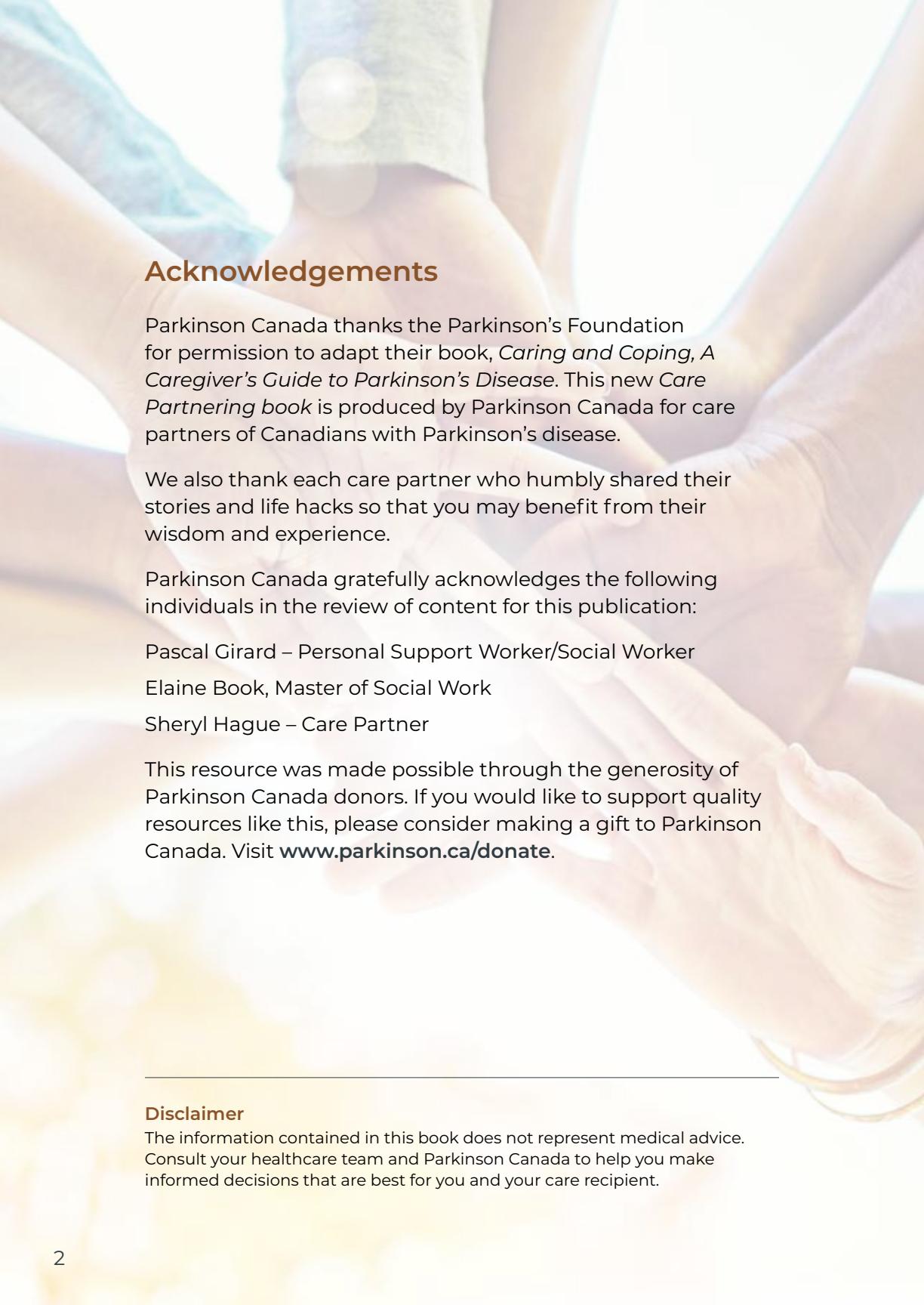




Care Partnering

Managing Parkinson's Disease **Together**



Welcome

Acknowledgements

Parkinson Canada thanks the Parkinson's Foundation for permission to adapt their book, *Caring and Coping, A Caregiver's Guide to Parkinson's Disease*. This new *Care Partnering* book is produced by Parkinson Canada for care partners of Canadians with Parkinson's disease.

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

Parkinson Canada gratefully acknowledges the following individuals in the review of content for this publication:

Pascal Girard – Personal Support Worker/Social Worker
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Sheryl Hague – Care Partner

This resource was 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 www.parkinson.ca/donate.

Disclaimer

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

Welcome to Parkinson Canada's *Care Partnering: Managing Parkinson's Disease Together*. This book was developed to help you and the one whom you care for, to co-manage daily life with Parkinson's. We encourage you to use this book as a valuable tool to spark conversations between you and your care recipient, and help you partner with the healthcare providers that treat your care recipient.

A person's life story changes after a diagnosis of Parkinson's. 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. And 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 receiving the care. Whether you are newly embarking 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 --

HEALTHCARE PROVIDER CONTACT INFORMATION

PROVIDER	NAME	PHONE	FAX	ADDRESS/ EMAIL
Primary Care Physician				
Neurologist				
Parkinson Disease Nurse Specialist				
Pharmacist				
Neuropsychiatrist/ Psychologist				
Ophthalmologist				
Optometrist				
Social Worker				
Occupational Therapist				
Physiotherapist				
Speech-Language Pathologist				
Massage Therapist				
Dentist Dentist/ Dental Hygienist				
Personal Support Worker/Paid Caregiver				

In this book, you will find:

- Contact lists for national, provincial and territorial resources
- Tip Sheets
- Worksheets
- Information on Parkinson Canada's ACT on Time™ program
- Care Partner Inspirations
- Glossary of Terms



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Introduction

Whether the Parkinson's diagnosis is new or the care recipient has been living with Parkinson's disease 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.

What is caregiving?

“Caregiving often calls us to lean into love we didn’t know possible.”

-- *Tia Walker* --

A precise definition of caregiving remains elusive, despite growing numbers of people serving in the role of care partner. One definition describes the Canadian care partner 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 8.1 million care partners in Canada and that 6.1 million of these are juggling work as well as other family and caregiving responsibilities.

Just over half of care partners are women. And, approximately 50% of all care partners are between the ages of 45 and 65, so the caregiving is often occurring during a care partner's peak earning years. There is a societal term for those who belong to this particular group. They have become known as *The Sandwich Generation* because these care partners are working and raising families while also caring for an ill or injured individual.

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

There are five universal priorities that care partners and their support groups from across Canada have identified. And these priorities make up the Manifesto that provides the foundation for facilitating a collaborative action plan that ensures care partners have a voice in policy, programming and services. The following are the five priority areas:

1. Safeguarding the health and well-being of care partners
2. Minimizing the financial burden placed on care partners
3. Enabling access to user-friendly information and education
4. Creating flexible workplace/educational environments that respect caregiving obligations
5. Investing in research on unpaid caregiving as a foundation for evidence-based decision-making

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 or by phone) to support and bring social connection to the care recipient.

“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

This book focuses on the role of the care partner, their needs, and the needs of the people with Parkinson's for whom they are providing care. It also provides tips on how to better manage the disease to ease the care partner's burden.

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



Look for this symbol for worksheets



Look for this symbol for tips and strategies



Look for this symbol for resources





The Care Partner Identity

Parkinson's disease is a progressive disease. The degeneration and changes that take place over time can make it hard for you to define your role within the journey the 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.

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, 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 disease is unique, and so is each care partner. As you start your care partnering 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 type of 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. And remember, care is not limited to physical tasks. Care can take the form of emotional and spiritual support, as well as physical.

Care can also be a spectrum – changing and progressing as the disease progresses. You may find yourself going from being a care partner to a caregiver. And farther 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 disease together.



TIP SHEET:

How to Talk With Your Family About Parkinson's

Who are you?

Early on, learn all you can about the disease so you can anticipate changes, participate in healthcare discussions, make informed decisions and provide emotional and physical support now and as needed in the future. Expect that there will be changes in your relationship as the disease 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 unnecessary 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, and 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 interest 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 fulfills our very different needs.”

-- Diana – Ottawa, Canada --

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

First, you must understand the disease yourself. Ask for information and do some research on your own. And, be sure to understand the specific needs and wishes of the person for whom you care. 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 places they can go to learn more about Parkinson's
- Refer them to Parkinson Canada for support group referrals or answers to other questions

Parkinson Canada offers several options to help you and your family learn all about Parkinson's, including the signs, diagnosis, symptoms, treatment, living well and much more. You can find a wealth of information online at www.parkinson.ca.

You can call Parkinson Canada at **1-800-565-3000** to speak to one of our Information and Referral associates or to order any educational resources.

You can also email info@parkinson.ca with any questions you may have.



TIP SHEET:

How to Talk With Your Family About Parkinson's

Your family may also have questions or they may express fears about Parkinson's and genetics. For the vast majority of people, Parkinson's is not inherited. There is no test that can accurately predict who will develop Parkinson's. Extensive gene and biomarker research is underway to uncover the possible precursors—not necessarily causes—to disease development. But the real cause or causes remain elusive.

People unfamiliar with Parkinson's often think of it only as a disorder of movement. It is important to help family and others understand that there are other facets of the disease, and these can have an even greater impact on quality of life than the motor (or movement) symptoms. Emphasize that Parkinson's is an ongoing journey, one in which you will all need to face realities little by little. You will all need to adapt and stay connected to each other and things that are important to you while living each day in the best way possible.

The 7 Strengths of Care Partners

Care partners are strong. They have to be in order 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 him/her 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 --



The 7 Strengths of Care Partners

1 – Patience

- They have the ability to 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 with 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 set-backs 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 have the ability to find the humour in life, the silver lining
- 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

Care partners have many more strengths that they call upon to help them manage the needs of people with Parkinson's. This list will likely be just the beginning of a much longer and more comprehensive description of the care partner you are, or will become.



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 manage your needs in order 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 disease
- 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 illness
 - Research shows that people with Parkinson's who take an active role in the management of their disease feel more self-control and that this relieves some of the care partner strain

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
- 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 if possible and guard 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 time out
- 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?

The 7 Needs of Care Partners

- 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 the care partner and deal with 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 disease. 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 --

How to Prioritize Needs

- ① Identify your concerns according to the 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.

4 – Supportive Needs

- “Share the care”. Explore ways to get the assistance and support that you need. This includes physical, emotional and spiritual help
 - Engage the support of a social worker or counselor to guide you to community resources that support the care partners and deal with the resultant stress and strain

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

-- Anonymous --

- 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, 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. Research shows that 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 healthcare team (physician, nurse, social worker, etc.), family, friends, neighbors, 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 and 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.

The 7 Needs of Care Partners

- 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.

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 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

7 – Community Resource Needs

- Take advantage of any product, physical and practical assistance that may be available
- See what local resources have to offer
- Seek out educational materials and information
 - Go to www.parkinson.ca to learn all you can
- Organize and get all your legal documents (POAPC, and others) 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, in order to plan your budget
- Reach out to a variety of health professionals, social workers and clergy



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 disease can be a full-time job, especially as the disease 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 I 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 contact 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

This book focuses on the role of the care partner, their needs, and the needs of the people with Parkinson's for whom they are providing care. It also provides tips on how to better manage the disease to ease the care partner's burden.

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



Look for this symbol for worksheets



Look for this symbol for tips and strategies



Look for this symbol for resources



Care for the Care Partner

You Need Care, Too!

Care partners have an enormous and often under-appreciated 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 particular caregiving situation, so caregiving can continue to be — or return to being – a healthy, viable, even rewarding role for you.



TIP SHEET: 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 --

- Your daily routine will definitely 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 illness 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.



TIP SHEET: Caring for You

- 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 onto 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 cares. 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 professional who can help you through this process.

Finding Meaning in Caregiving

“From caring comes courage.”

-- Lao Tzu --

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.

