubborn, difficult, or intentionally hurtful. Remember, these behaviours are not part of who the person is or was. They are part of the condition.

Here are some tips on how to manage the care recipient if they exhibit changes of this type:

- Avoid confrontations or attempts to reason with the person with Parkinson's
- Attempt to change the subject or distract the person with another activity
- Suggest a coffee or tea break
- Try not to get angry or take things personally
- Speak in reassuring tones
- Consider the causes of the behaviour and see if they are simply hungry, thirsty, tired, in pain, frustrated, or bored
- Take a break yourself: "If you can't stop this now, we will try again in a few minutes" and walk out of the room (provided the person is safe). This gives you a moment to collect yourself, rather than react to the behaviour

Remember, they may be reacting to a trigger that you may not be aware of, so it's important that you observe when these episodes occur and what preceded them. However upsetting this may be to you, it's just as or more upsetting to them. The most important thing to keep in mind is your safety and theirs; so stay calm and stay safe.

Managing pain

Pain is often a symptom of Parkinson's and can be attributed to many causes. Complaints of pain should be discussed with the primary care physician or neurologist. Most people can safely take over-the-counter analgesics for the pain, but you must check with the physician on which pain reliever is best.

Here are other ways to help manage pain:

- Use heat to control pain by applying a microwaveable or air-activated heat wrap
- Use ice packs after acute injuries sustained during falls or other accidents to reduce swelling and pain
- Consider a massage to aid circulation and decrease muscle soreness
- Add cushions as needed for comfort and support
- Be aware that increased wandering, agitation or unexplained crying in people with some forms of dementia (including that associated with Parkinson's) may be a sign of pain
- See a physiotherapist for specific pain evaluations and additional recommendations

Activities at home

Advanced Parkinson's symptoms often decrease one's ability to participate in leisure activities and hobbies. Mood and thinking changes can also affect the care recipient's interest in participating in the daily routine. They may feel fatigued or have a loss of motivation to engage in things they used to enjoy. It is important to encourage physical, mental, and social activities whenever possible to maximize their mobility and quality of life.

Movement and exercise

Regular exercise helps people with Parkinson's retain flexibility, improve circulation, and maintain their ability to complete daily tasks. It is important to practice speech, too. If you do not have ample time to complete regular exercises and speech routines with your care recipient, enlist the help of someone who can take over – a family member, friend, or other care provider.

Work with the physiotherapist or occupational therapist to design an appropriate exercise program

- Work with the speech-language pathologist to design an appropriate breathing and speech practice program
- Encourage regular movements of the arms, legs, and neck as part of their daily routine
- Split the exercises into several short sessions
- Do some of the exercises during dressing or bathing

- Focus on maintaining large, exaggerated motions whenever possible
- Use small, inexpensive equipment like balls or balloons during exercise activities to help stimulate movement
- Have them stand or walk often, with assistance, to maintain leg strength and bone health
- Engage them in the activities that can be done to music, such as marching, dancing, singing, swaying, etc.
- Provide no more assistance than is necessary with daily activities and allow as much independence as possible without sacrificing safety or causing frustration to the person with Parkinson's
- Have them practice frequently-used words and phrases while focusing on maintaining loudness

Vision, thinking, and memory

Parkinson's impacts visual and thinking/memory skills and may alter the person's interests and abilities. Consider a visit to the optometrist to rule out any other causes of visual problems. Have the care recipient participate in familiar activities which may provide some stimulation and a sense of comfort to them.

- Stimulate their thinking skills by encouraging them to read or listen to the news or current events
- Place meaningful objects and pictures in clear view to inspire memories and encourage sharing of stories
- Play audiobooks for brief intervals to have them practice their focus
- Encourage visits from friends, family, and neighbors to offer companionship and stimulation each day
- Share TV viewing time of game shows, documentaries, or history programming to provide mental stimulation
- Play games or work on puzzles, and select ones that will not cause them frustration
- Involve them in small ways in your daily tasks, such as folding laundry, sorting the mail, reviewing the weekly flyers and specials, and so on

Travel and transportation

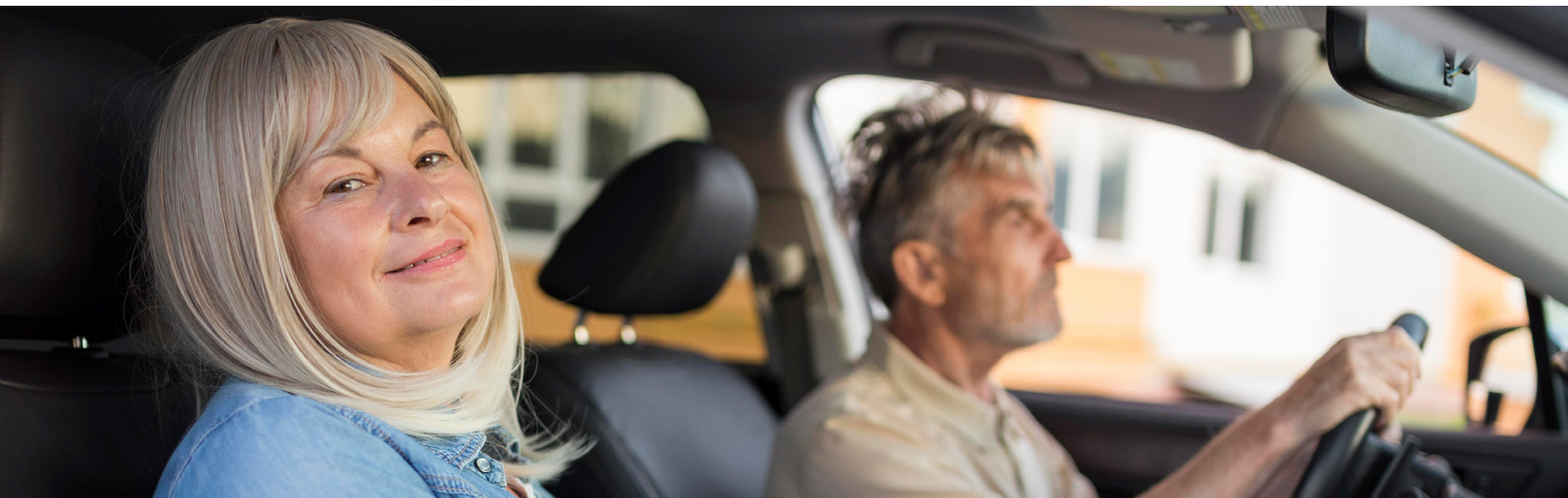
Leaving the home for medical appointments, family events, or other activities can be a cumbersome process for a person with advanced stage Parkinson's. These outings are sometimes needed, and often add to the quality of life of the person with Parkinson's; so, it is important to consider methods that promote safety and decrease care partner stress.

Traveling to medical appointments

- Try to schedule appointments at times when they are rested and their Parkinson's medications are working well (ON-period)
- If their energy is good, try to schedule a few appointments on the same day, especially if the visits are to the same clinic or medical facility
- Pack medication information and tracking tools in a bag along with their medications, snacks, and any other items they might need
- Make sure they are dressed for the weather and elements before leaving the house, and bring along a small shawl or blanket as feeling cold tends to be a problem with Parkinson's

Getting in and out of the house

- Make sure that outside stairways have sturdy railings in place
- Consider building a ramp if they cannot negotiate stairs or steps, especially if they rely on a walker or use a wheelchair
- Have outside pathways widened or repaved in a safe material



Travel by car

Your main form of transportation will likely be a car, so it is important to be comfortable and capable of getting them – and their assistive devices – into and out of the vehicle.

- Make sure they move close to the car and align their body properly before attempting to sit down in the car, and before they move their legs into the vehicle
- Place a slippery type of fabric (like a satin square or cushion) on the car seat to make it easier for the person with Parkinson's to move and get positioned
- Discuss both your needs with an occupational therapist
- There may be adaptive equipment that makes travel by car easier, some of which may be covered by provincial health care plans, and some may need to be purchased or rented
 - ◆ A portable handle can be placed at the side of the seat to act as an armrest, providing a support from which to push off during transfers
 - ◆ A seat belt grasp provides more ease when reaching across to grab the seat belt and put it on
 - ◆ A seat belt extender will make the belt easier to align and lock into place
 - ◆ A rotating seat cushion allows you to seat a person with Parkinson's, sideways with their legs outside the car, and then allows you to easily turn them while lifting their legs into the car
- Practice putting their walker or wheelchair into the trunk or back seat of the car. Make sure you can lift a walker/wheelchair before purchasing it (an occupational therapist may have other recommendations if you are unable to do so)
 - ◆ Learn how to lift it safely so you don't injure yourself while doing it
- Consider the type of vehicle you drive and if there comes a time when you will be changing it, consider one that provides you with more ease for travel
- Consider getting a walker you can fold or a transport wheelchair for outings as they are lighter, fold, and are more portable than standard wheelchairs

Accessible transportation services

If the care recipient requires a wheelchair for travel at all times, then consider contacting an accessible transportation service to get them to their medical and other appointments. Some operate as parallel public transportation systems, and some may be community-based. These services are available in many parts of the country and will often allow for a member of the family to ride along. Check your local area for more details.