Connection

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

Benefits of Support Groups

- ① Commonality among members
- ② Education and information
- ③ Learning to adjust to diagnosis
- ④ Practical techniques and strategies
- ⑤ Safe environment for sharing in confidence
- ⑥ Feelings of understanding
- ⑦ Reduction of stigma
- ⑧ Socialization and friendships

Finding Meaning in Caregiving

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 rise up. 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; 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. And, subsequently, the person with Parkinson's 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 are not limited to the points above. You may also experience some of the following:

- Taking pleasure in giving of yourself
- Seeing positives where you once saw deficiencies
- New or renewed spirituality
- Pride and purposefulness

Encouragement
Support Hope
Awareness Knowledge
Laughter A Safe Place
Caring

Wordcloud courtesy Parkinson's Support Group of Sudbury (ON)



TIP SHEET: 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 technique(s) you choose to use, be sure to do it/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 while enjoying 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
 - You can 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 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 taking in/breathing 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
 - Allow your focus to fall on those areas for a few seconds to assess if you feel any muscle tension or pain
 - Tighten each area for several seconds (5-7) 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 of 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

For a listing of educational videos, visit the Parkinson Canada YouTube channel or www.Parkinson.ca/Knowledge for more information.

Good Sleep Habits Checklist

- 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 remain asleep and not check the clock all night.
- Limit your use of prescription sedatives (if you use them) to a two-week period.



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

Ultimately, finding balance in your mind and body will help you cope with the daily stresses of life. This may mean limiting your exposure to environmental stressors or using complementary therapies. Such approaches are wonderful ways to lower anxiety, lower blood pressure and improve your well-being.

If you feel that you are totally overwhelmed by your feelings, consult with your physician. He or she can refer you to a mental health professional. Seeking help is actually a sign of strength, not weakness.



Perform this self-assessment at regular intervals to identify your risk factors and shed light on your needs. (See Appendices – WORKSHEET 1) There is great value in assessing yourself.

The care partner role is one where there are both rewards and challenges; days of positive progress and periods of decline. Parkinson's disease is chronic and progressive, and the inevitability of degeneration is unavoidable. You don't have to join the care recipient on that decline; and, 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. And 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 lessons, skills and knowledge about your role and you

Review your self-assessment for new insights. Share the results of it 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, 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.

Care Partner Self-Assessment

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

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

Be sure to get good sleep, every night. That time is crucial for the 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 the 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 disrupt your nighttime sleep further.

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 disease is RBD or REM-sleep behaviour disorder. This involves the person with Parkinson's physically acting out their dreams and possibly hitting you, waking you or harming you during the night. It is absolutely necessary for your safety that you sleep separately if this is an issue.

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 (See Appendices – WORKSHEET 2). This scale measures your experience of burden. If, after completing this worksheet, you rated higher than you expected, then 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.

When the Care Giver is the Care Recipient

Many people with Parkinson's are the recipients of their own care. This is because many more people today are living alone, without a primary care partner, than ever before in our history. This has been verified by Statistics Canada in their most recent census (2016). Caring for oneself when ill has become more the norm 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 the disease progresses. Because Parkinson's is a chronic condition without a cure, 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 disease 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.



When the Care Giver is the Care Recipient

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 with the symptoms of Parkinson's disease. Exercise has been shown to be neuroprotective. It is an important contributor to improved balance, flexibility and walking. Research has even shown that it is good for the non-motor symptoms of the disease, such as cognition, as well as being a non-medicinal way to alleviate the constipation that often predates and accompanies the condition.

The results of a review of the current research (Lauzé, Daneault & Duval, 2016) shows us that exercise improves so much more than one's physical capacity. It has statistically positive effects on cognitive functional capacities, as well. This stresses the importance of 'working out' both your body and your mind. Furthermore, a multi-site trial led by Northwestern University Medicine and the University of Denver, demonstrates that high-intensity exercise three times a week is not only safe, but slows the progression of the disease and worsening of symptoms for people with early-stage Parkinson's.

Motivation, or the lack of, 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. You can use some of the ACT on Time™ program tools to do this. Stay engaged in social and personal relationships that will stimulate your mind and keep it sharper, 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, to a community that cares about us and for whom we care. According to Abraham Mazlow, 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, 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. Consider joining a support group, or communicating with others online through email, Skype® or WhatsApp®. Join online forums and contribute your thoughts, feelings and life hacks. You never know who you might be helping or inspiring.



When the Care Giver is the Care Recipient

Keep working for as long as you can. Speak to your employer about disability accommodations as your disease 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 (see information in the previous section) which will help you with your physical 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 diagnosis of Parkinson's, it may present hazards that increase your risk of injury. People with Parkinson's disease are generally at a greater risk of falling due to walking and balance issues. And, 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 fall-out of not getting your medications on time, every time.



Begin minimizing your risk of falling by doing the following:

- 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 it to the walls
- Install better and brighter lighting everywhere, especially over stairs and in walk-in closets
- Install night lights in your bedroom 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
- De-clutter 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 tall toilet or a raised toilet seat with strong armrests
- Remove any wheels or coasters from the legs of your bed to stop any movement that may occur when you get in and out of it
- 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

When the Care Giver is the Care Recipient

- Check your smoke alarms and carbon monoxide detectors to be sure they are working properly
- Invest in an emergency device that contacts 911 should you fall
- 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 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 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

For more information, see Appendices —
WORKSHEET 3: Home Safety Evaluation Checklist.



Know Who to Call On

Although you may be living alone with Parkinson's disease, 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 they are 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; or, 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 acknowledgement of their efforts and kind acts of gratitude. What that looks like is up to you, your resources and abilities.

When it comes to your health, keeping a detailed contact list of all your healthcare providers is essential. Use the table at the front of this book to jot down all the information you will need. Then place this book, and 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 home line). If you have a cellular phone, then 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 cellular numbers. Let them know your routines so they can be watchful of anything out of the ordinary. Ask them to check in on you from time to time. And, remember to acknowledge and show appreciation for their support.

When the Care Giver is the Care Recipient

Get Your Affairs in Order

Living with Parkinson's disease affects each minute of every day. There is no cure. 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 disease. 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 (or DNR).

Property is another issue. *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 if you want to ensure you get what you want. 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 in which you reside, 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 healthcare 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 or 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 8: Planning Ahead, and visit the websites of your respective provincial attorney generals (Please refer to the Resources section at the back of this book).



Chapter 3:

Tips and Strategies

This book focuses on the role of the care partner, their needs, and the needs of the people with Parkinson's for whom they are providing care. It also provides tips on how to better manage the disease to ease the care partner's burden.

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



Look for this symbol for worksheets

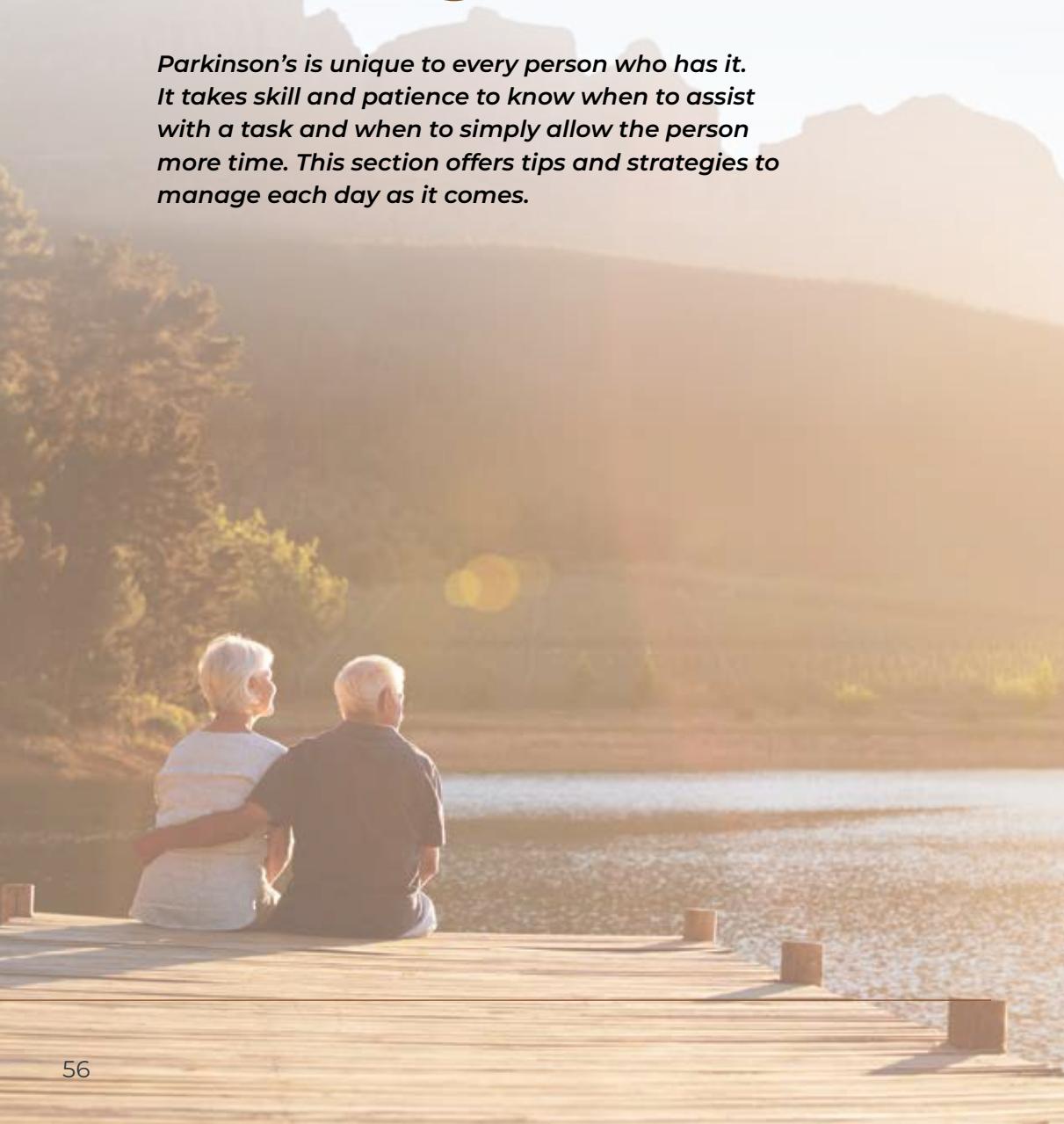


Look for this symbol for tips and strategies



Look for this symbol for resources





Tips and Strategies

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 disease 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 management and care of the person with Parkinson's.

To assist you with this, Parkinson Canada has created the ACT on Time™ program. This includes several tools and documents that can help you maintain a record, manage the medications, monitor the symptoms and address the needs of the person with Parkinson's. Familiarize yourself with each piece and use it in the way it is recommended. You will soon find that it will ease your workload. Keep these tools accessible in case of an emergency.

In the Appendices of this book, we have included a copy of the ACT on Time™ Parkinson's Disease Daily Diary which you can use to track symptom patterns (i.e. ON and OFF periods, as well as other non-motor symptoms) as they relate to the medication dosing schedule. (See Appendices – WORKSHEET 6)

For more information on Parkinson Canada's ACT on Time™ program, please visit our website at www.parkinson.ca and click on the Resources link.

To help prepare you for any potential life-changing events, use the *What-If Plan*. In the Appendices of this book, you will find a template (WORKSHEET 7: 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.

Communicating with Healthcare Professionals

Open, direct and respectful communication with any healthcare professional is very important. They depend on you and the person living with Parkinson's to provide them with relevant information at each visit in order to provide appropriate support and treatment. Along with the care recipient, decide in advance of the visit, what needs to be shared with the healthcare 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 one into and out of the car or bed; how to manage Parkinson's non-motor symptoms such as hallucinations, delusions, depression, anxiety or any other mental health or mood issues.

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

Building a comprehensive, interdisciplinary healthcare team is a goal that people with Parkinson's and their care partners should strive toward. This team would include the primary care physician, plus some or all of the following:

- Neurologist or Movement Disorders Specialist
- Nurse practitioner or nurse specializing in Parkinson's disease
- Pharmacist
- Physical Therapist (PT)
- Occupational Therapist (OT)
- Speech-Language Pathologist (SLP)
- Social Worker (SW)
- Dietitian
- Psychologist or Psychiatrist

If any of the members of your healthcare team need to know more about Parkinson's refer them to the Parkinson Canada website (www.parkinson.ca) and to the Resources tab where they can get the answers to their questions along with other valuable information.