- Learn about your local area's accessible transportation service
 - ◆ What their eligibility criteria are
 - ◆ What they will or will not do
 - ◆ What their wait times are like
 - ◆ How far in advance you have to book
 - ◆ How frequently they run
 - ◆ Where they will travel
- Keep the company's contact information with you

Travel by plane

Airline travel requires pre-planning. With possible security issues and overcrowding at airports, it's important to know and understand all of the details before you set out on any journey.

- Book ahead and ask to be seated in an aisle seat or bulkhead row if they need the extra space
- Make arrangements ahead of time with the airport for transportation and assistance to the gate
- Avoid checking in the walker or wheelchair with the luggage until you have the airport assistance
- Be prepared for travel delays and carry extra medications and other essentials in your carry-on bags
- Airlines usually permit priority boarding to those who require assistance, so use that opportunity to accept assistance right to your seats

Special events

While it may be difficult to get there, family events and other social activities can maximize the quality of life and help keep connections strong for the both of you.

- Make sure your destination is accessible and support is available during the event
- Enlist other family members or friends to help with transportation arrangements or support at the event
- Consider their energy level and routines to avoid fatigue
- Schedule a rest period before the event and make sure medications are working



Rest and sleep

Getting adequate sleep and rest is important to overall health and quality of life, for both of you. Parkinson's creates many challenges to a good night's rest, so if the care recipient is not sleeping well, it is highly likely that your sleep pattern is being disrupted as well.

Bed set-up

There are many things you will need to consider when designing the ideal sleeping arrangements for both of you.

- Choose a bed that is comfortable and conducive to sleep
- Consider getting twin beds or sleeping in separate rooms to ensure better rest for both of you
- Use a call button, alert system, or monitor to listen from another room
- Use a firm mattress to make rolling and movements easier for them
 - ◆ Avoid waterbeds or very soft mattresses
- Adjust the bed height to allow feet to reach the floor when they sit on the edge of the bed
- Obtain a side-rail or bed pole to use as a sturdy grip when they roll over or try to get into or out of bed
- Use satin sheets or a satin-based fabric square in the middle third of the bed to accommodate shoulders and hips and make movement easier
 - ◆ Avoid flannel sheets and the top sheet between the comforter
- Consider using a hospital-style bed which provides adjustments to height and has a secure side rail

Getting into bed

- Provide cues to help them align their body when getting into bed
- Make sure both their legs are up against the bed before sitting down
- Once seated, lean their upper body down towards their pillow
- Help them bring their legs up as they lie down
- Avoid having them crawl into bed

Getting out of bed

- Start by having them lie on their back looking up to the ceiling
- Bend their knees while leaving their feet planted on the mattress
- If they experience morning stiffness, move their knees side to side to improve flexibility
- Help them turn to their side using the side rail or bed pole if necessary
- Help them get their feet off the bed and begin to push up on the side rail or bed pole into a seated position
- Have them plant their feet and wait a minute before rising into a standing position, with your help if necessary
- Consult with a physiotherapist on proper techniques for transfers

Sleep environment

- Make sure they avoid caffeine several hours prior to bedtime
- Avoid watching stressful, loud, or disturbing television programs or news just before sleep
- Set the bedroom temperature at a comfortable level that is slightly cooler than room temperature
- Reduce interruptions and excessive noise at sleep time
- Use recorded nature sounds or white noise to achieve a more restful environment
- Darken the room as much as possible by using light-blocking blinds or turning off any lights that can enter the room
- Remove all objects that may create shadows or be misinterpreted as a person or animal
- Consult with the primary care physician if they experience tremors, stiffness, or mobility changes during the night that make it uncomfortable to sleep, or, if they experience vivid nightmares or hallucinations



Chapter 9: Planning ahead and decision-making

Be prepared

Maintaining important information

Power of attorney for personal care (POAPC)

Power of attorney for property (POAP)

Care facilities

Palliative care

Hospice care

Medical assistance in dying (MAID)

There are planning steps every adult should take, regardless of their health status. Aligning your wishes, values, and preferences with the medical care you receive is a right everyone should have. It is important to take time to develop these plans for both of you. Planning is even more important when someone is diagnosed with a chronic condition, and knows that their health could seriously decline and that they may not be able to make decisions for themselves. This section will help you discuss and prepare for the future. Start your planning whenever you are ready, but don't wait too long. The present is here, and the future is not promised.

Be prepared



Planning is bringing the future into the present so that you can do something about it now.

Alan Lakein



While no one can predict the future, planning ahead gives you the confidence to face different possibilities and the freedom to make choices that reflect your values.

If the care recipient has been newly diagnosed or is still functioning fairly well, it can be hard to imagine a time when they will need skilled nursing care or will not be able to make competent decisions. The best time to plan for these situations is now, before they occur. In fact, many people report a sense of relief, optimism, and better control of the challenges and decisions they face once plans have been made.

A good habit to develop is to periodically assess your care partnering situation to evaluate your strengths, and identify your weaknesses and personal limits. Here are some questions you and your care recipient may wish to address early on so potential disasters may be avoided:

- What areas of your caregiving are becoming too much for you?
- Are those areas emotionally or physically challenging?
- Who in the family or personal network can you call upon to supplement the care that you provide, so you can find some respite?
- How much longer can you continue to provide care for them, without sacrificing your own health?
- Have you planned for emergency situations that may come up?
- Do you know what to do and who to contact if an emergency situation occurs?
- Who would take over the care partnering role if you become unable to do so due to your own health crisis?
- What do you do if you have to leave your home due to a fire or other emergency?

The answers to these and other questions should go into your planning.

Maintaining important information

It is important to keep an up-to-date record of medical information and keep these records handy at all times. Parkinson Canada has tools to track medications, health care visits, and other information that first responders can access in an emergency situation. Contact Parkinson Canada to access these tools.

Keep health records in a location that is easily visible and accessible in case of an emergency. Place a copy in a travel bag and keep the bag close to your front door so it can be quickly grabbed if you have to leave in a hurry.

Important information includes but is not limited to:

- Date of last update to information
- Name, address, phone number, and date of birth of the person with Parkinson's
- Name, address, and phone number of the person with Parkinson's primary caregiver
- Contact information for the care physicians (primary care physician, neurologist, movement disorder specialist), as well as for other health care providers
- Other emergency contacts
- Current medications (prescription and non-prescription), dosages, frequency, and purpose of each
- Allergies
- Other medical conditions
- Power of Attorney for Personal Care (POAPC)
- Power of Attorney for Property (POAP)

Power of attorney for personal care (POAPC)

A Power of Attorney for Personal Care (POAPC) allows the person with Parkinson's to legally express their wishes about future health care treatments and designates a person – the substitute decision-maker (or SDM) – who will advocate for their health care wishes in the event that they become incapable of expressing their wishes directly.

It is highly recommended that all adults, regardless of their health status, create and sign a POAPC. Once completed, this document should be shared with the primary care physician, the substitute decision-maker, and family members so that everyone understands the person's wishes.

This document allows you to put your wishes into writing. This may include:

- Medical treatment, should you have a terminal condition and be unable to communicate your wishes yourself
- Life-prolonging procedures you do or do not want, such as:
 - ◆ Transfusions
 - ◆ Dialysis
 - ◆ Tracheostomies and artificial breathing
 - ◆ Tube feeding — whether nasal (through the nose) or gastric (directly into the stomach)
 - ◆ Emergency lifesaving interventions (e.g., CPR)
- Organ donation
- Disposal of remains

A substitute decision-maker can make decisions on behalf of someone who is unable to express their wishes or make their own decisions. They must be a legal adult who will be required to speak according to instructions specified in the POAPC. If that substitute decision-maker is unable to do so, an alternate substitute decision-maker may be named.

A POAPC should be reviewed and updated periodically to ensure that the person for whom it applies has their wishes met. Termination of the document can take place at any time with notice to the substitute decision-maker and anyone else who may have been advised of it. It is recommended that the old POAPC be destroyed after replacing it with an updated version.

Hospitals also have a document known as a Do Not Resuscitate (or DNR) order or form. If the care recipient chooses to do so, they can sign this document to ensure that if their heart or breathing stops, the attending health care providers will not make attempts to revive them.

A DNR requires patient consent and their signature, along with the signatures of witnesses and the attending physician. It will then be placed in the patient's medical record.

A DNR may also be signed by a family doctor if the patient is still at home. Keep this in a visible and accessible place (e.g., your refrigerator) in case you have to call 911, as emergency responders will attempt to revive them unless presented with this form.

Power of attorney for property (POAP)

A Power of Attorney for Property (POAP) allows a substitute decision-maker to perform financial transactions in the event that a person becomes incapable of expressing their wishes directly.

The substitute decision-maker can then access the person's bank account to pay bills, or file taxes, for example. There may be different levels of control they may have over financial matters, and a limited duration of time that they may act as the representative. Speak to your lawyer to ensure you know the differences. Share the plans with the substitute decision-maker and family members so everyone understands what the person wishes.

Care facilities

People with advanced Parkinson's require safe and effective care at all times. The day may come when this level of care cannot be provided at home. If this day comes, you should consider a transition to a more supportive living environment.

There are many benefits to providing care for the person with Parkinson's at home. The environment is familiar and comforting to them and will not elicit the anxiety that unfamiliar surroundings might. You won't have to travel to see them, either. Despite the challenges of care partnering, the relationship between the two of you often becomes stronger over time. There can also be considerable savings in health care costs.