Parkinson Canada has produced two very useful education and communication tools that will help better manage the disease for those who live with it. The Managing My Parkinson's Disease in Healthcare Settings™ booklet and the My Parkinson's Disease Navigator™ tool.

For more information on these two items, and others from the ACT on Time™ program, visit our website or call to order your tools today.

Open communication is essential. Your ability to communicate with healthcare 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 disease, their symptoms and their needs. This will help the healthcare professional address the issues with a greater awareness and understanding.



Communicating with Healthcare Professionals

It is important to make sure the person with Parkinson's feels empowered to speak and advocate on their own behalf. Encourage him or her to be open 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 or through email.

Take the time to get to know the entire health 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 healthcare professionals can teach you how to provide better care to the person living with Parkinson's. As the disease progresses, the symptoms will increase and worsen. Ask the team members how to properly perform techniques and 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 ordering the Parkinson Canada ACT on Time™ resources and having them prepared and ready to go. Contact Parkinson Canada at **1800 565 3000** to order your tools, or request them online at www.parkinson.ca.

Review each piece so you can be prepared. Read the *Managing My Parkinson's Disease in Healthcare Settings™* booklet for information on preparing for medical appointments and hospital stays.

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 disease is not a disease 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 home care and encourage more frequent brushing and flossing
 - Add adjunctive home therapies such as an antiseptic mouth rinse or a rinse for dry mouth
- Diet can affect the symptoms of Parkinson's
 - Encourage them to drink 6-8 glasses of fluid a day non-caffeinated
 - Have them consume high fiber foods such as fresh or frozen fruits, vegetables and whole grain pasta and bread
 - This should also help with the constipation
 - Protein can interfere with the absorption of some Parkinson's medications, so talk to the doctor about medication timing and meals
- Blood pressure (BP)
 - Parkinson's medications can cause drops in blood pressure resulting in orthostatic hypotension — a dizziness that may occur when standing up
 - Have the doctor test for orthostatic hypotension by measuring BP in both sitting and standing positions

General Health

- Skin cancer
 - People with Parkinson's are at a higher risk of skin cancer (some research indicates it's as high as four times)
 - Apply sun screen before going outside
 - Have their doctor check/monitor any pigmented marks or areas (they may be melanomas)



TIP SHEET: Importance of Exercise and Activity

Staying active is important for people with Parkinson's disease. 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 or health club.
- 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 physical therapist for recommendations on an exercise regime and monitoring.



Cueing Strategies

Parkinson's disease impacts the ability to perform movements that are usually done automatically and without conscious thought.

As the disease progresses, one's movements will become smaller and less automatic. Parkinson's can also result in an inaccurate perception of movement size and quality, so one 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 the shuffling when walking
 - "March" when turning to keep knees high
- Repeat cues on a regular basis

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.



TIP SHEET: Communication Challenges

Parkinson's disease 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 to 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 unable to express their emotions through their facial muscles as previously, so their feelings can be hard to read.
- Monitor their mood. Mood changes can be symptoms of the disease, especially depression or anxiety.
- Seek referrals to a speech-language pathologist to help with their voice and assess swallowing, if needed.



TIP SHEET:

Fatigue

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.
- Lowered 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 improve 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 they are 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.



TIP SHEET:

Making Daily Life Easier

Even simple, routine tasks can become more challenging as Parkinson's disease 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. (See Appendices — Worksheet 3)

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 one'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.

For more information on driving while living with Parkinson's, visit the Parkinson Canada website at www.parkinson.ca, or order the Parkinson Canada booklet entitled, *Parkinson's Disease and Driving*.

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 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.



ACT on Time™ Program

This book focuses on the role of the care partner, their needs, and the needs of the people with Parkinson's for whom they are providing care. It also provides tips on how to better manage the disease to ease the care partner's burden.

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



Look for this symbol for worksheets



Look for this symbol for tips and strategies



Look for this symbol for resources



Chapter 5:

Tips and Strategies

ACT on Time™ Program

The *Alerts, Care and Treatment* or ACT on Time™ program was created to meet the unique needs of people living with Parkinson's, their care partners, and the various healthcare professionals who treat them. Each piece of the program was designed to:

- educate those affected by the disease;
- facilitate the management of the symptoms;
- make recordkeeping easy; and
- support effective communications with those who provide services and health care to people with Parkinson's.

The program alerts healthcare providers to the unique needs of people with Parkinson's — especially relating to getting their medications on time — and to specific treatment needs, and methods of providing care.

Contact Parkinson Canada at **1 800 565 3000** to order ACT on Time™ resources, email info@parkinson.ca or visit online at www.parkinson.ca.





TIP SHEET: Secondary Care Partnering

Tips and Strategies

Parkinson's disease 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, the disease and its impact can be felt. This chapter 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. (See Appendices – WORKSHEET 4)



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 faithfully. 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 setting up *Skype®*, *Facetime®* or *WhatsApp®* so you can see each other on the call. 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. housecleaning, yard services, snow plowing or other services).



TIP SHEET:

Secondary Care Partnering

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, patient 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 disease than anyone else realized. If the person with Parkinson's is able to 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 healthcare 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.



TIP SHEET:

What Not to Do

It might sometimes feel like you need permission to help; or, it may feel as if the primary care partner will not or cannot delegate any of the responsibilities. This can be frustrating and emotional for you. Use the strategies mentioned in the previous tip sheet, and avoid the following common mistakes.

Not Understanding the Symptoms

Many care partners will say that the person with Parkinson's is at his or her 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 provided an average of 14 hours of care daily. This shines a light on how little time the care partner really has for themselves.

Offering Unsolicited Advice

Friends and relatives, who do not provide direct care, often have an unhindered perspective. They can sometimes see beyond the details to the overall picture. However, this objective wisdom must be expressed with delicacy and care; and certainly, without criticism for the primary care partner. Offer opinions and views in general terms with 'I' statements when asked.

Dishonoring the Pre-existing Relationship of the Care Partner and Care Recipient

Most often, the care partner and the person with Parkinson's will have had a long-standing and intimate relationship with one another. A spouse, for example, may be accustomed to doing things their way, as they have likely done for years. Trying to change things at that stage will only serve to frustrate and hurt the feelings of everyone involved.

Communication Tips

- ① Always listen to what is being said instead of thinking about what you are going to say next.
- ② 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.
- ③ Do not expect any of the healthcare 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).
- ④ Offer assistance to the primary care partner and wait for them to provide you with ways in which you can help.
- ⑤ Not all problems can be resolved, so, sometimes, all you can do is be patient and provide a listening ear, or a supporting shoulder.



TIP SHEET:

Long-Distance Primary Care Partnering

Many long-distance, primary care partners enter into 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 disease, 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 the disease 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 call in 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 disease and/or the atypical parkinsonisms. Familiarize yourself with the motor and non-motor symptoms, the medications used to treat the specific disease, 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 (OT) 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 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.

Visit the resources listed at the end of this book for more tips and tools.



Chapter 6: Paid Help

Communication Tips

- ① 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.
- ② Talk about many things when you have conversations with the person with Parkinson's. It should not always be about the disease.
- ③ If the goal is to move the care recipient closer to you as the disease progresses, then have those discussions earlier rather than later. Be considerate of their feelings and encourage a mutually agreeable decision.
- ④ 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.



Time to Get Help

Paid Help

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 on in the process to make it easier to add other resources as the disease progresses.

This chapter 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.



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.

You cannot meet all of the needs of the person with Parkinson's all of the time. This becomes increasingly true as the disease progresses. As one's needs change and increase, you must continually reevaluate your ability to meet those needs, as well as how this might be affecting you and your 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 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 situation or the disease has progressed so much you can't meet the care recipient needs). Making well-thought-out decisions early on will help prevent rushed decisions later on when the need for 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 --

Time to Get Help

Communication Tips

- ① Know how to contact outside resources, if needed.
- ② Prepare for any illness or temporary disability on your part by including others in the care plan.
- ③ Discuss the emergency plan with the care recipient.
- ④ Maintain contact lists for healthcare providers, and others, who may need to be consulted.
- ⑤ Make sure everyone knows their part and their role in the care of the person with Parkinson's.
- ⑥ Take the time to train them if they don't know enough about the disease or 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 disease 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 cannot 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 as a result of this, you may experience feelings of failure or betrayal. 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 outside help is there, 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. Don't avoid addressing this in favour of just letting them have their way. 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

Our health care system in Canada, although universal, varies from province to province. There may be certain provincially covered in-home and/or equipment services that are covered in one province, but not in another. Please see the Resources section of this book for links and contacts to the information and help you may need.

In-Home Care Providers

There are many home health care service providers in each province. 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 covered 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.



TIP SHEET: 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 disease, 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 (See Appendices – Worksheet 5)
 - 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



TIP SHEET:

Hiring In-Home Care Providers

- 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 home-care 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 (ideally, in Canada)
 - 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

Pros and Cons of Hiring Privately

Leg-Work

- 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 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 relatively quickly

Bonding

- Privately hired support workers may not be bonded and your insurance may not include this type of coverage
- Agencies usually bond their employees

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

Preparing Paid Care Providers

Part of your job, when you hire an outside care provider, is to take your care recipient through an orientation process that includes familiarizing them with their particular needs. Only then can you feel comfortable leaving them in someone else's care. (See Appendices — Worksheet 5)

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 the 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 disease and the unique set of challenges and symptoms that the person with Parkinson's may have. Provide the support worker with print and online information and have them go through it.

Getting to Know the Care Recipient

Once they learn what they can about the disease, then 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, their occupation, favorite hobbies, likes and dislikes and daily routines. Include information on family, friends and healthcare 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 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. Complete the Daily Needs and Routine Tracker — found in the Appendices section of this book — and go over it with them to ensure they understand what they are 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. Follow up to make sure that the problem has been addressed.

Communication Tips

- ① Use short, concise sentences with common vocabulary for better understanding.
- ② Focus discussions on the work, not the person, when addressing actions or behaviours of the support worker.
- ③ Use 'I' statements and avoid using "You always" or "You never."
- ④ Provide regular, meaningful feedback and praise.
- ⑤ Ask for feedback and suggestions from the support worker.
- ⑥ If you need time to think about something, take it. You don't need to respond too quickly.

Preparing Paid Care Providers

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, to 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:

1. In-Home Respite Care — A bonded employee of an agency comes to the home and generally stays with them 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.

2. 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:

a. 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

b. Residential Facilities often offer rooms for short-term respite care.

Respite Care

Benefiting from Respite Care Services

Beyond the immediate relief that respite care provides, there are several other benefits:

- Relaxation and peace of mind, and a renewed sense of humor 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 to do the things you like
- Enrichment and nurturing of your own growth and development

“So much energy 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?
- 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 they 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 Disease

Skilled rehabilitation therapies — including physical therapy (PT), occupational therapy (OT), and speech 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 settings, as well as private practice. Some provincial health systems and most personal health insurance plans will cover them, depending on the specific circumstances. Check with your primary care physician and private insurance company (if you have a plan) to see if they are eligible for coverage. Otherwise, these will be out-of-pocket health care expenses.

In-Patient Rehabilitation

Large, dedicated rehabilitation facilities may offer inpatient rehab stays as well as all other levels of rehab treatment. 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 the 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. falls prevention program).

Out-Patient Therapy

Out-patient 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 weekly or biweekly shorter appointments; or may be followed periodically.

In-Home Therapy

When there is a particular acute need (e.g. recovering from 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 plans.



This book focuses on the role of the care partner, their needs, and the needs of the people with Parkinson's for whom they are providing care. It also provides tips on how to better manage the disease to ease the care partner's burden.

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



Look for this symbol for worksheets



Look for this symbol for tips and strategies



Look for this symbol for resources

Chapter 7:

Advanced Parkinson's



What is advanced Parkinson's disease?

Advanced Parkinson's

Despite the challenges that advanced Parkinson's disease presents, there is still a lot that you can do to make life easier and more enjoyable. In this chapter, 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.



Advanced Parkinson's disease — with or without significant motor disability 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 healthcare providers to measure how severe the disease has become and how far it has progressed. Generally speaking, it is described as a person with Parkinson's who 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.





TIP SHEET: 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 the 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 the various pieces of the ACT on Time™ program 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 information 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



TIP SHEET: 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 healthcare 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.