However, as Parkinson's progresses and requires more and more care on your part to meet their growing needs, keeping them at home may start to feel overwhelming, as meeting their needs can come at the expense of your own well-being. If you are caring for them at home, the escalating demands of the condition might negatively impact the relationship you have with anyone else who is also living in the house. In addition, your own health may suffer because of caregiving. In some cases, the care partner may predecease the care recipient. It's important to have a plan in place, just in case.



Again and again, the impossible problem is solved when we see that the problem is only a tough decision waiting to be made.

Robert H. Schuller



Tough decisions

Making the decision to move your care recipient out of the home is a challenging emotional process. People have called it the hardest decision of their lives. Be prepared for potential accusations of abandonment and your own feelings of guilt. Other family members living out of town or not providing direct care may disagree with it. A family meeting facilitated by a neutral professional, such as a social worker, may help get everyone on the same page and make the transition easier.

Remember, the move to a care facility does not take away your role as the care partner. Many care partners spend a lot of time at the care facility after the transition to help ease the anxiety they may be experiencing. They may also spend time explaining Parkinson's – and the unique set of symptoms – to the facility staff so they are better able to care for the care recipient once this transitional period has passed. They may also be advocating on behalf of the person with Parkinson's to ensure they get the right care, medications, and treatment.

The person with Parkinson's may enjoy the potential benefits of a care facility:

- Increased access to social activities offered at the residence
- Decreased feelings of isolation and lack of socialization
- Opportunities for involvement by on-site medical and rehab professionals
- A more accessible environment
- Availability of staff to provide assistance at all hours of the day or night



In any moment of decision, the best thing you can do is the right thing, the next best thing is the wrong thing, and the worst thing you can do is nothing.

Theodore Roosevelt



Considerations

As Parkinson's progresses and needs increase, the following factors must be considered when determining whether assistance with in-home care will continue to work for you:

- Level of responsibilities, apart from providing care, that the care partner has
 - ◆ If you are the primary care partner and you have a job, it will be difficult to provide comprehensive at-home care
 - ◆ You may choose to hire outside help to provide round-the-clock care
 - ◆ Consider how that will impact your household and routine
- Personal care needs
- Arrangements that need to be made for assistance with medication timing and dosing, meals, personal care, housekeeping, transportation, and companionship
- Size of your home to accommodate the needs of the person with Parkinson's
 - ◆ Space is required for walkers, wheelchairs, bedside commodes, medical equipment
- Layout of your home to accommodate declining motor skills and need for safety
 - ◆ Environment must be safe and supportive of maximum independence
 - ◆ All on one floor, if possible
- Equipped with handrails, bathroom alterations, ramps, etc.



Funded occupational therapy assessments

Some provinces and territories offer publicly funded in-home occupational therapy assessments, that can identify modifications to help you age in place.

Home care may not be an option in the following circumstances:

- Finances are stretched or simply not available
- Time and family responsibilities, such as young children at home
- Care partner's emotional and/or physical strength is depleted or they have their own health challenges
- Person with Parkinson's condition requires more skilled care, such as that of a nurse
- Person with Parkinson's size and condition requires two people to get them out of bed, out of a chair, off the toilet, etc.
- Limited space in your home
- Physical layout of the home is unsuitable or is a high risk for falls
- Person with Parkinson's prefers to live independent of their family

Options for the future

If considering a move to a facility, it is important to understand the various types of facilities that may be offering service. Certain terms for these facilities may be used interchangeably by the public, but are very different. Some may be for-profit facilities, while others are legislated by provincial governments. They range from independent living to round-the-clock long-term care.

Independent living

- These may be called "senior residences" or "senior communities"
- They are typically private, for-profit buildings, which are geared to healthy seniors, and may be ideal for mid-stage Parkinson's where a person is independent but a house is too much work for them to maintain and manage
- These types of facilities/buildings do not provide personal or nursing care, although residents can and do contract private care providers just as they would if they lived in their own homes
- These amenities offer 24-hour security, transportation, and activity programs
- They may also provide group dining facilities with prepared meals

Assisted living

- Provide supervision and assistance with care as needed
- Typically, the main criteria are that a person can self-direct their own care or their live-in care partner can direct care
- These programs may be provincially funded or privately run, which will determine additional cost
- Care providers include nurses, personal support workers, and others
- Provide housekeeping services, social programs, transportation, errand-running, and group outings
- May also offer rehabilitation services, hospice care, and specialized care for various disorders

Long-term care

- These are the places most people think of as “nursing homes”
- Residents require 24/7 supervision and care due to issues of cognition and/or mobility but are not ill enough to be in hospital
- In Canada, there are publicly funded long-term care facilities. These facilities are licensed and regulated by the provincial/territorial governments and must adhere to specific legislation. Public funding covers the bulk of costs, particularly clinical care, and residents generally pay for costs associated with room and board, which vary by location and room type. Provinces and territories subsidize long-term care facilities to varying degrees.
- For-profit long-term care facilities exist as well and can operate outside the provincial/territorial system without public funding.
- Care providers include personal support workers, nurses, and access to doctors, physiotherapists, and other professionals as needed or as available.
- Everything from activities, nutrition, personal care, safety, transportation, and other services are provided.