TIP SHEET:

Movement Challenges

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 disease 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 disease 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 (increasing pace of walking), 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 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 (OT) 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
- Choose a rollator (walker with wheels) as it works best and provides the safest movement

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 (OT) 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





TIP SHEET: 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 neighbor 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. For more information, order your copy of the Parkinson Canada falls prevention publication.

- 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



TIP SHEET: 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



TIP SHEET: Mealtime and Swallowing

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 in order 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 (OT) 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 to ease swallowing
- 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 (SLP) for a swallowing assessment
- Get your CPR and learn how to perform compressions for choking
- After a professional assessment by a SLP (speech-language pathologist), a feeding tube may be suggested. Become aware of 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 the medications



TIP SHEET: Need for Gaining Weight

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 healthcare team.

General Tips

- 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



TIP SHEET: 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 tolettes 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 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 back rest for safety
- Use a non-slip mat to decrease the risk of slips or falls



TIP SHEET: Bathroom Routines

Bathing (continued)

- Adjust the water temperature before the care recipient steps into the bath/shower
- Rinse skin and hair well
- Wrap them in a bath robe 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 (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 (as gels tend to foam more)
 - Using a dry brush prior to adding the 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)





TIP SHEET:

Mind, Mood and Dementia

A broad-spectrum of potential thinking and memory changes can occur in people with Parkinson's disease, including slowed thought processes, forgetfulness, confusion, judgement 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 disease progression or as a side effect of the Parkinson's medications. The form of hallucination in Parkinson's is typically visual, and the person often 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 (see the recommendations in the *Medications to Treat Parkinson's Disease* booklet published by Parkinson Canada or check the website at www.parkinson.ca)

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 some 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 medical 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 disease.



TIP SHEET:

Mind, Mood and Dementia

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.



TIP SHEET:

Medications – On Time, Every Time

Receiving their medications on time is crucial to the effective management of Parkinson's for those who live with it. 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.

General Tips

- Complete the various forms and use the tools of the ACT on Time™ program 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



TIP SHEET: Medications – On Time, Every Time

For detailed information on medications and contraindications, please refer to the Parkinson Canada *Medications to Treat Parkinson's Disease* booklet, available in English and French, and the ACT on Time™ program materials.

Swallowing Problems

Swallowing changes seen in Parkinson's disease may result in difficulty taking pills. Since the majority of medications to treat the disease 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 disease meds with pudding or ice cream as the protein content in them will interfere with the absorption of the meds
- 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



TIP SHEET: Skin Protection and Managing Pain

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

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.

- Use heat to control their 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 form of dementia (including that associated with Parkinson's) may be a sign of pain
- See a physical therapist (PT) for specific pain evaluations and additional recommendations



TIP SHEET: 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 health bones
- 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 disease impacts visual and thinking/memory skills and may alter their interests and abilities. Consider a visit to the eye doctor to rule out any other causes of visual problems. Have them 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



TIP SHEET: 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 their ACT on Time™ 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 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 OT
- There may be adaptive equipment that makes travel by car easier, some of which may be covered by provincial healthcare 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 allow you to easily turn them while lifting their legs into the car
- Practice putting their walker or wheelchair into the truck or back seat of the car. Make sure you can lift a walker/wheelchair before purchasing it (your OT 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



TIP SHEET:

Other Travel

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 and in the ACT on Time™ tools

Travel by Plane

Airline travel requires pre-planning. With today's 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





TIP SHEET:

Rest and Sleep

Getting adequate sleep and rest is important to the overall health and quality of life, for the 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 the 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 water beds or very soft mattresses
- Adjust the bed height to allow their 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 PT 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

This book focuses on the role of the care partner, their needs, and the needs of the people with Parkinson's for whom they are providing care. It also provides tips on how to better manage the disease to ease the care partner's burden.

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Look for this symbol for worksheets



Look for this symbol for tips and strategies



Look for this symbol for resources

Chapter 8:

Planning Ahead



Be Prepared

Planning Ahead

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. This section will help you discuss and prepare for the future. Start your planning whenever you are ready. And don't wait too long. The present is here, and the future is not promised.



“Failing to plan is planning to fail.”

-- Alan Lakein --

No one can predict future needs. It is wise to consider a variety of possible scenarios and be prepared for any one or all of them.

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.

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 they may wish to address early on so potential disasters may be avoided:

- What areas of your caregiving are becoming too much for you?
- Are they 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?
- Who would take over the care partnering role if you are unable to 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. To do so, you can use the My Parkinson's Disease Navigator™ to track medications, health care visits and other information that first responders can access in an emergency situation. Keep this record handy at all times. Contact Parkinson Canada to order your ACT on TIME™ Kit or go to the website to download specific components.

Keep health records in a location that is easily visible and accessible in case of an emergency. Place them 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.

Each of the components of the ACT on Time™ program should be completed ahead of time and kept current. Information that can be garnered from the tools includes, but is not limited to, the following:

- Date of last update to information
- Name, address, phone number and date of birth of the person with Parkinson's
- Current medications (prescription and non-prescription), dosages, frequency and purpose of each
- Information on primary and other care physicians (GP, neurologist, movement disorder specialist), along with other healthcare providers
- Allergies
- Other medical conditions
- Emergency contacts
- 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 allows the person with Parkinson's to legally express their wishes about future health care treatments and designates a person — the Substitute Decision Maker — who will represent 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 everyone understands the person's desires.

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
 - tracheotomies, and artificial breathing
 - tube feeding — whether nasal (through the nose) or gastric (directly into the stomach)
 - emergency lifesaving interventions (e.g. CPR or a Do Not Resuscitate - DNR - form)
- Organ donation
- Disposal of remains

A Substitute Decision Maker or SDM 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 SDM is unable to do so, an alternate Substitute Decision Maker may be named.

Maintaining Important Information

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 'DNR', which stands for "Do Not Resuscitate". If the care recipient chooses to do so, they can sign this document to ensure that if their heart or breathing stops, the attending healthcare 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 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 your bank account to pay your bills, or file your taxes, for example. There may be different levels of control they may have over financial matters, and limited time length that they may act as your representative. Speak to your lawyer to ensure you know the differences. Share your plan with the Substitute Decision Maker and family members so everyone understands what the person desires.

Long-Term 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 illicit 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.

As the person with Parkinson's disease progresses, however, and requires more and more care on your part to meet their growing needs, keeping them at home may begin to seem like a battle between your survival and theirs. If you are caring for them at home, the escalating demands of the disease might negatively impact your relationship with anyone else who is also living in the house. In addition, a care partner's health may suffer as a result 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.

"There is a fine line between stoic acceptance and just giving up."

-- J. Warren Welch --

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.

Long-Term Care Facilities

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 be taking the time to explain Parkinson's disease – and the unique set of symptoms – to the facility staff so they are better able to care for them 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

Considerations

As Parkinson's progresses and needs increase, the following factors must be considered when determining whether assistance with home-care will 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 home-care
 - You may choose to hire outside help to provide round-the-clock care
 - Consider how that will impact your household and routine
- 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.
- Personal care needs
 - Arrangements can be made to have assistance with medication timing and dosing, meals, personal care, housekeeping, transportation and companionship

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

- Finances are stretched or simply not available
- Family responsibilities, such as young children, time, and space in your home, create limitations
- 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 him/her out of bed, out of a chair, off the toilet, etc.
- 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



Long-Term Care Facilities

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.

1. 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
- Also, may provide group dining facilities with prepared meals

2. 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 spouse 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
- Also 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 facilities are licensed and regulated by the province and must adhere to specific legislation
- 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
- 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.



Chapter 9:

Planning and Decision- Making

This book focuses on the role of the care partner, their needs, and the needs of the people with Parkinson's for whom they are providing care. It also provides tips on how to better manage the disease to ease the care partner's burden.

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Look for this symbol for worksheets



Look for this symbol for tips and strategies



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Planning and Decision-Making

“A goal without a plan is just a wish.”

-- Antoine de Saint-Exupéry --

Every adult, especially as they age, should take the time to think about what they want their final years to be like, if they had the choice. 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.

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, 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.

For more information on these and other topics, please see the Resources section of this book.

Many people understand hospice or end-of-life care, but the term ‘palliative care’ can still be unfamiliar. Both palliative and hospice care can provide services to assure the highest quality of life and, when the time comes, the best possible end-of-life care. The information here will help you to better understand the differences between the two and so you can make informed choices for care. By learning about and discussing the available options before they are immediately needed, people with Parkinson's and their family members can make careful, informed decisions instead of being pressured or rushed during a stressful crisis situation.

Palliative Care

Many believe that palliative care refers to care at the end-of-life. But in actuality, it begins at the time of diagnosis and continues through to end-of-life care. Palliative care is comfort care. It offers the person with Parkinson's and the care partner an opportunity to be active participants in the decision-making, person-centered care plan. This optimizes quality of life by anticipating, preventing and treating suffering. It involves not only care of the physical needs, but also of the emotional, social and spiritual needs of everyone involved – the care recipient, their family members and care partners. Palliative care stresses autonomy and access to information and choices.

Palliative care can be accessed by anyone with Parkinson's at any time. You do not have to be dying to receive this type of care. As mentioned, it ought to begin at the time of diagnosis and continue as on-going treatment through every stage of the disease.

Studies have shown that people who receive palliative care report less pain and other adverse symptoms – like nausea or shortness of breath – and, they report better communication with their physicians, more emotional support from family members, and more accommodation of their needs and wishes.

Palliative and Hospice Care

Palliative care is usually provided by a team of healthcare 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, too, can be provided in various settings -- at home, in a nursing home, as an in-patient of a hospital or in an assisted-living setting. Hospice care is not a 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 -- or any other neurological, degenerative disease -- the maximum amount of autonomy, dignity and comfort during the dying process in the final weeks and days of their life. The person with advanced Parkinson's in hospice care has chosen to give up receiving any life-extending treatments.

The hospice care team consists of many of the same health professionals included in the palliative team, but may also include other skilled care. Because Parkinson's is a chronic and progressive disease with an individualized disease course, 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)

Assistance with dying occurs when a medical professional – a doctor or nurse-practitioner – administers drugs that will initiate death in a person who has made the decision to end their life of suffering.

Physician-assisted dying may not be for everyone. But more and more, people with conditions that cause them great and long-standing suffering are considering this option. Here in Canada, it is known as Medical Assistance in Dying (or MAID) and has become another choice on the continuum of palliative care for Parkinson's disease and certain parkinsonisms, especially in the very advanced stages.

In Canada, there are two types of medically-assisted dying that meet the requirements of the law. A person may have a doctor or a nurse practitioner attend and administer medications that will initiate the dying process; or, they may choose to do it on their own using medications that have been specifically prescribed by their doctor for this purpose. The law requires the person be able to give their informed consent at the time that the medical assistance is provided.

Although the right to choose to have a physician-assisted death became law in mid-2016, a large polarity of opinion on the issue still exists. People hold varying religious, spiritual, cultural and existential beliefs and values, and these will inevitably dictate their choices and their opinions. This is, after all, a very personal choice of whether to persevere and see it to its natural end, or to close a book of life in a manner of their choosing. And choices ought to be made after sufficient information is acquired and honest discussions with all relevant stakeholders, including the primary care physician, are held.

Palliative and Hospice Care

A person who wishes to have medical assistance in dying must meet several criteria. They include, but are not limited to:

- Having a disease, illness or disability that is serious and incurable;
- Being in a state of decline that is irreversible and affects their capabilities;
- Suffering from an intolerable level of physical and psychological pain;
- Heading towards a reasonably foreseeable death.

For more information on MAID, please visit the Government of Canada website.

Before you both make any decisions, begin by understanding what rights you have under the laws of the province in which you live. The rights will be different for each of you, and may also vary from province to province. Find out what rights the care recipient has relating to treatment options, advance care planning and Substitute Decision Makers. Generally speaking, they have the right to refuse treatment, food, drink and medications. S/he also has the right to a second opinion and to choose to end their life with dignity.

Discussing medical assistance in dying may not be an easy topic to broach or to have introduced to you. It may or may not be suitable for discussion with other family members or close friends. It will be up to the two of you – you and the person with Parkinson's – to assess whether or not this option is aligned with both of your beliefs, wishes and ability to tolerate the difficult changes that come with advanced Parkinson's. The final decision, however, remains with them.