Be prepared

It is a good idea to visit several facilities before a transition is necessary to get an idea of the choices you may have. It will also allow time for you to make a decision without the stress and pressure of having to do so after an unplanned hospital stay, for example, that necessitates finding a place on short notice. Take a family member or friend with you to help you assess the facility and care services. Familiarize yourself with the palliative care options that are provided, so that if the need arises, you know where to turn.



Things to consider when visiting and evaluating long-term care facilities

- **Location and environment:** Consider proximity to family and friends, the physical environment of the facility, and the overall atmosphere
- **Parkinson's care:** Ask whether staff have specific training in Parkinson's care, including medication timing, mobility issues, and communication challenges
- **Staffing and overall care:** Assess the staff-to-resident ratio. Does the facility feel welcoming, clean, and comfortable? Do residents appear engaged?
- **Services and amenities:** Are there opportunities for physiotherapy, speech therapy, or exercise programs tailored to mobility and balance? What types of social and recreational activities are offered?
- **Resident experience:** Talk to current residents and their families to get a sense of their satisfaction with the facility
- **Accreditation and licensing:** Is the facility licensed and accredited by a recognized body (e.g., Accreditation Canada, CARE, provincial regulators)?



A goal without a plan is just a wish.

Antoine de Saint-Exupéry



Before things become unmanageable — and the care recipient still has the capacity to make decisions about their care, their health and provisions for their property — it is best to have those conversations that will ensure that their wishes regarding care are clarified and put into writing. It is also the time, if it hasn't been done earlier, to solidify the terms and conditions of wills, and powers of attorney (POAs) for personal care and for property.

If planning begins at diagnosis, it gives control to the person with Parkinson's and minimizes decision-making stress for the care partner. It also mitigates any potential family disagreements. It is a gift the person with Parkinson's can give to their family.

Visit Parkinson Canada's website or contact us to learn more about supports available for advance care planning.



parkinson.ca



1-888-664-1974



support@parkinson.ca

Palliative care

Many believe that palliative care refers to care at the end-of-life – but in reality, it ideally begins at the time of diagnosis and continues through all stages of illness. It offers holistic, person-centered support within any setting and ensures both the individual with Parkinson's and their care partner remain central in decision-making. By anticipating, preventing, and treating suffering in all its forms—physical, emotional, social, and spiritual—palliative care helps optimize quality of life through autonomy and access to choices.

Palliative care can be accessed by anyone with Parkinson's at any time. It is not limited to those nearing the end of life and can be provided alongside other treatments.

Across multiple randomized trials, palliative care has been linked to better symptom control and improved quality of life. Studies also show that palliative care's emphasis on emotional and supportive interventions also contributes to improved mental well-being, patient and family satisfaction, and fewer feelings of isolation. A population-based study in Ontario showed that individuals with Parkinson's who received palliative home-care services were significantly less likely to die in a hospital.

Palliative care is usually provided by a team of health care professionals along with the person with Parkinson's chaplain, counselor, and others. Together, they help the care recipient, their care partner, and family make informed decisions about care and treatment options in advance of end-of-life hospice care. It can be provided in various settings, including outpatient clinics, hospitals, nursing homes, and even at home.

Palliative care does not exclude curative treatments, if there are any. It can, however, transition to hospice care if the doctor believes that death is likely within a few months or weeks.

Hospice care

Hospice care can be provided in various settings — at home, in a nursing home, as an inpatient of a hospital, or in an assisted-living setting. Hospice care is not “giving up” on life, or a withdrawal from it. It is not a form of medically-assisted dying. Hospice care is an approach to treatment that recognizes death as the natural ending to life and provides the person with Parkinson's who is nearing the end of life the maximum amount of autonomy, dignity, and comfort in the final weeks and days of their life. A person with advanced Parkinson's in hospice care has chosen to give up receiving any life-extending treatments in favour of care that helps them live each day to the fullest. Treatments focus on symptom and pain management, assistance with everyday needs, and emotional and spiritual supports for the person with Parkinson's and their family members.