If one is considering medical assistance in dying, then it's important for them to take the time and reflect on their wishes. These are not decisions left to the last minute; but rather, ones that ought to be made when health and cognition permit them to make rational and informed decisions. Don't wait until one's competence is questioned. Visit a lawyer or notary, have the necessary documents drawn up, signed and witnessed to ensure one's wishes are executed properly.

A healthcare 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 compelled to assist with dying. 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 medical assistance in dying, regulatory requirements and guidelines please see the resources section of this book.



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Chapter 10:

When Care Partnering Ends



When Care Partnering Ends

When Care Partnering Ends

Parkinson's disease 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, loss of independence, and even loss of "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.

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 grief and no right or wrong way to experience it. You may feel numb and in shock despite knowing 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; 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. Elliot --

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 most 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 resentment that all your resources went into the person with Parkinson's. Anyone who has not experienced the care partnering 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 important 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, book club, 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, wood-working 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?

When Care Partnering Ends

- 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 or your career; making new living arrangements or downsizing; perhaps, you are ready to retire altogether. Whatever those changes look like, they are inevitable. Reflection and putting your life into 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 --



RESOURCES: Income Assistance

Canada (national programs)

EI Sickness Benefits

<https://www.canada.ca/en/services/benefits/ei/ei-sickness.html>

Toll free: 1-800-206-7218

Canada Pension Plan – Disability Benefits (for those 64 and younger)

<https://www.canada.ca/en/employment-social-development/programs/pensions/reports/disability-benefits.html>

Toll free: 1-800-277-9914

Canada Pension Plan (for those 65 and older)

<https://www.canada.ca/en/services/benefits/publicpensions/cpp.html>

Alberta

Assured Income for the Severely Handicapped (AISH)

<https://www.alberta.ca/aish.aspx>

British Columbia

Disability Assistance

<https://www2.gov.bc.ca/gov/content/family-social-supports/services-for-people-with-disabilities/disability-assistance/on-disability-assistance>

Toll free: 1-866-866-0800



RESOURCES: Income Assistance

Income Assistance

<https://www2.gov.bc.ca/gov/content/family-social-supports/income-assistance>

Toll free: 1-866-866-0800

Manitoba

55 PLUS Program

<https://www.gov.mb.ca/fs/eia/55plus.html>

Toll free: 1-800-563-8793

Employment and Income Assistance for Persons with Disabilities

https://www.gov.mb.ca/fs/eia/eia_disability.html

Toll free: 1-800-855-0511

New Brunswick

Social Assistance Program

http://www2.gnb.ca/content/gnb/en/services/services_renderer.10295.Social_Assistance_Program.html

For local office contacts, visit:

http://www2.gnb.ca/content/gnb/en/services/services_renderer.10295.Social_Assistance_Program.html#serviceLocation



RESOURCES: Income Assistance

Newfoundland and Labrador

Income Support

<http://www.aesl.gov.nl.ca/income-support/>

For regional office contacts, visit:

<http://www.aesl.gov.nl.ca/income-support/application.html>

Northwest Territories

Income Assistance Program

<https://www.ece.gov.nt.ca/en/services/income-security-programs/income-assistance>

Toll free: 1-866-973-7252

NWT Senior Citizen Supplementary Benefit

<https://www.ece.gov.nt.ca/en/services/income-security-programs/nwt-senior-citizen-supplementary-benefit>

Toll free: 1-866-973-7252

Nova Scotia

Income Assistance

https://novascotia.ca/coms/employment/income_assistance/index.html

Toll free: 1-877-424-1177



RESOURCES: Income Assistance

Nunavut

Income Assistance

<https://www.gov.nu.ca/family-services/programs-services/income-assistance-ia>

Qikiqtani: 867-473-2615 1-800-567-1514

Kivalliq: 867-645-5040 1-800-953-8516

Kitikmeot: 867-983-4032 1-800-661-0845

Ontario

Ontario Works

<https://www.mcsp.ontario.ca/en/mcsp/programs/social/ow/index.aspx>

To find local office, visit: <http://www.officelocator.mcsp.gov.on.ca/?lang=en>

Ontario Disability Support Program

<https://www.mcsp.ontario.ca/en/mcsp/programs/social/odsp/income-support/index.aspx>

To find local office, visit: <http://www.officelocator.mcsp.gov.on.ca/?lang=en>



RESOURCES: Income Assistance

Prince Edward Island

Seniors Independence Initiative

<https://www.princeedwardisland.ca/en/information/seniors-independence-initiative>

Toll free: 1-877-569-0546

Social Assistance Program

<https://www.princeedwardisland.ca/en/information/services-a-famille-et-a-personne/social-assistance-program>

General Inquiries: 1-866-594-3777 or visit above link for local office

Quebec

Social Assistance and Social Solidarity Programs

<http://www.emploiquebec.gouv.qc.ca/en/citizens/obtaining-financial-assistance/social-assistance-and-social-solidarity-programs/>

Toll free: 1-877-767-8773

Saskatchewan

Saskatchewan Assured Income for Disability (SAID)

<https://www.saskatchewan.ca/residents/family-and-social-support/people-with-disabilities/income-support-for-people-with-disabilities>

Toll free: 1-888-567-SAID (7243)



RESOURCES: Income Assistance

Yukon

Yukon Social Assistance

<http://www.hss.gov.yk.ca/sa.php>

See the above link for phone contacts in your area

Yukon Seniors Income Supplement

<http://www.hss.gov.yk.ca/ysis.php>

Telephone: 867-667-5674

Toll Free (Yukon, Nunavut and NWT): 1-800-661-0408 ext. 5674

Yukon Supplementary Allowance

<http://www.hss.gov.yk.ca/ysa.php>

Telephone: 867-667-5674; Toll Free (Yukon, Nunavut and NWT): 1-800-661-0408 ext. 5674



RESOURCES:

Drug Coverage

Alberta

Coverage for Seniors Benefit

<http://www.health.alberta.ca/services/drugs-seniors.html>

Non-Group Coverage Benefit (under 64)

<http://www.health.alberta.ca/services/drugs-non-group.html>

British Columbia

Fair PharmaCare Plan

<https://www2.gov.bc.ca/gov/content/health/health-drug-coverage/pharmacare-for-bc-residents/who-we-cover/fair-pharmacare-plan>

Manitoba

MB Pharmacare Program

<https://www.gov.mb.ca/health/pharmacare/index.html>

Phone: 204-786-7141, Toll free: 1-800-297-8099

New Brunswick

New Brunswick Drug Plan

<http://www2.gnb.ca/content/gnb/en/departments/health/MedicarePrescriptionDrugPlan/NBDrugPlan.html>

Toll free: 1-855-540-7325



RESOURCES:

Drug Coverage

New Brunswick Drug Plans for Seniors

http://www2.gnb.ca/content/gnb/en/services/services_renderer.8875.html

Toll free: 1-800-332-3692

Prescription Drug Program - Nursing Home Residents

http://www2.gnb.ca/content/gnb/en/services/services_renderer.8935.html

Toll free: 1-800-332-3692

Newfoundland and Labrador

Foundation Plan – for those on income support

http://www.health.gov.nl.ca/health/prescription/nlpdp_plan_overview.html#1

Automatically enrolled once accepted by Income Support

65Plus Plan

http://www.health.gov.nl.ca/health/prescription/nlpdp_plan_overview.html#2

Automatically enrolled, when receiving OAS and GIS

Access Plan – for those with low income

http://www.health.gov.nl.ca/health/prescription/nlpdp_plan_overview.html#3

Toll free: 1-888-859-3535



RESOURCES:

Drug Coverage

Assurance Plan – for those with high drug costs

http://www.health.gov.nl.ca/health/prescription/nlpdp_plan_overview.html#4

Toll free: 1-888-859-3535

Northwest Territories

Extended Health Benefit Seniors' Program

<http://www.hss.gov.nt.ca/en/services/supplementary-health-benefits/extended-health-benefits-seniors-program>

Toll free: 1-800-661-0830

Metis Health Benefits

<http://www.hss.gov.nt.ca/en/services/supplementary-health-benefits/metis-health-benefits>

Toll free: 1-800-661-0830

Nova Scotia

Family Pharmacare Program – under 65

<https://novascotia.ca/dhw/pharmacare/family-pharmacare.asp>

Toll free: 1-877-330-0323

Seniors' Pharmacare Program – 65+

<https://novascotia.ca/dhw/pharmacare/seniors-pharmacare.asp>

Toll free: 1-800-544-6191



RESOURCES:

Drug Coverage

Department of Community Services Pharmacare Benefits – income assistance and disability support Program Clients: <https://novascotia.ca/dhw/pharmacare/DCS-drug-program.asp>

Toll free: 1-877-424-1177

Nunavut

EHB Full Coverage Plan

<https://gov.nu.ca/health/information/ehb-full-coverage-plan>

Toll free: 1-800-661-0833

Non-Insured Health Benefits – Inuk

<https://gov.nu.ca/health/information/non-insured-health-benefits>

Toll free: 1-800-661-0833

Extended Health Benefits – non-Inuk

<https://gov.nu.ca/health/information/health-insurance-extended-health-benefits>

Toll free: 1-800-661-0833

Ontario

Ontario Drug Benefit should be automatic when someone turns 65. You should receive notice of eligibility 3 months prior to turning 65.

Recipients of Ontario Works or Ontario Disability Drug Program (ODSP) will receive a drug card.

If none of these apply to you, you may be eligible for the Trillium Drug Plan. Applications can be found in all pharmacies, or call 1-800-575-5386.

<https://www.ontario.ca/page/get-coverage-prescription-drugs>



RESOURCES:

Drug Coverage

Prince Edward Island

Catastrophic Drug Program – for those with high drug costs

<https://www.princeedwardisland.ca/en/information/sante-i-p-e/catastrophic-drug-program>

PEI Pharmacare, Toll free: 1-877-577-3737

Financial Assistance Drug Program – for those on social assistance

<https://www.princeedwardisland.ca/en/information/sante-i-p-e/financial-assistance-drug-program>

PEI Pharmacare, Toll free: 1-877-577-3737

Generic Drug Program – for those under 65

<https://www.princeedwardisland.ca/en/service/apply-generic-drug-program>

PEI Pharmacare, Toll free: 1-877-577-3737

Nursing Home Drug Program – for those in long term care

<https://www.princeedwardisland.ca/en/information/sante-i-p-e/nursing-home-drug-program>

PEI Pharmacare, Toll free: 1-877-577-3737

Quebec

Prescription Drug Insurance - public plan

<http://www4.gouv.qc.ca/en/Portail/citoyens/programme-service/Pages/Info.aspx?sqctype=sujetbsqid=139>

Telephone: 514-864-3411

Toll Free: 1-800-561-9749



RESOURCES:

Drug Coverage

Saskatchewan

The Saskatchewan Drug Plan

<https://www.saskatchewan.ca/residents/health/prescription-drug-plans-and-health-coverage/extended-benefits-and-drug-plan/saskatchewan-drug-plan>

High Drug Cost Assistance

<https://www.saskatchewan.ca/residents/health/prescription-drug-plans-and-health-coverage/extended-benefits-and-drug-plan/special-support-program>

Yukon

Chronic Disease Program

<http://www.hss.gov.yk.ca/drugformulary.php>

Telephone: 867-667-5209



RESOURCES: Equipment Loans or Funding

Canada (national program)

Check annually for potential tax credits

<https://www.canada.ca/en/revenue-agency/services/tax/individuals-segments/tax-credits-deductions-persons-disabilities.html>

Toll free: 1-800-959-8281

Alberta

Health Equipment Loan Program (HELP) -- Red Cross

<http://www.redcross.ca/how-we-help/community-health-services-in-canada/alberta-health-equipment-loan-program>

Alberta Aids to Daily Living

<http://www.health.alberta.ca/services/aids-to-daily-living.html>

Residential Access Modification Program (RAMP)

<http://www.humanservices.alberta.ca/disability-services/residential-access-modification-program.html>

British Columbia

Health Equipment Loan Program (HELP) -- Red Cross

<http://www.redcross.ca/how-we-help/community-health-services-in-canada/bc-health-equipment-loan-program>

Tax Benefits for People with Disabilities – medical supplies and equipment

<https://www2.gov.bc.ca/gov/content/taxes/sales-taxes/pst/exemptions>



RESOURCES: Equipment Loans or Funding

Manitoba

Assistive Technology

<https://www.gov.mb.ca/fs/imd/atech.html>

New Brunswick

Disability Support Program

http://www2.gnb.ca/content/gnb/en/services/services_renderer.200972.Disability_Support_Program.html

For local office contact, visit:

http://www2.gnb.ca/content/gnb/en/services/services_renderer.200972.Disability_Support_Program.html#serviceLocation

Newfoundland and Labrador

Special Assistance Program – medical supplies and equipment

http://www.health.gov.nl.ca/health/personsdisabilities/fundingprograms_hcs.html#sap

Regional Health Authority – contact http://www.health.gov.nl.ca/health/findhealthservices/in_your_community.html#contact

Northwest Territories

Equipment Loans or Funding

<http://www.hss.gov.nt.ca/en/services/supplementary-health-benefits/extended-health-benefits-seniors-program>

Toll Free: 1-800-661-0830



RESOURCES:

Equipment Loans or Funding

Nova Scotia

Health Equipment Loan Program/Community Bed Loan Program

<https://novascotia.ca/dhw/ccs/health-equipment.asp>

Continuing Care, Toll free: 1-800-225-7225

Seniors Community Wheelchair Loan Program

<https://novascotia.ca/dhw/ccs/wheelchair-loan-program.asp>

Continuing Care, Toll free: 1-800-225-7225

Personal Alert Service

<https://novascotia.ca/dhw/ccs/personal-alert-service.asp>

Continuing Care, Toll free: 1-800-225-7225

Nunavut

EHB Full Coverage Plan

<https://gov.nu.ca/health/information/ehb-full-coverage-plan>

Toll free: 1-800-661-0833

Ontario

Assistive Devices Program

<https://www.ontario.ca/page/assistive-devices-program>



RESOURCES:

Equipment Loans or Funding

Prince Edward Island

Disability Support Program

<https://www.princeedwardisland.ca/en/information/family-and-human-services/disability-support-program>

General Inquiries: 1-866-594-3777 or visit above link for local office

Quebec

Home Care Support

<http://www4.gouv.qc.ca/EN/Portail/Citoyens/Evenements/aines/Pages/service-soutien-domicile.aspx>

Access via Les centres locaux de services communautaires (CLSC)
- local community services centers <http://www.sante.gouv.qc.ca/en/repertoire-ressources/clsc/>

Saskatchewan

Saskatchewan Aids to Independent Living

<https://www.saskatchewan.ca/residents/health/accessing-health-care-services/health-services-for-people-with-disabilities/sail>

Toll free: 1-888-787-8996



RESOURCES: Equipment Loans or Funding

Yukon

Chronic Disease Program

<http://www.hss.gov.yk.ca/chronicdisease.php>

Phone: 867-667-5092

Toll Free (Yukon, Nunavut and NWT): 1-800-661-0408 ext. 5092

Health Equipment Loan Program (HELP) -- Red Cross

<http://www.redcross.ca/how-we-help/community-health-services-in-canada/bc-health-equipment-loan-program>

Northern BC and Yukon

Toll free: 1-800- 278-7177

Telephone: 250-564-6566

Whitehorse

Telephone: 867-456-7359

Facsimile: 867-456-7024



RESOURCES: In-Home Help

Canada (national program)

Check annually for potential tax credits

<https://www.canada.ca/en/revenue-agency/services/tax/individuals-segments/tax-credits-deductions-persons-disabilities.html>

Toll free: 1-800-959-8281

Alberta

Home Care

<http://albertahealthservices.ca/cc/Page15488.aspx>

Call 811 or use above link to get zone offices

British Columbia

Home Support

<https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/home-support>

Visit link above for contact information for local home and community care offices

Manitoba

MB Provincial Home Care Services

<https://www.gov.mb.ca/health/homecare/>

Visit link for regional health authority office number



RESOURCES: In-Home Help

New Brunswick

Disability Support Program

http://www2.gnb.ca/content/gnb/en/services/services_renderer.200972.Disability_Support_Program.html

For local office contacts, visit: http://www2.gnb.ca/content/gnb/en/services/services_renderer.200972.Disability_Support_Program.html#serviceLocation

Newfoundland and Labrador

Provincial Home Support Program

http://www.health.gov.nl.ca/health/personsdisabilities/fundingprograms_hcs.html#phsp

Regional Health Authority – Contact http://www.health.gov.nl.ca/health/findhealthservices/in_your_community.html#contact

Northwest Territories

In-Home Help

<http://www.hss.gov.nt.ca/en/services/continuing-care-services/home-and-community-care>

List of offices to contact: <http://www.hss.gov.nt.ca/en/services/continuing-care-services/contact-information-home-care>



RESOURCES: In-Home Help

Nova Scotia

Home Care

<https://novascotia.ca/dhw/ccs/home-care.asp>

Continuing Care, Toll free: 1-800-225-7225

Self-Managed Care

<https://novascotia.ca/dhw/ccs/self-managed-care.asp>

Continuing Care, Toll free: 1-800-225-7225

Supportive Care – for those with cognitive impairment

<https://novascotia.ca/dhw/ccs/supportive-care.asp>

Continuing Care, Toll free: 1-800-225-7225

Caregiver Benefit

<https://novascotia.ca/dhw/ccs/caregiver-benefit.asp>

Continuing Care, Toll free: 1-800-225-7225

Nunavut

Home and Community Care

<https://www.gov.nu.ca/health/information/home-and-continuing-care>

Telephone: 867-975-5776 or 867-975-5709



RESOURCES: In-Home Help

Ontario

Home and community care

<https://www.ontario.ca/page/homecare-seniors>

Call: 310-2222

Prince Edward Island

Disability Support Program

<https://www.princeedwardisland.ca/en/information/family-and-human-services/disability-support-program>

General Inquiries: 1-866-594-3777 or visit above link for local office

Home Care Program

<https://www.princeedwardisland.ca/en/information/health-pei/home-care-program>

Visit above link for regional office

Quebec

Home Care Support

<http://www4.gouv.qc.ca/EN/Portail/Citoyens/Evenements/aines/Pages/service-soutien-domicile.aspx>

Access via Les centres locaux de services communautaires (CLSC)
- local community services centers <http://www.sante.gouv.qc.ca/en/reperoire-ressources/clsc/>



RESOURCES: In-Home Help

Saskatchewan

Home Care

<https://www.saskatchewan.ca/residents/health/accessing-health-care-services/care-at-home-and-outside-the-hospital/home-care>

Visit the Saskatchewan Health Authority to find local office or call 811

<https://www.saskhealthauthority.ca/Services-Locations/Pages/Home.aspx>

Yukon

Home Care Program

<http://www.hss.gov.yk.ca/homecare.php>

Visit above link for local office numbers



RESOURCES: Long-Term Care Facilities

Alberta

Long-Term Care

<http://albertahealthservices.ca/cc/Page15491.aspx>

Call: 811

British Columbia

Long-Term Residential Care

<https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/long-term-residential-care>

Visit link above for contact for local home and community care office

Manitoba

Personal Care Homes

Arranged through the local Regional Health Authority

Visit individual sites:

- <http://www.wrha.mb.ca/ltc/access.php>
- <https://www.ierah.ca/default.aspx?cid=6125&lang=1>
- <http://www.northernhealthregion.ca/>
- <http://www.prairiemountainhealth.ca/index.php/personal-care-home-placement>
- <https://www.southernhealth.ca/finding-care/find-a-service/personal-care-homes/>



RESOURCES: Long-Term Care Facilities

New Brunswick

Long-Term Care Services for Seniors

http://www2.gnb.ca/content/gnb/en/departments/social_development/persons_disabilities/content/services-persons-with-disabilities/services_renderer.10115.Long-Term_Care_Services_for_Seniors.html

For local office contacts, visit: http://www2.gnb.ca/content/gnb/en/departments/social_development/persons_disabilities/content/services-persons-with-disabilities/services_renderer.10115.Long-Term_Care_Services_for_Seniors.html#serviceLocation

Newfoundland and Labrador

Personal Care Homes – private option

http://www.health.gov.nl.ca/health/seniors/residentialoptions_pch.html

Regional Health Authority - Contact http://www.health.gov.nl.ca/health/findhealthservices/in_your_community.html#contact

Long-Term Care Facilities – public option

Regional Health Authority - Contact http://www.health.gov.nl.ca/health/findhealthservices/in_your_community.html#contact

Northwest Territories

Long-Term Care Homes

<http://www.hss.gov.nt.ca/en/services/continuing-care-services/long-term-care>

867-767-9030



RESOURCES: Long-Term Care Facilities

Nova Scotia

Long-Term Care

<http://www.nshealth.ca/content/long-term-care>

Toll free: 1-800-225-7225

Nunavut

Long-Term Care Homes

<https://www.gov.nu.ca/health/information/home-and-continuing-care>

Telephone: 867-975-5776 or 867-975-5709

Ontario

Long-Term Care

<https://www.ontario.ca/page/homecare-seniors>

Call: 310-2222

Prince Edward Island

Long-Term Care

<https://www.princeedwardisland.ca/en/information/health-pei/long-term-care>

Telephone: 902-368-5313



RESOURCES: Long-Term Care Facilities

Quebec

Residential and Long-Term Care Centre

Access via Les centres locaux de services communautaires (CLSC) - Local community services centres <http://www.sante.gouv.qc.ca/en/repertoire-ressources/clsc/>

Saskatchewan

Personal Care Homes

<http://personalcarehomes.saskatchewan.ca/Home/Faq>

Community Care Branch Telephone: 306-787-7239

Yukon

Continuing Care Facilities

<http://www.hss.gov.yk.ca/residentialcare.php>

Telephone: 867-667-8961 or 867-456-6806

Toll Free (Yukon, Nunavut and NWT): 1-800-661-0408 ext. 8961



RESOURCES: Powers of Attorney

Canada (national program)

Powers of Attorney: Rights and Responsibilities

<https://www.canada.ca/en/financial-consumer-agency/services/rights-responsibilities/rights-banking/rights-power-attorney.html>

Seniors' Guidebook to Safety and Security

<http://www.rcmp-grc.gc.ca/en/seniors-guidebook-safety-and-security>

Alberta

Enduring Power of Attorney

<https://www.alberta.ca/enduring-power-of-attorney.aspx>

Personal Directive

<https://www.alberta.ca/personal-directive.aspx>

British Columbia

Substitute Decision-Making and Incapacity Planning

<https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/financial-legal-matters/substitute-decision-making>

Advance Care Planning

<https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning>



RESOURCES: Powers of Attorney

Manitoba

Powers of Attorney Program

http://www.gov.mb.ca/publictrustee/services/powers_of_attorney.html

Enduring Power of Attorney: A Guidebook for Donors and Attorneys, Public Guardian and Trustee of Manitoba

https://www.gov.mb.ca/publictrustee/pdf/power_of_attorney_guidebook.pdf

New Brunswick

Powers of Attorney

http://www.legal-info-legale.nb.ca/en/powers_of_attorney

Newfoundland and Labrador

Seniors and the Law

http://www.cssd.gov.nl.ca/seniors/pdf/seniors_law.pdf

Legal Planning Guide for Newfoundland and Labrador

<http://publiclegalinfo.com/wp-content/uploads/2016/04/PLIAN-Legal-Planning-Guide.pdf>

Northwest Territories

Powers of Attorney

<https://www.justice.gov.nt.ca/en/power-of-attorney/>
1-867-767-9252



RESOURCES: Powers of Attorney

Nova Scotia

Personal Directives in Nova Scotia

https://novascotia.ca/just/pda/_docs/PersonalDirective_Booklet.pdf

Power of Attorney

<https://www.legalinfo.org/wills-and-estates-law/power-of-attorney>

Nunavut

Powers of Attorney

<https://www.justice.gov.nt.ca/en/power-of-attorney/>
1-867-767-9252

Ontario

Powers of Attorney

<https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.php>

Powers of Attorney Kit

<https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf>

Prince Edward Island

Do-It-Yourself Power of Attorney Kit (Community Legal Information Association of Prince Edward Island)

http://www.cliapei.ca/content/page/programs_poa/



RESOURCES: Powers of Attorney

Quebec

Mandate, Will, Power of Attorney

<https://www.curateur.gouv.qc.ca/cura/en/majeur/client/prevoyant/mandat/type.html>