The hospice care team consists of many of the same health care professionals included in the palliative team but may also include other skilled care. Because Parkinson's is a chronic and progressive condition with an individualized journey, it can be difficult to determine when the end of life is near. However, when symptoms such as dementia, recurrent aspiration pneumonia, weight loss, urinary incontinence, infections, and pain are advanced, hospice care may be appropriate. As symptoms worsen, ask your care recipient's primary care physician for a referral to a hospice team before it becomes an absolute necessity.

Medical assistance in dying (MAID)

Physician-assisted dying is a process that allows a person who meets certain eligibility requirements to make the choice to end their life with the compassionate support of a medical practitioner.

Physician-assisted dying may not be for everyone. But more and more, people living with conditions that cause them great and enduring suffering are considering this option. Here in Canada, it is known as medical assistance in dying (MAID) and has become another choice

on the continuum of palliative care for Parkinson's and certain atypical parkinsonisms, especially in very advanced stages of these conditions.

In Canada, there are two types of medically-assisted death that meet the requirements of the law. A person may choose to have a doctor or a nurse practitioner present to directly administer the medications that will initiate the dying process. Alternatively, a person may choose to self-administer the prescribed medications themselves. In this case, a medical professional must still be present to provide support and ensure that all legal and medical requirements are followed. In both situations, the law requires that the person be able to give their informed consent at the time the medical assistance is provided.

MAID is a deeply personal and sometimes polarizing topic. Each person brings their own religious, spiritual, cultural, and existential beliefs to it, and those values naturally shape how they understand – and ultimately decide about – medical assistance in dying. Because it's such a profoundly personal decision, it's essential to make sure it's informed: take time to gather accurate information and engage in honest conversations with trusted members of your care team, including the primary care physician.

To be eligible for MAID, a person must meet all of the following criteria:

- Be eligible for health services funded by a province or territory, or the federal government
 - ◆ They may also be eligible if you meet your province or territory's minimum period of residence or waiting period
- Be at least 18 years old, mentally competent, and capable of making their own health care decisions
- Have a grievous and irremediable medical condition, defined by all of these:
 - ◆ A serious and incurable illness, disease, or disability
 - ◆ An advanced state of irreversible decline in capability
 - ◆ Enduring physical or psychological suffering that is intolerable to the person and can't be relieved under conditions they find acceptable
- Make a voluntary request that is not influenced by external pressure
- Provide informed consent at the time MAID is provided

The laws surrounding MAID are set by federal legislation, which means they are generally consistent across Canada. However, provinces and territories may have additional health-related laws or policies that shape how services are provided. Before making any decisions,

it's important to understand your rights as a care partner and the rights of the person you support. In general, people have the right to refuse treatments, food, drink, and medications; to seek a second medical opinion; and, if eligible, to choose MAID as a way of ending their life with dignity.

Talking about MAID is not easy. It can be difficult to raise, and sometimes just as difficult to hear. For others, it can provide a sense of comfort to know that choices exist. Ultimately, the decision belongs to the person with Parkinson's. Your role as a care partner is to listen, support, and help ensure their wishes are respected.

If the person you care for is considering MAID, it's important to take time to reflect on their wishes and begin discussions early, while they are able to think clearly and communicate their decisions. These conversations are best held with their health care providers, and may also involve you, other family members, or trusted friends — depending on what feels right.

Under Canadian law, someone must meet specific eligibility requirements before receiving MAID. They must be fully informed, capable of making the decision, and give their consent at the time of assessment. In situations where a natural death is reasonably foreseeable, the law also allows for what's called a "waiver of final consent." This means that if the person has already been approved for MAID but is at risk of losing decision-making ability before their chosen date, they can make a written agreement with their doctor or nurse practitioner to proceed even if they are no longer able to consent in that moment. This protects their wishes while also ensuring safeguards are in place.

While these choices may feel overwhelming, starting conversations early, gathering information, and putting the right legal documents in place can bring peace of mind. Doing so helps ensure that the care recipient's voice is respected, and that both of you can move forward with clarity and compassion.

A health care provider that may be administering, assisting with, or even assessing a care recipient's eligibility for medical assistance in dying must follow the provincial guidelines set out by their respective regulatory bodies. Keep in mind, physicians and nurses are not legally obligated to assist with dying if they have personal objections. If they receive a request for MAID and they decline to provide assistance, they may be required to refer the person to another provider or agency that will.

For more information on MAID, please visit the [Government of Canada website](#).



Chapter 10: When care partnering ends

Parkinson's is chronic, progressive, and degenerative. And, you will likely have experienced feelings of loss and grief all along your care partner journey. Your care recipient's loss of mobility, independence, and even "their former selves" can trigger grief for you - and them - many times along the way. But, ultimately, there will come a time when you will grieve the final loss. You may come to realize that you have been grieving long before they passed away.

Looking ahead, all of the emotions associated with grief are normal, so give yourself permission to feel and experience each one. Reach out to trusted family and friends for support. And if necessary, talk to a social worker, medical professional, clergy member, or grief counsellor.