Powers of Attorney (mandate)

<https://www.justice.gouv.qc.ca/en/your-money-and-your-posessions/power-of-attorney-and-protective-supervision/power-of-attorney-mandate/>

Advance Medical Directives

<https://www.educaloi.qc.ca/en/capsules/advance-medical-directives>

Saskatchewan

Powers of Attorney for Adults

<https://www.saskatchewan.ca/residents/justice-crime-and-the-law/power-of-attorney-guardianship-and-trusts/powers-of-attorney-for-adults>

Powers of Attorney Guide

<http://www.publications.gov.sk.ca/details.cfm?p=10485>
<http://www.publications.gov.sk.ca/deplist.cfm?d=9&c=5299>



RESOURCES:

Powers of Attorney

Yukon

Enduring Power of Attorney

<http://www.publicguardianandtrustee.gov.yk.ca/1485.html>

Do You Need an Enduring Power of Attorney?

http://www.publicguardianandtrustee.gov.yk.ca/pdf/GUIDEBOOK_DO_You_Need_Power_of_Attorney_WEB.pdf



RESOURCES:

Medical Assistance in Dying – Position Statements and Other Information

Parkinson Canada

http://www.parkinson.ca/wp-content/uploads/ENG_SUPPORTING_DOCUMENTATION_-_MEDICAL_ASSISTANCE_IN_DYING.pdf
http://www.parkinson.ca/wp-content/uploads/ENG_POSITION_STATEMENT_MEDICAL_ASSISTANCE_IN_DYING.pdf

College of Family Physicians of Canada (CFPC)

<http://www.cfpc.ca/ProjectAssets/Templates/Category.aspx?id=10000&terms=MAID>

Canadian Medical Association (CMA) – Information for Physicians

<https://www.cma.ca/En/Pages/education-eol-care-medical-assistance-dying.aspx>

Canadian Nurses Association (CAN)

<https://www.cna-aiic.ca/en/news-room/news-releases/2017/cna-leads-the-development-of-a-national-nursing-framework-on-medical-assistance-in-dying>



RESOURCES:

Medical Assistance in Dying – Information by Province

Alberta

<http://www.health.alberta.ca/health-info/medical-assistance-dying.html>

British Columbia

<https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/end-of-life-care/medical-assistance-in-dying>

Manitoba

<http://www.wrha.mb.ca/maid/>
<http://www.gov.mb.ca/health/maid.html>

New Brunswick

<http://en.horizonnb.ca/home/patients-and-visitors/patient-information-resources/medical-assistance-in-dying.aspx>
<http://www2.gnb.ca/content/gnb/en/departments/health/patientinformation/content/MedicalAssistanceInDying.html>

Nova Scotia

<http://www.novascotia.ca/dhw/publications/preparing-for-an-expected-death-at-home-brochure.pdf>



RESOURCES:

Medical Assistance in Dying – Information by Province

Ontario

<http://health.gov.on.ca/en/pro/programs/maid/>

Prince Edward Island

[https://www.princeedwardisland.ca/en/information/health-peি/medical-assistance-dying](https://www.princeedwardisland.ca/en/information/health-peि/medical-assistance-dying)

Quebec

<http://sante.gouv.qc.ca/programmes-et-mesures-daide/loi-concernant-les-soins-de-fin-de-vie/>

Saskatchewan

<https://www.saskatchewan.ca/residents/health/accessing-health-care-services/medical-assistance-in-dying>



RESOURCES:

Medical Assistance in Dying – Guidelines from Regulatory Bodies

Alberta

Physicians

<http://www.cpsa.ca/standardspractice/medical-assistance-dying/>

Nurses

http://www.nurses.ab.ca/content/dam/carna/pdfs/DocumentList/Guidelines/MAIDGuidelinesForNurses_March2017.pdf

British Columbia

Physicians

<https://www.cpsbc.ca/files/pdf/PSG-Medical-Assistance-in-Dying.pdf>
<https://www.cpsbc.ca/files/pdf/PSG-Medical-Assistance-in-Dying-FAQ.pdf>

Nurses

<https://www.crnbc.ca/Standards/resourcescasestudies/beinganurse/MAID/Pages/Default.aspx>

Manitoba

Physicians

<http://cpsm.mb.ca/front-page-column-2>

Nurses

<https://www.crnmb.ca/support/medical-assistance-in-dying>



RESOURCES:

Medical Assistance in Dying – Guidelines from Regulatory Bodies

New Brunswick

Nurses

<http://www.nanb.nb.ca/media/resource/NANB-MAID-FAQ-November2016-E.pdf>

Newfoundland & Labrador

Physicians

<https://www.cpsnl.ca/web/files/2017-Mar-11%20-%20MAID.pdf>

Nurses

<https://www.arnnl.ca/arnnl-commentary-medical-assistance-dying-maid-update>

Northwest Territory & Yukon

Physicians

<https://www.hss.gov.nt.ca/en/services/medical-assistance-dying-maid>
<http://www.yukonmedicalcouncil.ca/pdfs/MAID.pdf>

Nurses

<http://www.rnantnu.ca/professional-practice/medical-assistance-dying-maid>



RESOURCES:

Medical Assistance in Dying – Guidelines from Regulatory Bodies

Nova Scotia

Physicians

<https://cpsns.ns.ca/standards-guidelines/medical-assistance-in-dying/>

Nurses

<http://crnns.ca/publication/medical-assistance-in-dying-a-guideline-for-nurses/>

Ontario

Physicians

<https://www.cpso.on.ca/cpso/media/documents/policies/policy-items/medical-assistance-in-dying-public-faq.pdf>

<https://www.cpso.on.ca/cpso/media/documents/policies/policy-items/medical-assistance-in-dying-faq.pdf>

<https://www.cpso.on.ca/cpso/media/documents/policies/policy-items/medical-assistance-in-dying.pdf>

Nurses

<http://www.cno.org/en/trending-topics/medical-assistance-in-dying/>

Prince Edward Island

Physicians

<http://cpspei.ca/wp-content/uploads/2018/04/Medical-Assistance-in-Dying-March-13-2017.pdf>

Nurses

<https://www.arnpei.ca/data/Guidelines%20on%20Medical%20Assistance%20in%20Dying%202017.pdf>



RESOURCES:

Medical Assistance in Dying – Guidelines from Regulatory Bodies

Quebec

Physicians

<http://www.cmq.org/page/en/Soins-medicaux-fin-de-vie.aspx>

Nurses

<https://www.oiiq.org/aide-medicale-a-mourir?inheritRedirect=true>

Saskatchewan

Physicians

http://www.cps.sk.ca/imis/CPSS/Legislation__ByLaws__Policies_and_Guidelines/Legislation_Content/Policies_and_Guidelines_Content/Medical_Assistance_in_Dying.aspx

Nurses

http://www.rpnas.com/wp-content/uploads/MAiD_RN12_12_2016.pdf



WORKSHEET 1:

Care Partner Self-Assessment Worksheet

Adapted from *Caring and Coping, A Caregiver's Guide to Parkinson's Disease*, published by the Parkinson Foundation, 2016.

Rate the following statements according to how closely they apply to you. Add all the numbers you have selected and enter into the Total Score section.

1 Almost Always 2 Frequently 3 Occasionally 4 Rarely 5 Never

#	STATEMENT	RATING
1	I exercise on a regular basis.	(1) (2) (3) (4) (5)
2	I make and keep preventive health appointments.	(1) (2) (3) (4) (5)
3	I have a job or activity that is personally 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 hobbies or recreational activities I enjoy.	(1) (2) (3) (4) (5)
8	I eat at least three balanced meals a day.	(1) (2) (3) (4) (5)
9	I have at least one person in whom I can confide.	(1) (2) (3) (4) (5)
10	I take time to do things that are important to me.	(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 take steps to achieve them.	(1) (2) (3) (4) (5)

TOTAL

ASSESSMENT RESULTS:

- 12 – 24** You are doing very well at taking care of yourself.
- 25 – 36** You have room for improvement. Assess where you experience challenges and seek help from family, friends or a professional and make changes.
- 37 – 48** You are unsuccessful in caring for yourself and at moderate risk of personal health problems. Talk to a healthcare provider or others who can help you formulate and enforce a self-care plan.
- 48 – 60** You are at an extremely high risk for personal health problems. It is vital that you speak to a healthcare provider as soon as possible. Stay focused on the fact that you must stay healthy to provide proper care for the care recipient.

This is an adaptation. Original version was 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.

Appendices

The following worksheets may be photocopied so that you can have several copies on which to write and maintain the original version blank for future copies. You can also find full-sized (8.5" x 11") downloadable and printable copies of each of these worksheets on our website. Visit parkinson.ca



WORKSHEET 2:

Care Partner Burden Calculator

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

For each statement, circle the rating to indicate how often you feel this way.
Add all the numbers you have selected and enter into the Total Score section.

0 Never **1** Rarely **2** Sometimes **3** Frequently **4** Nearly Always

I feel my care recipient	
1 Asks for more help than they actually need.	0 1 2 3 4
2 Takes up so much of my time, there's none left for me.	0 1 2 3 4
3 Behaves in a way that is embarrassing.	0 1 2 3 4
4 Makes me angry.	0 1 2 3 4
5 Makes the future look bleak.	0 1 2 3 4
6 Depends on me too much.	0 1 2 3 4
7 Causes me additional strain and stress.	0 1 2 3 4
8 Affects my relationship with other family members in a negative way.	0 1 2 3 4
9 Condition means less privacy for me.	0 1 2 3 4
10 Has impacted my social life in a negative way.	0 1 2 3 4
11 Makes me embarrassed to invite others over.	0 1 2 3 4
12 Attempts to control me.	0 1 2 3 4
13 Expects a lot from me, and me alone.	0 1 2 3 4
14 Doesn't understand the financial burden placed on me as a result of providing them care.	0 1 2 3 4
15 Doesn't know that I am exhausted and cannot take care of them for much longer.	0 1 2 3 4
TOTAL <input type="text"/>	

ASSESSMENT RESULTS:

0-15 Little or No Burden
Your experience of the burden is manageable.

16-30 Mild to Moderate Burden
Your experience of the burden is somewhat stressful.

31-44 Moderate to Severe Burden
Your experience of the burden is increasingly stressful and may have an impact on your health.

45-60 Severe Burden
Your experience of the burden is extremely stressful and puts you at a high risk of stress-related health issues.



WORKSHEET 3:

Home Safety Evaluation Checklist

Adapted from Caring and Coping, A Caregiver's Guide to Parkinson's Disease, published by the Parkinson Foundation, 2016.

THROUGHOUT THE HOUSE

- Floors are stable, non-skid surfaces without excessive patterns.
- Lighting is good throughout the home, with no dark or shadowy pockets.
- Walking paths are wide, allowing easy access and/or use of a walker or wheelchair, if needed.
- Electrical/phone/computer cords do not pose a tripping/falls risk when walking or moving about.
- Stairs are in good shape, have railings and can be blocked for safety, if needed.
- Chairs are stable, have arm rests and adequate seat height to make standing up easier.
- Dining area can be easily accessed.
- A communication system is in place to allow you to hear the person with Parkinson's in another area of the house.

TO DO:

- Remove any small area rugs/throw rugs/scatter rugs.
- Remove any clutter to decrease the risk of tripping or falling.
- Store medication in a safe place.

BEDROOM

- Environment is quiet and relaxing.
- Bed height allows feet to touch the floor when seated at bedside.
- Half side-rail or bed pole is in place to assist in rolling and getting up.
- Nightlight is placed in easily accessible spot and bright enough to fully light the path to the bathroom.
- Bedside commode/urinal made available for nighttime use, if needed.
- Communication system or monitor is in place, so you can hear calls for help at night.

TO DO:

- Place slippery fabric or draw sheet on the middle third of the bed to make rolling easier.
- Remove the top sheet and instead use only a lightweight comforter on the bed.
- Avoid flannel sheets and nightwear as they impeded movement.

BATHROOM

- Grab bars are installed near the toilet, tub and shower to avoid using towel racks, faucets or soap dishes as substitutes.
- Toilet has an elevated seat and arm rests or grab bar within easy reach.
- Tub/shower has a sturdy bench with back support for bathing/shower safety.
- Seating is available when performing tasks like brushing teeth, shaving, and combing hair, if needed.
- Communication system or monitor is in place so you can hear calls for help.



WORKSHEET 4:



Activities of Daily Living Support Schedule by Week

Adapted from the Caregiver's Handbook of Nova Scotia, 2014.

ACTIVITY	MON	TUES	WED	THURS	FRI	SAT	SUN
----------	-----	------	-----	-------	-----	-----	-----

AROUND THE HOME

Cooking/Preparing							
Doing Dishes							
Tidying Kitchen							
Floor/Carpet							
Cleaning							
Dusting/Tidying							
Cleaning Bathrooms							
Laundry/Ironing							
Yard Work/							
Gardening							
Snow Shoveling							
Taking Out Garbage/ Recycling							
Sending/ Picking Up Mail							

PERSONAL CARE

Administering Medications							
Eating							
Oral Care							
Bathing							
Dressing							
Toileting							
Other Hygiene							

	MON	TUES	WED	THURS	FRI	SAT	SUN
--	-----	------	-----	-------	-----	-----	-----

TRANSPORTATION

Health Care Appointment							
Exercise							
Social Event							
Shopping							
Other Appointment							

COORDINATION OF OTHER ACTIVITIES

Booking Appointments							
Filling/Picking Up Prescriptions							
Banking							
Paying Bills							
Income Tax Preparation							
Car Servicing							
Pet Care							

PSYCHOSOCIAL SUPPORT

Social Visits							
Check-In Calls							

WORKSHEET 5:



Daily Needs and Routine Tracker

Copy and complete this worksheet so any alternate care providers (paid or unpaid) will have a list which describes the specific needs and schedule of the person with Parkinson's disease

SLEEPING SCHEDULE

Waking Time	
Napping Time	
Sleeping Time	
Special Notes/ Preferences:	

ACTIVITIES SCHEDULE

Mornings	
Afternoons	
Evenings	
Special Notes/ Preferences:	

MEDICATION SCHEDULE

Dose 1	
Dose 2	
Dose 3	
Dose 4	
Dose 5	
Special Notes/ Preferences:	

PERSONAL CARE SCHEDULE

Bathing	
Dressing	
Oral Hygiene	
Other	
Special Notes/ Preferences:	

DIET AND MEAL SCHEDULE

Breakfast	
Snack	
Lunch	
Snack	
Dinner	
Snack	
Special Notes, Allergies/Dietary Restrictions:	

OTHER SCHEDULE

WORKSHEET 6:



Parkinson's Disease Daily Diary

Source: Parkinson Canada ACT on Time® program.

Name: _____ Date: _____

Instructions: This is a tool to track responses to medication and will be used to adjust the doses and timing of medications. For each time of day, place a check mark in the corresponding column that best describes your motor state. (i.e. in the 7:00 a.m. row indicate the average motor state from 7:00 to 7:59 a.m. or if asleep check **Asleep** in that column. If you take a medication dose at 7:45 p.m. write the time in the PD Medication column of the 7:00 p.m. row.

Motor State	"ON" with Dyskinesia Too Much Movement	"ON" Normal Movement	"OFF" Too stiff and slow	Asleep	PD Medication Time
6:00 a.m.					
7:00 a.m.					
8:00 a.m.					
9:00 a.m.					
10:00 a.m.					
11:00 a.m.					
Noon					
1:00 p.m.					
2:00 p.m.					
3:00 p.m.					
4:00 p.m.					
5:00 p.m.					
6:00 p.m.					
7:00 p.m.					
8:00 p.m.					
9:00 p.m.					
10:00 p.m.					
11:00 p.m.					
Midnight					



WORKSHEET 7:

What-If Plan

Use this template to complete the *What-If* statements with intended actions. Add your own statements in the blank spaces provided.

WHAT IF MY CARE RECIPIENT HAS A SUDDEN ILLNESS?

Then...	
Then...	
Then...	
Special Notes:	

WHAT IF MY CARE RECIPIENT HAS AN UNPLANNED ADMISSION TO THE HOSPITAL?

Then...	
Then...	
Then...	
Special Notes:	

WHAT IF THERE IS A FAMILY EMERGENCY?

Then...	
Then...	
Then...	
Special Notes:	


WHAT IF I OR MY CARE RECIPIENT HAS AN EMOTIONAL CRISIS?

Then...	
Then...	
Then...	
Special Notes:	

WHAT IF MY HEALTH IS COMPROMISED AND AFFECTS MY ABILITY TO PROVIDE CARE?

Then...	
Then...	
Then...	
Special Notes:	

WHAT IF

Then...	
Then...	
Then...	
Special Notes:	

WHAT IF

Then...	
Then...	
Then...	
Special Notes:	

Glossary of Terms

Activities of daily living (ADLs)

The things a person normally does for themselves such as personal hygiene including bathing and grooming; feeding themselves; dressing and toileting; cooking; walking; shopping, driving, etc.

Assisted living, retirement home or seniors' home

A residential facility for seniors that provides medical care and personal assistance, but emphasizes the resident's independence.

Atypical parkinsonisms

Includes several neurodegenerative disorders, such as Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP), and Corticobasal Syndrome (CBS).

Caregiver

Usually a paid professional who typically assists and supports a person with a chronic condition or illness, who cannot fully care for themselves.

Care partner

A spouse, relative or friend who assists and supports a person with whom they share a relationship and who lives with a chronic illness.

Care partnering

The act of caring for and with a care recipient.

Care recipient

The person receiving the care.

Cardiopulmonary resuscitation (CPR)

Life-saving chest compressions that circulate oxygenated blood to keep the brain alive when a person's heart stops for any reason.

Clinical care team

A group of health professionals who coordinate care for patients.

Dialysis

An artificial means by which the blood is cleaned of impurities; used in cases where there is kidney dysfunction.

Glossary of Terms

Dietition	A health professional who advises clients/patients about their diet or about the manner in which they eat.	Motor symptoms	Symptoms related to skeletal muscles and movement.
Do not resuscitate (DNR)	A medical order written by a doctor that instructs other healthcare providers not to do cardiopulmonary resuscitation (CPR) if a patient's breathing or heart stops.	Movement disorders specialist (MDS)	A neurologist who has received additional training and specializes in illnesses and disorders that affect movement, including Parkinson's disease.
Early-onset Parkinson's	Diagnosis of Parkinson's disease before the age of 50 years. See also Young-onset Parkinson's Disease (YOPD).	Multidisciplinary care	A term that describes care or treatment that is provided independently by several different healthcare providers on a referral basis, with one provider being the primary care physician.
Homecare	A term that describes the form and manner of the care being provided; usually taking place in the home of the care recipient.	Nasogastric tube	A tube used to reach the stomach through the nose.
Inpatient care	A term that refers to the care of a patient who has been admitted overnight or longer; typically administered in a hospital setting.	Neurodegenerative	A term that describes any illness or disorder characterized by a degeneration or breakdown of any parts of the nervous system, especially the neurons of the brain.
Interdisciplinary healthcare team	A group of various types of healthcare professionals who consult, collaborate and coordinate the care of a patient—with the patient, care partner and family—to address needs, improve patient outcomes and levels of satisfaction. Typically done in one clinical setting.	Neurologist	A physician who specializes in diagnosing and treating disorders of the nervous system, including diseases of the brain, spinal cord, and peripheral nerves.
Long-term care	A term that describes a type of residential healthcare facility; also a term used to describe the type of care provided to patients/residents. Typically, involves 24-hour, 7-days-a-week care.	Neuropsychiatry	A branch of psychiatry that specializes in mental and emotional disturbances related to brain functioning.
Medical assistance in dying (MAID)	Physician-assisted intervention to end the life of a person who is experiencing intolerable suffering due to an incurable medical condition; provided only to those legally eligible.	Non-motor symptoms	A diverse group of symptoms that do not relate to movement and are typically not immediately obvious, such as constipation, depression, anxiety, dizziness, sleep issues, taste and smell decline, cognitive changes, urinary problems and others.

Glossary of Terms

Nursing home	Another term used to describe a long-term care facility.	Power of Attorney (POA) Document	A legally binding document that permits a person to act on behalf of another. There are different kinds of Powers of Attorney that cover making decisions on behalf of someone. Requirements may vary across provinces and territories.
Occupational therapist	Also called an OT. A rehabilitation healthcare professional that uses assessments and interventions to develop, recover and maintain a patient's ability to perform their activities of daily living (ADLs).	Psychiatrist	A medical doctor who specializes in diagnosing and treating mood and mental disorders, including prescribing medications.
"ON/OFF" periods	Terms that describe the fluctuation periods related to medication timing; "OFF" periods occur when medications are wearing off; and "ON" periods occur when medications are at peak effect.	Psychologist	A recognized and credentialed expert in the field of psychology; one who assesses, diagnoses and treats those with psychological distress and mental illness.
Outpatient or ambulatory care	Terms referring to the care a patient receives in a hospital or clinical setting, without requiring an overnight stay; care can be administered in a medical office, clinic or hospital.	Respite care	Temporary, in-patient care of an ill, elderly or disabled person in order to provide relief for their care partner.
Parkinsonism(s)	A broad term that describes a set of symptoms characterized by tremor, rigidity, slowness of movement and postural instability; includes Parkinson's disease and the atypical parkinsonian syndromes.	Self-care	Actions taken to maintain or improve one's own health.
Patient-centered care	An approach to treatment that considers the needs and desires, life circumstances, and health choices of the patient, their care partner and family.	Side effect(s)	An effect of a medication that is not the original intended purpose.
Peer review	The evaluation of scientific, academic or professional work by others working in the same field or discipline.	Sleep medicine specialist	A medical practitioner who diagnoses and treats sleep disturbances and disorders.
Physical therapist or physiotherapist	Also called a PT. A rehabilitation healthcare professional that provides services and interventions to restore and maintain function, improve mobility, relieve pain, and prevent further damage or disability.	Social worker (SW)	A credentialed professional that provides support to patients and their families to better cope and manage in times of crisis; as well as, access to the community resources they may need.
		Speech-language pathologist (SLP)	Also called an SLP. A healthcare professional that assesses, diagnoses and treats speech, language, communication and swallowing disorders.

Glossary of Terms

Syndrome	A clinical set of symptoms and signs that occur together and characterize a disease or disorder.
Toileting	The act of bodily waste elimination; also, the act of assisting a dependent person with his/her elimination needs. Includes urination and the passing of bowel movements.
Tracheotomies	Incisions into the windpipe to allow air to enter the lungs when there is an obstruction to breathing.
Transfusion(s)	A procedure in which blood from a donor is given to someone who needs it through an intravenous line into a vein.
Tube feeding	A way in which food and liquids are delivered into the body to ensure nourishment is received. Delivery is through a tube inserted directly into the stomach through the abdomen (PEG or <i>percutaneous endoscopic gastrostomy</i>) or one through the nose leading down into the stomach (<i>nasogastric tube</i>).
Young-onset Parkinson's disease (YOPD)	Diagnosis of Parkinson's disease before the age of 50 years. See also Early-onset Parkinson's disease .

If you are not familiar with certain terms used within the book, or you would like a more detailed explanation of the content, we are pleased to provide one-to-one, confidential support specific to your unique situation. Connect with us by telephone at 1 800 565 3000, or by email at info@parkinson.ca.

About Parkinson's disease

Parkinson's is a chronic and progressive brain disease that affects both movement and many other systems of the body. It has no known cause(s) and has no cure. Parkinson's is complex. No two cases of Parkinson's are alike, and progression varies from person to person. The information contained in this book applies to care partners of those with Parkinson's disease, as well as those who care for people with the less common atypical parkinsonisms.

About Parkinson Canada

Parkinson Canada provides education, advocacy and support services nation-wide to individuals and the healthcare professionals that treat them, since 1965. The Parkinson Canada Research Program funds innovative research for better treatments and a cure. Parkinson Canada is an Imagine Canada accredited charitable organization.

Contact 1 800 565 3000 www.parkinson.ca
www.ParkinsonClinicalGuidelines.ca

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