There is no set period of time for grief and no right or wrong way to experience it. You may feel numb and in shock despite having known it will come. As time passes, you will most likely experience a wide range of other emotions including deep sadness, relief that suffering is over and your caregiving challenges have ended, loneliness, guilt, anger, and even confusion as to what you will do next. Grieving is not a staged or linear process, and you may believe you have come through it, only to be struck by something simple and familiar and have the emotions sweep through you all over again.



Only those who will risk going too far can possibly find out how far one can go.

T.S. Eliot



You might wonder: Is there life after caregiving? Yes, there is. But things will never go back to how they were before Parkinson's.

Caregiving has had a profound impact on the person you have become, and the journey has changed you in ways you may not even be aware. You are not the same person that existed before you became a care partner. The all-consuming role you played is over now, and you may need to re-establish relationships with friends, family, and others in your community. You may even encounter some feelings of resentment that all your resources went into the person with Parkinson's. Anyone who has not experienced the caregiving process cannot fully understand what it was like and why you did what you did.

Rest assured, you can navigate this new chapter in your life. It is helpful to start by establishing or creating daily routines with activities that are meaningful to you, before the care recipient is gone. Try to schedule several activities each week where others are dependent on you to show up. Volunteer to lead a class of some kind – yoga, painting, a book club, or religious study. Join a committee working for change in the community. You can probably come up with a list of interests and goals aligned with your values.

Here are some suggestions:

- Tap into your creativity by journaling, taking up photography, painting, woodworking or crafting
 - ◆ How have your interests changed since your care partner journey began?
 - ◆ Do you now have new skills that may enhance your work or your life?
 - ◆ What are you motivated to do and what inspires you?
- Consider continuing to attend your support group for care partners of people with Parkinson's until you transition away from defining yourself as a care partner
 - ◆ How do you envision yourself and your life...a year from now, two years from now, five years from now, and so on?

- Join a bereavement support group or seek out individual grief counseling and make the transition after a period of time when you feel your grief lessening
 - ◆ What have you discovered about yourself and your coping abilities?
 - ◆ What valuable lessons have you learned that you can share with others?
- Take time to heal and think about all the fun and happy moments you shared
 - ◆ What new things have you learned about yourself?
 - ◆ What new things have you learned about life?
- Consider making a memory book with pictures and stories you want to keep, and share this with family and friends in the future
- Re-evaluate your life and your relationships, and focus on where you have been, where you are, and where you wish to go
 - ◆ What have you learned about your family and friends during your care partner journey?
 - ◆ What did that mean for the care recipient?
 - ◆ How have you come to define those relationships?
 - ◆ How will those relationships support you going forward?

Many things may change for you once your care partner journey has ended. You may find yourself going back to work, making new living arrangements, or downsizing; perhaps you are ready to retire altogether. Whatever those changes look like, they are inevitable. Reflection and viewing your life in its new context will help you to more effectively move forward and find your place in your new life.

We hope that we have assisted you in making that transition successfully. Here is a quote to carry with you down the path you face ahead...



All the art of living lies in the fine mingling of letting go and holding on.
Havelock Ellis



About Parkinson's

Parkinson's is a complex brain condition that affects both movement and many other systems of the body. Everyone's journey is different – from the symptoms they experience to the progression of the condition – Parkinson's varies from person to person. The information in this book applies to care partners of those with Parkinson's, as well as those who care for people with the less common atypical parkinsonisms.

About Parkinson Canada

At Parkinson Canada, people with Parkinson's are at the centre of everything we do. We empower the Parkinson's community through tailored programs, innovative research, and raising the voice of people affected by Parkinson's across Canada. A national registered charity, Parkinson Canada fulfills its mission through the generosity of donors and is an accredited organization under the Imagine Canada Standards Program.

For more support and information

This book focuses on supporting you and the person with Parkinson's you are providing care for. It aims to provide practical information, and be a tool to spark meaningful conversations, strengthen your partnership, and work together with health care providers in managing care.

Beyond the information in this book, Parkinson Canada provides reliable, practical, and evidence-informed information for people affected by Parkinson's.

For more information on living better with Parkinson's, visit our website or connect with us in any of the ways below.

Connecting with Parkinson Canada

For additional support, reach out to Parkinson Canada to get connected to:

- A dedicated support and information team providing reliable guidance by phone or email
- Peer support programs including in-person and virtual support groups and 1:1 peer mentoring
- Educational webinars, courses, and publications to help you stay informed
- CareFinder, an online directory to help you find tailored support in your area or online

Visit parkinson.ca or connect with us by phone at 1-888-664-1974 or by e-mail at support@parkinson.ca.

Notes



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